# ASSESSING THE HEALTH OUTCOMES OF THE FAMILY MEMBERS OF DISABLED INDIVIDUALS

by

© Alyssa Coombs

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# ABSTRACT

The health utilization and death rates were captured for the family members of disabled individuals over a fifteen-year period to determine if exposure to disability in the family manifests poor health outcomes. Data from the Newfoundland Adult Health Survey (1995) was linked to fifteen years, 1995- 2010, of provincial health administrative data including hospital data, physician claims, and death records from the provincial health care system. The health records and survey data were analyzed in relation to the disability exposure burden experienced when a family member is disabled. The level of disability exposure burden was quantified based on the addition of individual disability scores for each family member. Disability exposure burden was associated with increased number of hospital separations, total hospitalization days and the number of physician visits, both General Practitioner and Specialist ($p<0.1$) but there was no association between death ($p>0.1$) and disability exposure burden. Family members of disabled individuals experienced increased rates of hospital separations, hospitalization days, and physician visits suggesting that deleterious health outcomes may be introduced when individuals are exposed to disability in the family unit.

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# CHAPTER 1

# INTRODUCTION

## 1.1 Background of Study

As disabilities become a prominent cause of hospitalization and disease burden in the Canadian population (Institute for Health Metrics and Evaluation, 2013), the consequences of being disabled are becoming critical to the health care system. A large body of research focusing on the health of disabled individuals has led to an improved understanding of the health consequences inflicted by disability, but there is a lack of information available concerning the consequences of having a disabled family member. The available literature on the topic typically focuses on outcomes for the individual (Drum, Horner-Johnson, & Krahn, 2008; Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010) and there is a dearth of information explaining how the effects of disability translate onto others (e.g. coworkers, friends or family members of those close to a disabled individual). There is a need to assess the broader impacts of disability in society to determine the health outcomes for those who are disabled and their family members.

Research on the effects of disabilities reveals detrimental effects on health and social outcomes for disabled individuals (Drum et al., 2008; Hartley, 2010; Singleton, 2012; Urbano, Hodapp, & Floyd, 2007) and suggests that others may also be affected by the disability (Gelkopf & Roe, 2014). In particular, family members of disabled individuals may require additional health services or social supports (Bakker, Demerouti, & Burke, 2009; Hwang & Kearney, 2014; Pessar et al., 1993). For example, in a 1992 study by Jamison & Walker, the parents of children with chronic pain reported higher levels of parental disability, pain, and emotional distress while children of parents with chronic pain reported more frequent abdominal pain (Jamison & Walker, 1992). Hospitalization rates and physician visits for families affected by a disabling injury were also found to increase for all family members in a study conducted by Gorman, Fitzgerald & Blow (2009). The evidence in the literature discussing the health outcomes for family members of disabled individuals typically focuses on the burden of caregiving in relation to stress. However there is little mention of the long-term impacts of the burden associated with caregiving or the impacts of disability on the family unit.

Current programs and benefits concerning disability in Canada have been geared toward ensuring the health and finances of the disabled individual are stable with little consideration of the needs of the family. The family's total household income may be considered for financial benefits relating to one's disability but benefits that consider the family unit often only relate to families that have children with disabilities (Government of Canada, 2014; Government of Newfoundland & Labrador, 2012; Workers Health, Safety, and Compensation Commission, 2014). However evidence of the financial distress caused to families, via direct and indirect disability costs, may invite policies that consider the family's size, income level, and financial needs. In addition, evidence concerning poor health outcomes for family members of disabled individuals may lead to the development of programs or policies concerning the potential increased health care costs endured by the health care system (Dewa, Chau, & Dermer, 2010). Program development allowing families, inflicted with disability, to come together to discuss their commonalities and concerns may also address the psychological distress associated with caring for or living with a disabled family member. Learning more about the potential or imminent effects of disabilities on families can lead to improved policy decisions regarding disabilities, as well as improved information to stakeholders regarding the direct and indirect effects of disabilities.

Although there are a number of people affected by an individual's disability, we focus on families in this research. It is expected that, beyond the disabled individual, family members will be affected the most by disability due to their close relationships with the direct victims of disability. Families have a vested interest in actively coping with a crisis, such as disability, that has affected a loved one producing stress, financial concerns, and/or relationship dissatisfaction.

### 1.2 Rationale

Although there is a plentiful array of data detailing the health outcomes and status of disabled individuals, there is little evidence on how disabilities affects families. To overcome this knowledge gap the linked Newfoundland Adult Health Survey and health administrative data, will be used to investigate the evolving health needs associated with disability. The study is a population-based, retrospective study that assesses the long-term health impacts of disabilities on families by using the linked health administrative records of Newfoundland adults and their family members to survey data collected in 1995. The longitudinal data collected linked to the Newfoundland Adult Health Survey combined with survey records of disabled participants and their family members will be utilized to capture health outcomes. Assessing the personal and familial health outcomes of disability will allow for an in-depth understanding of how disabilities influence the health needs for individuals and their families.

## 1.3 Objectives

There are two primary research objectives that this thesis achieved:

1. To examine the health utilization trends of the family members of disabled Newfoundlanders to determine if disabled individuals and their family members utilize health care services at higher rates than families not affected by disability.
2. To examine the number of deaths for the family members of disabled individuals compared to families not exposed to disability.

## 1.4 Outline

Following the introductory chapter, the remainder of the thesis is organized as follows: Chapter 2 summarizes current literature on consequences of disability for the disabled individual and their family. Chapter 3 describes the methodology used in this study including a description of the data sources, study population, variables, and methods of analysis. Chapter 4 presents the results by describing the study population and an analysis of health outcomes for family members who are exposed to disability (and as such likely put in a caregiver role) as compared to those living in households that are free of disability. Chapter 5 discusses the results by drawing on previous research in the area for comparison and contrast. There is also a discussion of the study's strengths and limitations. Chapter 6 provides a summary of the findings and conclusions of the study as well as a discussion of the potential for future research in the area.

# CHAPTER 2

# LITERATURE REVIEW

The objective of this chapter is to provide a comprehensive literature review of the relevant and pertinent evidence on how disability affects families. This is followed by a discussion of how administrative data can provide evidence regarding the broadening impact of disabilities in the province of Newfoundland and Labrador.

A review of the available literature on the causes and consequences of disability was conducted. The research question, assessing the health outcomes of disability on families, required a strategic literature search to encompass sources that reflected the health outcomes related to living with someone with a disability. Relevant articles from the review were identified by the use of key search words such as “disability,” “consequence,” and “health” among other terms. The search terms were also altered to reflect the article search index being utilized. Only those articles that discussed disability health outcomes after disability incurred or social consequences of disability were selected for review.

## 2.1 Introduction

Disability has been recognized as a growing concern for the Canadian population as it is one of the primary causes of poor health and mortality across the country. As a long-term health concern, disability affects nearly 3.8 million Canadians and the burden of disability on the Canadian health care system is significant. Disability can be a difficult term to define, as there are varying conceptions of what comprises disability (Statistics

Canada, 2008). To avoid confusion disability will be identified as any difficulty performing tasks as the result of a long-term condition or health-related problem that causes a limitation in daily activities (Statistics Canada, 2014).

Kress & Herridge (2012) performed a review of the pertinent literature available on the medical and economic impacts of disability premised on the notion that as medical technologies improve so do the number of survivors of critical illness or disability. Improvements in the health care sector have translated into longer life expectancies and higher rates of disabilities across the country (Institute for Health Metrics and Evaluation, 2013). The 2010 Global Burden of Diseases, Injuries, and Risk Factors Study, conducted by the Institute for Health Metrics and Evaluation (2013), has stated that disease burden is becomingly increasingly defined by disability. Kress & Herridge (2012) note that there is an increase in the number of mood disorders, psychological impairments, financial strain, and/or caregiver burden that result from an increase in the number of disabled individuals.

The burden of disability is especially difficult for family members who often act as caregivers for their disabled family member. Family caregivers are subject to potential burnout, reduced health-related quality-of-life, or caregiver burden, which may lead to the development of detrimental health conditions (Kress & Herridge, 2012). Man (2002) interviewed 50 families who provided caregiving services for a brain-injured loved one. Caregivers often found themselves overwhelmed by the needs of their family members, as they did not have sufficient training, time, or energy for the role. The caregivers also often reported neglecting their own health when caring for family members.

Furthermore the pain, suffering, and reduced quality of life associated with caring for a disabled family member are enormous detriments to one's well being (Man, 2002) and familial satisfaction (Williamson, Elliott, Berry, Underhill, Stavrinos, & Fine, 2013). Williamson et al. (2013) recruited brain-injured individuals, identified by their hospital records, from a larger longitudinal study assessing adjustment following disability. Consenting participants were asked to complete a set of questionnaires as well as telephone interviews that sought information concerning family satisfaction and health-related quality-of-life. Individuals who reported high levels of functional impairment also reported lower family satisfaction and health-related quality-of-life.

## 2.2 The Effect of Disability on Families

There is growing evidence suggesting that the impacts of disability extend beyond the disabled individual to those around them. Families, in particular, may be largely impacted by the disability of a family member, as disability is a shared experience among those in the family. The disability of a loved one may induce financial strain, lifestyle changes, or relationship dissatisfaction (Boden, 2005; Earle & Heymann, 2012; Kress & Herridge, 2012). Disability in the family may also equate to changing family roles (Whiting, 2014) if the disabled individual requires caregiving. Adjusting to life with a disability can be especially difficult for the family members of a disabled individual as most of their attention is focused on the affected individual.

### 2.2.1 Familial Health Consequences

Living with a disabled family member can have detrimental physical and mental health implications for other family members (Whiting, 2014), especially if they neglect their own health (Kress & Herridge, 2012). This is especially true for family members in a caregiver role as the burden of caregiving can produce a stressful environment (Canadian Mental Health Association, 2014). Stress has been identified as a risk factor for a myriad of health concerns including; heart disease, mental illness, substance abuse, insomnia, and headaches (Canadian Mental Health Association, 2014). In this context, exposure to disability has the potential to manifest ill health in family members.

Stress induced by disability can become a chronic and serious ailment for the family unit (Gelkopf & Roe, 2014). Gelkopf & Roe (2014) reviewed the outcomes of caregiving using 43 different instruments, such as the Zarit Burden Interview, and found stress to be highly associated with caregiving. Disability can cause psychological, cognitive, and behavioral changes in the individual that may produce an enduring and significant family stressor (Kress & Herridge, 2012; Crompton, 2010). This stress may be amplified if a family member is met with the burden of caregiving as caregivers can find themselves overwhelmed by the needs of their disabled family members (Kress & Herridge, 2012). Although caregiving is usually seen as manageable for families (Man, 2002), it can put additional stress on available resources: financial, time, and support (McDougall, Buchanan, & Peterson, 2014) available to the family (Stabile & Allin, 2012). Thus caregiving may produce conflict within the family (Hartley et al., 2010; Singleton, 2012; Urbano et al., 2007) as caregivers experience frustration, stress, emotional and financial hardship, and burnout following the onset of a disability (Hwang & Kearney, 2014; Kress & Herridge, 2012).

There is also evidence suggesting that elevated health risks in stressful situations can be transferred to children from parents and vice versa through crossover effects (Whiting, 2014; Bakker, Demerouti, & Burke, 2009). Crossover effects can cause family members to experience similar levels of stress through common stressors paired with communication or interaction among the family members (Bakker, Westman, & Schaufell, 2007). An example of this crossover effect was explored in a 2009 study by Gorman, Fitzgerald, & Blow. Gorman et al. (2009) studied the impact of disabling injuries in veterans on child development using a meta-ethnographic literature review. With regards to health, several sources documented the ill effects of parental illness on a child's health. The Adverse Childhood Experiences study observed several potential categories of adverse childhood events including exposure to physical or sexual abuse, violence against a parent, living with substance abusers, imprisonment, or mental illness. The Adverse Childhood Experiences study found that as the number of adverse events experienced in childhood increased so did the elevated health risks; such as poor nutrition, delayed development, or increased medication use; for the child later in life. The child's health could also be affected by the level of pain his/her parent experiences. The self-reported pain level of a parent was found to be an indicator of emotional distress and somatic symptoms for children (Gorman et al., 2009) as well as self-perceived pain in children (Jamison & Walker, 1992; Mikail & von Baeyar, 1990; Rickard, 1988). A 1992 study conducted by Jamison & Walker found that the parents of children with chronic pain had significantly higher reports of self-perceived pain, emotional distress, and disability than parents of children who did not report having chronic pain symptoms.

The stress of coping can be dealt with in a multitude of ways meaning most families will not cope with disability in the same way (Man, 2002). Some families may opt for support from other family members or friends (Man, Tam, & Li, 2003) while others internalize their concerns. The coping strategy or mechanism that one chooses when dealing with a health condition can also have an effect on how well they cope (Man, 2002). Man (2002) interviewed 50 families who provided caregiving services for a brain-injured loved one. The caregivers were interviewed in relation to their coping methods and mechanisms. It was found that while all families differed in their coping mechanisms not all families coped well with the news of the injury (Man, 2002). Caregivers often found themselves overwhelmed by the needs of their family members, as they did not have sufficient training, time, or energy for the role. The caregivers also neglected their own health when caring for family members. Some families also experienced intense psychological reactions including depression and irritability. However, families who were given information regarding their family member's injury and rehabilitation process felt empowered by the knowledge. Man (2002) suggests empowering family caregivers by supporting them with knowledge and resources that will aid in their coping process.

For the disabled individual family members may either be used as a support system for coping with their disability or avoided because the disabled individual assumes he/she is a burden. Disabilities can cause rifts in families when the affected individual feels isolated (Crompton, 2010). If there is little family support, individuals may report deteriorating relationships and difficulties coping with their condition (Man, 2002; Ponsford et al., 2014). However, those with a strong family support system fare better than those without a strong sense of familial support (Crompton, 2010). Families who actively cope with the presence of disability in the family are said to have a stronger familial resilience (Williamson et al., 2013).

Williamson et al. (2013) found that families with a brain-injured member reported higher family satisfaction in flexible, resilient, and cohesive family environments. Post-disability family satisfaction was also positively correlated with overall well-being. Stronger resilience paired with social support (Crompton, 2010) may potentially buffer the ill health effects of stress induced by disability (Farrell & Krahn, 2014; Williamson et al., 2013). The restorative health effect exhibited by social support (Crompton, 2010; Voigt & King, 2014) should be considered for incorporation into disability rehabilitation plans. Including family members in rehabilitation plans can improve self worth and esteem by improving the physical capacity, personal satisfaction, and overall quality of life for those affected by disability (Williamson et al., 2013). It is preferred to incorporate families into the rehabilitation process so that their psychological needs and feelings can also be addressed (Kress & Herridge, 2012). Family caregivers can be so immersed in care that they neglect their own physical and psychological health status and needs (Stabile & Allin, 2012). Thus it must be stressed how important it is to take time for themselves to avoid burnout (Hwang & Kearney, 2014; Kress & Herridge, 2012).

### 2.2.2 Family Structure Consequences

There is evidence that disabilities cause changes in the family structure with the disability of a spouse or child inciting divorce (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010; Singleton, 2012; Urbano, Hodapp, & Floyd, 2007). A 2010 study conducted by Hartley et al. compared the occurrence and timing of divorce for families with no known disability and those who had a child diagnosed with Autism Spectrum Disorder. Children with Autism Spectrum Disorder were identified for this study from the Adolescents and Adults with Autism study, a longitudinal study that collected data on families who had children diagnosed with Autism Spectrum Disorder from 1998-2004. A random sample and parents from the Adolescents and Adults with Autism study were contacted via telephone and interviewed regarding divorce. Hartley et al. (2010) found that divorce rates were higher for parents of children with Autism Spectrum Disorder (23.5%) in comparison to other families (13.8%). For parents with a child with Autism Spectrum Disorder, divorce rates also remained high throughout the child's adolescence and early adulthood. Meanwhile families with children, who did not report any disabilities, saw a drastic decrease in divorce rates after the child's eighth birthday. Stabile & Allin (2012) also found that caring for a disabled child affected the mother's health detrimentally while placing strain on the parental relationship (Stabile & Allin, 2012). Spouses or partners who cannot or choose not to remain in the relationship cite that the disability placed insurmountable stress, hardship, or financial strain on the relationship (Hartley et al., 2010; Urbano et al., 2007).

Parental disabilities also appear to cause rifts in the parent-child relationship with behavioral, emotional, and social problems for children following disabling injuries

(Gorman et al., 2009; Pessar et al., 1993). Pessar et al. (1993) had brain-injured individuals and their spouses complete questionnaires concerning changes in their child's behavior since the parent's brain injury occurred, changes in the injured parent's behavior or parenting, the parent's psychological health, and any physical functional or disabling impairments experienced by the injured parent. The questions related to instances of the child acting out, relationship problems with the injured parent, or emotional problems for any of the family members. The majority of the families, 22 of 24, reported negative changes in their child's behavior since the time of the parent's injury; 23 of the 24 families reported there were negative changes in the injured individual's parental duties and an increased number of relationship problems between children and their parents were reported. These problems may arise from the disruption of the parental relationship during the rehabilitation stage following injury but can be sustained for years by the child if the injury persists into a long-term disability.

Though there is evidence to support these effects, the overall impact of disability on the family structure is not yet defined, as not all families are privy to the same detrimental effects.

### 2.2.3 Familial Work Consequences

If a disability is severe enough to alter one's daily routine, it may mean altering the employment circumstances of their family members. Individuals may be required to alter their work responsibilities to assimilate their disability into their employment or care for a disabled loved one (Earle & Heymann, 2012; Stabile & Allin, 2012). In some contexts, individuals may need to take time off of work (Earle & Heymann, 2012) to care for a disabled family member recovering from symptoms associated with their disability or they may be forced to resign from their employment to fulfill a full-time caregiving role  (McDougall et al., 2014; Stabile & Allin, 2012).  McDougall et al. (2014) conducted semi-structured interviews with caregivers for intellectually disabled individuals in rural environments. The intent of the interviews was to learn how being a primary caregiver impacted their occupational engagement outside of their caregiving role. It was presumed that their caregiver role would overshadow other employment roles or opportunities. As predicted, caregivers revealed that their duties as a caregiver limited their opportunities to progress other occupational aspirations, to develop or adapt to current occupations or caused them to cease working altogether.

Stabile & Allin (2012) reviewed the literature on the costs associated with childhood disabilities and found that parental employment circumstances were a sizable indirect cost to both the family and society. Mothers, more so than fathers, would reduce their hours of work outside the home or discontinue working altogether when their child had a disability. A review of the long-term costs focused on the future economic implications for the child. As disabilities have the ability to compromise a child's development and schooling, later employment opportunities could be compromised. This effect could be especially detrimental for children with mental disabilities in comparison to those with physical disabilities.

Any or all of these possibilities may equate to changes in one's income producing financial strain (Earle & Heymann, 2012). Earle & Heymann (2012) assessed the national US Work, Family and Community Nexus survey data to identify special needs caregivers who were employed. Those caregivers comprised a sample population who were asked if they had lost wages or income due to caregiving responsibilities. Approximately 21% of the sample reported that they had lost wages to perform their caregiving duties. Earle & Heymann (2012) also found that as the number of individuals who required care increased so did the likelihood of the loss of wages.

## 2.3 Using Administrative Data

Due to the amount of information captured by administrative databases, they are commonly utilized for health research purposes. Administrative data is the routine information collected for non-research purposes (Evans, Grella, Murphy, & Hser, 2010). Administrative data is electronically collected from hospitals, physician's offices, clinics, and other spaces where health services are provided (Iezzoni, 2002). This information is collected for patient management, care and resource tracking and billing (Evans et al., 2010). The breadth of information available in such databases provides a plentiful and accurate source for potential health research data (Nadathur, 2010).

Administrative databases linked with a unique identifier, can also provide a more comprehensive set of data than a single administrative data source (Spangler, Chaudhari, Barlow, Newton, Inge, Hujoel, Genco, & Reid, 2012). Linked data can track patient information throughout multiple sources of data allowing for an inclusive observation of one's health status and utilization. This data can then provide a snapshot of a large population of patient data with minimal resources and efforts required (Iezzoni, 2002). Administrative databases also tend to be reliable sources of data as they are objective and, generally, factually accurate.

Administrative databases do have some disadvantages with regards to their involvement in health research. As the information is collected for administrative purposes, rather than research, it may lack contextual information (Spangler et al., 2012), such as diagnosis severity or health related quality of life. There may also be issues concerning the quality of the data (Iezzoni, 2002), as the researcher has not personally collected or verified the data source. However the linked survey data does address some of these concerns by supplementing the information from the administrative data.

Health surveys, such as the Newfoundland Adult Health Survey, capture a wealth of health information making them an advantageous data source for research. Health surveys are often used to collect a variety of health related information including health status, health conditions, lifestyle choices, and disease prevalence at regional, provincial, or national levels (Statistics Canada, 2015) allowing for comparison. The surveys also typically have high response rates and standardized collection processes. Health surveys can also be tailored to retrieve data for specific population health trends (Iezzoni, 2002).

However there are some disadvantages to utilizing data collected in health surveys. Data is often meant to be a snapshot of health information and only collects data over a short period of time. There are some health surveys that do collect information on a recurring basis, such as the annual Canadian Community Health Survey, (Statistics Canada, 2015) so that the results can be compared from year-to-year but not all health surveys recur year-to-year. Health surveys may also not be representative of an entire population due to exclusion criteria, such as Canadian Aboriginal communities, in health surveys (Statistics Canada, 2015). Additionally, participants in health surveys may not provide factual or honest information in the surveys if it includes unfavorable or private information (Iezzoni, 2002).

Health surveys and administrative databases are often used in conjunction in research as they complement one another. Unique identifiers, such as provincial Medical Care Plan numbers in Newfoundland and Labrador, linked with administrative data allows patient data to be observed over time and across various health care settings (Iezzoni, 2002; Spangler et al., 2012). Health behaviors, lifestyle choices, or perceived health status can be compared to actual health care service utilization to research population health trends.

## 2.4 Measuring Health Outcomes

Health outcomes can be defined as changes in health status due to a health care intervention (Canadian Institute for Health Information, 2012B). Interventions may include but are not limited to, prescriptions, surgeries, hospital stays or treatment regimes. Evaluating a health intervention once it has been instituted or utilized allows providers, policymakers, and patients to consider the effectiveness and efficiency of such an intervention (Canadian Institute for Health Information, 2008). To effectively evaluate health outcomes, the metric should reflect the population's physical, social, and mental well being at any given time (Robert Wood Johnson Foundation, 2010).

Patient-related outcomes usually fall into one of three categories: health status, health-related outcomes, and non health-related outcomes (Canadian Institute for Health Information, 2008). The main outcome of interest usually involves a change in health status following a health intervention. This could be observed through well-being indicators, such as perceived health, or standardized health scores, such as a Health Utility Index score, which can be compared pre and post intervention (Canadian Institute for Health Information, 2012A). If changes in health status cannot be directly measured then health-related measures may be observed instead of health status. These indirect measures include hospital admissions or readmissions, infection rates or test results that denote changes in one's health (Canadian Institute for Health Information, 2012B). Non health-related outcomes, such as patient satisfaction, can also be collected when assessing the function and efficiency of an intervention (Canadian Institute for Health Information, 2008).

Early research on the topic of health outcome evaluation used the concept of the five D's as outcome assessors. The five D's were death, disability, disease, discomfort, and dissatisfaction (American College of Emergency Physicians, 2013; Landry, 1992). Three of these assessors; death, disability, and disease; will be evaluated in this study. Conversely, discomfort and dissatisfaction are representative of the non health-related outcomes and will not be assessed in this study.

Using administrative data to assess health outcomes is not a new concept. As previously noted, administrative data is readily available, consistently updated, and is less expensive than collecting primary data (Iezzoni, 2002; Keating, Landrum, Landon, Ayanian, Borbas & Guadagnoli, 2003). The health outcomes measured using administrative data depend on the nature of the study, who is performing the research, and what outcomes they hope to observe (Iezzoni, 2002). Health and non-health related outcomes are typically evaluated to determine the effectiveness of programs, treatments, medications, or health system performance (Canadian Institute for Health Information, 2014B). Studies that focus on the health outcomes for patients typically focus on the patient's interaction with the health care system.

Previous studies have observed the number of times an individual visits a physician or health professional via physician claim data (Cameron et al., 2008; Canadian Institute for Health Information, 2014B; Wideman & Sullivan, 2010). Other studies have combined the number of physician claims with the number of hospital discharges or separations (Cameron et al., 2008; Knight et al., 2009; Stroka, 2014; Wideman & Sullivan, 2010) using hospital administrative data. Hospital administrative data also provides information regarding the total number of hospitalization days, which can be used to determine severity of the condition (Cameron et al., 2008; Canadian Institute for Health Information, 2014B). Past research endeavors have also combined administrative data with self-reported health status, pain levels, medication use (Stroka, 2014; Wideman & Sullivan, 2010), and psychological distress (Wilson, Derrett, Cameron, Samaranayaka, Davie & Langley, 2013). The combination of self-reported data and administrative data provides a more comprehensive understanding of the interaction between health behaviors and the health care system.

### 2.5 Summary of Literature Review

The growing number of disabilities in Canada is a concern for individuals, families, the Canadian health care system, and the general public (Statistics Canada, 2014). As previously discussed in this chapter, there is evidence indicating that those with disabilities have worse health and social outcomes than their non-disabled counterparts. There is also growing evidence indicating that the family members of disabled individuals may also suffer from detrimental health outcomes. However, this is less well established. Using linked survey and administrative data will allow for the recognition of disability within a family unit as well as the observation of longitudinal health trajectories to examine the extent to which family members health is affected by the disability of a loved one.

# CHAPTER 3

# METHODS

This is a retrospective cohort study that utilized the previously linked Newfoundland Adult Health Survey data and the Medical Care Plan fee-for service claims, Clinical Database Management System, and Mortality Surveillance System databases. The linked survey and administrative data arose from a research project conducted in 2010 by the Newfoundland and Labrador Centre for Health Information in partnership with the Division of Community Health & Humanities at Memorial University of Newfoundland. This study uses linked data to assess the effect of exposure of disability on familial health outcomes, allowing for an in-depth understanding of how disabilities are associated with health needs for individuals and their families.

## 3.1 Data Linkage Process

In 2010 the Division of Community Health and Humanities at Memorial University requested that the Newfoundland and Labrador Centre for Health Information build a linked dataset from the 1995 Newfoundland Adult Health Survey responses and administrative data. The project was entitled, *15 years on- A follow up of the 1995 Newfoundland Adult Health Survey using administrative data*, and aimed to create a linked database for health research in the province. The product of this request was a linked database consisting of information from the Newfoundland Adult Health Survey, the Medical Care Plan fee-for-service database, the Clinical Database Management System, and the Newfoundland and Labrador Centre for Health Information Mortality

Surveillance System. This population-based database linked 15 years of successive data, from 1995- 2010, and was built with the intention of becoming a longitudinal database for future research proposals or projects, such as this. The linkage process also involved de-identifying the data before release.

As the data was housed at the Newfoundland and Labrador Centre for Health Information an employee of the Centre completed the data extraction and de-identification process before releasing the data. The de-identification process removed the personal identifier, the provincial Medical Care Plan number, from the survey and administrative datasets and replaced it with a new identifier unique to this study. This new unique identifier was identical for the survey and administrative datasets allowing the datasets to be linked (Newfoundland and Labrador Centre for Health Information, 2015). The de-identification process was a necessary procedure, before releasing the data, to ensure that individuals could not be identified in the Newfoundland Adult Health Survey or provincial health administrative data.

## 3.2 Data Sources

### 3.2.1 The Newfoundland Adult Health Survey

The Newfoundland Adult Health Survey was completed in 1995 as part of a larger project, the Newfoundland Panel of Health and Medical Care, with the primary goal of assessing the accessibility and variation of care across the island portion of the province (Segovia, Edwards, & Bartlett, 1999). Given the known relationship between health status and health care utilization, the study was initiated to assess the demographic characteristics, health status, health practices, and health care utilization practices.

The Newfoundland Adult Health Survey employed a cross-sectional, random telephone survey to the island portion of the province. The survey sample was selected by random digit dialing, using a computer program that included phone numbers provided by the provincial telephone company to generate phone numbers for each prefix. At the time of the survey in 1995, 98% of Newfoundland had telephone access and were potential participants in the survey sample population (Segovia, Edwards, & Bartlett, 1997). However, the survey required telephone access so those without access to a household telephone were not eligible to participate. Non-institutionalized Newfoundland residents, 18 years of age or older, were eligible to participate. Anyone younger than 18 years of age was excluded from participating. RCMP members, members of the armed forces, and foreign students were also excluded because they were not covered by the provincial health care plan. The survey was reserved to residents of the island portion of the province so Labrador residents were excluded from participating in the study.

Eligible participants were contacted by telephone and asked to provide information to the interviewer to complete a household information form. The household information form collected data on family composition, changes of address, family members in nursing homes, and deaths in the three years prior to the beginning of the survey. The survey was then administered via telephone to 11,789 adult residents, 18 years of age or older. Multiple responses from a single household were allowed for up to nine individuals. Participants were also asked to provide their consent for the use of their survey information and medical utilization data via their provincial Medical Care Plan number (Segovia et al., 1999). There were 9,237 Newfoundland Adult Health Survey participants who provided their Medical Care Plan number with consent so that their health information could be used in future health research.

The study provided a plentiful source of data, specific to the Newfoundland population, which can be applied to present health studies. If individuals reported that they were disabled during data collection ("Are you now suffering from any disability? [A condition that stops you from doing your routine activities]") (Segovia, Edwards, & Bartlett, 1996), linking their health records and utilization rates, via their Medical Care Plan number, would allow for observations regarding health care utilization over time. The survey also contained a household identification key that could be used to link health status and behavioral information for up to nine family members, who were Newfoundland residents aged 18 or older, who also participated in the survey. This data source will allow for a longitudinal analysis of the effects of disabilities to be analyzed in terms of evolving health status. Utilizing this already established data set for assessing the effects of disabilities will provide further insight on how these effects of disability translate to families and the health status of an individual.

### 3.2.2 Medical Care Plan Claims File

In accordance with the Canada Health Act, the province of Newfoundland and Labrador provides a health insurance plan to its residents at no cost. At the point of provision, the Newfoundland and Labrador Medical Care Plan provides a unique identification number to each resident creating a database of provincial fee-for-service physician visits.  The Medical Care Plan claims file database consists of fee-for-service physician billing claims specifying demographic and clinical information for visits to fee-for-service physicians in the province. For the purposes of this study, the Medical Care Plan number, age, sex, date of service, fee code, and the provider's specialty code were extracted from the database. More visits to family doctors or more visits to specialist physicians per-person are interpreted to be indicative of poorer health. However it is important to note that only services submitted by fee-for service physicians can be obtained from the Medical Care Plan database, as salaried physicians do not submit claims.

The Medical Care Plan data from 1995-2010 was extracted and linked to the Newfoundland Adult Health Survey data by an employee of the Newfoundland and Labrador Centre for Health Information.

### 3.2.3 Clinical Database Management System

The Clinical Database Management System collects demographic, clinical, and administrative data from hospitals when patients are discharged from inpatient or surgical day services. The system maintains information on hospital services received by in the province of Newfoundland and Labrador including Newfoundland and Labrador residents as well as out-of-province patients. Though there is a wealth of information available in the Clinical Database Management System databases, only the unique identifier number, age, sex, date of admission, date of discharge, and total hospitalization days were extracted from the database for this study. The number of hospital separations and number of total hospitalization days per-person were used as indicators of health with more hospital separations and hospitalization days representing poorer health

The extraction of the Clinical Database Management System was performed and compiled by an employee of the Centre.

### 3.2.4 Newfoundland and Labrador Centre for Health Information Mortality Surveillance System

The Newfoundland and Labrador Centre for Health Information Mortality Surveillance System is an administrative database containing demographic, clinical, and administrative data on all deaths that occur in the province. The age at death, date of death, cause of death, and Medical Care Plan number are some of the variables collected for the database. However, for this study, only the unique identifier or Medical Care Plan number, age, and date of death were extracted from the database. An employee of the Newfoundland and Labrador Centre for Health Information was responsible for the de-identification, and extraction of this data when access was granted.

## 3.3. Study Population

The study population is exclusive to adult residents from the island portion of the province. The 1995 Newfoundland Adult Health Survey collected household health information from Newfoundland residents who were 18 years of age or older. The Newfoundland Adult Health Survey initially planned to sample 14,000 residents, to allow for non-eligible households or out-of-service numbers, with the intention of achieving a sample of approximately 12,000 residents. Residents were also asked to sign a letter of consent for use of their Medical Care Plan number to allow access to health utilization data.

The survey was limited to the residents living on the island portion of the province. Labrador residents were excluded from the study due to as the methodology and design of the Newfoundland Adult Health Survey would have had to be modified to account for Labrador's dispersed population. Children younger than 18 years old, were also excluded from the survey as interviewing children would have required specialized interviewing techniques and analyses. For simplification of the study design, methodology, and data analysis only adult residents of Newfoundland were included in the Newfoundland Adult Health Survey.

Although 9,237 Newfoundland Adult Health Survey participants provided their Medical Care Plan number not all 9,237 cases could used for this study. Some individuals provided incorrect Medical Care Plan numbers and other individuals could not be re-linked following the issuing of new Medical Care Plan numbers, likely due to emigration from the province since the time of the survey.  The study sample consisted of 7,791 participants from the Newfoundland Adult Health Survey who had provided their Medical Care Plan number and written consent for access to administrative health databases. For individuals who provided this consent, the Medical Care Plan number was used to link the Newfoundland Adult Health Survey data and the administrative health databases.

## 3.4. Required Approvals

### 3.4.1 Health Research Ethics Authority Approval

All health-related research in the province of Newfoundland and Labrador must be reviewed and approved by the Health Research Ethics Authority. This study was submitted for review and approved on August 6, 2013 (Reference number 13.182) (Appendix A).

### 3.4.2 Newfoundland and Labrador Centre for Health Information Secondary Uses Committee Approval

As the study necessitated secondary use of an already existing database in the province, approval to use the database was mandatory. The database, the linked Newfoundland Adult Health Survey data, was linked and housed by the Newfoundland and Labrador Centre for Health Information. In the data linkage process, described above, the Newfoundland and Labrador Centre for Health Information took responsibility for housing the data and agreed to subject future requests for data use to its Secondary Use Committee. A formal application was submitted to the Secondary Use Committee and approval was given on November 6, 2013 (Reference number IM00050975) (Appendix B).

### 3.4.3 Department of Health and Community Services Approval

The use of provincial Medical Care Plan data, for research or surveillance is subject to the approval of the provincial Department of Health and Community Services.

Under the legislation of the Medical Care Insurance Act and the Personal Health Information Act, the department is responsible for protecting the health information of its residents. To ensure that the appropriate privacies and confidentialities associated with this information are maintained, research endeavors wishing to utilize this information must apply for approval.

Copies of all ethical applications, approvals, and a proposal were submitted as application to the Privacy Manager of the Department of Health and Community Services. The application was then forwarded to the Minister of Health's office for final approval. The Deputy Health Minister, Bruce Cooper, granted approval on December 13, 2013 (Appendix C).

## 3.5 Study Variables

The Newfoundland Adult Health Survey, Medical Care Plan fee-for-service, Clinical Database Management System, and the Mortality Surveillance System databases all contained a number of variables that were pertinent to the purpose of this study. The data dictionaries from all of the above databases were reviewed to ensure all pertinent variables were available for analyses. The goal of the study was to determine the health effects of disability on the family unit.

The Newfoundland Adult Health Survey data contained information on both an individual's health, including whether one was disabled or not, as well as health practices, geography, employment, education, age, and personal relationships. The main predictor variables and a number of control variables, described in the following sections, were requested from the Newfoundland Adult Health Survey dataset. The main predictor or independent variables were disability exposure burden and individual's own disability score. The key predictor variable in the study was disability exposure burden as it was the variable that captured how much disability there is in the household, independent from individual disability. The disability exposure burden variable was used to understand the extent to which disability in the household, independent from individual health status, impacts on health outcomes. Additional variables in the study included; sex, age, rural/ urban, body mass index, education, employment status, marital status, number of family members, number of close relatives, number of close friends, and smoking and drinking status.

The dependent, the health outcome variables, were captured from the Medical Care Plan, Clinical Database Management System, and the Mortality Surveillance System databases to assess health service utilization rates and outcomes. The outcome variables were the number of physician claims variable from the Medical Care Plan database, the number of hospital separations from the Clinical Database Management System database, the total hospitalization days variable from the Clinical Database Management System database, and death from the Mortality Surveillance System.

### 3.5.1 Main Predictor Variables

**Individual Disability Score-** Newfoundland Adult Health Survey participants were asked to self-report whether or not they were disabled in the original Newfoundland Adult Health Survey data ("Are you now suffering from any disability [A condition that stops you from doing your routine activities]?") (Segovia et al.,1996). This variable was used to identify disabled individuals in the study sample. Individuals who identified as disabled were categorized as disabled individuals while other household members, with the same household identification number, were categorized as family members.

It was hypothesized that the more severe a disability was, the more severe the health consequences for the family. The individual disability score variable was created to determine if disability severity had an effect on familial outcomes.

Five disability categories were developed, using SPSS 21.0 (Statistical Package for the Social Sciences), based on whether or not an individual was disabled and the number of functional impairments individuals reported in the Newfoundland Adult Health Survey. In the survey there were questions on seven activities on daily living that individuals could report being able or unable to do. These were bathing themselves, dressing themselves, going to the bathroom alone, continence, eating without help, walking outside without help, and climbing stairs.

If an individual reported that they were unable to perform one of the aforementioned activities it was considered a functional impairment and they were assigned a score of one. Scores from each impairment category were added together to get a range of functional impairment scores between zero and seven. An individual's disability was categorized into one of five categories based on whether or not the individual was disabled and the number of functional impairments or the severity of their disability (See Table 3.1 *Disability Score Descriptions).* This variable is a categorical variable; the categories were 0, 1, 2, 3, and 4 (See Table 3.1).

Table 3.1 *Disability Score Descriptions*

| **Disability Score** | **Description** |
|---|---|
| 0 | Not Disabled with No Functional Impairment |
| 1 | Not Disabled with a Functional Impairment |
| 2 | Disabled with No Functional Impairment |
| 3 | Disabled with One Functional Impairment |
| 4 | Disabled with Two or More Functional Impairments |

**Disability Exposure Burden**- To capture how much disability exposure there is in the household, separate from an individual's own disability, a variable measuring the burden of disability exposure was created. The amount of burden projected onto each member in the family unit due to disability exposure was quantified by adding the disability scores of each individual household member. The addition of these scores gave the family's total disability score, ranging from 0-10. A family disability score above four indicated that more than one individual in the family was affected by disability.

Subtracting an individual's own disability score from the familial disability score quantified the subjective disability exposure burden on each individual family member, ranging again from 0-10. This variable, named disability exposure burden, was created to measure the extent to which exposure to disability and potential caregiving increases the risk of adverse health outcomes. This variable, measured at the individual level, allowed the amount of burden placed on each individual in the family, due to disability, to be measured. It is a categorical variable with the following categories; 0, 1, 2, 3, 4+.

Table 3.2 *Disability Exposure Burden Score Descriptions*

| **Disability Exposure Burden Score** | **Description** |
|---|---|
| 0 | No Exposure to Disability and No Disability Exposure Burden |
| 1 | Exposed to Disability with a Disability Exposure Burden Score of One |
| 2 | Exposed to Disability with a Disability Exposure Burden of Two |
| 3 | Exposed to Disability with a Disability Exposure Burden of Three |
| 4+ | Exposed to Disability with a Disability Exposure Burden of Four or Higher |

### 3.5.2 Outcome Variables

In this study Newfoundland Adult Health Survey participants were retrospectively followed from 1995, the time of their participation in the Newfoundland Adult Health Survey study, to 2010. As many interactions with the provincial health care system occurred during the 15-year period not all details of health care utilization could be studied. The health outcomes observed in this study were limited to the number of hospital separations, the respective total hospitalization days, the number of physician visits (General Practitioner and Specialist), and instances of death. All health outcome measures were per-person rates.

The aforementioned health outcomes were selected to provide an overview of the type and number of interactions that individuals had with the provincial health care system. The health outcomes are also being used as a general indicator of overall health status.

The health outcomes were tabulated using provincial administrative datasets that were linked to Newfoundland Adult Health Survey participant data, when a provincial health care number was provided. The usage of most services in the provincial health care system are electronically recorded when an individual utilizes a service. The provincial Medical Care Plan number also acted as a unique identifier allowing health care utilization data to be compiled per an individual basis. However, information could only be compiled for provincial fee-for-service claims given that or out-of-province claims and visits to salaried or Alternate Payment Plan physicians were not included in the data or subsequent analysis.

Health outcomes variables, derived from the administrative databases (See Table 3.2 *Health Outcome Variables from Administrative Databases)*, were included as the dependent variables to determine how disability in a family affects health (Cameron et al., 2008; Canadian Institute for Health Information, 2014B; Wideman & Sullivan, 2010). It was presumed that higher health service use rates, via hospital or physician visitations, indicated worse health outcomes, as healthier individuals would not utilize health care services as much. Health care service use was measured using an individual's number of hospital discharges, total hospitalization days, and number of physician visits. Death rates were also observed as an additional health outcome measure.

Table 3.3 *Health Outcome Variables from Administrative Databases*

| **Variable** | **Description** | **Database** | **Variable Type** |
|---|---|---|---|
| Number of Hospital Visits | The total number of hospital visits, per person, from 1995-2010 | Clinical Database Management System | Discrete (count) |
| Total hospitalization days | The total number of days spent in a hospital, per person, from 1995-2010 | Clinical Database Management System | Discrete (count) |
| Number of Physician Visits (General Practitioner and Specialist) | The total number of physician visits, per person, from 1995-2010 | Medical Care Plan | Discrete (count) |
| Death | Deaths that occurred from 1995-2010 | Mortality Surveillance System | Binary |

**Number of Hospital Visits/ Separations**- The total number of hospital separations variable measured the total number of hospital visits, per person, from 1995-2010. This is a discrete variable that ranged from 0-111 visits, per person. Each visit recorded in the Clinical Database Management System dataset, from 1995-2010, by an individual patient was grouped together via the unique identifier or subject id. The variable was used to measure health service utilization.

**Total hospitalization days**- The total hospitalization days variable was another discrete variable used to measure health service utilization. The total number of days spent in a hospital setting from 1995-2010 was totaled from the Clinical Database Management System dataset. The vast majority (90.0%) of hospital stays lasted less than 65 days with the total hospitalization days, per person, ranging from 0-1,010 days, after the removal of outliers. The distribution of the discrete variables in the dataset was used to identify outliers, values outside three standard deviations of the mean. Fifty-four values for the total hospitalization days were identified as outliers in the data and removed.

**Number of Physician Visits-** This variable was the total number of physician visits, General Practitioner and Specialist, from 1995-2010. Physician specialty codes were used to distinguish between visits to a General Practitioner or a Specialist physician. The total number of visits, regardless of the type of physician, was totaled for analysis. The total number of visits was also totaled based on the type of physician, General Practitioner and Specialist. Although there was a large range in the number of visits to a physician, the vast majority of individuals had fewer than 100 visits to either over this period of time. This was a discrete variable used to measure health service utilization.

**Death-** This variable, derived from the Mortality Surveillance System, was used to indicate if an individual had died between 1995-2010. It was a binary variable coded 1 for yes and 0 for no.

### 3.5.3 Control Variables

**Sex-** The sex variable was derived from the Newfoundland Adult Health Survey dataset. This variable was included to determine if one sex would experience poorer health outcomes than the other. This was a binary variable coded 1 for females and 0 for males.

**Age-** Age, at the time of the 1995 survey, was recorded in the Newfoundland Adult Health Survey dataset. This variable was used to determine if age affected health outcomes. Age is an integer, ranging from 18 to 100 years of age, reported in the Newfoundland Adult Health Survey.

**Rural/ Urban-** The rural/ urban variable, from the Newfoundland Adult Health Survey dataset, was used to determine the potential effect of proximity to health care services. Newfoundland was split into three areas including St. John's, the urban corridor (smaller cities and towns) and all other small or isolated communities. Telephone prefixes were used to determine which of the three areas a participant resided in. St John's and the urban corridor were defined as urban and the remainder of the province was considered rural. The rural/ urban variable used in the study was a binary variable coded 1 for rural and 0 for urban.

**Body Mass Index-** Body mass index is a measure used to classify overweight and obesity. It is calculated by dividing an individual's weight, in kilograms, by the square of their height, in meters ($kg/m^2$) (World Health Organization, 2014C). The World Health Organization (2014C) defines a body mass index greater or equal to 25 as overweight and a body mass index greater than or equal to 30 as obese.

The body mass index variable used in the regression analysis was a categorical variable used to determine the effect of weight on health outcomes and health service utilization. The body mass index variable was created using the height and weight variables from the Newfoundland Adult Health Survey dataset. Newfoundland Adult Health Survey participants were asked to self report their height and weight; these values were then used to calculate body mass index. Body mass index values were then placed into one of six categories derived from the World Health Organization's (2014C) classifications. The categories were; body mass index equal to or less than 20 (underweight), body mass index greater than 20 but less than 25 (normal weight), body mass index greater than 25 but less than 30 (overweight), body mass index greater than 30 but less than 35 (obese I), body mass index greater than 35 but less than 40 (obese II), and body mass index greater than 40 (obese III) (See Table 3.3 *Body Mass Index Category Score Descriptions*).

Table 3.4 *Body Mass Index Category Score Descriptions*

| **Body Mass Index Category** | **Description** |
|---|---|
| Underweight | Body Mass Index Score less than 20.0 |
| Normal weight | Body Mass Index Score between 20.0- 24.9 |
| Overweight | Body Mass Index Score between 25.0- 29.9 |
| Obese I | Body Mass Index Score between 30.0- 34.9 |
| Obese II | Body Mass Index Score between 35.0- 39.9 |
| Obese III | Body Mass Index Score greater than 40.0 |

**Education-** The Newfoundland Adult Health Survey included four variables related to education. These were: highest grade completed in school (" What was the last grade you completed in school?") (a discrete variable ranging from 0-13); if there was any education beyond high school completed ("Do you have any education beyond high school?") (a binary variable [yes/no]); what kind of education beyond high school had been completed (" What kind of education is it?") (a categorical variable [trade school, diploma courses, university]); and whether or not they had received an university degree ("Do you have a university degree?") (a binary variable [yes/no]) (Segovia et al.,1996).

Prior to the regression analysis the education variables was recoded into three new variables: completed less than high school (a binary variable coded 1 for yes and 0 for no), completed high school (a binary variable coded 1 for yes and 0 for no), and completed some post-secondary education (a binary variable coded 1 for yes and 0 for no).

The education variables were used to determine if socio-economic status had a protective effect on the health outcomes of disability.

**Employment Status-** Employment status was a categorical variable in the Newfoundland Adult Health Survey dataset. Survey participants could classify themselves as ("Not including voluntary work, are you now…"); working year round, seasonally employed, looking for employment, laid off, on strike, retired, unable to work, keeping house, studying, or other (Segovia et al., 1996). These categories were recoded in SPSS 21.0 to create three new binary variables; working full-time, working part-time, or not working. Anyone who classified themselves as working year round was considered to be working full-time, anyone who reported they were seasonally employed was considered to be working part-time, and all other categories were collapsed into the not working category. The new binary variables were coded 1 for yes and 0 for no.

Employment status was used for descriptive analysis and to determine if socioeconomic status had a protective effect on the health outcomes of disability.

**Marital Status-** Marital status was a categorical variable derived from the Newfoundland Adult Health Survey dataset ("What is your current marital status?"). Participants could choose from seven categories; married, common-law, living with partner, single, widowed, separated, or divorced (Segovia et al., 1996). The original Newfoundland Adult Health Survey marital status categories were collapsed to create a new binary variable coded as 1 for married (married, common-law, or living with partner) and 0 for not/ no longer married (single, widowed, separated, or divorced).

Marital status was used to determine if being married provided a protective effect against poor health outcomes via higher health service utilization.

**Number of family members-** The number of family members was a variable created in STATA 11.0 using the household identification numbers in the Newfoundland Adult Health Survey dataset. Household identification numbers were clustered together to identify how many individuals were in each household. This was a discrete variable with values ranging between 1-9.

The number of family members was used to determine the effects of social support on health outcomes.

**Number of close relatives-** The number of close relatives was a numerical variable in the Newfoundland Adult Health Survey dataset ranging from 0-60. Newfoundland Adult Health Survey participants were asked to self-report how many close relatives they had ("How many close relatives do you have? These are people that you feel at ease with, can talk to about private matters, and can call on for help.") (Segovia et al., 1996). This was a discrete variable was used determine the effects of social support on health outcomes.

**Number of close friends-** The number of close friends was a numerical variable in the Newfoundland Adult Health Survey dataset ranging from 0-70. Newfoundland Adult Health Survey participants were asked to self-report how many close friends they had ("How many close friends do you have? These are people that you feel at ease with, can talk to about private matters, and can call on for help.") (Segovia et al.,1996). This discrete variable was used determine the effects of social support on health outcomes. The number of close friends was used to determine the effects of social support on health outcomes.

**Smoking-** Newfoundland Adult Health Survey participants, at the time of the 1995 survey, were asked if they were current smokers ("Are you smoking cigarettes now?") (Segovia et al.,1996). This was a binary variable coded 1 for yes and 0 for no. This variable was used to determine if smoking cigarettes affected health service utilization or health outcomes.

**Drinking-** Newfoundland Adult Health Survey participants, at the time of the 1995 survey, were asked if they drank (or were drinking) alcoholic beverages ("Do you drink any alcoholic beverages, that is beer, wine, or liquor?") (Segovia et al.,1996). This was a binary variable coded 1 for yes and 0 for no. This variable was used to determine if alcohol consumption affected health service utilization or health outcomes.

**Drinking and smoking-** This variable was created in SPSS 21.0 using the smoking and drinking variables from the Newfoundland Adult Health Survey dataset, previously mentioned. Newfoundland Adult Health Survey participants who responded “yes” to the smoking variable and the drinking variable were recorded as smokers and drinkers. Participants who responded “no” to both the smoking variable and the drinking variable were recorded as not being smokers and drinkers. This was a binary variable coded 1 for yes and 0 for no. This variable was used to determine if health behaviors, such as smoking and drinking, affected health service utilization or health outcomes.

### 3.6 Data Analysis

Data analysis began with an analysis of the descriptive statistics for the study population. Data was analyzed using SPSS 21.0 and STATA 11.0 statistical software. This analysis generated an overview of the demographic characteristics of the study sample. Univariate analyses were performed using SPSS 21.0 to produce the mean, mode, median, standard deviation, and range for each of the variables in the dataset. The distribution of the dataset was explored to determine if there were any extreme values or outliers in the dataset and to discern broad trends. When outliers were present in the data, values outside three standard deviations of the mean, they were identified and removed. Fifty-four values for the total hospitalization days variable were identified as outliers in the data and removed. Frequency distributions were also produced for each of the discrete variables in the dataset. The frequency distributions were used to recode variables into new categorical variables based on the breadth of distribution, such as the aforementioned individual disability score variable.

Bivariate analyses of the study variables allowed potential relationships among the variables to be observed. Crosstabulations and correlations were produced as forms of bivariate analyses. Those variables that showed potential relationships with the disability exposure burden score variable, the key predictor variable, were chosen to be control variables in the subsequent regression analyses. Disability exposure burden captured the disability that each individual in the family is exposed to, independent of an individual's own disability. Individual disability score was also used as a predictor variable to determine the effect of disability on health service utilization and death rates for the disabled individual and their family members.

The purpose of the study was to determine if exposure to disability leads to higher health service utilization rates or death rates and consequently, poorer health outcomes for the family members of disabled individuals. To investigate the association between disability exposure burden and health outcomes, the predictor or independent and outcome or dependent variables were identified. The independent or predictor variables were the disability exposure burden variable and individual disability score variables. The dependent or outcome variables were the number of hospital visits/ separations, number of physician visits, number of hospitalization days, and death. Control variables were chosen using measures that were available and broadly consistent with the determinants of health framework (Raphael, 2009). To isolate the impact of exposure to a family members' disability a number of control variables were selected to capture the effects. The control variables included the individual's own health status, age, gender, Body Mass Index, employment status, education level, number of close friends and family, and lifestyle behaviors (smoking and drinking).

Regression analyses were used to investigate the association of disability exposure burden, measured by exposure to disability and potential caregiving, with health service utilization and outcomes. The main options for regression analysis with count data, data whose values can only take non-negative integer values, are Poisson or negative binomial regression analysis. Negative binomial regression analysis is used to model count data that is over dispersed. Data tends to be over dispersed when the standard deviation is greater than the mean, as it was for the number of hospital separations, total number of hospitalization days, General Practitioner visits, and the Specialist practitioner visits in this study.

Regression analyses were performed using STATA 11.0 statistical software. The cluster option, in STATA, was used since there is a possibility that family members are not independent of each other. The cluster option makes an upward adjustment of the standard errors to reflect this possible lack of independence between observations nested in the same family. Negative binomial regressions were performed to assess whether there was an association between the disability exposure burden score, and other control variables, and the number of hospital separations, total number of hospitalization days, General Practitioner visits, or Specialist practitioner visits. Binary logistic regression was used to determine if the burden of being exposed to a disabled family member was associated with increased risk of death.

Following the regression analyses several diagnostic measures were conducted to ensure the results were valid and reliable. The $R^2$ values of the analysis were also assessed to determine their predictive ability for health service utilization rates or outcomes. Finally, a correlation matrix for all of the independent variables was developed to verify that significant relationships existed between the independent variables and the dependent variables and to demonstrate that there are no major concerns regarding multicolinearity of independent variables. The results are described in Chapter Four.

# CHAPTER 4

# RESULTS

## 4.1 Introduction

The results are presented in three sections. The first section describes the characteristics of the overall study population and the characteristics for the differing levels of disability exposure burden. The second section describes the health service utilization rates and characteristics of the study population by level of disability exposure burden. Finally, the third section describes the results of the regression analysis.

## 4.2 Study Population

The Newfoundland Adult Health Survey initially had a sample size of 11,789 participants when it was first conducted in 1995 (Segovia et al., 1999). A large majority of the Newfoundland Adult Health Survey participants, 9237 participants (78.3%), also provided their Medical Care Plan number allowing their health information to be linked to their survey data. However, some individuals provided incorrect Medical Care Plan numbers and other individuals could not be re-linked following the issuing of new Medical Care Plan numbers. These individuals are likely to have migrated from the province. The linked dataset contained administrative data from the provincial fee-for-service physician claims (which includes almost all specialists and a large majority of family doctors), the Clinical Database Management System, and Mortality Surveillance System. For the regression analyses involving total hospitalization days, outliers, identified as values beyond three standard deviations of the mean, were removed by SPSS before analysis. There were fifty-four values identified as outliers for the total hospitalization days variable. There were also some missing values in the Newfoundland Adult Health Survey data and these cases were dropped from the analysis. Thus, the regression analyses included 7,766 of the 7,791 cases.

Table 4.1 describes the characteristics of the 7,791 cases in the study population. Sex was evenly distributed among the study population with slightly more females (52.3%) than males (47.7%). The ages of the study participants ranged from 18-100 years of age with a mean age of 44.1 years of age (SD= 15.7). There were 202 individuals (2.6%) less than 20 years old, 44.5% between 20-40 years of age, 36.6% between 41-60 years of age, 14.9% aged 61-80, and 1.4% aged 81 years of age or older. The majority of the study sample (60.8%) lived in an urban area while 39.2% lived in a rural area. 36.7% did not attain a high school diploma, 13.9% completed high school only, and 49.4% completed at least some post-secondary. There were 352 individuals (4.5%) in the study population who were considered to be underweight, according to the Body Mass Index scale. 36.5% were of normal weight and 40.8% were overweight. The remaining 18.2% of the study population were considered to be obese. There were 1079 individuals (13.8%) in the obese I category, 251 individuals (3.2%) in the obese II category, and 97 individuals (1.2%) in the obese III category.

There were 1077 Newfoundland Adult Health Survey participants (13.8%) who reported experiencing a disability indicating they have some difficulty performing tasks as the result of a long-term condition or health-related problem that causes a limitation in daily activities (Statistics Canada, 2014). There were 6432 individuals (82.6%) with no disability exposure burden, 1.4% with a disability exposure burden score of one, 10.8%

with a disability exposure burden score of two, 1.8% with a disability exposure burden score of three, and 3.4% with a disability exposure burden score of four or higher.

Table 4.1 *Characteristics of the Study Population (N=7791)*

| **Characteristic** | **N** | **%** |
|---|---|---|
| **Sex** | | |
| Male | 3720 | 47.7% |
| Female | 4071 | 52.3% |
| **Age** | | |
| <20 | 202 | 2.6% |
| 20-40 | 3469 | 44.5% |
| 41-60 | 2850 | 36.6% |
| 61-80 | 1158 | 14.9% |
| 81-100 | 112 | 1.4% |
| **Urban** | | |
| Urban | 4737 | 60.8% |
| Rural | 3054 | 39.2% |
| **Education** | | |
| Did not attain a high school diploma | 2863 | 36.7% |
| Had a high school diploma | 1080 | 13.9% |
| Completed some post-secondary | 3848 | 49.4% |
| **Body Mass Index (BMI)** | | |
| Underweight | 352 | 4.5% |
| Normal Weight | 2833 | 36.5% |
| Overweight | 3179 | 40.8% |
| Obese I | 1079 | 13.8% |
| Obese II | 251 | 3.2% |
| Obese III | 97 | 1.2% |
| **Disability (own)** | | |
| Yes | 1077 | 13.8% |
| No | 6714 | 86.2% |
| **Disability Exposure Burden** | | |
| 0 | 6432 | 82.6% |
| 1 | 107 | 1.4% |
| 2 | 844 | 10.8% |
| 3 | 140 | 1.8% |
| 4+ | 268 | 3.4% |

As previously discussed, the individual disability score was quantified based on the number of functional impairments individuals reported in the Newfoundland Adult Health Survey. The majority of the study population, 7431 individuals, experienced no functional impairments as they reported being able to bathe themselves, dress themselves, go to the bathroom alone, eat without help, walk outside without help, climb stairs, and continence. There were 231 individuals who experienced a single functional impairment and 129 individuals experienced two or more functional impairments. Table 4.2 describes the frequency distribution of the functional impairment scores for the study population.

Table 4.2 *Functional Impairment Frequency (N=7791)*

| **Number of Functional Impairments** | **Frequency** | **Percentage** | **Cumulative Percentage** |
|---|---|---|---|
| 0 | 7431 | 95.4% | 95.4% |
| 1 | 231 | 3.0% | 98.3% |
| 2 | 64 | 0.8% | 99.2% |
| 3 | 29 | 0.4% | 99.5% |
| 4 | 17 | 0.2% | 99.8% |
| 5 | 11 | 0.1% | 99.9% |
| 6 | 5 | 0.1% | 100.0% |
| 7 | 3 | 0.0% | 100.0% |

An individual's disability score was categorized into one of five categories based on whether or not they self reported as disabled and the number of functional impairments the individual experienced. The frequency of each individual disability score can be seen below in Table 4.3.

Table 4.3 *Individual Disability Score Frequency (N=7791)*

| **Individual Disability Score** | **Frequency** | **Percentage** | **Notes** |
|---|---|---|---|
| 0 | 6601 | 84.7% | No reported disability or impairments |
| 1 | 113 | 1.5% | No reported disability and 1 reported impairment |
| 2 | 830 | 10.7% | Reported disability and no impairments |
| 3 | 123 | 1.6% | Reported disability and one reported impairments |
| 4 | 124 | 1.6% | Reported disability and two or more reported impairments |

The individual disability scores for each family member were then added together to create a family disability score, ranging from zero to ten (see Table 4.4). The majority of individuals, 5574, were in a family with a disability score of zero. There were 173 individuals with a family disability score of one, 1230 individuals with a score of two, 228 individuals with a score of three, and 378 individuals with a score of four. The remaining 208 individuals experienced a family disability score between five and ten.

Table 4.4 *Family Disability Score Frequency (N=7791)*

| **Family Disability Score** | **Frequency** | **Percentage** |
|---|---|---|
| 0 | 5574 | 71.5% |
| 1 | 173 | 2.2% |
| 2 | 1230 | 15.8% |
| 3 | 228 | 2.9% |
| 4 | 378 | 4.9% |
| 5 | 71 | 0.9% |
| 6 | 97 | 1.2% |
| 7 | 23 | 0.3% |
| 8 | 10 | 0.1% |
| 9 | 0 | 0.0% |
| 10 | 7 | 0.1% |

Disability exposure burden was calculated by subtracting an individual's own disability score from the family disability score. The majority of the study population, 6432 individuals, experienced no disability exposure burden. Only 107 individuals (1.4%) of the study population experienced a disability exposure burden of one and 844 individuals (10.8%) had a disability exposure burden score of two. There were 140 (1.8%) individuals with a score of three and the remaining 268 individuals (3.4%) had a disability exposure burden score of four or more (See Table 4.5).

Table 4.5 *Disability Exposure Burden Frequency (N=7791)*

| **Disability Exposure Burden Score** | **Frequency** | **Percentage** | **Cumulative Percentage** |
|---|---|---|---|
| 0 | 6432 | 82.6% | 82.6% |
| 1 | 107 | 1.4% | 83.9% |
| 2 | 844 | 10.8% | 94.8% |
| 3 | 140 | 1.8% | 96.6% |
| 4 | 188 | 2.4% | 99.0% |
| 5 | 29 | 0.4% | 99.3% |
| 6 | 38 | 0.5% | 99.8% |
| 7 | 9 | 0.1% | 99.9% |
| 8 | 3 | 0.0% | 100.0% |
| 10 | 1 | 0.0% | 100.0% |

There were 4,363 different households, including both single-person and multi-person households, represented in the study. While a large number of households experienced no disability exposure burden, signified by a score of zero (n=3320, 76.1%) there were 1043 households (23.9%) who experienced some degree of disability exposure burden. Table 4.6 details the household frequency of each level of disability exposure burden for all households. There were 93 households (2.1%) who experienced a disability exposure burden score of one, 627 households (14.4%) with a disability exposure burden score of two, 109 households (2.5%) with a score of three, and 157 households (3.6%) with a disability exposure burden score of four. There were 57 households (1.4%), those with disability exposure burden scores above four, which means there were multiple individuals with disabilities clustered in the household.

Table 4.6 *Household Disability Exposure Burden Frequency for all Households (N=4363)*

| **Level of Disability Burden** | **Total Disability Exposure Burden per Household** | **Percentage** |
|---|---|---|
| 0 | 3320 | 76.1% |
| 1 | 93 | 2.1% |
| 2 | 627 | 14.4% |
| 3 | 109 | 2.5% |
| 4 | 157 | 3.6% |
| 5 | 21 | 0.5% |
| 6 | 29 | 0.7% |
| 7+ | 7 | 0.2% |

There were 3288 multi-person households, households with more than one individual, represented in the study. The vast majority of the multi-person households (74.8%) experienced no disability exposure burden. There were 68 multi-person households (2.1%) who experienced a disability exposure burden score of one, 494 multi-person households (15.0%) with a disability exposure burden score of two, 76 multi-person households (2.3%) with a score of three, and 133 multi-person households (4.1%) with a disability exposure burden score of four. There were 57 multi-person households (1.7%) with disability exposure burden scores above four.

Table 4.7 *Household Disability Exposure Burden Frequency for Multi-person Households (N=3288)*

| **Level of Disability Burden** | **Total Disability Exposure Burden per Household** | **Percentage** |
|---|---|---|
| 0 | 2460 | 74.8% |
| 1 | 68 | 2.1% |
| 2 | 494 | 15.0% |
| 3 | 76 | 2.3% |
| 4 | 133 | 4.1% |
| 5 | 21 | 0.6% |
| 6 | 29 | 0.9% |
| 7+ | 7 | 0.2% |

Table 4.8 further describes the study population by the level of disability exposure burden at the individual level. There were 6432 individuals in the study population who experienced no disability exposure burden and did not have a family member affected by disability. Over half (52.2%) were female and 47.8% were male. There were 155 individuals (2.4%) aged less than 20 years old, 46.9% were aged 20-40, 35.9% were aged 41-60, 14.8% were 61-80, and 1.4% were 81 years of age or older. The majority of those without burden lived in an urban area (61.2%) with the remaining 38.8% living in rural areas. In terms of education, 34.4% did not attain a high school diploma, 16.8% had a high school diploma, and 48.8% completed at least some post-secondary education. The majority (88.1%) of the individuals with no disability exposure burden were not disabled themselves while 11.9% did experience some form of disability.

The majority of those experiencing a disability exposure burden score of one were male (72.9%). Individuals under the age of twenty comprised 1.9% of those experiencing a disability exposure burden score of one, 38.3% were 20-40, 41.1% were between the ages of 41-60, 15.0% were 61-80, and the remaining 3.7% among those aged 81 years or older. Approximately half of those experiencing a disability exposure burden level of one did not attain a high school diploma (48.6%), 14.9% had a high school diploma, and 36.5% completed at least some post-secondary education. Those with a disability exposure burden score of one were evenly distributed among rural (49.5%) and urban (50.5%) areas. 79.4% of the individuals with a disability exposure burden score of one reported they were not disabled themselves while 20.6% experienced some form of disability.

There were slightly more females (56.9%) than males (43.1%) among the 814 individuals experiencing a disability exposure burden score of two. There were 28 individuals (3.3%) that were less than 20 years old, 32.2% were between the ages of 20-40, 40.5% were 41-60, 22.0% were 61-80, and 1.9% were 81 years of age or older. The majority of individuals (61.4%) with a disability exposure burden score of two lived in urban areas with 38.6% living in rural communities. Almost half of the individuals with a disability exposure burden of two did not attain a high school diploma (46.2%), while 16.8% had a high school diploma, and 37.0% had completed at least some post-secondary education. The majority (76.1%) of those with a disability exposure burden score of two reported that were not disabled, with only 23.9% experiencing some form of disability themselves.

Only 140 individuals were assigned a disability exposure burden score of three. Of those 140 individuals, 51.4% were female and 48.6% were male. There were 7 individuals (5.0%) below the age of 20, 30.7% were 20-40, 37.1% were between the ages of 41-60, and 27.1% were 61 years of age or older. The majority of the individuals with a disability exposure burden score of three reported that they were not disabled (77.9%), while 22.1% experienced some disability. Approximately half of the individuals lived in an urban area (51.4%) and the other half in a rural area (48.6%). Nearly half (48.6%) did not attain a high school diploma, 17.1% had a high school diploma, and 34.3% had completed at least some post-secondary education.

Two hundred and sixty-eight individuals had a disability exposure burden score of four or higher. There were 155 females (57.8%) and 113 males (42.2%) with 42.2% of individuals living in rural communities and 57.8% living in an urban area. Approximately 77.0% of those experiencing a disability exposure burden score of four or higher reported that they were not disabled, while 23.0% did report some form of disability. Over half (54.1%) of the individuals with a disability exposure burden of four or higher did not attain a high school diploma, 18.7% had a high school diploma, and 27.2% had completed at least some post-secondary education. Ten individuals (3.7%) were less than 20 years of age, 36.6% were between the ages of 20-60, 37.7% were 40-60 years old, 20.5% were 61-80, and 1.5% were 81 years of age or older.

Table 4.8 *Characteristics of the Study Population by Level of Disability Exposure Burden (N=7791)*

| | **Level of Disability Exposure Burden** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **0** | | **1** | | **2** | | **3** | | **4+** | | **Total** | |
| | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** | **N** | **%** |
| **Sex** | | | | | | | | | | | | |
| Male | 3075 | 47.8% | 78 | 72.9% | 364 | 43.1% | 68 | 48.6% | 135 | 50.4% | 3720 | 47.7% |
| Female | 3357 | 52.2% | 29 | 27.1% | 480 | 56.9% | 72 | 51.4% | 133 | 49.6% | 4071 | 52.3% |
| **Age** | | | | | | | | | | | | |
| <20 | 155 | 2.4% | 2 | 1.9% | 28 | 3.3% | 7 | 5.0% | 10 | 3.7% | 202 | 2.6% |
| 20-40 | 3015 | 46.9% | 41 | 38.3% | 272 | 32.2% | 43 | 30.7% | 98 | 36.6% | 3469 | 44.5% |
| 41-60 | 2311 | 35.9% | 44 | 41.1% | 342 | 40.5% | 52 | 37.1% | 101 | 37.7% | 2850 | 36.6% |
| 61-80 | 864 | 13.4% | 16 | 15.0% | 186 | 22.0% | 37 | 26.4% | 55 | 20.5% | 1158 | 14.9% |
| 81-100 | 87 | 1.4% | 4 | 3.7% | 16 | 1.9% | 1 | 0.7% | 4 | 1.5% | 112 | 1.4% |
| **Urban** | | | | | | | | | | | | |
| Urban | 3938 | 61.2% | 54 | 50.5% | 518 | 61.4% | 72 | 51.4% | 113 | 42.2% | 4737 | 39.2% |
| Rural | 2494 | 38.8% | 53 | 49.5% | 326 | 38.6% | 68 | 48.6% | 155 | 57.8% | 3054 | 40.8% |
| **Education** | | | | | | | | | | | | |
| Less than high school | 2208 | 34.4% | 52 | 48.6% | 390 | 46.2% | 68 | 48.6% | 145 | 54.1% | 2863 | 36.7% |
| Finished high school | 1083 | 16.8% | 16 | 15.0% | 142 | 16.8% | 24 | 17.1% | 50 | 18.7% | 1315 | 16.9% |
| Some post-secondary | 3141 | 48.8% | 39 | 36.4% | 312 | 37.0% | 48 | 34.3% | 73 | 27.2% | 3613 | 46.4% |
| **Disability** | | | | | | | | | | | | |
| Yes | 767 | 11.9% | 22 | 20.6% | 195 | 23.9% | 31 | 22.1% | 62 | 23.1% | 1077 | 13.8% |
| No | 5665 | 88.1% | 85 | 79.4% | 649 | 76.1% | 109 | 77.9% | 206 | 76.9% | 6714 | 86.2% |
| **Disability Score** | | | | | | | | | | | | |
| 0 | 5575 | 86.7% | 83 | 77.6% | 633 | 75.0% | 106 | 75.7% | 204 | 76.1% | 6601 | 84.7% |
| 1 | 90 | 1.4% | 2 | 1.9% | 16 | 1.9% | 3 | 2.14% | 2 | 0.8% | 113 | 1.5% |
| 2 | 594 | 9.2% | 17 | 15.9% | 149 | 17.7% | 22 | 15.7% | 48 | 17.9% | 830 | 10.7% |
| 3 | 89 | 1.4% | 2 | 1.9% | 20 | 2.4% | 6 | 4.3% | 6 | 2.2% | 123 | 1.6% |
| 4 | 84 | 1.3% | 3 | 2.8% | 26 | 3.1% | 3 | 2.1% | 8 | 3.0% | 124 | 1.6% |

Table 4.9 provides a further overview of the study population by individual disability status, whether or not an individual identified as disabled or not. There were 1077 disabled individuals in the study population with slightly more males (52.3%) than females (47.7%). The majority (71.2%) of the disabled population had a disability exposure burden score of zero, indicating that they had no other disabled family members. A small percentage (2.0%) of the disabled individuals had a disability exposure burden score of one, 18.1% had a disability exposure burden score of two, 2.9% had a disability exposure burden score of three, and 5.8% had a disability exposure burden score of four or higher.

Age was distributed among the disabled population with 1.0% less than 20 years of age, 23.9% aged 20-40 years old, 37.8% aged between 41 and 60 years of age, and 37.3% aged 61 or older. There were 645 disabled individuals (59.9%) living in a rural environment and 432 disabled individuals (40.1%) living in an urban environment. The disabled sample had less education than their nondisabled counterparts with over half (58.1%) of the disabled population having less than a high school education, 15.2% having a high school diploma, and 26.7% completing at least some post-secondary education.

There were 6714 individuals in the study population who identified as nondisabled with slightly more females (53.0%) than males (47.0%). Almost half (47.8%) of the nondisabled population fell between the ages of 41 and 60 with only 2.8% aged between 18 and 40, 36.4% aged between 61 and 80, and 11.8% aged 81 or older. The majority of the nondisabled population resided in rural communities (60.9%) with only 39.1% living in urban areas. Almost half of the nondisabled individuals in the study population completed some post-secondary education (49.6%), 17.1% had completed high school, and 33.3% had completed less than high school.

The majority (84.4%) of the nondisabled population also had a disability exposure burden score of zero. There were 85 individuals (1.3%) who experienced a disability exposure burden score of one, 9.7% had a disability exposure burden score of two, 1.6% had a disability exposure burden score of three, and 3.0% had a disability exposure burden score of four or higher.

Table 4.9 *Characteristics of the Study Population by Individual Disability Status (N=7791)*

| | **Disabled (N=1077)** | | **Not Disabled (N=6714)** | |
|---|---|---|---|---|
| | **N** | **%** | **N** | **%** |
| **Sex** | | | | |
| Male | 563 | 52.3% | 3157 | 47.0% |
| Female | 514 | 47.7% | 3557 | 53.0% |
| **Age** | | | | |
| <20 | 11 | 1.0% | 191 | 2.8% |
| 20-40 | 257 | 23.9% | 3212 | 47.8% |
| 41-60 | 407 | 37.8% | 2443 | 36.4% |
| 61-80 | 362 | 33.6% | 796 | 11.9% |
| 81-100 | 40 | 3.7% | 72 | 1.1% |
| **Urban** | | | | |
| Urban | 432 | 40.1% | 2622 | 39.1% |
| Rural | 645 | 59.9% | 4092 | 60.9% |
| **Education** | | | | |
| Did not attain a high school diploma | 626 | 58.1% | 2237 | 33.3% |
| Completed high school diploma | 164 | 15.2% | 1151 | 17.1% |
| Completed some post-secondary | 287 | 26.7% | 3326 | 49.6% |
| **Disability Exposure Burden** | | | | |
| 0 | 767 | 71.2% | 5665 | 84.4% |
| 1 | 22 | 2.0% | 85 | 1.3% |
| 2 | 195 | 18.1% | 649 | 9.7% |
| 3 | 31 | 2.9% | 109 | 1.6% |
| 4+ | 62 | 5.8% | 206 | 3.0% |

The health outcomes, which will be discussed below, also varied depending on the level of disability exposure burden, as displayed in Table 4.10. Those with no disability exposure burden utilized health care services the least with an average of 4.1 hospitalizations, 41.2 hospitalization days, 61.9 General Practitioner visits, and 55.3 Specialist visits, per-person. Of the 6432 individuals with no disability exposure burden, 751 individuals (11.7%) died in the fifteen-year period following the 1995 survey.

Those with a disability exposure burden score of one experienced an average of 5.4 hospitalizations, 51.5 hospitalization days, 64.2 General Practitioner visits, and 59.8 Specialist visits. There were 107 individuals with a disability exposure burden score of one. 20.6% of those with a disability exposure burden score of one died following the 1995 survey. Those with a disability exposure burden score of two experienced the highest rates of health service utilization, per-person, with an average of 6.0 hospitalizations, 67.6 hospitalization days, 82.2 General Practitioner visits, and 74.7 Specialist visits. There were 844 individuals with a disability exposure burden score of two of which 154 individuals (18.2%) died.

Those with a disability exposure burden score of three experienced an average of 4.3 hospitalizations, 46.3 hospitalization days, 69.6 General Practitioner visits, and 57.1 Specialist visits. Of the 140 individuals with a disability exposure burden score of three, 24 individuals (17.1%) died. Those with a disability exposure burden score of four or higher experienced the second highest rates of health service utilization with an average of 5.7 hospitalizations, 56.7 hospitalization days, 78.2 General Practitioner visits, and 69.3 Specialist visits. There were 268 individuals with a disability exposure burden score of four or higher. 18.7% of those individuals with a disability exposure burden score of four or higher died following the 1995 survey.

There was a consistent increase in health service utilization for disability exposure burden levels zero through two. However, there was no dosage response with disability exposure burden scores above two resulting in a linear increase in utilization. Nevertheless those exposed to disability in the family, beyond their own disability, had greater health service utilization than those who were not exposed to disability. Those with no disability exposure burden experienced the least number of hospitalization days, the fewest number of hospital visits, the fewest number of hospital separations, and the lowest mortality rates.

Table 4.10 *Health Service Outcomes by Level of Disability Exposure Burden (per-person) (N=7791)*

| | **Level of Disability Exposure Burden** | | | | |
|---|---|---|---|---|---|
| | **0** | **1** | **2** | **3** | **4+** |
| **Hospital Visits** | | | | | |
| Mean | 4.1 | 5.4 | 6.0 | 4.3 | 5.7 |
| Standard Deviation | 7.6 | 9.2 | 9.7 | 7.3 | 10.6 |
| **Total hospitalization days** | | | | | |
| Mean | 41.2 | 51.5 | 67.6 | 46.3 | 56.7 |
| Standard Deviation | 339.6 | 133.9 | 245.6 | 141.8 | 192.3 |
| **General Practitioner Visits** | | | | | |
| Mean | 61.9 | 64.2 | 82.2 | 69.6 | 78.2 |
| Standard Deviation | 64.2 | 73.2 | 82.4 | 74.7 | 72.3 |
| **Specialist Visits** | | | | | |
| Mean | 55.3 | 59.8 | 74.7 | 57.1 | 69.3 |
| Standard Deviation | 72.5 | 73.4 | 77.4 | 60.4 | 97.1 |
| **All Physician Visits** | | | | | |
| Mean | 117.2 | 124.0 | 156.8 | 126.7 | 147.5 |
| Standard Deviation | 116.1 | 130.7 | 137.4 | 118.2 | 143.6 |
| **Deaths** | | | | | |
| Total Number of Deaths | 751 | 22 | 154 | 24 | 50 |
| Proportion | 11.7% | 20.6% | 18.2% | 17.1% | 18.7% |

## 4.3 Description of Health Outcomes

Table 4.11 describes the health service utilization of patients in the Newfoundland health care system by looking at the number of hospital separations, total hospitalization days, and the number of fee-for-service physician visits from 1995-2010 for the linked study population. Over the fifteen-year period, 1001 (12.9%) of the 7791 Newfoundland Adult Health Survey participants died.

There were 3123 participants (40.1%) in the study sample that had no hospital separations and consequently no recorded hospitalization days during the fifteen-year period. Nonetheless, there were 33927 total recorded hospital separations with a mean number of 4.4 hospital separations (SD= 8.0), per person, with the number of separations ranging from zero to 111. The mean total hospitalization days was 10.3 days (SD= 179.7), per person, with a range of zero to 1,010 days. Although there was a large range associated with the total hospitalization days for the population, 90.0% were for less than a total of 65 days over the described time period.

Although almost half of the population did not have a hospital admission or discharge, only 1.6% did not visit a fee-for-service physician over the fifteen-year period. The mean number of fee-for-service physician visits per person was 122.8 (SD= 120.5) with the number of visits ranging from zero to 1980. For General Practitioner visits, the mean number of visits, per person, was 64.8 (SD= 67.4) with a range of zero to 1443 visits over the fifteen-year span. The mean number of specialist visits, per person, was 58 (58.0, SD= 74.1) with a range of zero to 1755 visits.

Table 4.11 *Description of the Health Service Utilization of the Study Population (per-person rates) (N=7791)*

| **Health Outcome Variable** | **Mean (proportion) (per person)** | **Standard Deviation (per person)** | **Range (per person)** | **Total Number** |
|---|---|---|---|---|
| Death | 12.9% | - | - | 1001 |
| Hospital Separations | 4.4 | 8.0 | 0-111 | 33927 |
| Total hospitalization days | 10.3 | 179.7 | 0-1010 | 349260 |
| Physician Visits | 122.8 | 120.5 | 0-1980 | 956744 |
| General Practitioner | 64.8 | 67.4 | 0-1443 | 504767 |
| Specialist | 58.0 | 74.1 | 0-1755 | 451977 |

## 4.4 Predictors of Health Service Utilization

The goal of the study was to determine whether being exposed to disability in the family had an impact on health outcomes, measured by health service utilization and mortality. The level of disability exposure burden is measured for each individual by taking the total household disability and subtracting the individual's own disability score to leave the amount of disability exposure burden in the household, independent from the individual's own disability. The individual's own disability is also included in the regression equation to proxy for the individual's own health status.

As described in Chapter Three, the health utilization data is over-dispersed count data, and as such negative binomial regressions were performed to determine whether there was a relationship between disability exposure burden and health service utilization rates per-person, for disabled Newfoundland adults and their family members. A binary logistic regression was also performed to assess the relationship of death with disability exposure burden. The number of cases included in the regression analyses had small discrepancies due to the inclusion and exclusion of outliers and missing values in the study population. The 'cluster' function was used in Stata to correct for potential non-independence of individuals coming from the same family.

Incident rate ratios for the negative binomial regressions and odds ratio for the binary logistic regression were treated as significant if $p < 0.1$, since the implications of making a Type I error in this study are not detrimental as the implications would be in a clinical trial. However, coefficients with p-values between 0.05 and 0.1 should be treated with caution.

### 4.4.1 Number of Hospital Separations

The results of the negative binomial regression for the number of hospital separations an outcome variable, are presented in Table 4.12. Incident rate ratios were calculated to determine the rate at which health service utilization occurred (UCLA: Statistical Consulting Group, 2015). The independent or predictor variables were disability exposure burden, individual disability score, sex, age, urban or rural residency, the number of family members, body mass index, education level, marital status, employment status and smoking or drinking behaviors.

Disability exposure burden ($p<0.05$) and individual disability score ($p<0.01$) were significantly associated with an increased number of hospital separations. A unit increase in disability exposure burden was associated with a 21% increase in the number of hospital separations while a unit increase in individual disability score was associated with a 20% increase in the number of separations. Being in an older age group ($p<0.05$) was also associated with a higher number of hospital separations per-person, relative to being aged less than 20 years old. Individuals between the ages of 20-40 ($p<0.05$) experienced a 1.57 factor increase in the number of hospital separations compared to those less than 20, individuals aged 41-60 ($p<0.01$) showed a 5.17 factor increase in the number of hospital separations, individuals aged 61-80 ($p<0.01$) experienced a 14.47 factor increase in the number of hospital separations, and individuals aged 81-100 ($p<0.01$) showed a 5.70 factor increase in the number of hospital separations.

Working part-time ($p< 0.01$) was associated with a lower number of hospital separations, relative to being unemployed. Those who work part-time had 37% fewer hospital separations per-person. Smoking ($p<0.05$) was associated with an increase in the number of hospital separations by a factor of 1.53.

The association between body mass index and the number of hospital separations varied depending on the body mass index category, using normal weight as the reference category. The overweight category ($p<0.1$) was associated with a 1.22 increase in the number of hospital separations relative to being normal weight. An obese I body mass index ($p<0.05$) was associated with a 1.65 increase compared to those of normal weight. The obese III category ($p<0.01$) was associated with a 2.28 factor increase in the number of hospitalizations relative to being normal weight. However the underweight category and the obese II category were not significantly associated with the number of hospital separations ($p>0.1$), relative to normal weight.

Education level (relative to finishing less than high school), marital status, sex, rural or urban residency, working full-time (relative to being unemployed), drinking as well as smoking nor drinking were not associated ($p>0.1$) with the number of hospital separations. The number of family members, close relatives, and close friends were also not associated (p>0.1) with the number of hospitalizations.

Table 4.12 *Negative Binomial Regression for Hospital Separations*

| **Model (N=7766)** | **Incident Rate Ratio** | **Standard Error** | **p-value** |
|---|---|---|---|
| Disability Exposure Burden | 1.207433 | 0.1075798 | 0.034** |
| Individual Disability Score | 1.204798 | 0.0696114 | 0.001*** |
| Sex (female) | 0.8781498 | 0.1041735 | 0.273 |
| Age (20-40) | 1.571817 | 0.3142862 | 0.024** |
| Age (41-60) | 5.171908 | 1.158968 | 0.000*** |
| Age (61-80) | 14.47023 | 3.303303 | 0.000*** |
| Age (81-100) | 5.695878 | 1.656111 | 0.000*** |
| Urban | 0.9746963 | 0.1063471 | 0.814 |
| Body Mass Index (Underweight) | 0.9444656 | 0.1259515 | 0.668 |
| Body Mass Index (Overweight) | 1.223966 | 0.1276742 | 0.053* |
| Body Mass Index (Obese I) | 1.645363 | 0.3814589 | 0.032** |
| Body Mass Index (Obese II) | 1.104237 | 0.2186138 | 0.616 |
| Body Mass Index (Obese III) | 2.281313 | 0.6891833 | 0.006*** |
| Completed High School | 0.9882238 | 0.1398007 | 0.933 |
| Attended Post-secondary | 1.023576 | 0.1357078 | 0.860 |
| Married | 0.9469626 | 0.1432511 | 0.719 |
| Working Full-time | 0.9305678 | 0.121428 | 0.581 |
| Working Part-time | 0.6219499 | 0.0783486 | 0.000*** |
| Number of Family Members | 0.9892082 | 0.0751388 | 0.886 |
| Smoker | 1.527845 | 0.3002484 | 0.031** |
| Drinker | 1.007266 | 0.1305579 | 0.955 |
| Smoker and Drinker | 0.7220254 | 0.1670692 | 0.159 |
| Close Relatives | 1.005599 | 0.0112258 | 0.617 |
| Close Friends | 0.9949394 | 0.0089385 | 0.572 |

*(Asterisks in the p-value column were used to denote level of significance; p <0.1*, p <0.05**, p <0.01***)*

### 4.4.2 Total Hospitalization Days

The results of the negative binomial regression, for the total number of hospitalization days, as a dependent or outcome variable, are presented in Table 4.13. Incident rate ratios were calculated to determine the rate at which health service utilization occurred (UCLA: Statistical Consulting Group, 2015). The independent or predictor variables included were disability exposure burden, individual disability scores, sex, age, urban or rural residency, the number of family members, body mass index, education level, marital status, employment status and smoking or drinking behaviors.

Disability exposure burden ($p<0.01$) and individual disability score ($p<0.01$) were both positively associated with the total number of hospitalization days. An increase in disability exposure burden score was associated with an increase total hospitalization days by a factor of 1.43. An increase in individual disability score by one unit would increase total hospitalization days by a factor of 1.29. Age ($p<0.01$) was also significantly associated with an increased number of total hospitalization days, relative to being aged less than 20 years old. Individuals between 20 and 40 years of age ($p<0.01$) experienced a 3.28 factor increase in total hospitalization days. Those aged 41-60 ($p<0.01$) experienced a 27.17 factor increase while those aged 61-80 ($p<0.01$) experienced a 82.73 factor increase and those aged 81-100 ($p<0.01$) experienced a 46.55 factor increase in the total number of hospitalization days. Gender ($p<0.01$) was associated with a reduced number of hospitalization days for females. Females are expected to have 51% fewer total hospitalization days than their male counterparts.

Being married ($p<0.05$), relative to not being married or in a committed relationship, was expected to decrease total hospitalization days by a factor of 0.64.

Working part-time, relative to being unemployed, decreased hospitalization days by a factor of 0.30. Smoking ($p<0.01$) increased the total hospitalization days by a factor of 4.07. Conversely, smoking when coupled with drinking ($p<0.01$) decreased total hospitalization days by a factor of 0.23, per-person.

Body mass index, relative to the normal weight category, was not significantly associated with the total number of hospitalization days with the exception of the obese I category ($p<0.01$). Those in the obese I category ($p<0.01$) were expected to have an increase in the total hospitalization days by a factor of 3.46, relative to being normal weight. Education level (relative to finishing less than high school), rural or urban residency, working full-time (relative to being unemployed), and drinking alcohol were not significantly associated ($p>0.1$) with the total number of hospitalization days. The number of family members, close relatives, and close friends were also not significantly associated ($p>0.1$) with the total number of hospitalization days.

Table 4.13 *Negative Binomial Regression for Total Hospitalization Days*

| **Model (N=7766)** | **Incident Rate Ratio** | **Standard Error** | **p-value** |
|---|---|---|---|
| Disability Exposure Burden | 1.426547 | 0.1444159 | 0.000*** |
| Individual Disability Score | 1.287358 | 0.1081919 | 0.003*** |
| Sex (female) | 0.4869131 | 0.0840748 | 0.000*** |
| Age (20-40) | 3.282543 | 0.9338439 | 0.000*** |
| Age (41-60) | 27.16925 | 9.013439 | 0.000*** |
| Age (61-80) | 82.72673 | 26.34793 | 0.000*** |
| Age (81-100) | 46.55099 | 18.41811 | 0.000*** |
| Urban | 0.9157395 | 0.1635684 | 0.622 |
| Body Mass Index (Underweight) | 1.151486 | 0.495493 | 0.743 |
| Body Mass Index (Overweight) | 1.064135 | 0.2079789 | 0.750 |
| Body Mass Index (Obese I) | 3.46432 | 1.408537 | 0.002*** |
| Body Mass Index (Obese II) | 0.9307858 | 0.2813906 | 0.812 |
| Body Mass Index (Obese III) | 1.604542 | 0.5011391 | 0.130 |
| Completed High School | 0.8769617 | 0.2071336 | 0.578 |
| Attended Post-secondary | 0.8388582 | 0.176431 | 0.403 |
| Married | 0.6359457 | 0.1352849 | 0.033** |
| Working Full-time | 0.804997 | 0.1660713 | 0.293 |
| Working Part-time | 0.3002738 | 0.0732255 | 0.000*** |
| Number of Family Members | 0.8824153 | 0.0774893 | 0.154 |
| Smoker | 4.06722 | 1.914444 | 0.003*** |
| Drinker | 1.361963 | 0.2665533 | 0.114 |
| Smoker and Drinker | 0.2323961 | 0.1183766 | 0.004*** |
| Close Relatives | 1.017245 | 0.0128696 | 0.177 |
| Close Friends | 0.9791304 | 0.013023 | 0.113 |

*(Asterisks in the p-value column were used to denote level of significance; p <0.1*, p <0.05**, p <0.01***)*

### 4.4.3 Number of Physician Visits

Two regressions were performed to examine prediction of number of physician visits: General Practitioner and Specialist visits. The independent or predictor variables were disability exposure burden, individual disability scores, sex, age, urban or rural residency, the number of family members, body mass index, education level, marital status, employment status and smoking or drinking behaviors.

#### 4.4.3.1 General Practitioner Visits

The results of the negative binomial regression for the number of General Practitioner visits, an outcome variable, are presented in Table 4.14. Incident rate ratios were calculated to determine the rate at which health service utilization occurred (UCLA: Statistical Consulting Group, 2015).

Individuals were more likely to have a higher number of physician visits if they experienced a higher amount of disability exposure burden ($p<0.05$) and a higher individual disability score ($p<0.01$). An increase in disability exposure burden was associated with an increase in the number of General Practitioner visits by a factor of 1.10 while an increase in individual disability score increased the number of visits by a factor of 1.18. Sex ($p<0.01$) was associated with an increase in the number of General Practitioner visits with females visiting a General Practitioner 1.40 times more than males. Age was also significantly associated ($p<0.01$) with the number of General Practitioner visits, relative to being aged less than 20 years old. Those between 20 and 40 years of age ($p<0.01$) were expected to have a 1.26 factor increase in the number of visits, compared to those less than 20 years old. Those aged between 41 and 60 years of age ($p<0.01$) experienced a 2.30 factor increase in the number of visits. For those aged between 61-80 ($p<0.01$) a 7.81 factor increase in the number of visits was expected and those in the 81-100 age category experienced a 4.40 factor increase in the number of visits.

There were also significant associations for the urban residency variable (p<0.01), marital status variable (p<0.1), as well as the working full-time (p<0.05) and working part-time variable (p<0.01). Individuals who lived in an urban environment were expected to visit a General Practitioner 47% more than those who lived in a rural environment. There was a moderate association (p<0.1) between being married (relative to not being married or in a committed relationship) with married individuals experiencing a 1.13 increase in the number of General Practitioner visits.

Employment status appeared to have a protective effect with a reduced number of General Practitioner visits among those who work full-time or part-time (relative to being unemployed). Working full-time (p<0.05) was associated with a 12% decrease in the number of General Practitioner visits while working part-time (p<0.01) was associated with a 20% factor decrease in the number of visits.

The association between the number of General Practitioner visits and body mass index varied among the body mass index categories, using normal weight as the reference category. Individuals in the overweight category (p<0.01) experienced a 1.24 factor increase in the number of General Practitioner visits. The obese I body mass index category (p<0.01) increased the number of visits by a factor of 1.63 and the obese III category (p<0.05) was expected to increase the number of General Practitioner visits by a factor of 1.45. However the underweight category and the obese II category were not associated with the number of General Practitioner visits (p>0.1).

The number of close relatives or friends and number of family members were not associated (p>0.1) with number of General Practitioner visits. Likewise smoking, drinking, smoking and drinking, and education level (relative to finishing less than a high school education) were also not significantly associated with the number of General Practitioner visits.

Table 4.14 *Negative Binomial Regression for General Practitioner Visits*

| **Model (N=7766)** | **Incident Rate Ratio** | **Standard Error** | **p-value** |
|---|---|---|---|
| Disability Exposure Burden | 1.102647 | 0.0545422 | 0.048** |
| Individual Disability Score | 1.17549 | 0.0536961 | 0.000*** |
| Sex (female) | 1.397419 | 0.0869334 | 0.000*** |
| Age (20-40) | 1.258563 | 0.1087766 | 0.008*** |
| Age (41-60) | 2.20398 | 0.2299145 | 0.000*** |
| Age (61-80) | 7.80721 | 1.26734 | 0.000*** |
| Age (81-100) | 4.392733 | 1.294187 | 0.000*** |
| Urban | 1.466628 | 0.0890492 | 0.000*** |
| Body Mass Index (Underweight) | 1.080407 | 0.128019 | 0.514 |
| Body Mass Index (Overweight) | 1.239154 | 0.0724558 | 0.000*** |
| Body Mass Index (Obese I) | 1.634822 | 0.2106541 | 0.000*** |
| Body Mass Index (Obese II) | 1.154496 | 0.1036254 | 0.109 |
| Body Mass Index (Obese III) | 1.452353 | 0.2351885 | 0.021** |
| Completed High School | 0.9382982 | 0.0834452 | 0.474 |
| Attended Post-secondary | 0.8892456 | 0.0665735 | 0.117 |
| Married | 1.125574 | 0.077627 | 0.086* |
| Working Full-time | 0.87616 | 0.0588523 | 0.049** |
| Working Part-time | 0.7797235 | 0.0621382 | 0.002*** |
| Number of Family Members | 0.9699072 | 0.0302453 | 0.327 |
| Smoker | 1.433881 | 0.3496863 | 0.139 |
| Drinker | 1.005786 | 0.0820731 | 0.944 |
| Smoker and Drinker | 0.6645047 | 0.1688785 | 0.108 |
| Close Relatives | 0.9941922 | 0.0067631 | 0.392 |
| Close Friends | 0.9969871 | 0.005673 | 0.596 |

*(Asterisks in the p-value column were used to denote level of significance; p <0.1*, p <0.05**, p <0.01***)*

#### 4.4.3.2 Specialist Visits

The results of the negative binomial regression for the number of Specialist visits, an outcome or dependent variable, are presented in Table 4.15. Incident rate ratios were calculated to determine the rate at which health service utilization occurred (UCLA: Statistical Consulting Group, 2015). The independent or predictor variables were disability exposure burden, individual disability scores, sex, age, urban or rural residency, the number of family members, body mass Index, education level, marital status, employment status and smoking or drinking behaviors.

Disability exposure burden was weakly associated ($p<0.1$) with the number of Specialist visits. An increase in disability exposure burden score increased the number of visits, per-person, by a factor of 1.10. Individual disability score was also associated ($p<0.01$) with number of Specialist visits with an increase in the disability score variable increasing the number of Specialist visits by a factor of 1.20, per-person, for each increase in individual disability score. Individuals aged 20-40 ($p<0.01$) experienced a 1.87 times increase in the number of Specialist visits compared to those less than 20, those between 41 and 60 years of age experienced a 4.77 factor increase in the number of visits relative to those less than 20 years of age, those aged 61-80 experienced a 14.16 factor increase in the number of visits compared to those less than 20 years old, and there was an expected 6.38 factor increase for 81-100 year olds, relative to being less than 20 years old.

Additionally living in an urban environment ($p<0.01$), being married ($p<0.01$), and smoking ($p<0.1$) were associated with an increased number of Specialist visits, per-person. Living in an urban environment ($p<0.01$) was expected to increase the number visits by a factor of 1.31. Being married ($p<0.01$), relative to being not being married or in a committed relationship, was associated with a 1.24 factor increase in the number of visits, and smoking ($p<0.1$) increased the number of visits by a factor of 1.33. Conversely working part-time (p<0.01), relative to being unemployed, was expected to reduce the number of Specialist visits by 31%.

The body mass index categories, relative to the normal weight category were not associated with number of Specialist visits with the exception of the overweight and obese I categories. The overweight body mass index (p<0.05) category was associated with a 1.20 factor increase in the number of Specialist visits and those in the obese I body mass index category (p<0.05) were expected to have a 1.48 factor increase in the number of visits.

There was no association (p>0.1) found between sex, education level (relative to finishing less than high school), full-time employment (relative to being unemployed), drinking, or drinking and smoking combined and the number of Specialist visits. The number of close relatives or friends and number of family members were not associated (p>0.1) with the number of Specialist visits.

Table 4.15 *Negative Binomial Regression for Specialist Visits*

| **Model (N=7766)** | **Incident Rate Ratio** | **Standard Error** | **p-value** |
|---|---|---|---|
| Disability Exposure Burden | 1.101311 | 0.0582379 | 0.068* |
| Individual Disability Score | 1.201837 | 0.053438 | 0.000*** |
| Sex (female) | 1.055858 | 0.088016 | 0.514 |
| Age (20-40) | 1.871812 | 0.2325215 | 0.008*** |
| Age (41-60) | 4.769221 | 0.7043503 | 0.000*** |
| Age (61-80) | 14.16339 | 2.813992 | 0.000*** |
| Age (81-100) | 6.377748 | 2.217191 | 0.000*** |
| Urban | 1.308953 | 0.0972655 | 0.000*** |
| Body Mass Index (Underweight) | 1.030227 | 0.1113591 | 0.783 |
| Body Mass Index (Overweight) | 1.198566 | 0.0981117 | 0.027** |
| Body Mass Index (Obese I) | 1.484827 | 0.2501989 | 0.019** |
| Body Mass Index (Obese II) | 1.003245 | 0.1102234 | 0.976 |
| Body Mass Index (Obese III) | 1.293887 | 0.222423 | 0.134 |
| Completed High School | 0.9978068 | 0.0949504 | 0.982 |
| Attended Post-secondary | 1.094752 | 0.1094112 | 0.365 |
| Married | 1.243971 | 0.0941485 | 0.004*** |
| Working Full-time | 0.9049366 | 0.0723249 | 0.211 |
| Working Part-time | 0.6916826 | 0.0734857 | 0.001*** |
| Number of Family Members | 1.039979 | 0.0664898 | 0.540 |
| Smoker | 1.335424 | 0.2227486 | 0.083* |
| Drinker | 0.9456494 | 0.1052074 | 0.615 |
| Smoker and Drinker | 0.7689309 | 0.1454329 | 0.165 |
| Close Relatives | 1.000874 | 0.0070929 | 0.902 |
| Close Friends | 0.9927617 | 0.0060912 | 0.236 |

*(Asterisks in the p-value column were used to denote level of significance; p <0.1*, p <0.05**, p <0.01***)*

### 4.4.4 Death

The results for the binary logistic regression for mortality are presented in Table 4.16. A cox proportional hazard model was also estimated to examine how the factors included in this model are associated with the time to death. The results are qualitatively similar to the results from the binary logistic regression and as such only the results of the binary logistic regression analysis are described here. The odds ratio for each variable was reported as a measure of association between exposure to a disability exposure burden and mortality. The odds ratio will signify the odds that mortality rates increase due to exposure of disability within a family, in comparison to the odds of mortality occurring in the absence of such exposure (Raphael, 2009).

The independent or predictor variables modeled in the regression were disability exposure burden, individual disability scores, sex, age, urban or rural residency, the number of family members, body mass index, education level, marital status, employment status and smoking or drinking behaviors.

Disability exposure burden was not significantly associated with mortality rates ($p>0.1$). Individual disability score ($p<0.01$) was associated with a 50% odds increase in mortality. Female sex ($p<0.01$) was associated with a 49% reduction in mortality. Age was associated with increased mortality ($p<0.01$) relative to the 20-40 age category. No one in the study population under the age of 20 died during the observation period so the reference category was changed to the 20-40 age category. Those aged 41-60 ($p<0.01$) experienced a 6.49 odds increase in mortality rates, those aged 61-80 ($p<0.01$) experienced a 48.84 odds increase in mortality rates, and those 81-100 ($p<0.01$) experienced a 521.10 odds increase in mortality rates.

Working full-time ($p<0.01$) or part-time ($p<0.05$), relative to being unemployed, was associated with reduced mortality. Working full-time was associated with a 46% decrease while working part-time was associated with a 31% decrease in mortality, per-person. Attending a post-secondary institution ($p<0.05$), relative to finishing less than a high school diploma, was also associated with reduced mortality, decreasing mortality odds by 23%.

Social support in the family appeared to provide a protective effect against mortality. Being married ($p<0.05$), relative to not being married or in a committed relationship, was associated with reduced mortality, decreasing mortality odds by 22%. The number of close relatives ($p<0.1$) was also associated with slightly reduced mortality. The number of close relatives decreased mortality odds by 2%. However, the number of close friends ($p<0.05$) was associated with increased mortality, increasing mortality odds by 2%.

Smoking and drinking combined was not associated with mortality ($p>0.1$) but smoking was significantly associated with increased mortality and drinking ($p<0.01$) was associated with reduced mortality. Smoking ($p<0.01$) increased mortality odds, per-person, by 91% while drinking ($p<0.01$) reduced mortality odds by 26%, per-person.

There were a number of variables in the regression that were not associated with mortality. In addition to disability exposure burden, urban residency, completing high school (relative to finishing less than a high school diploma), and the number of immediate family members were not associated ($p>0.1$) with mortality rates. Body mass index, regardless of category (relative to normal weight) was also not associated with mortality.

Table 4.16 *Binary Logistic Regression for Death*

| **Model (N=7776)** | **Odds Ratio** | **Standard Error** | **p-value** |
|---|---|---|---|
| Disability Exposure Burden | 1.03465 | 0.0429105 | 0.411 |
| Individual Disability Score | 1.495861 | 0.0620203 | 0.000*** |
| Sex (female) | 0.5123558 | 0.0477325 | 0.000*** |
| Age (41-60) | 6.493379 | 1.047904 | 0.000*** |
| Age (61-80) | 48.84304 | 8.207025 | 0.000*** |
| Age (81-100) | 521.1011 | 206.2714 | 0.000*** |
| Urban | 1.09007 | 0.1053166 | 0.372 |
| Body Mass Index (Underweight) | 1.370018 | 0.2966255 | 0.146 |
| Body Mass Index (Overweight) | 0.9799121 | 0.1011049 | 0.844 |
| Body Mass Index (Obese I) | 0.9388451 | 0.1344162 | 0.659 |
| Body Mass Index (Obese II) | 1.00833 | 0.25607 | 0.974 |
| Body Mass Index (Obese III) | 1.779392 | 0.6461352 | 0.113 |
| Completed High School | 1.032389 | 0.1384177 | 0.812 |
| Attended Post-secondary | 0.7737966 | 0.0939166 | 0.035** |
| Married | 0.7813021 | 0.0843211 | 0.022** |
| Working Full-time | 0.543926 | 0.0716013 | 0.000*** |
| Working Part-time | 0.6985431 | 0.1242153 | 0.044** |
| Number of Family Members | 0.9629173 | 0.0509761 | 0.475 |
| Smoker | 1.905504 | 0.3707571 | 0.001*** |
| Drinker | 0.7391433 | 0.0818551 | 0.006*** |
| Smoker and Drinker | 1.058806 | 0.2361898 | 0.798 |
| Close Relatives | 0.9824628 | 0.0103707 | 0.094* |
| Close Friends | 1.019581 | 0.0099871 | 0.048** |

*(Asterisks in the p-value column were used to denote level of significance; p <0.1*, p <0.05**, p <0.01***)*

### 4.5 Conclusion

It was originally hypothesized that families that were exposed to higher levels of disability exposure burden would experience higher rates of health service utilization, indicating poorer overall health outcomes. The results did find significant associations between the level of disability exposure burden and the number of hospitalization days, the number of hospital separations, number of General Practitioner visits, and the number of Specialist visits. However, mortality rates were not found to be associated with the level of disability exposure burden experienced by a family member of a disabled individual. The results of the study will be discussed in more detail in the next chapter.

# CHAPTER 5

# DISCUSSION

## 5.1 Introduction

The aim of this study was to capture the health trajectories and outcomes of family members of a disabled individual to assess whether or not exposure to disability manifests ill health via increased health service utilization or mortality. This study specifically captured the health outcomes, health utilization trends, and death rates for the disabled Newfoundlanders and their family members from 1995-2010. Health outcomes were observed over a fifteen-year period, from 1995-2010, allowing for an analysis of the potential ill health effects derived from caring for or living with a disabled family member. Administrative data sets allowed for health utilization trends of the disabled individuals and their family members to be tracked throughout the provincial health care system (where fee-for-service claims applied), thus data on the number of hospital or physician visits and corresponding total hospitalization days could be examined.

It was originally hypothesized that families exposed to higher levels of disability exposure burden would experience poorer health outcomes via increased health service utilization or mortality. Disability exposure burden was the variable used to measure the amount of burden placed on each individual in the family, due to disability. The present study found significant associations between the level of disability exposure burden and the number of hospital separations, total number of hospitalization days, number of General Practitioner visits, and the number of Specialist visits. Conversely, death rates were not found to be significantly associated with the level of disability exposure burden experienced by a family member of a disabled individual. There were also significant associations found between the individual's own disability score and the five health outcomes variables (i.e., number of hospital separations, total hospitalization days, number of General Practitioner visits, number of Specialist visits, and death rates), as was expected.

## 5.2 Characteristics of the Study Population

The study included 7,791 cases from the Newfoundland Adult Health Survey that had been linked with provincial health administrative data. The study population was restricted to the island portion of the province encompassing both urban and rural Newfoundland. The majority of individuals, 4,737 individuals (60.8%), lived in an urban area of the province while 3,054 individuals (39.2%) resided in rural areas. There were 3,720 males (47.7%) and 4,071 females (52.3%) included in the study. The ages of the study population ranged from 18-100 years of age. In terms of the highest level of education completed, 2863 members (36.7%) of the study population did not attain a high school diploma and 1080 individuals (13.9%) had a high school diploma. Almost half (49.4%) of the study population completed at least some post-secondary education.

The Newfoundland Adult Health Survey also collected information about height and weight allowing Body Mass Index scores to be calculated and converted into Body Mass Index categories. There were 352 individuals (4.5%) who were underweight, 2833 individuals (36.5%) who were normal weight, 3179 individuals (40.8%) who were overweight, and 1427 individuals (18.2%) who were obese.

There were 1077 Newfoundland Adult Health Survey participants (13.8%) who self-identified as disabled. Individuals who identified as disabled had reported that they had difficulty performing tasks as the result of a long-term condition or health-related problem that causes a limitation in daily activities (Statistics Canada, 2014).

Individual disability score was categorized into one of five categories based on whether or not they self reported as disabled and the number of functional impairments the individual experienced. There were 6601 individuals (84.7%) who were not disabled with no reported impairments, 113 individuals (1.5%) who were not disabled with one reported impairment, 830 individuals (10.7%) who were disabled with two reported impairments, 123 individuals (1.6%) who were disabled with three reported impairments, and 124 individuals (1.6%) who were disabled with four or more reported impairments (See Table 4.3 *Individual Disability Score Frequency [N=7791]).* The range of individual disability score was 0-4 with a standard deviation of 0.85.

There were 6432 individuals (82.6%) who were not exposed to any disability burden, 107 individuals (1.4%) with a disability exposure burden score of one, 844 individuals (10.8%) with a disability exposure burden score of two, 140 individuals (1.8%) with a disability exposure burden score of three, and 268 individuals (3.4%) with a disability exposure burden score of four or higher (See Table 4.5 *Disability Exposure Burden Frequency [N=7791]).* The range of disability exposure burden scores was 0-10 (categories 4-10 were collapsed into one category due to low frequencies) with a standard deviation of 1.08.

Other studies that examine the health outcomes of disability often use census data or national surveys, such as the Canadian Community Health survey, to capture the number of disabled individuals in a given population (Cameron et al., 2006; O’Reilly, Connolly, Rosato, & Patterson, 2008; Ramsay, Grundy, & O’Reilly, 2013). For example, O’Reilly et al. (2013) used secondary data from the Northern Ireland Census for 162, 884 individuals who had self-identified themselves as a personal caregiver for a family member. However, there is also literature on the health effects of disability that use smaller matched samples to observe how disability affects the health outcomes of families, particularly mortality rates (Brown, Smith, Schulz, Kabeto, Ubel, Poulin, & Langa, 2009; Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; Ho, Chan, Woo, Chong, & Sham, 2009; Roth, Haley, Hovater, Perkins, Wadley, & Judd, 2013). For example, Ho et al. (2009) studied and compared the mortality outcomes of 246 caregivers and 492 non-caregivers. The current study used a sample size of 7,791 participants, which falls into the large range of sample sizes used in comparable literature.

Although the sample size in the literature varied, most of the referenced literature included a measure of disability severity. Disability severity was measured by the level of impairment (Wideman & Sullivan, 2011; Williamson et al., 2013; Wilson et al., 2013), as it was in the current study, or the number of health service utilization claims (Cameron et al., 2006). Wilson et al. (2013) used New Injury Severity Scores, a scale that measures the number of impairments an individual experiences to rank the participant’s own disability. New Injury Severity Scores between 1-3 (42.6%) were the least severe, scores of 4-6 (38.9%) were of moderate severity, and scores above 6 (14.5%) were the most severe injuries. The most severe injuries in the current study, an individual disability score of 3 or 4 (3.2%) comprised the smallest proportion of the sample, as it did in the Wilson et al. (2013) study. In some instances the referenced studies were limited to a particular type or form of disability (i.e. brain injury) so there was no measure of severity included (Man, 2002; Man et al., 2003; Pessar et al., 1993).

There were a higher number of female participants in the current study and in the referenced literature. Females represented 52.3% of the sample population and 51.0% (Schulz & Beach, 1999)- 82.0% (Man, 2002) of the sample populations in the referenced literature. The higher number of female participants in the referenced literature was expected, as the studies focused on the effects of caregiver burden. The responsibility of caregiving for a family member is often placed onto females (Man, 2002; Stabile & Allin, 2012) leading to a greater number of female participants.

The current study included a broader range of ages, 18- 100 years of age, in comparison to the literature. The majority of study participants (83.7%), in the current study, were between 18-60 years of age. This is consistent with the studies in the referenced literature, which typically used participants between the ages of 18 and 65 (Cameron et al., 2006; Ho et al., 2009; Man et al., 2003; O'Reilly et al., 2013; Wideman & Sullivan, 2011; Wilson et al., 2013). Although a range of ages is usually encompassed in studies on the health effects of disability and disability burden, there are some studies that only include older participants (i.e. participants aged 65 or older) (Brown et al., 2009; Roth et al., 2013; Schulz & Beach, 1999). The studies by Brown et al. (2009) and Schulz & Beach (1999) excluded participants younger than age 65 to observe the effects of caregiving on mortality rates. Roth et al. (2013) only included participants who were 45 years of age or older to determine the health effects associated with caregiving. However, most studies include a range of ages to compare the effects of age and health outcomes

(Cameron et al., 2006; Ho et al., 2009; Man et al., 2003; O'Reilly et al., 2013; Wideman & Sullivan, 2011; Wilson et al., 2013), as was the intention of the current study.

The referenced literature also included studies that utilize families to determine the impact of social support on the health related effects of disability (Ho et al., 2009; Man, 2002; Man et al., 2003; Roth et al., 2013; Williamson et al., 2013). Several studies used only married couples to focus on the effects of marriage and social support on the health effects of disability (Brown et al., 2009; Pessar et al., 1993; Schulz & Beach, 1999). However, as families provide a large amount of social support (Crompton, 2010;Gorman et al., 2009; Ponsford et al., 2014; Voigt & King, 2014) the current study used families regardless of marital status. In the current study 5,788 (74.3%) participants were married. This is comparable to the referenced literature whose samples included anywhere from 58.3% (Roth et al., 2013) to 88% (Man, 2002) married individuals.

### 5.3 The Effects of Disability Exposure Burden and Individual Disability Score on Health Outcomes

This study investigated the health impacts of living with and caring for a family member with a disability by assessing the relation of disability exposure burden and the number of hospital separations, respective total hospitalization days, number of physician visits, and rates of death. The household identification number included in the Newfoundland Adult Health Survey allowed family member data to be clustered to assess familial health outcomes. There were 4,363 household clusters (or families) included in the study sample. It was hypothesized that families who were exposed to disability would experience poorer health outcomes. It was presumed that this effect would be inflated in the presence of multiple disabilities within households.

Higher level of disability exposure burden, the amount of subjective burden a family member experiences due to disability in the family unit, was related to a higher number of hospital separations and physician visits, (i.e., General Practitioner and Specialist physicians). This finding is consistent with the evidence that cites adverse health impacts for the family members of disabled individuals (Gorman et al., 2009; Kress & Herridge, 2012; Whiting, 2014).

Higher health care utilization rates of disabled individuals over their non-disabled counterparts have been documented in the literature (Balogh et al., 2010; Cameron et al., 2008). However the literature available on the health impacts of disability on family members is mixed. Some families faced detrimental health impacts (Stabile & Allin, 2012) due to stress or burnout related to living with or caring for a disabled loved one (Gorman et al., 2009; Kress & Herridge, 2012; Pessar et al., 1993; Stabile & Allin, 2012; Whiting, 2014) while other ill health effects were buffered with social support (Crompton, 2010; Voigt & King, 2014) and resilience (Farrell & Krahn, 2014; Williamson et al., 2013). This study aimed to examine the impact of disability exposure burden on the health outcomes of disabled individuals and their family members. As will be discussed, disability exposure burden did affect the health outcomes for the family members of disabled individuals. Family members experienced higher levels of hospital separations, hospitalization days, and physician visits.

The level of disability exposure burden and individual disability score experienced by a family unit was associated with higher health service utilization. A binary logistic regression analyses was performed to assess if there was a relationship between death rates and the level of disability exposure burden experienced. There were also four negative binomial regression analyses conducted to determine potential associations between levels of disability exposure burden and total hospitalization days, the number of hospital separations as well as the number of physician visits, (i.e., General Practitioner and Specialist physicians). The number of hospital separations, total number of hospitalization days, and number of physician visits were associated with the level of disability exposure burden indicating higher health utilization rates for the family members of disabled individuals. However death rates were not significantly associated with disability exposure burden. The higher health service utilization rates may be due to disability exposure burden involving health service utilization for minor, chronic, or non-life threatening health conditions. This would increase the rate of interaction with the provincial health care system while not inciting health conditions that are severe enough to provoke death.

The regression analyses for individual disability score also supported the literature regarding the increased rates of health service utilization among the disabled population (Balogh et al., 2010; Cameron et al., 2008). Individual disability score was associated with an increased number of hospital separations, increased total hospitalization days, increased number of physician visits, and increased death rates. Thus clearly establishing a link between an individual's disability status and poor health outcomes.

The level of disability exposure burden and individual disability score will be discussed in relation to each of the four health outcomes in the subsequent sections of this chapter.

### 5.3.1 Number of Hospital Separations

The current study found a difference between those subjected to disability exposure burden and those who were not with relation to the number of hospital separations. A unit increase in disability exposure burden was associated with a 21% increase in the number of hospital separations compared to those not exposed to disability. Individual disability score was also associated with a 20% increase in the number of hospital separations. Disabled individuals had an average of 7.14 hospital separations compared to 3.90 visits, per-person, for the nondisabled individuals in the study.

Family members of disabled individuals may experience higher hospitalization rates due to the stress (Gelkopf & Roe, 2014; Kress & Herridge, 2012) and physical demands of living with or caring for a loved one with a disability (Whiting, 2014). There is also evidence in the literature that implies that family caregivers will neglect their own health when caring for a loved one due to their preoccupation with caregiving (Kress & Herridge, 2012; Man, 2002). A 2009 study conducted by Ho et al., (2009) found that family members who acted as caregivers experienced 1.5 times the number of hospitalizations compared to non-caregiver family members. This is similar to the results of tis study, which found a 1.21 factor increase in the number of hospital separations for those exposed to disability burden.

The literature cites higher hospitalization rates for the disabled population in comparison to the non-disabled population (Balogh et al., 2010; Cameron et al., 2008) Balogh et al. (2010) found individuals with an intellectual disability were hospitalized at a rate 6.1 times higher than that of individuals without an intellectual disability. Cameron et al. (2008) also found that those suffering from a long-term injury had 1.63 times the number of hospitalizations than those without an injury. The results of the current study support this finding, as disability score was associated with a 1.20 factor increase in the number of hospital separations.

### 5.3.2 Total Hospitalization Days

The total hospitalization days for individuals who participated in the Newfoundland Adult Health Survey had a wide range, 0- 21,942 days. However any total hospitalization days exceeding 1,010 days, values beyond three standard deviations of the mean, in the Newfoundland Adult Health Survey linked dataset was considered to be an outlier and removed prior to data analysis. The average number of hospitalization days, per-person, for the Newfoundland Adult Health Survey study sample was 40.43 days. The average number of hospitalization days for the disabled individuals in the study population was 99.10 days and the average number of days for nondisabled individuals was 31.03 days.  Those exposed to disability in the household also had a higher average number of hospitalization days than those not exposed to disability.

As few studies have examined the health effects of disability on family members there is a dearth of literature available explaining how the total hospitalization days are affected by those afflicted with a disability within their family unit. It was hypothesized that the additional burden, which could be physical, financial and emotional, would have a deleterious effect on the family member’s health; the current study revealed a difference for disability exposure burden and the total hospitalization days. A unit increase in the disability exposure burden variable was associated with a 43% increase in total hospitalization days. Individual disability score was also associated with a 29% increase in the total hospitalization days. This finding is consistent with evidence in the literature that cites longer lengths of stay for disabled individuals such as the study conducted by Cameron et al. (2008). Cameron et al. (2008) compared the rates of the length of stay in days for injured and uninjured individuals in the Manitoba Injury Outcome Study and found that injured individuals reported 3.22 times longer lengths of stay than their uninjured counterparts.

### 5.3.3 Number of Physician Visits

The majority of physician visits in the province of Newfoundland are billed on a fee-for-service basis whereby physicians are remunerated for each patient visit they conduct. This practice requires rigorous data collection and recording, which can be used to develop administrative databases as viable research tools. Fee-for-service physician claims were used as a health outcome indicator in this study. Previous studies have also utilized physician visit data via administrative data sources to study health indicators or predictors (Cameron et al., 2008; Canadian Institute for Health Information, 2014B; Iezzoni, 2002; Wideman & Sullivan, 2010).

The negative binomial regression analyses revealed a difference in the number of General Practitioner or Specialist physician visits between those exposed to disability and those who were not. The association between these two variables suggests that higher levels of disability exposure burden are associated with higher rates of physician visits as well. A unit increase in disability exposure burden score was associated with a 10% increase in General Practitioner and Specialist visits. This is consistent with evidence in the literature citing negative health impacts or outcomes for the family members of disabled individuals (Ho et al., 2009; Stabile & Allin, 2012). For example, a 2009 study by Ho et al. found that family caregivers visited a physician 1.5 times more than the family members who did not provide caregiving services.

Disabled individuals report higher rates of hospitalizations and physician visits than the non-disabled population (Balogh et al., 2010; Cameron et al., 2008) so it was hypothesized that there would be a strong, significant relationship between one's own disability score and the number of physician visits. Cameron et al. (2008) observed several health outcome indicators, including the number of physician visits, for Manitobans who had experienced a disabling injury and compared their health service utilization rates to a non-disabled population. The injured cohort had a 1.28 times higher rate of physician visits than the non-injured population. Balogh et al. (2010) conducted a similar study comprised of individuals with intellectual disabilities and concluded that the individuals with intellectual impairments experienced higher interactions with the health care system, including physician visits and hospitalizations, at a rate 6.1 times greater than those without an intellectual disability. This evidence supports the association between the individual's own disability score and the number of physician visits, General Practitioner and Specialist, found in the current study. An increase in disability score was associated with a 1.18 increase in the number of General Practitioner visits and a 1.20 increase in the number of Specialist visits which was similar to increases seen in the literature (Balogh et al., 2010; Cameron et al., 2008).

Disabled individuals have increased numbers of physician visits (Balogh et al., 2010), but the relationship between disability exposure burden and the number of physician visits was of added importance for this study. Disability exposure burden can cause stress, burnout (Hwang & Kearney, 2014; Kress & Herridge, 2012), and psychological distress (Williamson et al., 2013; Wilson et al., 2013) among other health concerns. The stress of living with a family member afflicted with a disability can produce a number of adverse physical and mental health conditions. The Canadian Mental Health Association (2014) has identified stress as a risk factor for a number of physical and psychological health conditions including; heart disease, headaches, mental illness and trouble sleeping. These health concerns can also be further aggravated if a family member takes on a caregiving role (Kress & Herridge, 2012; Man, 2002). The stress and responsibility of caregiving may manifest ill health outcomes (Stabile & Allin, 2012; Whiting, 2014) especially if the caregiver neglects their own physical and psychological health (Kress & Herridge, 2012; Man, 2002; Stabile & Allin, 2012). Neglecting one's health may produce future health complications if one's condition worsens or deviates before seeking medical attention.

### 5.3.4 Death

Advances in modern medicine and technology have allowed the rates of premature death, death before age 75 (Canadian Institute for Health Information, 2012B), to gradually decrease from year-to-year in Newfoundland and Labrador (Canadian Institute for Health Information, 2012B). However the rates of premature death among disabled individuals in the province are still higher than those of the non-disabled population (World Health Organization, 2014B). There were 1001 recorded deaths, over the fifteen year period, in the linked Newfoundland Adult Health Survey data accounting for approximately 12.9% of the sample population.

In the current study, death was not associated with the disability exposure burden. This finding suggests that being exposed to disability within the family may not manifest higher instances of mortality. It was hypothesized that the family members of disabled individuals would be exposed to poorer health outcomes and experience higher rates of mortality. Although disability exposure burden was associated with additional hospitalizations, greater total hospitalization days and more frequent physician visits there was no difference found between mortality and disability exposure burden.

Early research on the health effects produced from caregiving suggested that the stress produced from caregiving would lead to premature mortality (Schulz & Beach, 1999). However, more recent literature on the topic has suggested that caregiving is associated with decreased levels of mortality (Brown et al., 2009; Fredman et al., 2010; O'Reilly et al., 2013; Roth et al., 2013). A study by Fredman et al. (2010) found that caregivers reported higher levels of stress, but their mortality rates were 26% lower than non-caregivers. A study conducted by O'Reilly et al. (2008) utilized data from the 2001 Northern Ireland Census and found that caregivers had 14% lower mortality rates than non-caregivers. Roth et al. (2013) also found that caregivers had reduced mortality rates with caregivers experiencing 18% lower mortality rates than non-caregivers.

In addition, it may be that the time spent providing care or the level of care influences the relationship between caregiving and mortality; both level of care and time spent providing care have an effect on mortality rates (Ramsay et al., 2013). Ramsay et al. (2013) compared the mortality rates of adult caregivers providing heavy care (more than

20 hours of care a week), caregivers providing light care (between 1-19 hours of care a week), and non-caregivers in England Wales. Caregivers, providing light or heavy care, were less likely to die than non-caregivers. However those providing light care were 19% less likely to die than non-caregivers, while those providing heavy care were only 13% less likely to die than non-caregivers.

The effect of caregiving burden on death may also be dependent on the level of care and time spent caring for a loved one. Those who do not provide a high level of care (more than 14-20 hours a week; Brown et al., 2009; Ramsay et al., 2013), or strenuous levels of care, may not be subject to higher mortality rates. Brown et al. (2009) found that the mortality rates of caregivers providing between 1-14 hours of care to a spouse did not differ from those of non-caregivers. While those providing more than 14 hours of care experienced a 0.64 decrease in mortality rates when compared to non-caregivers.
This finding is similar to the results of this study, which did not find a difference in the mortality rates among those exposed to disability in the family and those not exposed to disability. It is possible that the caregivers in the current study may have been providing lower levels of care.

Individuals exposed to disability in the study sample did not experience mortality rates that differed from those not exposed to disability in the family. Disability exposure burden was associated with higher health service utilization rates, hospitalizations and physician visits (Balogh et al., 2010; Cameron et al., 2008; Ho et al., 2009). However, this may be due to disability exposure burden rousing frequent, minor health conditions that would increase the rate of hospitalizations and physician visits while not inciting health conditions that are severe enough to provoke mortality.

The insignificant relationship between mortality and the level of disability exposure burden may also be due to the resiliency developed while caring for or living with a loved one with a disability  (Farrell & Krahn, 2014; Williamson et al., 2013). Williamson et al. (2013) observed that families who reported higher levels of familial satisfaction after adjusting to the news of a disabling injury to a loved one also reported higher levels of resiliency as they coped. This resiliency may provide a protective effect against stress, burnout, or other related health concerns that may exacerbate or promote mortality.

## 5.4 The Effects of the Control Variables on Health Outcomes

A number of variables were analyzed in the regression analyses to act as controls since it is established that disability exposure is associated with a wide range of the determinants of health. Each of the variables and their relation to the health outcomes are discussed in detail below.

### 5.4.1 Age

Generally speaking, older individuals tend to report higher rates of disability than their younger counterparts. The age effect cited in the literature (Statistics Canada, 2013B; Statistics Canada, 2008) is inconsistent with the findings from this study. Older individuals were expected to be exposed to higher rates of disability but individuals in the Newfoundland Adult Health Survey disabled population, aged 61 or older, only covered 37.3% of the disabled population. There were 11 disabled individuals less than 20 years old, 257 disabled individuals (23.9%) between 20 and 40 years of age and 407 disabled individuals (37.8%) between 41 and 60 years of age. However the majority (83.7%) of the study sample was comprised of individuals 60 years of age or younger with only 16.3% of the study population aged 61 or older. In addition, younger individuals, namely those aged 15-24, are cited as experiencing higher rates of pain, learning, and psychological disabilities in comparison to seniors, aged 65 or older, afflicted by disability (Statistics Canada, 2013B). It is possible that there were a high number of young individuals affected by pain, learning, or psychological disabilities in the study population responsible for inflating the rate of disability for the younger age group. There was also no difference in the number of males or females with regard to age and disability distribution in the population.

An increase in age was however associated with increased hospitalizations, total hospitalization days, General Practitioner visits, Specialist visits and death rates in the current study. Age was associated with higher health service utilization rates, relative to being aged less than 20 years old. Age was associated with a 1.57- 14.47 factor increase in the number of hospital separations. Age ($p<0.01$) was also associated with a 3.28- 82.73 factor increase in number of total hospitalization days, depending on age. The number of physician visits was also associated with age. Age was associated with a 1.26- 7.81factor increase in the number of General Practitioner visits and a 1.87- 14.16 increase in the number of Specialist visits.

The association between age and increased hospitalizations, hospitalization days, and physician visits is consistent with reports in the literature. Age and self-rated health are two variables that are typically negatively correlated, denoting that as one ages his/ her state of health decrease or deteriorates (McColl, Jarzynowska, & Shortt, 2010). The health impacts and outcomes of disability are also correlated with age producing higher health service utilization rates for older, disabled individuals (Statistics Canada, 2013B). Longer life expectancy rates have developed new needs in the health care system for chronic disease and disability management (Canadian Institute for Health Information, 2012B). Disease and disability management often requires increased health care service utilization to effectively manage disease or disability progression (Canadian Institute for Health Information, 2012B). Senior citizens, those aged 65 or older, are more likely to use hospital services, be admitted as an inpatients, and visit their physician than younger individuals (Canadian Institute for Health Information, 2011; Clarke, 2004).

Age was also associated with increased mortality rates, relative to the 20-40 age range category. The odds of mortality increased with age with the oldest individuals in the study, aged between 81 and 100 years old, experiencing the greatest odds of death. Death rates are higher among the elderly population (Clarke, 2004; Statistics Canaada, 2013A) thus the age effect found in this study was expected.

### 5.4.2 Sex

The literature on disability cites a gender effect whereby females report higher instances of disability than males in Canada (Council of Canadians with Disabilities, 2013A; Statistics Canada, 2013B). However there was no difference found between the rates of disability for the two genders in the study. This could be due to the phrasing of the question in the Newfoundland Adult Health Survey where participants were asked to self-report whether or not they were disabled ("Are you now suffering from any disability [A condition that stops you from doing your routine activities]?") (Segovia et al., 1996).

Phrasing the question in this manner may have led participants to falsely identify as disabled or not to identify as disabled, even though they were, if they did not wish to express the presence of their disability or felt that their disability did not alter their daily living conditions.

The number of hospital separations and the number of Specialist visits were not associated with gender when analyzed in the negative binomial regression analysis. However the number of total hospitalization days and number of General Practitioner physician visits were different by gender. Being female was associated with a reduced number of hospitalization days. Females were expected to have 51% fewer total hospitalization days than their male counterparts. Females were also associated with a 40% increase in the number of General Practitioner visits. There was no association found between sex and the number of hospital separations or Specialist physician visits. The binary logistic regression analysis also revealed that sex was associated with a 49% reduction in mortality rates, indicating lower instances of mortality for females. Males are expected to have higher instances of death than their female counterparts (Clarke, 2004; Statistics Canada, 2013A), as was found in the results of this study.

The literature suggests that the burden of caregiving falls disproportionately on females (Man, 2002; Stabile & Allin, 2012). Mothers, wives, and daughters often take on caregiving roles in the family subjecting themselves to increased psychological burden and stress (Man, 2002). Caregivers can be so immersed in the care of others that they neglect their own health (Hwang & Kearney, 2014; Kress & Herridge, 2012; Stabile & Allin, 2012). This may cause female caregivers, who are exposed to disability burden in the household, to avoid taking the time to seek medical care or heal when in poor health, as was seen in this study with females being associated with a 51% reduction in the total number of hospitalization days.

### 5.4.3 Urban Residency

The urban variable specified whether an individual lived in urban or rural Newfoundland. Newfoundland was split into two areas with St. John's and the urban corridor (smaller cities and towns) being classified as urban and all other small or isolated communities being classified as rural. The majority of the study sample lived in an urban area (60.8%) with 39.2% living in a rural area.

There was no difference in the number of hospital separations, total hospitalization days, or death rates found between those who lived in urban versus rural areas of the province. However, there was a difference found for the number of physician visits, General Practitioner and Specialist, such that those residing in urban areas had higher General Practitioner and Specialist visits. Prior to the regression analysis, bivariate analyses of the study variables revealed a negative correlation between the distance travelled to visit a physician and the number of physician visits, General Practitioner and Specialist. This is likely capturing the fact that salaried General Practitioners service the many rural and remote areas of the province and as such, reliable records of their utilization patterns do not exist. The statistical analysis provided support for this hypothesis given the association between the recorded number of recorded physician visits and the urban variable. Urban residency was associated with a 47% increase in General Practitioner visits, as recorded by the provincial Medical Care Plan. Living in an urban environment was associated with a 31% increase in the number of Specialist visits.

Consequently the convenience of living in close proximity to a physician does appear to influence the frequency of visiting a Specialist physician, as is reported in the literature.

McDonald & Conde (2010) used data from the Canadian Community Health Survey, 2002-2003, to investigate geographical variations in health care usage across the country. They found that individuals living in a rural area had 0.73 decreased odds of having a General Practitioner. Living in a rural area also decreased the odds of visiting a General Practitioner by 0.82 and decreased the odds of visiting a Specialist physician by 0.74, when compared to those living in urban areas. Sibley & Weiner (2011) found similar results using the data from the 2003 Canadian Community Health Survey. They further divided rural areas based on their proximity to a town with a population of 10, 000 into three categories; rural with a strong metropolitan influence zone, rural with a moderate metropolitan influence zone, and rural with a weak metropolitan influence zone. Living in a rural area with a strong metropolitan influence zone decreased the odds of visiting a General Practitioner by 0.85 while there was no difference found for the odds of visiting a Specialist physician. Living in a rural area with a moderate metropolitan influence zone decreased the odds of visiting a General Practitioner by 0.86 while the odds of visiting a Specialist physician were decreased by 0.90. Living in a rural area with a weak metropolitan influence zone decreased the odds of visiting a General Practitioner by 0.93 while the odds of visiting a Specialist physician were decreased by 0.81. Sibley & Weiner (2011) concluded that there is inequity of health care access and utilization given that those living in a rural area have lower odds of visiting a physician resulting in unmet health care needs. The findings from the McDonald & Conde (2010) and Sibley &

Weiner studies are consistent with the findings of this study which suggest residents of urban areas have higher numbers of physician visits.

### 5.4.4 Body Mass Index

Obesity has been linked to a myriad of health concerns (World Health Organization, 2014C). Generally speaking, those who are overweight or obese are at increased risk for developing heart disease, high blood pressure, diabetes, stroke, or mortality among other health concerns (World Health Organization, 2014C). Due to the health concerns associated with weight, body mass index is often used as a preliminary measure for assessing body fat and potential weight problems. Values at or above a body mass index score of 30.0 indicate that a person is obese and suggests that there are potential weight-related health risks (World Health Organization, 2014C).

As the Newfoundland Adult Health Survey data provided height and weight, body mass index was calculated for each participant to determine if it had an effect on health utilization rates or outcomes. It was hypothesized that those who were obese, with body mass index scores above 30.0, would be associated with poorer health outcomes and subsequently higher health service utilization rates or death. High body mass index scores were associated with increased hospital separations, total hospitalization days, and the number of physician visits, but there was no relationship found for body mass index scores and death rates.

There were associations found between the number of hospital separations and those who were overweight and obese, in comparison to a typical healthy weight range.

Being overweight or obese was associated with a 22%- 346% increase in the number of hospital separations. The total number of hospitalization days increased by 346% for those who were obese. Physician visits were also associated with an increased number of visits for those who were overweight and obese. Being overweight or obese was associated with a 24%- 63% increase in the number of General Practitioner visits. Specialist visits were associated with a 20%- 48% increase in the number of visits for those who are overweight and obese.

The associations found between the number of hospital separations, total hospitalization days, and physician visits with overweight or obese body mass index scores, support the hypothesis that poorer health outcomes would be associated with high body mass index values. Surprisingly death rates were not associated with body mass index values. This may suggest that overweight or obese Newfoundland Adult Health Survey participants were managing their health conditions by visiting physicians or hospitals by utilizing various health care services to a greater degree. For example, chronic disease management may require frequent physician or hospital intervention despite the fact that treatment regimes or medications may ease the ailment and prolong life expectancy. However it is also possible that obesity does not appear to have an effect on health outcomes when controlling for disability.

### 5.4.5 Education and Employment

Employment status and education levels were used as proxies for determining the effect of socioeconomic status on the individual's health outcomes. Generally speaking, education is positively correlated with income (Raphael, 2009). Using this correlation it was hypothesized that those who were employed with a high level of education would experience improved health outcomes due to the protective effect of income and the likelihood of working in jobs that would reduce the exposure to disability risk. Higher income would also allow individuals who did experience poor health conditions, whether personal or family member income, the resources necessary to treat the ailment.

Education was not associated with any of the health service utilization variables, relative to not having a high school diploma. There was no difference found between the level of education one has and the number of hospital separations, total hospitalization days, or the number of physician visits. However, completing at least some post-secondary education, relative to not having a high school diploma, was associated with a 23% decrease in mortality rates. This is finding is consistent with the literature that cites higher education is correlated with better health outcomes.

The 2006 Participation and Activity Limitation Survey, conducted by Statistics Canada, found that working-age disabled individuals were less likely to have a formal education; 27.4% of the disabled sample had not received a high school diploma compared to 18.3% of the non-disabled population (Council of Canadians with Disabilities, 2013B). Disabled individuals in the Participation and Activity Limitation

Survey were even less likely to report having a university degree, 13.2%, compared to their non-disabled counterparts, 20.7% (Council of Canadians with Disabilities, 2013B).

Full-time employment, relative to being unemployed, was not associated with the number of hospital separations, total hospitalization days, or the number of Specialist visits. However, there was a difference found for those who were employed full-time and the number of General Practitioner visits and mortality rates. Full-time employment, relative to being unemployed, was associated with a 13% decrease in the number of General Practitioner visits and a 46% decrease in death rates. Part-time employment, relative to being unemployed, was associated with a 38% decrease in the number of hospital separations and a 70% decrease in the total number of hospitalization days. Being employed part-time was also associated with a 22% decrease in the number of General Practitioner visits and a 31% decrease in the number of Specialist visits. Working part-time was also associated with a 31% decrease in mortality rates.

Disability can hinder one's ability to work or continue working if it places physical or mental barriers on the individual. Disabled individuals are twice as likely to have a low income compared to those without a disability (Council of Canadians with Disabilities, 2013B), likely explained by their employment circumstances. Physical or mental limitations imposed by disability can pose barriers in obtaining employment opportunities for the disabled community (Statistics Canada, 2013B). The Canadian Survey on Disability 2012 (Statistics Canada, 2013B) revealed a 49% employment rate for working-age adults with a disability compared to a 73% employment rate among non-disabled Canadians. This is similar to the proportion found in the study sample; 78.4% of disabled individuals were not employed compared to 42.5% of non-disabled individuals.

However, those exposed to disability burden did not experience rates of unemployment (45.0%) as high as those without any disability exposure burden (59.2%).

The associations suggest that socioeconomic status, derived from employment, may allow for a protective effect on health outcomes. This protective effect may allow for more favourable health conditions and lower health service utilization rates for those with steady employment and income. This effect parallels the literature citing detrimental health conditions occurring more often in low-income families or individuals (Raphael, 2009).

### 5.4.6 Health Behaviors (Smoking and Drinking)

Health risk behaviors, such as smoking (World Health Organization, 2014D) and drinking (World Health Organization, 2014A), can have detrimental impacts on health and lead to premature mortality (World Health Organization, 2014A; World Health Organization, 2014D).

Smoking was associated with an increased number of hospital separations, total hospitalization days, Specialist visits, and deaths. Smoking was associated with a 53% increase in the number of hospital separations, a 4.07 increase in the total number of hospitalization days, and a 34% increase in the number of Specialist visits. Smoking was also associated with a 91% increase in mortality rates. However, smoking was not associated with the number of General Practitioner visits. The association between smoking and the increased levels of health care utilization and rates of mortality suggests that increased levels of health care utilization as well as increased rates of mortality may have been at least partially due to smoking.

Drinking was not associated with the number of hospital separations, total hospitalization days, or number of physician visits. However, drinking was associated with a 26% reduction in mortality rates. Smoking when coupled with drinking was associated with a 77% decrease in the total number of hospitalization days, relative to not smoking or drinking. However, smoking when coupled with drinking was not associated with any other health outcome measure including the number of hospital separations, number of physician visits, or mortality rates. The association between the total hospitalization days with smoking and drinking was surprising; as previously mentioned, it was hypothesized that higher health service utilization rates would be observed among those who smoked, drank, or both smoked and drank based on the known health repercussions of these activities (World Health Organization, 2014A; World Health Organization, 2014D).

### 5.4.7 Social Support

Social support has been shown to have a protective effect on health producing better health outcomes for those with a high level of social support or inclusion (Crompton, 2010;Gorman et al., 2009; Ponsford et al., 2014; Voigt & King, 2014). As such it was hypothesized that the family members with higher levels of social support would utilize health care services less often and have lower death rates. Social support was measured using the following variables from the linked Newfoundland Adult Health Survey data; marital status, number of close friends, number of close relatives, and the number of individuals in the family unit.

There were no associations between the number of family members and any of the health service utilization outcomes.  The number of family members did not affect the number of hospital separations, total hospitalization days, or number of physician visits. The number of close family and friends did not significantly affect the number of hospital separations, total hospitalization days, or the number of physician visits. However mortality rates were associated with the number of close relatives or friends. The number of close relatives was associated with 2% lower mortality rates. Conversely, the number of close friends was associated with increased mortality rates, increasing mortality odds by 2%.

Marital status was not significantly associated with the number of hospital separations. However being married, relative to not being married or in a committed relationship, was associated with 36% fewer hospitalization days. Being married was associated with an increased number of physician visits with a 13% increase in the number of General Practitioner and a 24% increase in the number of Specialist visits. Being married, relative to not being married or in a committed relationship, was also associated with reduced mortality rates, decreasing the odds of mortality by 22%.

The literature cites that social support can have a positive effect on health (Crompton, 2010; Voigt & King, 2014) while social exclusion or little social support is associated is with poorer health outcomes (Gorman et al., 2009; Nosek et al., 2003). Overall the results on the social support variables were mixed as some social support variables were associated with disability exposure burden while others were not. For example, marital status was associated with fewer hospitalization days, an increased number of physician visits, and lower mortality rates. This may be a strong indicator of how social support affects the health outcomes of disabled individuals and the family members exposed to disability burden.

There is evidence in the literature that finds no significant association between household size or the number of family members and the number of interactions with the health care system (Melchiorre, Chiatti, Lamura, Torres- Gonzales, Stankunas, Lindert, Ioannidi-Kapolou, Barros, Macassa, & Soares, 2013), as was found in this study. However, Melchiorre et al. (2013) did find that marriage was associated with higher levels of social support and less frequent health care service utilization. This may suggest that the social support provided by marriage has a stronger effect than having a broad circle of family and friends, which has a limited influence. This study found that being in a marriage or committed relationship was associated with fewer hospitalization days and reduced mortality rates, which is consistent with the literature. However being married was associated an increased number of physician visits. This difference may be due to the social support of the marriage providing the impetus to care for oneself and seek health care intervention when necessary. The higher rates of physician visits may be due to seeking care for minor health conditions, such as the common cold, that are not long-lasting or life threatening.

## 5.5 Strengths and Limitations

Few studies have captured the health impacts manifested in families exposed to disability. This is the first known study that has examined the health outcomes of the family members of disabled adults in Newfoundland and one of the few studies that have examined this topic in any setting. This study observed the effects of disability exposure burden in families on health service utilization and mortality rates over a fifteen-year period, 1995-2010. The data linkage to administrative datasets did provide reliable and valid data for analysis. The linked administrative data combined with the fact that disability was present before the health care service utilization provides a good argument that it is the disability driving higher health care service utilization.

However, the lack of a standard or objective definition of disability in the Newfoundland Adult Health Survey may have led to participants to not identify as disabled even if they were. If individuals falsely identified as disabled or not disabled it may have led to a potential bias in the dataset. In addition to this, the Newfoundland Adult Health Survey data did not collect information about the type or severity of one's disability. Thus the measurement of the effects of disability may be an underestimation of the actual implications. Future studies should consider implementing a measure of the severity of disability for a true representation of the implications of being exposed to disability.

The sample population derived from Newfoundland Adult Health Survey participants may not provide a true representation of the Newfoundland disabled community and their family members. The sample may have had a sampling or selection bias, as it required participants to be reached by telephone. In 1995 approximately 98% of the population had access to a telephone (Segovia et al., 1999) however there are some residents that were unable to participate due to this. The study sample was also limited to the island portion of the province, extending the survey to Labrador would have required a differing study design and data collection method, thus the sample is not representative of the Labrador population of the province.

A limitation also existed with the use of administrative data as not all General Practitioner visits in the province were captured. Medical Care Plan claims data only includes fee-for-service physician claims in Newfoundland and Labrador. Approximately 70% of physicians in the province are fee-for-service. However, in rural areas of the province many General Practitioners are paid either salary or through alternate payment plans and these physicians are not included in the Medical Care Plan claims file (Government of Newfoundland and Labrador, 2007).

As administrative datasets were used for the analysis there were variables such as lifestyle factors (such as exercise), socioeconomic status, and health-related quality of life that were available at 1995 but could not be tracked over the next fifteen years. The absence of these variables, in a longitudinal format, was unfortunate, as they would have added value to the overall analysis. These variables would be especially useful for analysis related to comorbidities and health outcomes. Observing the effect of change in socioeconomic status among families affected by disability would be interesting as socioeconomic status may have differing effects on familial outcomes. Changes in socioeconomic status among families affected by disability may result in severe financial hardship in some instances while others may not be as affected.

Conversely, the presence of possible confounding variables, such as comorbidities, could artificially inflate the rates of health service utilization. However there was a control put in place to account for an individual's own disability status to reduce the potential effect of confounding variables. If future work can replicate the results of this study it will add further evidence that there are detrimental health impacts for the family members of disabled individuals and consequently, increased health service utilization rates. Working to decrease the likelihood of increased health service utilization among families with disability exposure burden may benefit both the health care system and the affected individual(s).

# CHAPTER 6

# CONCLUSION

## 6.1 Study Summary

This study utilized the previously linked Newfoundland Adult Health Survey data and the Medical Care Plan fee-for service claims, Clinical Database Management System, and Mortality Surveillance System databases to determine if disability exposure burden among families manifests poor health outcomes. The study sample consisted of 7,791 participants from the Newfoundland Adult Health Survey who had provided their Medical Care Plan number and written consent for access to administrative health databases. For individuals who provided this consent, the Medical Care Plan number was used to link the Newfoundland Adult Health Survey data and the administrative health databases. Negative binomial regression analyses were conducted to determine if disability exposure burden affected the rates of hospital separations, hospitalization days, or physician visits. A binary logistic regression was conducted to determine if probability of death was affected by disability exposure burden.

Disability exposure burden, the key predictor variable in the study, was associated with higher health care service utilization in comparison to those who were not exposed to disability. Higher disability exposure burden was associated with higher numbers of hospital separations, hospitalization days, and physician visits. However mortality was not associated with disability exposure burden. Individual disability was also associated with all of the health outcome variables. Individual disability score was associated with higher levels of health care utilization and mortality.

The literature on the health outcomes of disability typically focus on the detrimental health outcomes for the disabled individual (Drum et al., 2008; Hartley, 2010; Singleton, 2012; Urbano, Hodapp, & Floyd, 2007); the disabled individuals in this study did experience poorer health outcomes via increased hospital separations, hospitalization days, physician visits, and mortality rates. Higher disability exposure burden was also associated with higher levels of health care service utilization. This result is consistent with the burgeoning evidence in the literature suggesting that the families of disabled individuals experience poorer health outcomes as well (Gelkopf & Roe, 2014; Gorman et al., 2009; Whiting, 2014).

### 6.2 Study Contributions and Implications

There is an abundance of information available on how disability affects the health outcomes for the disabled individual (e.g. Drum, Horner-Johnson, & Krahn, 2008; Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010) but there is still a dearth of information available concerning how these effects translate onto family members. The current study has offered evidence of the ill health effects that result from disability exposure burden in families. Disability exposure burden was associated with a higher number of hospital separations, total hospitalization days, and physician visits indicating poor health outcomes for those exposed to disability in the family. It should also be noted that the level of disability exposure burden was not significantly associated with probability of death.

Advances in medical technology and interventions have introduced longer life expectancies and implemented a shift in health care to chronic disease and disability management (Canadian Institute for Health Information, 2012B). Disease and disability management often requires frequent health care utilization in an effort to monitor disease or disability progression. An increased number of health care services will provoke strain on the provincial health care system while also escalating costs. Decreasing the number of hospital and physician visits would be advantageous for both the family and the health care system. Improved health and health outcomes for the family members of disabled individuals would lead to better health related quality of life. A decrease in health service utilization rates would also benefit the health care system by decreasing health care costs and strain on the provincial health care system. However, a comprehensive understanding of how exposure to disability manifests ill health among families is needed to potentially decrease health service utilization rates for the family members of disabled individuals. This study has contributed to this area of research with the associations found between higher disability exposure burden and higher levels of health service utilization.

## 6.3 Future Research Potential

Future research assessing the health trajectories of the family members of those afflicted by disability or a chronic illness could utilize linked health administrative data in conjunction with qualitative data to collect information such as health related quality of life. Administrative data has been proven to be a useful tool for tracking health service utilization usage. The accuracy and detail of administrative data provides a reliable and valid source of longitudinal data for health research. Health research can also benefit from the ability of administrative datasets to be linked, as were those in this study.

It would be interesting if future studies furthered this research by representing disabilities among all age ranges, not just adults, as well as incorporating a larger sample population of families beset with disability. A larger sample would provide a more representative sample of the population and may produce new or different findings than those seen in this study due to the smaller sample size. Observing disabilities affecting younger individuals (e.g., those below the age of twenty years) could reveal differences in how the health care system is utilized in comparison to the interactions of older, disabled individuals with the health care system. Past research on the topic of familial health outcomes in relation to the disability of a family member have acknowledged poor health outcomes among parents, particularly mothers (Stabile & Allin, 2012) caring for a disabled child (Whiting, 2014). As this study only examined the health outcomes of adult family members, there is potential to observe the health outcomes of children in families beset with disability.

Recruiting a sample of familial caregivers for a future study would also provide insight into the specific health outcomes, physical and mental, affecting caregivers in comparison to other family members. Caregivers are often subjected to stress (Canadian Mental Health Association, 2014) and burden if the caregiver is overwhelmed by the needs of their disabled family member(s) (Kress & Herridge, 2012). The psychological and physical burden produced by caregiving may lead to poorer health outcomes than those experienced by other family members. To determine if caregivers experience poorer health outcomes than other family members further research on the topic is needed. Studying the experiences and health outcomes of caregivers will provide insight into the full extent of the health ramifications of caregiving for a disabled family member.

### 6.4 Concluding Remarks

If instances of disability continue to increase in the Newfoundland population, the demand on the health care system will grow (Institute for Health Metrics and Evaluation, 2013). The health of the family members of disabled individuals, particularly caregivers, could be observed to prevent the onset of severe health conditions. This would allow for the family members of disabled individuals, who may be at risk for poor health outcomes or increased health service utilization, to acknowledge the potential of exposure to disability to manifest poor health and to seek support that will help preserve their health.

Acknowledging the potential of disability to trigger detrimental health outcomes on the family members of those afflicted with a disability could introduce policy initiatives or programs given the literature regarding the direct and indirect effects of disabilities on health outcomes (Gorman et al. 2009; Jamison & Walker, 1992; Mikail & von Baeyer, 1990). Specific policy initiatives could be drafted to address the increased health care costs endured by the provincial health care system. Program development could allow families, affected by disability, to address the psychological distress associated with caring for or living with a disabled family member. Creating a safe space for families to meet and voice their concerns could provide a cathartic release for stress. Program development could also be targeted toward implementing a program for familial caregivers to ensure that they are comfortable, prepared, and knowledgeable about their new role. For example, a 2002 study by Man found caregivers often found themselves overwhelmed by the needs of their family members, as they did not have sufficient training, time, or energy for their new role as a caregiver. However, families who were given information regarding their family member’s injury and rehabilitation process felt empowered by the knowledge. Man (2002) suggests empowering family caregivers by supporting them with knowledge and resources that will aid in their role as a caregiver.

There are few studies that observe the health trajectories or outcomes of the family members of disabled individuals. Although there is some literature available citing unfavorable health outcomes for those close to individuals affected by disability ((Bakker, Demerouti, & Burke, 2009; Gelkopf & Roe, 2014; Hwang & Kearney, 2014; Pessar et al., 1993), the full extent of how caring for an individual with a disability affects the health care system is not yet known. Although tis study adds to the current research regarding the detrimental health effects of disability exposure in families, future research should continue to focus on this area of research.

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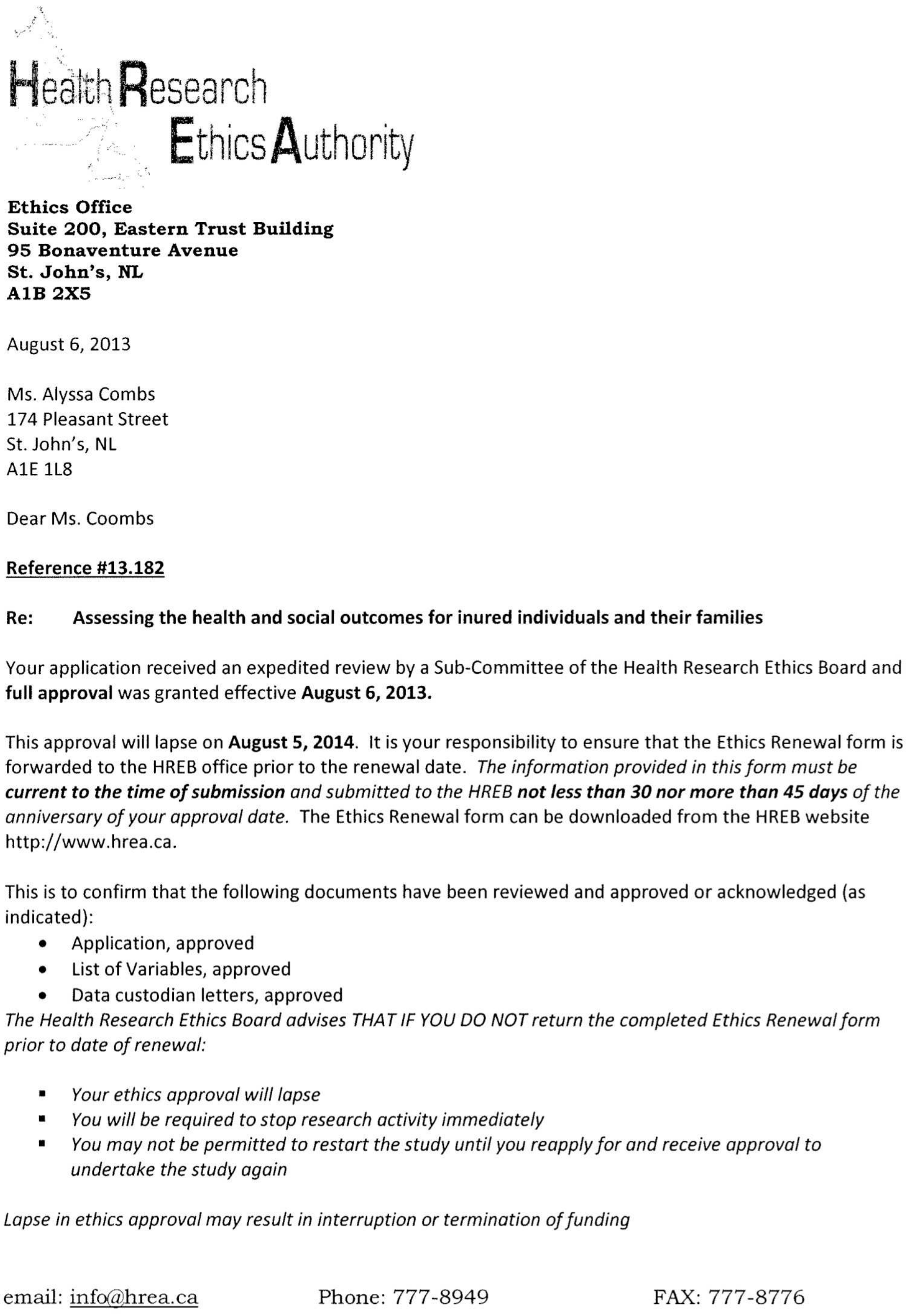
# Appendix A. Health Research Ethics Authority Approval Letter



Health Research
Ethics Authority

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

August 6, 2013

Ms. Alyssa Combs
174 Pleasant Street
St. John's, NL
A1E 1L8

Dear Ms. Coombs

**Reference #13.182**

**Re: Assessing the health and social outcomes for inured individuals and their families**

Your application received an expedited review by a Sub-Committee of the Health Research Ethics Board and **full approval** was granted effective **August 6, 2013.**

This approval will lapse on **August 5, 2014**. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date. *The information provided in this form must be* ***current to the time of submission*** *and submitted to the HREB* ***not less than 30 nor more than 45 days*** *of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HREB website http://www.hrea.ca.

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

- Application, approved
- List of Variables, approved
- Data custodian letters, approved

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

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

*Lapse in ethics approval may result in interruption or termination of funding*

email: info@hrea.ca Phone: 777-8949 FAX: 777-8776

It is **your responsibility to seek the necessary approval from the Regional Health Authority or other organization as appropriate**.

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

We wish you every success with your study.

Sincerely,

Patricia Grainger
Ms. Patricia Grainger
Vice-Chair Non-Clinical Trials
Health Research Ethics Board

C VP Research c/o Office of Research, MUN
VP Research c/o Patient Research Centre, Eastern Health
HREB meeting date: August 22, 2013

## Appendix B. Newfoundland and Labrador Centre for Health Information Secondary Uses Committee Approval Letter

Centre for
Health Information

November 20, 2013

Alyssa Coombs
174 Pleasant Street
St. John's, NL
A1E 1L8

Re: Record level information request, IM00050975

Dear Alyssa:

This letter is to advise you that the Secondary Uses Committee of the Centre for Health Information reviewed your information request application on November 6, 2013 for the study **"Assessing the health and social outcomes of injured individuals and their families"**. Having consulted with the Secondary Uses Committee, I authorize the release of information for your project.

The use of the National Adult Health Survey, the MCP Fee-for-Service Physicians Claims database, the Clinical Database Management System and the NLCHI Mortality System is conditional upon the following:

- The Centre is provided evidence of ongoing ethics approval from the Health Research Ethics Authority during the lifetime of the study.
- Members of the project team accessing the released information must not attempt to re-identify the subjects of the released information.
- Members of the project team must comply with Memorial University of Newfoundland's policy and procedures for storing data.
- The data must remain on a Memorial University of Newfoundland asset; it cannot be placed on the researcher's personal asset.
- The released information must be encrypted while held and stored.
- The dataset will be released under the supervision of Dr. Rick Audas, the applicants Academic Advisor.
- The applicant must receive approval from the Department of Health and Community Services to use the MCP Fee-for-Service database and this approval must be forwarded to the Centre for Health Information.

Newfoundland and Labrador Centre for Health Information

Ms. Alyssa Coombs
Page 2

My colleague, Yvonne Oram, will coordinate with you to address the outlined conditions and to transfer the information via the Managed File Transfer (MFT) system.

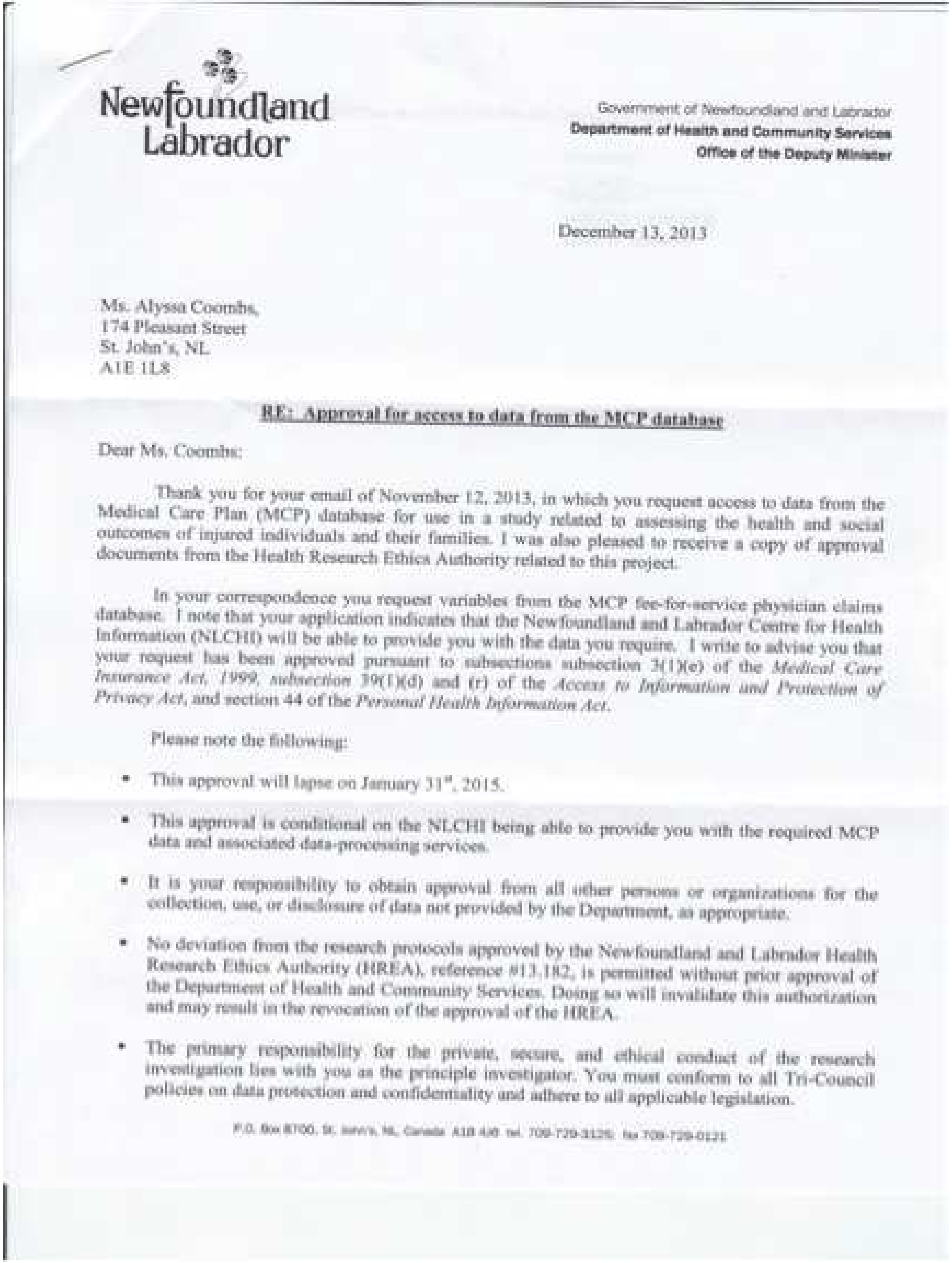
On behalf of the Centre for Health Information, I wish your team success in their research.

Yours sincerely,

Paul Caines,
Vice President Health Information Network and Chief Information Officer
Newfoundland and Labrador Centre for Health Information

cc: Yvonne Oram, Manager of Information Management

# Appendix C: Department of Health and Community Services Approval Letter



Newfoundland
Labrador

Government of Newfoundland and Labrador
**Department of Health and Community Services**
**Office of the Deputy Minister**

December 13, 2013

Ms. Alyssa Coombs,
174 Pleasant Street
St. John's, NL
A1E 1L8

**RE: Approval for access to data from the MCP database**

Dear Ms. Coombs:

Thank you for your email of November 12, 2013, in which you request access to data from the Medical Care Plan (MCP) database for use in a study related to assessing the health and social outcomes of injured individuals and their families. I was also pleased to receive a copy of approval documents from the Health Research Ethics Authority related to this project.

In your correspondence you request variables from the MCP fee-for-service physician claims database. I note that your application indicates that the Newfoundland and Labrador Centre for Health Information (NLCHI) will be able to provide you with the data you require. I write to advise you that your request has been approved pursuant to subsections subsection 3(1)(e) of the *Medical Care Insurance Act, 1999, subsection* 39(1)(d) and (r) of the *Access to Information and Protection of Privacy Act*, and section 44 of the *Personal Health Information Act*.

Please note the following:

- This approval will lapse on January 31st, 2015.
- This approval is conditional on the NLCHI being able to provide you with the required MCP data and associated data-processing services.
- It is your responsibility to obtain approval from all other persons or organizations for the collection, use, or disclosure of data not provided by the Department, as appropriate.
- No deviation from the research protocols approved by the Newfoundland and Labrador Health Research Ethics Authority (HREA), reference #13.182, is permitted without prior approval of the Department of Health and Community Services. Doing so will invalidate this authorization and may result in the revocation of the approval of the HREA.
- The primary responsibility for the private, secure, and ethical conduct of the research investigation lies with you as the principle investigator. You must conform to all Tri-Council policies on data protection and confidentiality and adhere to all applicable legislation.

I trust this is satisfactory and that you will find the data being provided useful in your research.

Sincerely,

**BRUCE COOPER**
**Deputy Minister**