

EXPLORING THE PREVALENCE AND PERCEPTION OF VISION IMPAIRMENT
AND DISABILITY AMONG CANADA'S IMMIGRANT POPULATION

EXPLORING THE PREVALENCE AND PERCEPTION OF VISION IMPAIRMENT
AND DISABILITY AMONG CANADA'S IMMIGRANT POPULATION

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Abstract

Immigrants are an important part of Canada and Canadian culture. Despite a large number of immigrants in Canada relatively few studies have focused on disability and immigrants. Even less research has been conducted on immigrants with visual impairments.

The first paper uses the Participation Activity Limitation Survey (PALS) from 2006 to examine the prevalence of vision impairment in immigrants compared to non-immigrants, 50 years of age and over. First, descriptive statistics were used to determine the prevalence rate of vision impairment. Then, multivariate logistic regression was utilized to examine differences in providers of support and characteristics of individuals who receive support. Results disclosed that there was no difference in the prevalence rates of adult immigrants and non-immigrants over 50 years of age when controlling for age and gender. Results confirmed that there is a relationship between having a vision impairment and living in a low income household. Results also showed that receiving support is linked to severity of impairment.

The second paper used qualitative analysis to examine visually impaired immigrants' perception of vision impairment and disability and if perception influenced utilization of care. Qualitative semi-structured interviews were conducted with 8 clients of the Canadian National Institute for the Blind (CNIB). Results showed that immigrants' employ three different views when explaining their impairment, these were; the medical view, social view and theological/ traditional view. All participants used two or more views interchangeably demonstrating that all views are important in understanding how immigrants perceive and navigate their impairment on an everyday basis. Results also suggested that negative perceptions did not keep most immigrants from accessing services; however, traditional barriers such as not being eligible to receive services and transportation were main barriers.

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Table of Contents

Abstract	iv
Acknowledgements	v
List of Tables	ix
List of Figures	ix
Abbreviations	x
Declaration of Academic Achievement	xi
Chapter One	1
Research context	1
1.1.1 The international perspective	1
1.1.2 The Canadian perspective	2
1.2 Immigrants in Canada	3
1.2.3 Immigrants and disability	4
1.3 Research objectives	6
1.4 The geographic perspective	7
1.4.1 Models of disability	9
1.5 Thesis overview	10
References	12
Chapter Two.....	16
2.1 Introduction.....	16
2.2 Literature Review.....	19
2.2.1 Healthy Immigrant Effect and Barriers to Services	19
2.3 Methods.....	20
2.3.1 Data Source	20
2.3.2 Analysis.....	23

2.4 Results.....	24
2.4.1 Prevalence and use of support services.....	24
2.4.2 Logistic Analysis	27
Logistic regression: Vision impairment.....	27
Logistic regression: Receiving support.....	28
2.5 Discussion	30
2.5.1 Limitations	33
2.6 Conclusion	34
References	36
 Chapter Three.....	 39
3.1 Introduction.....	39
3.1.1 Literature Review.....	40
3.2 Methods.....	44
3.3.1. Data Analysis	46
3.3 Results.....	47
3.4.1 Self-perception of vision impairment and disability.....	49
3.4.2. Perception by others: The invisible disability.....	52
3.4.5 Coping and Daily Geographies	56
3.5 Discussion	59
3.5.1 Limitations	61
3.6 Conclusion	62
References	65
 Chapter Four	 68
4.1 Introduction.....	68
4.2 Key Findings and Contributions	69
4.3 Future research directions	71
4.4 Limitations	72

4.5 Knowledge transfer	73
References	74
Appendix A	75
Appendix B	76
Appendix C	77
Appendix D	78
Appendix E	79
Appendix F	82
Appendix G	85

List of Tables

Chapter Two

Table 1: Caregivers for Adults with Visual Impairments.....	27
Table 2: Logistic Regression for Vision Impairment.....	28
Table 3: Receiving Support.....	29
Table 4: Logistic Regression for Adults who Receive Support.....	30

Chapter Three

Table 1: Participant Demographics.....	48
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List of Figures

Chapter Two

Figure 1: Proportion of Vision Impaired in Canada by Gender and Immigrant Status	25
Figure 2: Vision Impairment Prevalence Rates.....	26

Chapter Three

Figure 1: Location of the Four CNIB Offices.....	45
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Abbreviations

WHO: World Health Organization

OECD: Organisation for Economic Co-operation and Development

CNIB: Canadian National Institute for the Blind

UPIAS: Union of Physically Impaired People against Segregation

PALS: Participant Activity Limitation Survey

ICF: International Classification of Functioning

VA: Vision Acuity

AMD: Age-related Macular Degeneration

ADL: Activities of Daily Living

GTHA: Greater Toronto Hamilton Area

ODSP: Ontario Disability Support Program

Declaration of Academic Achievement

This thesis is comprised of two articles, which have been completed by Stine Hansen. I, Stine Hansen, am the primary author and was responsible for data collection, data analysis and writing of the manuscripts.

Chapter One

Research context

1.1.1 The international perspective

People with disabilities are the largest minority in the world, representing approximately one billion people or 15% of the world's population (United Nations, n.d.; World Health Organization, 2012). Disability is a broad term that encompasses both physical and mental disabilities, with the World Health Organization (WHO) defining disability as the following:

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (World Health Organization, n.d.)

Disability rates among people with a lower educational attainment, living in an Organisation for Economic Co-operation and Development (OECD) country, are significantly higher compared to people who are better educated (United Nations, n.d.). Unemployment rates are also known to be extremely high for people with disabilities, reaching as high as 80% in some countries (United Nations, n.d.). As a consequence of low employment levels, persons with disabilities are more likely to live in poverty compared to individuals with no disability (Stapleton, O'Day, Livermore, & Imparato, 2006). On a global level, employers are often not willing to employ people with disabilities because they do not believe that they will be able to perform the required job tasks, research however has showed that persons with disabilities have better retention

rates and that accommodation for person with disability often has little to no cost for the employer (United Nations, n.d.). Individuals with at least one disability are more likely to be living in poverty (Stapleton et al., 2006) given their inability to secure employment (United Nations, n.d.). Additionally, persons with disabilities are more likely to be victims of violence and women and girls are especially vulnerable to abuse. Women often face a double disability because they face exclusion both because of their gender and their disability (United Nations, n.d.). Women generally report higher incidents of disability than men in OECD countries (United Nations, n.d.).

Globally, approximately 314 million people have a vision impairment – the focus of the current research, with the majority of vision impaired individuals (87%) living in developing countries (World Health Organization, 2013). Vision impairment is highly correlated with age and 82% of all people who have a vision impairment are 50 years and older (World Health Organization, 2013). It is estimated that 85% of all visual impairments and 75% of blindness could be prevented worldwide with greater awareness and preventative treatment (World Health Organization, 2013). Globally, the most common causes of blindness are cataracts, uncorrected refractive errors, glaucoma and age-related macular degeneration (World Health Organization, 2013).

1.1.2 The Canadian perspective

In Canada, the four most common disabilities are pain (11.7%), mobility (11.5%), Agility (11.1%) and hearing (5%) (Employment and Social Development Canada, 2014), with approximately 3.8 million adults (13.7%) reporting a disability. Disability rates tend

to increase with age, and women are more likely to report a disability than men (14.9% and 12.5 percent, respectively) (Statistics Canada, 2013a). Visual impairment is the 5th most common disability in Canada, with an estimated 816,250 (3.2%) Canadian adults living with some type of visual impairment (Statistics Canada, 2009).

Like disability rates overall, vision impairment increases with age, and persons 75 years and older report the highest rates of vision impairment (13.4%) (Statistics Canada, 2009). Vision impairment has important impacts on employment and other daily actions. Amongst labour force aged individuals, 36.6% of persons aged 15-64 with a visual impairment reported that they were not in the labour force, 7.2% reported that they were unemployed and 20.5% were retired, leaving just 34.7% employed (Statistics Canada, 2009). The main causes of vision loss in Canada are age-related macular degeneration (AMD), diabetic retinopathy, glaucoma, cataracts and refractive error (Canadian National Institute for the Blind, n.d.).

1.2 Immigrants in Canada

Immigrants make up 20.6% of Canada's total population and 56.9% of all recent immigrants between 2006 and 2011 came from Asia and the Middle East (Statistics Canada, 2013b). Approximately 250,000 new immigrants enter Canada every year (Beiser & Stewart, 2005), making Canada the largest recipient of immigrants and refugees in the world (Perez, 2002).

Early research on immigrant health in North America was based on the sick immigrant paradigm, where immigrants were viewed as being sick and as a result the Canadian population needed protection from these immigrants (Beiser, 2005). In the mid-1990s

research introduced the healthy immigrant effect, which argues that immigrants are healthier than the native-born population upon arrival in Canada but that this health advantage is lost over time, depending on length of stay in Canada (Chen, Ng, & Wilkins, 1996; McDonald & Kennedy, 2004; Newbold, 2005). In addition to the healthy immigrant effect, the literature has also focused on the barriers to services that immigrants often face and especially the barriers that they face when seeking health care services. Research has shown that language, knowledge of services, transportation, lack of medical professionals from their own culture and cultural perceptions of health act as barriers (Lai & Chau, 2007; Shaw & Gold, 2009).

1.2.3 Immigrants and disability

While there is an extensive Canadian literature focusing on the healthy immigrant effect, access, and use of health care resources, very little research has focused on disability and immigrants in Canada. Some of the outstanding questions that arise from the gap in the literature are whether or not there is a difference in the prevalence rates of impairment between immigrants and non-immigrants and if there is a difference in the utilization of support. Studies that have measured disability prevalence in the past have not distinguished between immigrant statuses. It is unclear, for example, whether immigrants are more or less likely to report a disability than the native-born. It may be that because immigrants experience barriers to care and may be afraid to speak out, that reporting and diagnoses of disabilities are less common, leading to lower prevalence rates. Perceptions of disability, reflecting cultural or ethnic concepts of disability, may also influence willingness to report or disclose disabilities, once again leading to lower observed rates of

disability within the immigrant population. Likewise, use of support services may differ between immigrants and non-immigrants. Given well-known barriers to use of health care services (McDonald & Kennedy, 2004; Shaw & Gold, 2009), immigrants may be less likely to use support services. In particular, barriers such as low income, knowledge of English, or language may result in a lesser use of formal services and greater reliance on family and friends for support.

Further there is a lack of research on the perceptions of disability. The few papers that are available from a Canadian perspective focus on policy, prevalence of long term disability, and perception of disability and rehabilitation services (See, for example, work by Ei-Lahib and Wehbi (2012) and Daudji et al. (2011)). The majority of papers focus on rehabilitation services and perception from the perspective of parents who have children with disabilities. The literature indicated that there is a greater need for culturally sensitive care and training for service providers due to different perceptions of disability by parents (Lindsay, King, Klassen, Esses, & Stachel, 2012). Research also found that perception of disability by parents varies and that parents often apply different views interchangeably such as the western medical and traditional views. The medical view is the biomedical view which sees disability as something that should be cured, whereas the traditional view is a spiritual view where traditional Asian medicine and the will of God is applied (Daudji et al., 2011). Research from the United Kingdom also discovered parents of children with disabilities utilized both medical and traditional models when explaining their children's disabilities (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot, Grant, Cooper, & Mathers, 2008).

Overall, research on perception of immigrants with disabilities has been limited and the current Canadian literature focuses on parents' perception and how it influences their children's care and rehabilitation. No papers were found that dealt with the perception of immigrant adults' own disability. Little is therefore known on what adult immigrant's own perception of vision impairment and disability is and if it influences their utilization of support services.

1.3 Research objectives

Given gaps within the existing literature regarding immigrant disability prevalence and perceptions of disability, this thesis attempts to understand if there is a difference in the prevalence rates of vision impairment in immigrants and non-immigrants. This research will address two main objectives, which each has one sub-objective:

- I. To examine the prevalence of vision impairment in immigrants relative to non-immigrants in Canada,
 - a. To explore if there are differences in the use of support based on immigrants status.
- II. To explore the perception of vision impairment and disability among immigrant users of the Canadian National Institute for the Blind (CNIB) with visual impairments in Southern Ontario.
 - a. To investigate if perception of disability influences the utilization of support.

1.4 The geographic perspective

The sub-discipline of health geography has changed substantially since John Snow mapped the cholera outbreak in London in the 19th century. The first stream of medical geography, focused on a positivist medical geography with a primary focus on disease and was reliant on quantitative measures and based on the spatial revolution (Kearns & Moon, 2002; Parr, 2002). The second stream was known as the geographies of health care and focused on the study of health systems and planning such as mapping out health care facilities (Gregory, Johnston, Pratt, Watts, & Whatmore, 2009). Today, health geography has replaced medical geography as the more dominant stream within human geography, with health geography focusing on the individual as opposed to disease and illness. It applies a more critical social theory to understand the broader context the political, social and economic perspectives (Kearns & Moon, 2002).

The study of disability within geography went through a similar process as seen with medical geography. The geography of disability is a relatively new subfield within health geography, and its development was in part possible due to the emergence of political activism in the 1960s and 1970, which paved the way for different movements such as anti-war, environmental, and the feminist movement (Johnston & Sidaway, 2004). As a result, people with disabilities also began to demand that their human rights were recognized, with the Independent Living Movement being formed in the United States (Park, Radford, & Vickers, 1998). In 1976 the Union of Physically Impaired People Against Segregation (UPIAS) was formed in the United Kingdom, with this movement introducing the idea of disability as a social and political construct, thereby

rejecting the medical and rehabilitative conceptions of disability (Imrie & Edwards, 2007).

The work by Reginald Golledge (see, for example, (Golledge, 1993; Golledge, Loomis, Klatzky, Flury, & Yang, 1991) is considered by many to be some of the pioneering work within the geography of disability. Golledge, who was a vision impaired geographer, introduced the idea that disability was a socio-spatial issue (Gleeson, 1996). Golledge's work has later been heavily criticised by other geographers for his positivist behavioural approach (Gleeson, 1996), which was highly descriptive and had a significant focus on the built environment and technical solutions (Imrie & Edwards, 2007) as opposed to a political issue resulting from socio-spatial oppression of disabled people (Park et al., 1998). Golledge also used highly stigmatized terminology, for example the word 'retarded' to describe people with mental impairments (Imrie, 1996a).

The mid 1990s marked a shift in the geography of disability from Golledge's positivist approach to one based on Marxism, materialist geographies and social constructionism, for example, (Gleeson, 1998; Imrie, 1996b; Park et al., 1998; Parr & Butler, 1999), to increase the understanding of the struggles people with disabilities experience in a capitalist society (Imrie & Edwards, 2007). The introductions of the capitalist and materialistic society lead to great changes for people with disabilities. Gleeson (1999) argued that in feudal societies a disability was only considered an impairment because there was no separation of home and work lives, people with physical and mental impairments were therefore able to contribute and participate equally in society. With industrialization, there was a separation of work and home and people

started to work in the city instead of the home (Gleeson, 1999). This separation caused people with impairments to no longer be able to contribute to the labour market and society due to an increased focus on production (Gleeson, 1999). Gleeson (1999) argues that impairment becomes a disability when a person experiences a disadvantage, in this instance work in the city functions as a disabling environment. The idea of disabling environments is still used today and geographers argue that it is not the failings of the individual that creates disability, instead disability is a product of the attitudes and structures of oppression of an able-bodied society (Knox & Pinch, 2006). An example of the structures of oppression is presented by Imrie (1996), who explains how the built environment has been designed to accommodate the able-bodied person by assuming that all bodies are equal or the same. Therefore, people with impairments, for example someone who is confined to a wheelchair, becomes disabled when they are not able to navigate the built environment due to obstacles such as stairs, curbs and non-automatic doors.

1.4.1 Models of disability

There are several different definitions of disability, and as disability studies have changed so have the definitions. Two common models used are the medical model and the social model. The medical model of disability, also called the biomedical model, takes a positivistic approach to disability (Park et al., 1998) and regards disability as a condition that needs to be fixed by medical professionals. If the disabled person cannot be ‘fixed’, they are considered to be disabled and deficient compared to the norm (Gilson & Depoy,

2000). The medical model is often used by rehabilitation professionals as they work with individuals to get them back to the norm (Gilson & Depoy, 2000).

The social model of disability, takes a more critical stance with its main argument that disability is socially constructed by the dominant able-bodied views of society (Gilson & Depoy, 2000). Therefore, the social model defines impairment as an individual lacking all or part of a limb or having a defective mechanism of the body. Disability refers to the idea of the impaired being disadvantaged by a social organization, which takes no or little consideration of people who have physical impairments and thereby exclude them from social activities (Parr & Butler, 1999). The social model also examines disability from a political and economic perspective (Gregory et al., 2009).

1.5 Thesis overview

This thesis is organized into four chapters. Following the introductory chapter, Chapter two corresponds to the first objective and examines prevalence rates of vision impairment in immigrants and non-immigrants and explores if they receive care and possible differences in use of caregivers. The paper utilized data from Statistics Canada's 2006 Participation and Activity Limitation Survey (PALS) to conduct a quantitative analysis using prevalence measures and logistic regression. PALS recognizes that there are several definitions of disability and that these definitions are often fluid (McKenzie, Hurst, & Crompton, 2008). The PALS utilized the classification system used in the International Classification of Functioning (ICF), which was prepared by the WHO. This classification incorporates both the medical model and the social model with a focus on limitations in everyday life (McKenzie et al., 2008). The analysis will evaluate whether there is a

difference in the prevalence of vision impairment based on immigrant status and if there is a difference in the use of support services. The findings will provide a useful stepping stone to understand vision impairment in immigrants and the possible challenges that they face such as employment, caregivers, education and low income.

Chapter three explores objective 2 and investigates perceptions of vision impairment and disability amongst immigrant users of the CNIB¹. Further, it explores whether these perceptions influence their utilization of support services such as the CNIB. Qualitative analysis was used to fulfill this objective in the form of semi-structured interviews with eight immigrant users from the CNIB. This paper is an important example of how disability is perceived differently depending on ethnicity, gender and culture and provides an insight into self-perception of disability, perception by others and coping mechanisms. Finally, Chapter four provides an overall conclusion of major research findings from chapter two and three and suggestions for further research. None of the chapters have been submitted for publication at the time of writing, it is expected that at least one manuscript will be submitted for publication in fall 2014.

¹ Prior to interviewing participants for chapter number three, a key informant from the CNIB was interviewed to explore their opinions of immigrant's utilization of services from the CNIB and possible improvements. This interview gave the researcher an insight into the CNIB and its services. However, the interview itself was omitted from the study as it did not fit with the overall research objectives and was considered to not be rigorous because only one key informant participated. Despite several attempts it, was not possible for the researcher to gain access to more key informants

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Chapter Two

2.1 Introduction

A vision impairment, ranging from partial loss of vision to complete blindness, is when a person has sight loss which cannot be fully corrected by glasses or contact lenses (Canadian National Institute for the Blind, n.d.-a). Vision impairment is a disability that often occurs with age, and approximately 65% of all people who are visually impaired are 50 years or older (World Health Organization, 2013). Although there are various definitions of vision impairment (i.e., the World Health Organization's definition of low vision as a best corrected vision acuity (VA) of 20/60 but not less than 20/400), Canada's Canadian National Institute for the Blind (CNIB) defines legal blindness as worse than or equal to 20/200 and visual acuity cannot be worse than 20/50 when obtaining a driver's license (Canadian National Institute for the Blind, n.d.-b).

The number of people living with a vision impairment is increasing as the global population ages (Stevens et al., 2013). Worldwide, it is estimated that 285 million people have vision impairment, and 90% of this population live in developing countries (Stevens et al., 2013; World Health Organization, 2013). In 2006, Statistics Canada estimated that 816,250 Canadians had some form of vision impairment, accounting for 3.2% of the entire population (Statistics Canada, 2009), with vision limitations ranging from mild to severe, and with older individuals (aged 75+) typically having the highest rates of vision impairment (12.5%) (Statistics Canada, 2009). The main causes of vision impairment include aging and age-related macular degeneration (AMD) (Canadian National Institute for the Blind, n.d.-a). Other common causes of vision impairment in Canadians include

cataracts, glaucoma and diabetic retinopathy (Canadian National Institute for the Blind, n.d.-a).

Having a vision impairment influences quality of life, education, employment and income (Canadian National Institute for the Blind, n.d.-a; Statistics Canada, 2009; Stevens et al., 2013). The loss of vision has both social and emotional consequences (Hodge, Barr, Bowen, Leeven, & Knox, 2013), with individuals with vision impairment often experiencing social isolation (R. L. Evans, Werkhoven, & Fox, 1982), loneliness, and depression (Hodge et al., 2013; Mitchell & Bradley, 2006). Visual impairment also has a high societal cost in the form of loss of productivity, health care costs, care and rehabilitation etc., with the Canadian National Institute for the Blind (CNIB) estimating that the overall cost in 2007 for vision loss in Canada was \$15.8 billion (Canadian National Institute for the Blind, 2009).

While it would be reasonable to expect that prevalence rates of vision impairment are consistent across sub-groups of the population (such as immigrant or ethnic groups, after controlling for age and gender), the literature is relatively silent on this. Yet, given that immigrants represent 20.6% of the total Canadian population (Statistics Canada, 2013), understanding whether there are differences in vision impairment between immigrants and native-born Canadians, and the implications for support, are important. It is, for example, reasonable that differences in prevalence rates between immigrants and non-immigrants are observed, given potential differences in reporting, knowledge of conditions, and differential access to health care professionals between these two groups. Further, differences in the use of support services – including type, source and cost of

services – may also be observed, given observed differences in income and access to services.

For example, a 2004 study examined prevalence rates and cause of visual impairment among US adults while controlling for race/ethnicity (Eye Diseases Prevalence Research Group, 2004). Although this study focused on race/ethnicity and not immigrant status, its findings were intriguing as they found differences in prevalence rates depending on race/ethnicity, with Hispanics having a higher prevalence of low vision compared to white and black persons (Eye Diseases Prevalence Research Group, 2004).

The lack of knowledge of vision impairment amongst immigrants in Canada is the rationale for this paper. The purpose of this paper is to: (1) examine the prevalence of vision impairment based on gender in immigrants compared to non-immigrants in Canada using the Participation Activity Limitation Survey (PALS) from 2006; and (2) to determine immigrant's use of caregivers, highest education level, income status, and employment. The paper is structured as follows. First, it will present a review of the current literature on vision impairment and the health of immigrants in Canada. Second, methods of analysis are discussed, followed by a discussion of the results and a conclusion.

2.2 Literature Review

2.2.1 Healthy Immigrant Effect and Barriers to Services

It is well documented that immigrants living in Canada experience the so-called ‘healthy immigrant effect’ (Newbold, 2006; Perez, 2002), whereby recent immigrants to Canada are healthier than the Canadian born population at arrival, but this health advantage is lost with increasing duration of residence in Canada (Chen, Ng, & Wilkins, 1996). Recent immigrants are also less likely to report a chronic condition compared to the Canadian born population. However, levels of reported chronic conditions amongst immigrants after 20 years residency in Canada is closer to that of the Canadian born population (Perez, 2002).

It has been argued that the observed health advantage in new immigrants is a direct result of policy, as healthy immigrants are more likely to immigrate compared to immigrants with worse health (Beiser, 2005; De Maio & Kemp, 2010; Perez, 2002). McDonald and Kennedy (2005) found that the change in health status depended on assimilation and cultural community. For example, they argued that Chinese immigrant women who lived in a large Chinese community were less likely to be obese compared to Chinese women who lived in a small Chinese community, with the opposite observed with black immigrant women. Beiser (2005) argues that policy is to blame for the change in health status as immigrants are more likely to live in poverty in their first 10 years after immigrating to Canada. Changes in health conditions such as weight is likely to be from an adaptation to a Canadian lifestyle including diet and activity, which influences health such as Type II diabetes (Beiser, 2005; McDonald & Kennedy, 2005)

Immigrants also face many barriers to gaining access to health services in Canada, whether it be due to policy (Beiser(2005), language (Pottie et al. 2008), cost and/or presence of insurance, and/or place of residence (Lo 2011). Other common barriers limiting access to health care services include transportation, language, knowledge of services and gaining access to employment in Canada (Lo, 2011; Shaw & Gold, 2009).

While support for the vision impaired is available, vision impairment includes other difficulties. For example, approximately 64% of people with a vision impairment in the 2006 Canadian census reported not being employed² (Statistics Canada, 2009). Similarly, of the 34.7% of the people with vision impairments that there employed, more than 50% reported being limited in the type and amount of work that they could perform (Statistics Canada, 2009).

While the healthy immigrant effect does not necessarily apply to disability, it is helpful to keep it in mind, as it gives an overview of the literature on health and immigrants and the challenges and changes that occur in their health with immigration. This paper addresses the possible differences that there might be in the prevalence of visual impairment and use of support services between immigrants and non-immigrants.

2.3 Methods

2.3.1 Data Source

The data for this paper was obtained from Statistics Canada's Participation and Activity Limitation Survey (PALS), a post-censal national survey using the 2006 Census as a sampling frame. The purpose of the PALS was to collect data on adults and children with

² 20.5% of this population reported that they were retired.

disabilities in Canada (Statistics Canada, 2007a). The PALS adopts the WHO framework of disability provided by the International Classification of Functioning (Statistics Canada, 2007b), which states that;

Disability is an umbrella term for impairments, activity limitations, and participation restriction. Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports). (World Health Organization, 2011)

The PALS sample consists of persons who answered "yes" to either to questions on activity limitations in the 2006 census ("Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?" and "Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do a) at home? b) at work or at school? c) in other activities, for example, transportation or leisure?"). The same filter questions were repeated at the time of the PALS interview, followed by a series of screening questions meant to determine the nature of the disability (i.e., vision, hearing, mobility, etc.). If the respondent did not report a limitation to either the census disability filter questions or the PALS screening questions, they were dropped from the PALS sample. For example, a potential respondent may have reported a disability on Census day, but not to PALS because of a short-term disability. People with disabilities reported in the PALS are persons that *reported difficulties with daily living activities, or who indicated that a physical or mental condition or health problem reduced the kind of amount of activities they could do* (Statistics Canada, 2007b).

The population covered by PALS includes those living in private and some collective households (i.e., senior citizen residences) across Canada, including the three northern territories. Individuals residing on First Nations reserves are excluded from the survey, as were residents of some institutional and non-institutional collective dwellings (i.e., military bases, jails, armed forces and coast-guard vessels, campgrounds, and parks). The sample includes approximately 39,000 adults aged 15 years and over at the time of the survey (representing a weighted population of 2.4 million Canadians with a disability). All respondents reported that they had difficulties with activities of daily living (ADL, i.e., preparing meals, everyday housework, heavy chores, personal care, mobility, specialized treatments), or that a physical or mental condition or health problem reduced the kind or amount of activities they could do. PALS also asked each respondent to identify their relationship to their caregivers as well as the ADL with which they received help from each caregiver, and the survey includes a derived severity of disability index (defined by 4 levels: mild, moderate, severe and very severe). The level of severity depends on the frequency and intensity of the limitations associated with the disability, and the severity scale is a standardized score based on disability concepts from the World Health Organization (Statistics Canada 2007, 2008). All responses are self-reported, and therefore dependent on the respondent's perceptions. PALS also include variables drawn from the 2006 census, including immigrant status (immigrant or native-born Canadian) and date of arrival in Canada that are linked at the individual level.

Vision impairment was defined by the PALS as “*Difficulty seeing ordinary newsprint or clearly seeing someone's face from 4 meters away*” (Statistics Canada,

2007a). Subjective measures were used to determine if the person had vision impairment along with the severity of the impairment. The PALS also contains a ‘caregiver module’ where participants who receive care are asked to list the three main persons or organizations that help them because of their condition. Caregivers were grouped into four categories; spouse, immediate family, family & friends and other, for a complete list of individual caregivers in each category please see Appendix A.

2.3.2 Analysis

There were two stages to the analysis of this paper. First, descriptive statistics were used to examine the prevalence of vision impairment in adults age 50 and over to determine if there was a significant difference in prevalence rates based on immigrant status and gender. Prevalence was calculated using the standard formula for prevalence³.

Prevalence =	Persons with a given health indicator during a specific time period	x 100
	Population during the same time period	

Descriptive statistics allowed examination of prevalence rates, who the caregivers for immigrants and non-immigrants are, and the possible differences in caregiver groups. Multivariate logistic models were estimated to determine the covariates of vision impairment and who is more likely to receive support amongst those reporting a vision impairment. Independent variables included in the models were low income status (living in low income household, not living in low income household), education (no education,

³The PALS dataset contains false positives. False positives are people who were classified as disabled based on the 2006 Census but that were later ruled out as being disabled using the criteria of the PALS questionnaire.

high school education, College, University), employment (employed, not employed), age (50-69, 70+), immigrant status (immigrant or non-immigrant) and area of residence (rural or urban). Severity of impairment was only included for the receiving support model, all variables were categorical. Independent variables were chosen to give a socio-demographic context of people with visual impairments and because these variable are often linked to disability in general. Given the complex sampling design of the PALS, weights developed by Statistics Canada were utilized in all analyses, with reported values conforming to Statistics Canada guidelines.

2.4 Results

2.4.1 Prevalence and use of support services

When examining the proportion of vision impaired adults in Canada (Figure 1), immigrants make up roughly 26% of the vision impaired population. It appears that there is a higher proportion of non-immigrant vision impaired males and females, however, the proportions do not control for age effects.

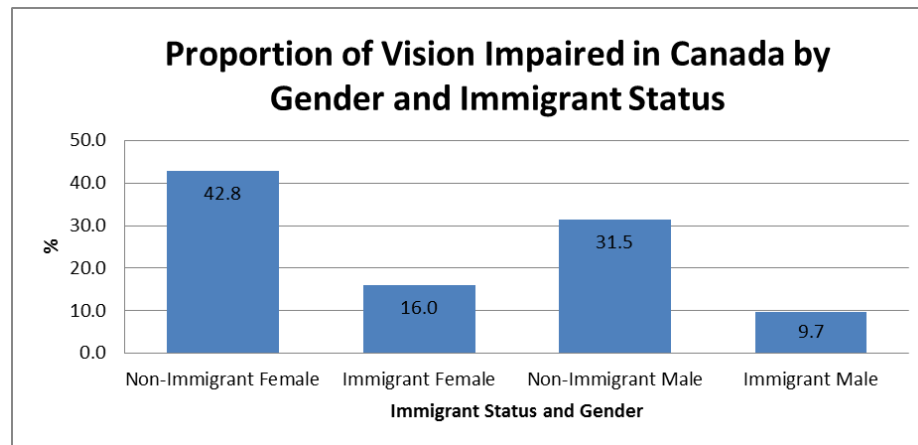


Figure 1

Turning to the prevalence rates, there was no consistent statistical difference in the prevalence rates of vision impairment in adults when controlling for immigrant status, age and gender (Figure 2). Male immigrants had the lowest prevalence rates in the 55-59 age cohort, with a prevalence rate of 2.0% compared to Canadian born males who had a prevalence rate of 4.5%. Canadian born females had the lowest prevalence rates (19.0%) of both genders in the 85 and over age cohort, whereas female immigrants had the highest (32.3%).

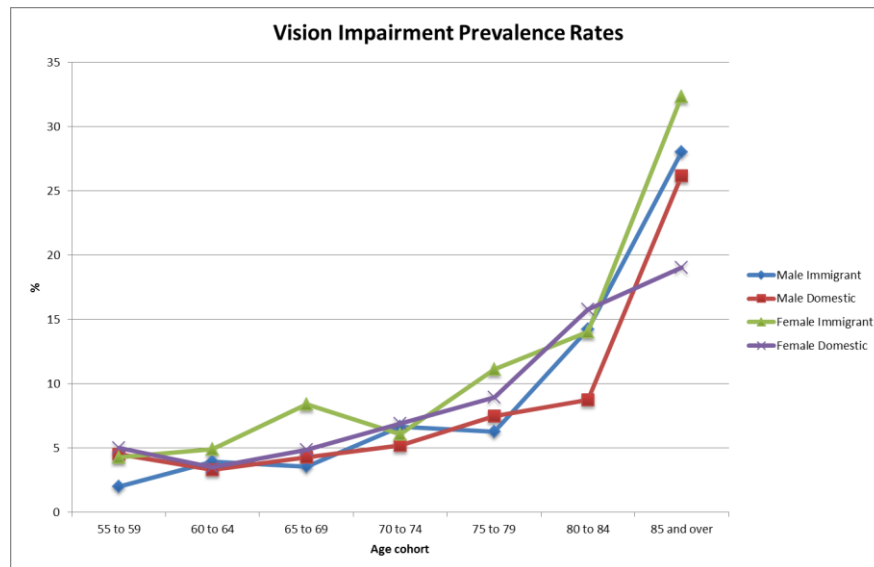


Figure 2

While there are no consistent differences in prevalence rates amongst immigrants and non-immigrants by gender and age, there may be differences in whether support is required and who provides support. Findings indicate (see table 1) that immediate family (parents, siblings, children) were the most common caregivers for both immigrants (48.2%) and non-immigrants (39.4%), this was also the case when controlling for gender. Immigrant males were the least likely to have family or friends help them, whereas immigrant women were the most likely to have family and friends help.

Table 1- Caregivers for adults with visual impairments

Caregiver Category (Females&Males)	Non-Immigrant (%)	Immigrant (%)
Spouse	21.6	21.9
Immediate Family	39.4	48.2
Family&Friends	18.0	16.8
Other	21.1	13.1
Caregiver Category (for Females)		
Spouse	19.7	8.0
Immediate Family	40.0	46.9
Family&Friends	17.3	21.8
Other	23.0	13.4
Caregiver Category (for Males)		
Spouse	24.8	29.2
Immediate Family	38.3	50.7
Family&Friends	19.2	7.6
Other	17.7	12.5

2.4.2 Logistic Analysis

We next turn to logistic analysis to explore covariates of (i) vision impairment beyond age, gender and immigrant status, and (ii) use of support services.

Logistic regression: Vision impairment

Table 2 presents the results of the logistic regression model of the correlates of vision impairment (vision impaired or not). Given the objectives of the current paper, we are particularly interested in the role of immigrant status – are immigrants more or less likely to be vision impaired? While largely reinforcing the descriptive results that immigrant status is related to vision impairment, results demonstrate that immigrant males were less likely to report having a visual impairment, but only at the 90% confidence level.

Beyond immigrant status, adults who have a visual impairment are 1.5 times more likely to be living in a low income household compared to individuals without a visual impairment. Results also indicated that individuals who are employed are less likely to have a visual impairment compared to people who are unemployed. Education level was not an indicator of whether a person had a visual impairment or not. The data also showed that people age 50-69 were less likely to have a visual impairment as compared to people age 70 and above.

Table 2 – Logistic Regression for Vision impairment

Independent Variables	Dependent Variable	
	Vision impairment	
	Unadjusted OR	p value for χ^2 test of Significance
Low Income	1.45	0.0001**
High School	0.946	0.4742
College	0.891	0.1045
University	0.865	0.1860
Employment	0.777	0.0035**
Age 50-69	0.773	<0.0001
Female Immigrants	1.098	0.3448
Male Immigrants	0.798	0.066*
Rural	0.815	0.0015**

** significant at the 95th confidence interval

* significant at the 90th confidence interval

Logistic regression: Receiving support

As previously shown, immediate family was the most common caregiver regardless of immigrant status and gender, however, no statistical significance was found in the use of caregivers when controlling for immigrant status. There were also no significant differences found in main caregivers when looking within the gender group. Data shows

that a large portion of vision impaired individuals received support (see Table 3). Roughly 80% of visually impaired females, immigrants and non-immigrants receive support, with a smaller proportion of non-immigrant males (67%) and immigrant males (65%) receiving support.

Multivariate results 1 (see table 4) showed that individuals who were severely vision impaired were 2.4 times more likely to receive support compared to individuals who were less severely visually impaired ($p < 0.0001$). Low income status did not affect whether or not a vision impaired individual was more or less likely to receive support. When examining education, university educated individuals with a visual impairment were less likely to receive support compared to individuals who had no schooling, high school or college. Employment data showed that visually impaired individuals who were employed were significantly less likely to receive support compared to individuals who were not employed ($p < 0.0001$). Visually impaired adults age 50-69 were less likely to be receiving support as compared to adults age 70 and above. When controlling for immigrant status, results show that male immigrants were least likely to report receiving any support ($p = 0.0027$).

Table 3 - Receiving Support

Immigrant Status	Receive Support (%)	Do Not Receive Support (%)
Female Non-Immigrant	79.54	20.46
Female Immigrant	79.07	20.93
Male Non-Immigrant	67.47	32.53
Male Immigrant	64.77	35.23

Table 4 - Logistic Regression for Adults who Receive Support

Independent Variables	Dependent Variable	
	Receives support	
	Unadjusted OR	p value for χ^2 test of Significance
Severity of Impairment	2.36	<0.0001**
Low Income Status	1.00	0.9908
High School Education	0.85	0.3493
College	0.83	0.2274
University	0.63	0.0374**
Employment	0.48	<0.0001**
Age 50-69	0.64	0.0016**
Female Immigrant	1.44	0.103
Male Immigrant	0.48	0.0027**
Rural	1.09	0.524

** significant at the 95th confidence interval

* significant at the 90th confidence interval

2.5 Discussion

The overall objectives of this paper were to determine whether immigrants experienced similar levels of vision disability as compared to non-immigrants, and whether the sources and level of support were similar. Overall, while the prevalence of vision impairment increased with age consistent with the literature (Buch et al., 2001; Eye Diseases Prevalence Research Group, 2004; Stevens et al., 2013), there were as no difference in prevalence rates of adults with visual impairments by immigrant status. A possible reason for the lack of difference between immigrants and non-immigrants could be that one of the main determinants of vision impairment is age (Eye Diseases Prevalence Research Group, 2004). As seen with the healthy immigrant literature, immigrants are relatively healthy upon arrival in Canada (McDonald & Kennedy, 2004),

however, immigrants age in the same way that the broader Canadian population does, and therefore differences in vision impairment prevalence should not be significantly different.

The PALS, also, does not include refugees, which could impact the prevalence rates. Refugees often come from developing countries where vision impairment is known to be more prevalent (World Health Organization, 2013) and they do not have the same medical assessments as the immigrant population.

The data revealed that females, regardless of immigrant status, reported higher prevalence rates of vision impairment compared to males. Some studies have found that women had a higher risk of blindness and low vision (Evans et al., 2002; Eye Diseases Prevalence Research Group, 2004). The higher prevalence of women is supported by the PALS analytical report (2007b), which found that women were generally more inclined to report a disability compared to males. This finding is also supported by Grönvik (2009) who found that when using a *subjective*⁴ definition to measure disability; women were overrepresented compared to men. The reverse relationships were found when using a *functional*⁵ or *administrative*⁶ definition to measure disability, with men more highly overrepresented (Grönvik, 2009). The PALS uses a subjective definition (see methods) and it is possible that men are less likely to view themselves as disabled, i.e., due to dominant norms such as masculinity and how masculinity should be performed (Grönvik,

⁴ Subjective definition: A person that conceives themselves as being disabled. Inclusion in the category 'disabled' is therefore voluntary (Grönvik, 2009).

⁵ Functional definition: People identified as disabled in the Living Conditions Survey (Sweden) (Grönvik, 2009).

⁶ Administrative definitions: Receivers of support covered by the Act concerning Support and Services for Persons with Certain Functional Impairments (LSS) and receivers of Assistance Allowance (Sweden) (Grönvik, 2009).

2009; Valentine, 1999). Self-reporting could therefore be a possible issue when interpreting the prevalence data. When people self-report they may or may not choose to identify themselves as having a visual impairment, which could in turn skew the data. It is possible that results would be different had the PALS utilized a different model, instead of the social/subjective model, as results often varies based on the used definition (Molden & Tøssebro, 2010).

The risk of living in a low income household when having a visual impairment was significant. This is arguably not surprising as other research has found associations between vision impairment and low income levels (Sit, Chipman, & Trope, 2004; Tielsch, Sommer, Katz, Quigley, & Ezrine, 1991). The risk of living with low income can be linked to difficulties gaining access to employment for people with visual impairments. Our data showed that people who were employed were less likely to be vision impaired, which means that people with vision impairments are less likely to be employed compared to other disabilities in the PALS. People with visual impairments often face barriers such as transportation, access and cost of technology and employer's attitudes and concerns (Leonard, D'Allura, & Horowitz, 1999). That education was not an indicator of whether an individual had a visual impairment or not could be ascribed to the connection between age and vision impairment. If vision impairment occurs with age it more than likely would not have an influence on educational attainment.

Our study also highlights who is more likely to receive support. Not surprisingly, receiving support was influenced by the severity of the vision impairment, with greater severity associated with individuals being more likely to receive support (Moore,

Rosenberg, & McGuinness, 1997). The fact that people who are employed are less likely to receive support could possibly speak to their abilities and the severity of their impairment. Regarding age, it was expected that the use of support would increase with age and people who are 50-69 years old are therefore less likely to receive support compared to visually impaired persons who are age 70 and over (Moore et al., 1997). Male immigrants were less likely to receive support compared to others. Moore et al. (1997) found that males who lived alone received more support than females, but males that did not live alone received less support compared to females. It could therefore be hypothesized that the low service utilization of males could be a result of them not living alone. Another possible explanation could be that males are less likely to report receiving support as seen with reporting disability, however, no literature is known to the author, which supports that claim. Higher education proved to be a determinant of whether a person receives support or not, persons with a university degree were less likely to receive support compared to others. While no other literature was found it can be hypothesized that education has a similar effect on care as it does on health outcomes. Moore (1997) suggest that persons with some postsecondary education are less likely to be disabled, it is possible that visually impaired persons with postsecondary education used for this study also had an advantage based on their socio-economic status.

2.5.1 Limitations

There were several limitations to this paper. The PALS was released in 2007 and had a sample frame of approximately 39,000 adults and roughly 30,000 respondents. Despite

this being a fairly large number of respondents, the number of vision impaired individuals was relatively small, limiting some analyses including amongst those aged less than 50.

Another possible limitation in the paper is the subjective definition of disability that the PALS' applies. It is possible that the use of a subjective measure results in an overrepresentation of women in the statistics as women are often more likely to self-identify as having a disability (Grönvik, 2009; Statistics Canada, 2007a) . The subjective definition of disability also highlights the lack of data on vision impairments in Canada. The PALS is the best data available for measuring vision impairment however there is a lack of clinical data, which relies on a medical model as compared to the subjective model. The subjective model is important for understanding vision impairment; however, it utilizes self-reporting which could account for discrepancy in the data. Finally, it is not possible to identify refugees within the PALS, although refugees may be more vulnerable and have greater difficulty accessing support services.

2.6 Conclusion

This paper examined the prevalence rates of vision impairment in immigrants and non-immigrants when controlling for age and gender. It also further explored the demographics of the vision impaired people in the PALS and the characteristics of people who receive support. While more research is needed to confirm the findings of the results on prevalence it highlights how both immigrants and non-immigrants are affected by vision impairment with age.

Although immigrant males were less likely to have a visual impairment at the 90th confidence interval, there was no consistent difference in vision impairment prevalence

rates in immigrants and non-immigrants over the age of 50. Our results also confirmed that having a visual impairment is connected to living in a low income household. More research is needed to examine the relationship between visual impairment and low income status, as low income could be a result of not being able to find employment due to visual impairment or the visual impairment could be a result of not having access or being able to afford ophthalmological care. The data from the PALS does not allow us to make that distinction. Use of support services is strongly linked with severity of vision impairment. Overall, the study confirms previous findings; however, it also gives an insight into what the current data is not able to tell us. Future research and data collection should focus on possible differences in prevalence based on ethnicity/ race, benefits of being employed while having a visual impairment and why immigrant males are less likely to report having a visual impairment.

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Chapter Three

3.1 Introduction

Disability as a topic has received increasing attention since the 1960s and 1970s with the civil rights movement (Johnston & Sidaway, 2004). The UN estimates that people living in countries with a life expectancy over 70 years will spend 8 years on average living with a disability (United Nations, n.d.) and disability rates are increasing as the population worldwide is aging (World Health Organization, 2013a). Globally, people with disabilities are often uneducated, living in poverty, and facing barriers to health care, while women with disabilities often face multiple disadvantages due to their gender compared to males (United Nations, n.d.).

Vision impairment is when a person has sight loss which cannot be fully corrected by glasses or contact lenses (National Health Service, 2013) and is one of the most common disabilities worldwide, with an estimated 285 million people living with a vision impairment (World Health Organization, 2013b). The main causes of vision impairment in Canada are age-related macular degeneration (AMD), diabetic retinopathy, glaucoma and cataracts (Canadian National Institute for the Blind, n.d.). Most of these causes occur with aging and do not discriminate based on gender, immigrant status, and ethnicity.

While a significant body of literature exists regarding vision impairment, including prevalence within the population and its causes, very little research has focused on perceptions of vision impairment and the use of support services, particularly amongst immigrants. Work by the author, for example, revealed that there was no statistical difference in the prevalence of vision impairment between immigrants and non-

immigrants. Likewise, there was no systematic difference in the use of support services between these two groups, even though barriers to care, knowledge of support services, accessibility, and income differentials could create differentials in the use of support services. But differences in perceptions of vision impairment, including what they mean for the person and how persons perceive individuals with a vision impairment, may still remain. Do, for example, immigrants and non-immigrants differ in their perceptions of vision impairment (i.e., acceptance or exclusion of individuals with vision impairment)? Could negative perceptions of vision impairment lead to reduced use of support services, community engagement, or social exclusion?

The purpose of this exploratory study is therefore to investigate the perception of disability and vision impairment in adult immigrants with a vision impairment living in Southern Ontario and whether or not their perception influences their utilization of support services. This paper is organized in the following sections, beginning with research methods, results from the qualitative analysis, followed by a discussion of the findings. Limitations of the study and ideas for further research are also addressed.

3.1.1 Literature Review

Canada admits the largest number of immigrants per capita in the world, with the majority arriving from Asia and the Middle East since 2006 (Statistics Canada, 2013). Literature has shown that immigrants face many challenges and barriers to accessing services and healthcare when immigrating to Canada, including such barriers as transportation, costs, language, knowledge of services etc. (Lai & Ishiyama, 2004; Lo, 2011; McDonald & Kennedy, 2004). Despite the large number of immigrant arrivals,

there is relatively little research regarding disability within the immigrant population, including research associated with visual impairment amongst immigrants. Given observed barriers to health care experienced by immigrants, it may be theorized that immigrants are less likely to report vision impairment and use vision support services such as those provided by the Canadian National Institute for the Blind (CNIB). Evidence from the UK, for example, suggested that there was a relative underuse of visual impairment support services by ethnic minorities, that language was a barrier to accessing services and that there were no appropriate materials for the visually impaired in the Asian community (Scase & Johnson, 2005). Yet, work by the author and based on Canadian data suggests that there is no difference in prevalence rates between immigrants and non-immigrants when age and gender are controlled, and that there was no systematic difference in use of support services.

While prevalence and service use are two common metrics, barriers to support use and perceptions of vision impairment may still be important and have the potential to alter use of support services. With perceptions of disability varying greatly throughout non-Western culture, displaying ideas of acceptance, negative discrimination and in some instances the possession of supernatural powers (Ingstad & Whyte, 1995). Daudji et al. (2011) demonstrated that South Asian mothers had a mixed perception of disability exhibiting both traditional and western beliefs and how their perception influenced the expectations they had for the rehabilitation of their children. Traditional beliefs referred to use of spiritual healers, homeopaths and the belief in God, the Western view

represented a biomedical view that relied on Western rationalized scientific medicine (Daudji et al., 2011).

Likewise, a US study explored if traditional beliefs kept immigrants from accessing preventative health care, with results demonstrating that although Vietnamese immigrants had traditional health care beliefs such as using Chinese herbal medicine and acupuncture, these beliefs did not keep them from accessing Western medical care (Jenkins, Le, McPhee, Stewart, & Ha, 1996). Another study from the United States, which examined traditional health beliefs and health seeking behaviour of parents for their children, found that unless it was an emergency 22% of participants would rather treat their child with home remedies as compared to seeing a doctor (Roy, Torrez, & Dale, 2004). They also found that African Americans had a high level of trust in the effectiveness of home remedies (Roy et al., 2004).

Previous studies from the United Kingdom found that Pakistani and Bangladeshi parents of children with disabilities utilized both a biomedical and traditional/theological explanations of their child's disability (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot, Grant, Cooper, & Mathers, 2008). Religious explanations are more likely to be used when parents do not have a clear understanding or medical definition for their child's disability (Bywaters et al., 2003). A biomedical explanation is often used by parents when dealing with shame, stigma and negative ideas in their community (Bywaters et al., 2003; Croot et al., 2008).

When associated with vision impairment, individual, societal and cultural beliefs and perceptions may also influence use of vision support services. Fahd et al. (1997)

examined women's experiences of disability in the Middle-East and found that visually impaired women had considerably different experience of being visually impaired compared to males. The study showed that strong traditions and religious views kept blind women from accessing education as opposed to their blind brothers (Fahd, Marji, Mufti, Masri, & Makaram, 1997). Blind women were also restricted in their daily lives as they were often not allowed to leave their homes since they would bring shame on their family because of their disability (Fahd et al., 1997). Visually impaired women often did not marry, however, there was a perception that it was common for blind males to marry abled-bodied women (Fahd et al., 1997).

Extending the idea of barriers to care and use of services to vision impairment in Canada, a 2008 CNIB study examined use of vision rehabilitation services within the South Asian and Chinese communities in Canada. Results demonstrated that language was the most significant barrier, along with lack of knowledge of services offered by the CNIB (Shaw & Gold, 2009). The perception of CNIB as an organization also worked as a barrier as immigrants believed that the CNIB was only for people who were completely blind, leading individuals to believe that they did not qualify for services (Shaw & Gold, 2009).

Understanding how other cultures perceive disability and health is also important when providing care, Lindsey et al. (2012) demonstrated this when they found that healthcare community service providers often faced challenges when providing care to families who were raising a child with a disability. Healthcare providers found differences in how disability was understood and responded to and they also found

differences based on gender, mothers were often most knowledgeable about their child however it was often males who were the head of the household and made the decisions regarding care, demonstrating the need for culturally sensitive care (Lindsay, King, Klassen, Esses, & Stachel, 2012).

Consequently, perceptions of vision impairment may alter use of vision support services, social engagement, and social exclusion of individuals. This paper therefore explores perceptions of vision impairment amongst Canadian immigrants, using a qualitative descriptive research design to examine immigrant's perceptions of vision impairment and disability and their utilization of care.

3.2 Methods

Face-to-face semi-structured interviews were conducted with participants from the Greater Toronto and Hamilton Area (GTHA). A purposeful sampling technique was employed to identify participants, with sampling criteria including adults age 18+ who were immigrants⁷, CNIB clients, and preferably English speaking.⁸ All participants were recruited with the assistance of four CNIB offices in the GTHA (Hamilton, Mississauga, Toronto and York (see figure 1)). The researcher attended staff meetings for all but one office (York) where the objective of the study and participant criteria was discussed. CNIB staff then recommended clients known to them based on the inclusion criteria. Following an introduction to the research agenda by the CNIB, potential participants

⁷ Immigrants were defined as persons not born in Canada, excluding persons born outside of Canada who are Canadian citizens by birth. The definition of immigrants closely follows the definition by statistics Canada; however, refugees were included in this study.

⁸ In one instance, an interpreter was used.

contact information was then given to the research who then coordinated a time for the interview. A total of eight (n=8) participants were recruited⁹.

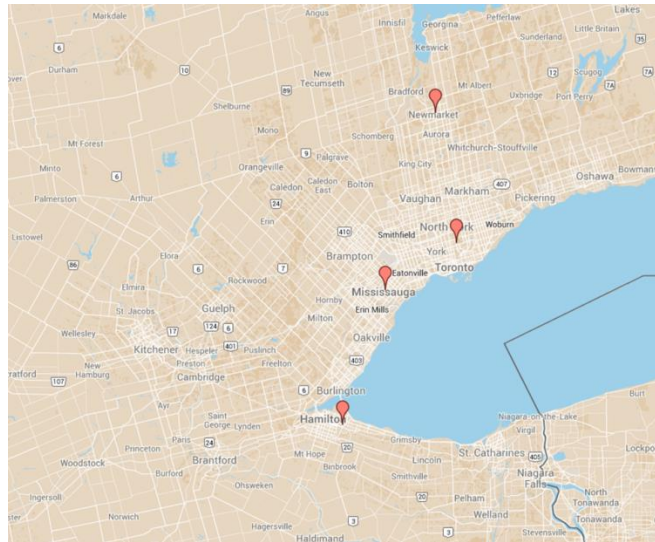


Figure 1 - Location of the four CNIB offices

Data was collected from December 2013 to March 2014 and the interview guide consisted of open-ended questions that explored the participant's background, vision impairment and perception of their vision impairment, disability, and utilization of support. Probes (Hay, 2010) were employed during the interview where necessary. Participants were either interviewed at their home or at a local CNIB office. Each interview was digitally recorded and detailed field notes were taken. All interviews were then transcribed verbatim using NVivo 10 for subsequent thematic coding. A thematic analysis was then conducted where key themes were generated deductively from the research objectives and inductively as they emerged from the interview data.

⁹ Participants received at \$15 honorarium for their participation

Ethics approval for this study was obtained from the McMaster University Research Ethics Board (see appendix B) and ethics was also obtained from the CNIB research department (see appendix C). It should be noted that the researcher had no previous relationship with the CNIB and that participants were advised before and during the interview that their participation would not in any way influence the services that they received from the CNIB.

3.3.1. Data Analysis

Two models inform disability studies; these are the medical model and the social model (Parr & Butler, 1999).

First, the medical model of disability, also referred to as the biomedical model, approaches disability from a positivistic perspective (Park, Radford, & Vickers, 1998), where disability is something that needs to be cured and if it cannot be cured the individual is outside the norm (Gilson & Depoy, 2000).

Second, the social model of disability (Burchardt, 2004; Gilson & Depoy, 2000) makes a distinction between impairment and disability, arguing that an impairment is an attribute of an individual such as a missing limb or having a depression (Burchardt, 2004). In this model, disability is considered to be a loss or limitation of opportunities to participate in social and community life equally with others, disability is therefore a result of the economic, social and physical environment that people with impairments inhabit (Burchardt, 2004). The social model is thereby emphasizing the role of society in the experience of impairment compared to the medical model, which considers disability to

be a medical condition that has to be fixed and is often associated with the idea of personal tragedy (Burchardt, 2004).

This study employs three different views in the results and discussion section to explain the different experiences of the participants; these views are the medical view, social view and the theological/traditional view. The medical view used in this paper, derives from the medical model and refers to the Western idea of clinical diagnosis and evidence based medicine (Brisenden, 1986; Daudji et al., 2011). The medical view also encompasses the idea that disability is the fault of the individual.

The social view, comes from the social model and refers to the idea that disability is a social construct created by the barriers that individuals face in their everyday lives, for example, other people's perception of them, uninviting built environments and lack of access to transportation.

A third interpretation of vision impairment is the theological/traditional view (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Croot, Grant, Cooper, & Mathers, 2008; Daudji et al., 2011). Although, this view does not come from any of the two models it is used to explain the use of traditional medicine, for example, Chinese herbs and the role that religion and God has on how participants view their impairments.

Despite the low number of participants, saturation was reached on the three different views as participants did not add any new information or insights.

3.3 Results

A diverse sample of participants was recruited. All had experienced vision impairment at different times in their lives: three were vision impaired from birth and the remainder

became vision impaired during adulthood. Participants' ranged from 20 to 75 years and originated from Europe, South America, Africa and the Middle East including Asia. None of the participants were employed at the time of the interviews. Three were students, two were retired and three did not currently have an occupation. See table 1 for a complete list of participant demographics. Participants' country of origin is listed in addition to age range to preserve confidentiality.

Table 1: Participant Demographics

Participant	Age Group	Gender	Region of Origin	Vision impaired since birth	Vision impaired in adulthood	Years since vision impairment	Years since Migration	Marital Status
1	40-49	F	Africa	No	Yes	5-9 years	10+	Divorced
2	40-49	M	Europe	No	Yes	< 5 years	30+	Never married
3	50-59	F	Middle East & Asia	Yes	No	Since birth	15+	Married
4	60+	F	Europe	No	Yes	20 + years	30+	Never married
5	60+	F	Europe/South America	No	Yes	< 5 years	40+	Married
6	30+	F	Middle East & Asia	No	Yes	10-14 years	< 5 years	Married
7	20-29	F	Middle East & Asia	Yes	No	Since birth	< 5 years	Never married
8	30-39	F	Middle East & Asia	Yes	No	Since birth	10+	Married

Based on the analysis of transcripts, 3 themes were identified: perceptions of self, perceptions of others, and daily geographies. Each of these is explored further below. Spanning these three themes is the realization that vision impairment is a continuum, with participants explaining how others did not understand this and that most people think you are either blind or not. As one participant stated:

People don't know how much blind people see (Participant 1, F)

3.4.1 Self-perception of vision impairment and disability

Overall, all of the participants had a dominant western view of disability displaying ideas of the medical and social model of disability. In this way, a majority of participants believed that their vision impairment was a disability that limited them in their everyday lives or because they had lost the ability to do certain things that they had been able to do before their impairment. For many participants the inability to drive functioned as a disabling factor:

I cannot drive, first of all, and then you know I cannot really do a lot by myself anywhere, because even with a cane, even with a dog, sometimes there are obstacles... (Participant 5, F)

...I can't get on my motorcycle that is sitting in my garage even though the weather was shit I couldn't ride my motorcycle here. I sold my car because I couldn't drive it anymore. (Participant 2, M)

Participants held different views about the severity of vision impairment, as it qualified as a disability. For some participants, vision impairment was considered a less severe disability compared to others. Participants used comparative techniques when describing the severity of their impairment:

...yes because you are unable to do various things. Yeah, it is. But it is not a grave disability. I can stand up and fool someone but if I had to be in a wheelchair I couldn't. (Participant 4, F)

For others, however, vision impairment was considered a more severe disability than other impairments, including missing limbs:

...she wants to say that vision is really important for peoples life and she is saying that sometimes she says to herself, I wish I didn't have arms or legs but I just want my, to have eyes so I can see. (Participant 6, F translator was used)

Two participants from the Middle East displayed a medical view of disability and associated their vision impairment and disability in general with being ‘damaged’ and ‘not normal’. Participant 3 believed that when one has a vision impairment or any disability, one is damaged and is therefore forced to make certain sacrifices in life for example when finding a match to marry. She further explains that because of the impairment the person will accept you with compromise:

...when someone lose something important in his or her body it is like, he is not going to be normal anymore (Participant 6, F)

Most participants, however, did not distinguish between impairment and disability, with one participant explaining that he believed that someone with a more severe condition was disabled because there were more things that they could not do or that they had a harder time in everyday life. He believed that he had impairment more so than a disability because he was still able to do most things that he had done before the impairment except for being able to drive.

While western notions of disability dominated discussions, several participants displayed both a Western view and a theological/traditional view of disability. One participant described her disability in relation to ability, saying that you are only disabled if there is something you cannot do; however, if you can do it you are not disabled. When deciding on treatment for her impairment, she turned to God for advice and God also played a role in her acceptance and perception of her disability:

It's very difficult for sure to accept but being a Christian I always say: maybe God wants to use me in this, in this way by allowing things like this to happen to me (Participant 1, F).

Spiritualism was another way that the theological/traditional view of disability was displayed. For some, spiritualism came in the form of religion and God, and one participant had used a medium and a psychic in the search for answers:

I asked will I get my eyesight back and she closed her eyes and she threw her head back... she goes I have never heard, so many angles yelling at me all at once saying yes, tell that poor boy that he is going have his eye sight back. (Participant 2, M).

Traditional perceptions were also seen through the belief and use of alternative medicine such as herbal supplements, Chinese herbs, aloe injections etc. to 'treat' or 'cure' their vision impairment. Some participants still had hope that their vision impairment would go away or that their vision would get better despite what medical professionals had told them. They were using alternative treatments such as herbal treatments to try and improve their vision. Only individuals who had become impaired in adulthood were trying to cure or better their vision through alternative treatments.

Self-perception was also apparent in how some participants coped with their impairment. Several participants mentioned that living with a visual impairment was better than losing one's life:

... it is hard in a way but I have to say it is okay. The main thing is also that I have my life; I am not taking any heavy medication, what I have seen before what I have seen before, what other people go through (Participant 1, F)

3.4.2. Perception by others: The invisible disability

Although vision impairment is a continuum, many respondents felt that the broader population categorized individuals as either blind or not. Participants, for example, explained how people would comment that they did not ‘look’ blind, exposing that people have a general idea of what blindness is supposed to ‘look’ like. Other’s perception of their disability was often related to what they expected people with a visual impairment to be capable of, such as going to school, taking the bus, working, or going grocery shopping alone. Participants generally agreed that Canadians had a greater awareness than people in their home country. However, awareness of vision impairment could still be improved.

... People don't know the meaning, now a day, of a white cane (Participant 5, F)

Perceptions were often flavoured by experiences in their home countries. Participants from Africa and the Middle East explained the stigma that surrounded vision impairment and disability in their home country:

In my country when you are disabled you are an outcast. And the services are very limited. You only afford maybe if you are very rich. Because even canes I remember when seeing blind people when, if you are blind you take your youngest sibling or whatever and you go downtown to beg for money.
(Participant 1, F)

Most disabled people cannot work, they live in the street, they cannot work and the government also don't have good facilities for that. Like there are some organization but they are poor. (Participant 7, F)

But in my country it is very hard, because people like me from my country, not like people like me... they think that they are not that good to be alive.
(Participant 6, F)

It's hard to have problem in that community in *home country*. They see you as a person that is not capable and they have empathy but you know but even for marriage I had a lot of problems with this because they see, they see you as a person who cannot handle life. (Participant 8, F)

In general, participants associated vision impairment in their home countries with lower socioeconomic status which would keep them from asking for help in certain situation in their country.

Perhaps because of these negative perceptions, in part stemming from their home countries and cultural backgrounds, as well as perceptions of blindness within the broader Canadian population, participants were generally apprehensive about how others perceived them and their impairment. Three participants explained how they consciously hide their vision impairment from others on an everyday basis, whether that meant not using the white cane, only having guests during night time to minimize the risk of people noticing the impairment, or wearing glasses to hide the severity of their impairment. One participant explained:

Participant: I don't walk with a cane either...

Interviewer: Is that a choice or is it because it wouldn't help you?

Participant: No, it is absolutely a choice because I am fucking embarrassed. Yeah, absolutely! (Participant 2, M)

Another way to control the perception by others was presented by participant 3, who had been impaired since birth. As a form of coping and control of perception by others she wore glasses even though they did not help her vision. The purpose of her glasses was to function as a fashion accessory that would keep people's attention away from her impairment.

So I feel that by wearing my glasses... I cover that up a little bit. It is mostly to cover up my, the movement of my pupil that I wear my glasses. (Participant 3, F)

Individuals who did not hide their impairment on a daily basis explained that they would occasionally hide it by avoiding going places where their impairment would not be understood, where they felt uncomfortable or where they were not accepted; these places included their church and cultural community centres. One participant felt that people in her cultural community did not understand her disability and she was therefore different than the others creating an otherness:

...there is always this feeling of otherness. So I am kind of like, I am not really accepted into this community. So kind of this alienation or otherness, so I don't like to be going to a new group of people where I would be initiated and then I would explain myself, it becomes uncomfortable. (Participant 3, F)

In trying to hide disabilities, support systems such as the CNIB were also avoided as their use would further concretize disability. One participant, for example, perceived his impairment as an embarrassment and this initially kept him from accessing services:

Interviewer: ... was it hard for you to make that call to the CNIB?

P: ... I never made it. If it was me I probably still be crawled up in the basement... it was through younger brother and who pushed me to get out there, to get in shape and to emotionally come out of this huge hole that I was in. (Participant 2, M)

When asking for help in Canada one participant found it hard to do so because others were not necessarily able to identify that she was impaired when asking for help. She explains:

I go to the store and I try to read the label of a something and then some people who will ask, I will ask, read to me and then help me, and some people wouldn't because they cannot see anything wrong with me (Participant 4, F)

All participants in general explained how the perceptions and awareness of others had shaped their lives. There was a consensus among participants that there is a lack of awareness around vision impairment in Canada and in their home countries which has made their life more difficult.

But negative or stereotypical perceptions were also identified within the immediate family, with participants discussing the repercussions of their impairment and how it had influenced their family as a whole. For participants who had become impaired as adults, family members in their home countries often did not understand their ability to do things on their own. One participant describes her brother's reaction:

I went home and my brother he said to me if you can't see why are you walking around? Go and sit down on a chair somewhere and go and sit there until you are ready to go back to Canada. And I said, well in Canada I do everything. (Participants 4, F)

Several participants mentioned their husband's lack of understanding for their impairment. One husband had become abusive as her sight had deteriorated, and another found that her husband was not willing to explain things to her and that she had to rely on her children. She explains:

... Once I got married it was a challenge adjusting with my husband and I think it still is a challenge. My husband is really nice, he is a good person but he doesn't understand the challenges, which I face so he would make a remark and all of a sudden I would look at him and think to myself oh my god this guy doesn't know a thing about me (Participant 3, F)

Another participant found that her family's negative perceptions changed when they saw what she was capable of, and that they no longer associated her impairment with negative factors such as socio economic status, cleanliness or lack of ability.

3.4.5 Coping and Daily Geographies

All participants emphasized that their impairment had influenced and changed their everyday lives. The experiences of these changes were different depending on whether the individual had been impaired from birth or became impaired during adulthood.

For individuals who had been impaired from birth, moving to Canada had changed their daily geography and the spaces that they occupy. One participant explained that she had relied on family support and taxis in her home country for transportation. In Canada, and living in a suburban area where the lack of sidewalks and crosswalks made it impossible for her to leave home without a family member or taxi, the built environment impacted her ability to navigate on her own. Because taxis are not as affordable in Canada as they are in the Middle East, she now has to rely on her husband for transportation, restricting her daily geography:

Accessibility you know, to the places and cost of life, I could get a taxi, I had private taxi in there and it was affordable it was, but in here no. Sometimes I take taxi for you know banking, taking my kids to appointment, it is 30-40\$ each time I go, that's a lot. (Participant 8, F)

Participants who lost their vision as adults also experienced a change in how they could movement throughout space. The majority of the participants had relied on their cars for getting around or for their jobs. With the inability to drive, they found that their daily

geographies were much smaller. The car had meant independence and the ability to travel almost anywhere, without the ability to drive they found that they were not able to maintain their previous lifestyles and thus their social life had been negatively impacted.

Participants explained:

I find that socially I don't actually go out anymore, for instance, I may get up and go, I like Niagara but now I can't go... (Participant 4, F)

I used to go out right, shopping and going you know with friends. Meeting with friends, to Toronto and little towns around here for a ride. You know, going around but now unless my friends come and pick me up, and not everybody drives. (Participant 5, F)

Most participants indicated that weather was a barrier when travelling. Long winters made it impossible to navigate the sidewalks and ice made it difficult to be outside, which confined several participants to their home. Participants were increasingly reliant on others for navigating the outdoors during the winter months. Daily or weekly chores had also been constrained. Grocery shopping and shopping in general had become a constraint due to mobility and sight ability. A majority of participants relied on others to transport them to stores, in addition they relied on assistance for daily activities such as seeing prices, determining the ripeness of fruit, and accessing bank machines.

Likewise, while participants expressed their preference to work, it was simply not possible due to job requirements and their vision impairment, with one participant explaining that most places of employment require a driver's license even if it was never used, she could therefore not apply for most jobs. Several participants had been employed when they experienced their vision loss; they were subsequently forced to terminate their

employment because they were not able to drive anymore.

Despite smaller daily geographies, participants were more likely to ask for help and utilize services in Canada compared to their home country. Most did not hesitate to ask for help in Canada when for example they were out grocery shopping as they did not find that their disability was associated with a lower socio economic status or shame. Regarding other services, participants did not utilize any other services besides the ones from the CNIB except for one participant who had someone clean their house for them. Several participants however did express that they would like more help but that it was simply not possible due to cost and being on Ontario Disability Support Program ODSP.

One participant explained how she did not access services in her home country because none were available and if they had been available she would not have been allowed to access them due to being a woman. When asked about reasons for accepting support in Canada she stated:

... Because this country is like a right country, everyone has rights in Canada.
(Participant 6, F)

She was able to accept the support from the CNIB because she perceived Canada to be an equal rights country where she as a woman had to opportunity to accept support. Other participants had similar views and the data suggests that their perception of Canada as a friendly, multicultural and equal rights country was an important influence when accepting assistance from the CNIB or any other form of support. One participant explained that she asked for help in both Canada and her home country but that there was

a difference, she explained:

In here (Canada) more comfortable to ask for help. But even in *home country* I didn't have problems with asking and people... that's the only part, the only part is difficult, is embarrassing, is shame on this in *home country*. (Participant 8, F)

3.5 Discussion

The main objective of this research was to explore the perception of vision impairment and disability among immigrant users of the CNIB services in Southern Ontario as well as to examine if these perceptions influenced their utilization of support. The results of this exploratory work demonstrated that all three views discussed in this research help to understand perceptions of vision impairment amongst immigrants. Moreover, some participants expressed more than one view, proving that the models are not mutually exclusive, which is also supported by Croot (2008).

All three views offer an insight into the complexities of defining vision impairment and disability. The medical view was embedded in the perception of disability and visual impairment by all participants, thereby demonstrating the power that medical professionals have in how disability is defined and what is considered the norm (Brittain, 2004). Participants described their disability using clinical diagnoses and linked their impairment to the idea of ability and the notion that they were less abled compared to the able-bodied. Some participants displayed stronger medical views of disability as compared to other participants, often emphasizing words such as “not normal” and “damaged”. Although, the participants used medical views to describe their disability, it is possible that this strong view is influenced by the traditional society of their origin countries, where impairment was associated with shame. Participants are therefore

employing medical views to explain their disability; however, this view is arguably created by social constructions in their home country.

The medical view was apparent in the way that participants controlled the perception of themselves by others. Participants described how they would hide their disability. For some this occurred on a daily basis, while others did it occasionally. By hiding their disability, participants were actively trying to control how others perceive them. In this way, they discard symbols of vision impairment and appeared ‘normal’ and able-bodied. When participants are actively trying to hide their disability, they are reinforcing the idea that they are outside the norm and have something to hide, thereby putting the blame on themselves as individuals instead of blaming society and its lack of understanding and accommodation. The social view was also apparent in the way that participants hid their disability. Participants had an expectation or knowledge of how others would perceive them and would therefore hide the impairment to avoid the negative perceptions by others and embarrassment.

The social view was also apparent in how participants presented barriers that they faced on a regular basis. Such barriers were; inaccessible built environments, transportation, accessing employment, being unable to be part of the cultural community due to negative perceptions and having family that did not understand the impairment. Understanding that they were not to blame for the built environment, transportation and others perception further confirms a social view. The social view was also apparent in how their daily geography had changed and the impact it had had on their lives, for example, becoming socially isolated.

Immigrants also drew on different conceptualizations of disability depending on the situation. Participants used multiple views interchangeably; such usage of the views shows how people with impairments create a narrative of different views to suit different purposes (Croot et al., 2008). This finding is confirmed by other studies, which also found that immigrants often manage multiple beliefs when it comes to impairment and disability (Croot et al., 2008; Daudji et al., 2011).

The results of this study show that all three views are used interchangeably by participants to shape their own perception of their disability. It is not possible to highlight one view as being more important than the others. As situations change, so do the views that immigrants employ to shape the narrative of their impairment, reflecting that participants are not a-theoretical, instead they draw on different views at different times to shape their perception.

It should be noted that negative perceptions of disability did not appear to act as a barrier for accessing services in Canada for the majority of participants. Instead analysis suggested that not being eligible to receive services and transportation were the main barriers that participants faced. However, there remains a need to inform individuals of services provided through the CNIB.

3.5.1 Limitations

While the results included several strengths, there were three principal limitations to the research. First, the study was of an exploratory nature due to the low number of participants. Although interviews resulted in over 10 hours of data and despite several attempts to recruit more participants for the study, only eight were able to participate.

Second, given the low number of participants, it was not possible to deduct if perception changed based on time spent in Canada. It would have been beneficial to know if participants had always had a Western (medical) view of disability or if this changed based on time in Canada. Third, all participants in this study were current clients of the CNIB. Therefore, they were already receiving services which likely had an influence on comments regarding the utilization of services. However, the difficulty some clients had in connecting with the CNIB, given that their use of CNIB services would concretize their disability and/or that they were not initially aware of CNIB services is telling. Moreover, we were not able to discuss vision impairment amongst individuals who did not use CNIB services, with these individuals potentially having different experiences and reasons for not using the CNIB. Finally, seven out of the eight participants were females, therefore, it could be argued that we do not have a sufficient representation of males' perception of vision impairment and disability.

3.6 Conclusion

All three theories, medical, social and theological/traditional, help us unravel how people with vision impairment view and navigate their impairment on an everyday basis. The three theories contribute to the knowledge and understanding of how perception is shaped for the individual. Results demonstrated how immigrants drew all theories interchangeably when dealing with self-perception, perception by others and how vision impairment had impacted their daily geography.

Participants had different perceptions of their own disability, with some drawing on a more medical view, while others discussed a more theological/traditional view or

social view of their disability. Results also showed that several participants used different views simultaneously when trying to explain and cope with their impairment. These different perceptions are important because they influence the way that individuals experience health and their disability (Croot et al., 2008). Knowing how immigrants perceive disability can be an important asset when providing culturally sensitive care. When service providers understand the perceptions that immigrants hold, they will be able to provide health information in a way that is understood by the immigrant within his or her beliefs. Being aware of the different perceptions should allow to assist service providers in providing services and to help avoid drawing immigrants away from their individual understanding, which might create a disconnect between the immigrant and health/service providers (Croot et al., 2008). Overall, participants experienced some form of social isolation and smaller daily geographies as a result of their impairment. This isolation was often from their cultural community, friends or former coworkers. Due to their impairment, the places that they were able to go on their own had decreased significantly and the built environment and the inability to drive had become disabling factors.

Although perception of disability did not appear to function as a barrier for accessing services, participants still faced traditional barriers such as transportation and not being eligible to receive services. More research is needed to determine if perception can function as a possible barrier for immigrants with disabilities. Results showed that cultural communities, family and the church were often not understanding or accepting of their disabilities and it is uncertain that if this would keep persons with disabilities from

accessing services. It would be a benefit to study only one ethnicity/region at a time, instead of having a small sample size of several different regions. This would allow for generalization of how perception could be a possible barrier. It would be crucial to examine people who are not receiving care to explore why they are not receiving care and if it is due to common barriers such as transportation, knowledge of services, language etc. or possibly perceptions of disability.

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Chapter Four

4.1 Introduction

This research has explored vision impairment in immigrants through the use of both quantitative and qualitative methods in order to explore prevalence rates, use of support services, and perceptions of vision impairment amongst immigrants in Canada. In doing so, the research addressed two main objectives and two sub-objectives:

1. To examine the prevalence of vision impairment in immigrants relative to non-immigrants in Canada,
 - a. To explore if there are differences in the use of caregivers based on immigrants status.
2. To explore the perception of vision impairment and disability among immigrant users of the CNIB with visual impairments in Southern Ontario.
 - a. To investigate if perception of disability influences the utilization of care.

This chapter provides a summary of key findings, contributions to the literature, ideas for future research directions and how knowledge transfer will be completed.

Although there is a larger literature addressing immigrant health issues, including the so-called health immigrant effect and use of health services (Beiser, 2005; Chen, Ng, & Wilkins, 1996; McDonald & Kennedy, 2004; Newbold, 2006), the literature addressing

disability amongst immigrants is limited, and has focused largely on the social-determinants of health and parent's perception of their child's disability.

Given the large number of immigrants entering Canada, knowledge of immigrant health, including disability issues, is vital. Immigrants and refugees often come from significantly different cultures and often have different cultural views which may affect use of health and support services as well as perceptions of health and disability. In Canada, only a small amount of research exists on immigrants and disability, with the exception including Daudji et al. (2011) who explored perceptions of disability among south Asian immigrant mothers of children with disabilities in Canada. The literature that does exist mostly provides the view from a rehabilitation setting, for example, how parents react to their child's disability when dealing with rehabilitation.

4.2 Key Findings and Contributions

Chapter two employed a quantitative analysis to examine difference in prevalence of vision impairment in immigrants and non-immigrants and variances in utilization of support. The findings revealed that there are no consistent differences in prevalence rates in immigrants and non-immigrants over the age of 50. Further multivariate logistic regression confirmed that having a visual impairment is connected to living in a low income household. Results further established that severity of vision impairment was linked to receiving support and that people who were employed were less likely to receive support. No differences were found in who provides the support for immigrants and non-immigrants.

Chapter three employed a qualitative analysis to examine the perception of vision impairment in immigrants and the role of perception when utilizing services. Findings revealed that three different theories (medical, social and theological/traditional explain immigrant perceptions of their impairment and everyday lives. Findings indicated that immigrants applied several theories interchangeably when dealing with self-perception, perception by others and how their impairment had influenced their daily geographies. Results showed that negative self-perception and perceptions by others did not function as a barrier for accessing services. However, immigrants still faced traditional barriers to services, including transportation, language barriers, and knowledge of services. Immigrants' perception of Canada was found to act as a positive factor when choosing to seek support in Canada. Findings also confirmed that vision impairment was connected to social isolation. Overall, participants experienced some form of isolation and smaller daily geographies as a result of their impairment.

Connecting the two papers, chapter two used the PALS data set, which determines disability based on self-reported disability. Because the PALS relies on self-reporting measures it is important to know if some groups or cultures are less likely reporting being disabled. Examining the perceptions of disability gives an insight into the factors that make people self-identify as being disabled, vision impaired and the factors that makes them hide it. Research has shown that the definition of disability can change the outcome of studies. It is therefore important for researchers to be critical of possible overrepresentation, for example of women when using a subjective and self-identifying definition (Grönvik, 2009).

This study makes several contributions to the literature on immigrants, disability, perception and visual impairments. First, the findings help fill the gap in the research on immigrants and disability and especially the lack of focus on vision impairment and adults perceptions of their own impairments. Second, the work adds to the literature of disability prevalence by examining vision impairment prevalence within the immigrant population, a group that had not previously been considered. Although, there was no difference in prevalence it allows us to theorize why this is the case and it also allows for a critical examination of the data that is used to determine prevalence. Third, chapter three illustrates the many theories are used to navigate perception by vision impaired individuals on an everyday basis. By examining how vision impaired immigrants perceive themselves, the work adds to the social model and social constructionist literature by examining how society and interactions with others have formed their self-perception and influenced their preparedness to receive support. The findings also have important implications for health care and service providers as it highlights the different aspects behind self-perception. Awareness of how self-perception is shaped can help guide how services are provided.

4.3 Future research directions

Several areas are identified for further research. First, chapter two only examines vision impairment. More research is needed to determine if there are differences in the prevalence of other disabilities between immigrants and non-immigrants. It would also be interesting to replicate Grönvik's study from 2009 to observe if there is a difference in prevalence rates of disability based on definitions used in Canada.

Due to the low number of participants in chapter three, the study is only exploratory. More research is needed on perceptions of disability in adults – both immigrants and non-immigrants – to determine if this influences their willingness to access care. It would be valuable to examine perception of adults who are not receiving care and it would be useful to focus on only one origin region of immigrants or ethnicity to make the results more generalizable.

4.4 Limitations

There are important limitations to this study that warrant further discussion. First, in the quantitative study, there was a small amount of vision impaired immigrants included in the PALS data set. The PALS data on vision impairment included severity, however, it was not possible to separate less severe and severe due to low cell counts. The PALS also applies a subjective definition of disability, which could account for the overrepresentation of women.

The qualitative study was only of an exploratory nature due to low number of participants. Participants were recruited through the CNIB, which means that we have not included people who do not access CNIB services. The study only included one male participant, it was not possible to get more males to participate, which results in this study presenting a dominant female view. It is possible that the views of the females in this study are the same as males; however, we are not able to deduct that from this research.

4.5 Knowledge transfer

The preliminary results of this thesis were presented at Association of American Geographers in April 2014.

In addition to academic knowledge transfer the qualitative study will be presented at a CNIB webinar either in the fall 2014 or winter 2015 to present main findings to CNIB employees and staff. An executive summary of qualitative findings will be produced for all participants after the defense of the thesis. Due to the vision impairment of the participants the summary will be distributed in an already agreed upon electronic format with large print or audio CDs.

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Appendix A

Caregiver module groups

Spouse

Spouse/partner of respondent

Same sex partner of respondent

Immediate family

Son of respondent

Daughter of respondent

Father of respondent

Mother of respondent

Brother of respondent

Sister of respondent

Family and friends

Ex-spouse/Ex-partner of respondent

Grandson of respondent

Granddaughter of respondent

Grandfather of respondent

Grandmother of respondent

Son-in-law of respondent

Daughter-in-law of respondent

Father-in-law of respondent

Mother-in-law of respondent

Brother-in-law of respondent

Sister-in-law of respondent

Nephew of respondent

Niece of respondent

Uncle of respondent

Aunt of respondent

Cousin of respondent

Close friend of respondent

Neighbour of respondent

Co-worker of respondent

Other



Non-Governmental Organization (Includes clients and patients of self-employed professionals)

Paid employee/worker of respondent

Other

Governmental

Appendix B

 <p>McMaster University Inspiring Innovation and Discovery</p>	<p align="center">McMaster University Research Ethics Board (MREB) c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca</p>		
<p align="center">CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</p>			
<p>Application Status: New <input type="checkbox"/> Addendum <input checked="" type="checkbox"/> Project Number: 2013 187</p>			
<p>TITLE OF RESEARCH PROJECT:</p>			
<p>Exploring the prevalence and perception of visual impairment and disability among Canada's immigrant population</p>			
<p>Faculty Investigator(s)/ Supervisor(s)</p>	<p>Dept./Address</p>	<p>Phone</p>	<p>E-Mail</p>
<p>B. Newbold</p>	<p>Geography</p>	<p>27948</p>	<p>newbold@mcmaster.ca</p>
<p>Student Investigator(s)</p>	<p>Dept./Address</p>	<p>Phone</p>	<p>E-Mail</p>
<p>S. Hansen</p>	<p>Geography</p>	<p>289-442-720</p>	<p>hanses2@mcmaster.ca</p>
<p>The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:</p> <p><input checked="" type="checkbox"/> The application protocol is cleared as presented without questions or requests for modification.</p> <p><input type="checkbox"/> The application protocol is cleared as revised without questions or requests for modification.</p> <p><input type="checkbox"/> The application protocol is cleared subject to clarification and/or modification as appended or identified below:</p>			
<p>COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.</p>			
<p>Amendment#1, cleared December 11, 2013</p>			
<p>Reporting Frequency:</p>		<p>Annual: Nov-01-2014</p>	<p>Other:</p>
<p>Date: Nov-01-2013 Vice Chair, C. Anderson: </p>			

Appendix C



Research Ethics Office

McMaster University

October 31, 2013

To Whom It May Concern:

I, Dr. Deborah Gold, National Director of Research and Program Development at the Canadian National Institute for the Blind (CNIB), pending ethics approval from McMaster University's IRB, have agreed to grant Stine Hansen, M.A. candidate from McMaster University, access to CNIB service managers in several Ontario cities. The purpose of this access is to ask for their assistance in recruiting visually impaired participants for the student's study "*Exploring the prevalence and perception of visual impairment and disability amongst immigrants in Canada*".

Sincerely,

A handwritten signature in black ink, appearing to read "D. Gold.", enclosed within a light gray rectangular box.

Dr. Deborah Gold

Appendix D

**Email Recruitment Script
Sent on Behalf of the Researcher
by the Holder of the Participants' Contact Information**

**Stine Hansen B.A.
Masters Candidate in Geography
Study Title:**

Exploring prevalence and perception of visual impairments/disability among Canada's
immigrant population

Sample E-mail Subject line: McMaster study of immigrant's perception of visual impairment

Dear CNIB client,

Stine Hansen, a McMaster student, has contacted the Canadian National Institute for the Blind asking us to tell our clients about a study she is doing on immigrants and vision impairment. This research is part of her Master of Arts program in Geography at McMaster University.

The following is a brief description of her study. She has asked us to attach a copy of her information letter to this email. That letter gives you full details about her study.

If you are interested in getting more information about taking part in Stine's study please read the brief description below and or **CONTACT Stine DIRECTLY** by using her McMaster email address or cell phone number.

[REDACTED]. The researcher will not tell me or anyone at CNIB who participated or not. Taking part or not taking part in this study will not affect your status or any services you receive at CNIB.

Stine Hansen is inviting you to take part in a 60-90 minute face to face interview that will take place during the day, in the evening or weekends (off hours) at your convenience either at a CNIB office near your home or workplace, a public library or at your home. She will work out those details with you. She hopes to learn what CNIB clients like you, think about vision impairment; how it influences your everyday life and any possible differences you have seen between Canada and your own culture when it comes to vision impairment and disability.

Miss Hansen has explained that you can stop being in the study at any time.

In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Fill in your name

Fill in position at CNIB

CNIB

Appendix E

Study: Exploring prevalence and perception of visual impairments/disability among Canada's immigrant population.

Researcher: Stine Hansen B.A

Oral Consent Script

Introduction:

Hello. I'm Stine Hansen and I am conducting interviews about immigrants, vision impairments and disability. I'm conducting this research as part of my Master's thesis at McMaster University's School of Geography and Earth Sciences in Hamilton, Ontario. I'm working under the direction Dr. K. Bruce Newbold of McMaster's department of School of Geography and Earth Sciences.

I located/found your name by contacting the CNIB asking if they knew of any clients who would be ideal for my study on immigrants and perception of vision impairment. The CNIB then contacted you for approval and then gave me your information.

What will happen during the study?

I'm inviting you to do a one-on-one interview face –to-face that will take about 60-90 minutes. I will ask you questions about vision impairment such as

Question #1: Do you consider yourself to be disabled? Or do you consider vision impairment a disability?

Question #2: How does your vision impairment influence your everyday life?

I will take handwritten notes to record your answers as well as use an audio recorder to make sure I don't miss what you say. We can set up a time and place that works for us both.

Are there any risks to doing this study?

There are minimal risks to participating in this study however I will be asking you questions about your vision impairment, feelings regarding vision impairment and disability and your everyday life. It is possible that this might make you upset or bring back memories that you had not thought about in a long time.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.... And you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Benefits:

It is unlikely that there will be direct benefits to you, however, by better understanding immigrant's perception of vision impairment researchers and others may be able to provide better and more culturally appropriate service in the future.

I will keep the information you tell me during the interview confidential. Information I put in my report that could identify you will not be published or shared beyond the research team unless we have your permission. Any data from this research which will be shared or published will be the combined data of all participants. That means it will be reported for the whole group not for individual persons.

Voluntary participation:

- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the interview for whatever reason
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop we will ask you how you would like us to handle the data collected up to that point.
- This could include returning it to you, destroying it or using the data collected up to that point.
- If at some future date (until approximately **January, 2014**) you decide that you do not want to share your comments, please contact the researcher and they will be removed.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- If you have any questions about this study or would like more information you can call or email Stine Hansen at [REDACTED].

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administration, Development & Support (ROADS)
E-mail: ethicsoffice@mcmaster.ca

I would be pleased to send you a short summary of the study results when I finish going over our results. Please let me know if you would like a summary and what would be the best way to get this to you. Also, please let me know if you would like the results in large print, an audio cd or any other accessible form.

Consent questions:

- Do you have any questions or would like any additional details?

- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?

Appendix F

Interview guide for Immigrants

Intro:

1. Can you tell me a bit about yourself?

Prompts for question #1:

- How long have you been in Canada?
 - How old were you when you arrived in Canada?
 - What country did you emigrate from?
 - Are you married?
 - Are you employed?
2. Can you tell me about your sight (disability)?

Prompts for question #2:

- Do you use any form of corrective lenses?
 - When/How did you become vision impaired?
 - Do you know the medical diagnosis of your vision impairment/sight problem?
 - Can you describe the severity of your vision impairment in your own words?
 - How does your vision impairment influence your everyday life? What do you do to compensate for your impairment?
3. Can you think about the time you found out about your vision impairment? Can you tell me a bit about that?

Prompts for question #3:

- Was it sudden or gradual?
 - How did you feel? Upset? Angry? Neutral?
4. Do you get any help for your sight problems/vision impairment?

Prompts for question #4:

- What kind of help do you get/receive?
 - How often do you get help? Daily basis? Couple of times a week?
 - Do you have someone that helps you on a daily basis?
 - Is this a family member?
 - Do you pay for this help?
 - What other services do you use?
 - Do you have more than one person helping you?
5. What CNIB services do you use?

Prompts for question # 5:

- Do you use services from other organizations? What are they?

Social experiences and views:

6. How do people interact with you because of your vision impairment/sight problems?

Prompts for question #6:

- Do you notice a difference?
 - Do you feel that people treat you differently?
 - Why do you think that is?
7. Do you consider your vision impairment/sight problems to be a disability? Why/why not?

Prompts for question #7:

- Does it restrict you from doing things on an everyday basis?
 - o None_____A little_____A lot
8. Do you think other people consider you to be disabled/handicapped/sick/ill?

Prompts for question #8:

- Who?
 - Why/Why not?
 - How would you say that your family member feel about vision loss?
 - Do you feel like there is a sense of shame in your family because you are not able to see so well anymore?
 - Do you feel like there are things you could do but that your family does not want you to do?
9. Do you think the views of vision impairment/sight problems are different in Canada compared to other countries that you have lived in?

Prompts for question #9:

- How would you say others in your cultural community feel about vision loss?
 - Do you feel that there is a sense of shame in your community about not being able to see well?
 - Are people more accepting of vision impairment in Canada or in other countries that you have lived in?
 - Do you feel that one country has a more negative view than the other?
10. Do you think there is a difference in how people feel about disabilities/handicap in general in other countries that you have lived in compared to Canada?

Prompts for question #10:

- Why do you think that is?

11. Is there anything else, ideas suggestions that you would like to add?

Generic prompts:

Can expand on that?

What do you mean by that?

How did that make you feel?

Appendix G

Study: Exploring prevalence and perception of visual impairments/disability among Canada's immigrant population.

Researcher: Stine Hansen B.A



Oath of Confidentiality

(Check the following that apply)

I understand that as:

☐ an interpreter

☐ transcriber

☐ audio assistant

☐ video assistant

☐ research assistant

☐ other (*Please specify*) _____

for a study being conducted by **Stine Hansen** of the Department of Geography and Earth Sciences, McMaster University, under the supervision of Professor Dr. K. Bruce Newbold, confidential information will be made know to me.

I agree to keep all information collected during this study confidential and will not reveal by speaking, communication or transmitting this information in written, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team.

Name: _____ Signature: _____
(*Please Print*)

Date: _____

Witness Name: _____ Witness Signature: _____