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'I am not disabled. It's my environment that makes me disabled': A critical ethnography of age-related vision loss (ARVL) in older adulthood

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Graduate Program in Health and Rehabilitation Sciences
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy
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'I am not disabled. It's my environment that makes me disabled':
A critical ethnography of age-related vision loss (ARVL) in older adulthood

(Thesis format: Integrated-Article)

by

Colleen McGrath

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Abstract

This thesis aims to deepen understandings of how various aspects of the environment shape how older adults with age-related vision loss (ARVL) negotiate and engage in occupation. The thesis further raises critical awareness of the ways in which environmental features, embedded in ageist and ableist assumptions, shape and perpetuate experiences of disability for older adults with ARVL. A critical ethnography was undertaken, informed by theoretical concepts drawn from critical gerontology, environmental gerontology, a critical occupational perspective, and critical disability theory. A total of ten older adults with ARVL participated in three data generation sessions consisting of a narrative interview, semi-structured in-depth interview, and participant observation session. Seven community organization representatives participated in a semi-structured in-depth interview and sixteen relevant documents were critically reviewed.

This work is comprised of five integrated manuscripts, in addition to the introduction, methodology, and discussion chapters. Chapter two presents a scoping review that explores pre-existing research addressing factors, including demographic, emotional, behavioral, diagnostic, and environmental, which influence the occupational engagement of older adults with ARVL. Chapter four provides a rationale for expanding the application of a critical sensibility to existing conceptualizations of the environment in an effort to expand the field of environmental gerontology beyond a micro-and meso-level approach towards a holistic view of the environment. Chapter five explores how a critical disability theory approach could lead to new research foci in the study of ARVL. Key findings of the critical ethnography are presented in chapters six and seven. Chapter six focuses on exploring those attributes that older adults with ARVL perceive as being the markers of a 'good old age' and how their negotiations of everyday occupation occur in relation to these markers. Chapter seven aims to highlight how experiences of disability for the informants are shaped through

interactions with environmental features, thereby highlighting the socio-political production of disability.

This work points to novel empirical, methodological, and theoretical insights relevant to the ARVL field. This work also has implications for persons with vision loss, vision rehabilitation professionals, and researchers as well as for the development of vision-friendly environments and inclusive social policy.

Keywords:

Critical ethnography, age-related vision loss, older adults, environment, critical gerontology, critical disability theory, occupational engagement, positive aging

Co-Authorship Statement

I, Colleen McGrath, acknowledge that this thesis includes five integrated manuscripts that evolved as a result of collaborative endeavours. In the five manuscripts, the primary intellectual contributions were made by the first author who: researched the methodology, designed the research, developed the ethics application, conducted the literature reviews, established relationships with gatekeepers, undertook the data collection, transcribed and coded the data, led the data analysis, and led the writing of the manuscripts. The contributions of the co-authors, Dr. Debbie Laliberte Rudman, Dr. Marlee Spafford, Dr. Barry Trentham, Dr. Jan Polgar, and Dr. Marita Kloseck were primarily through the supervision of the research, theoretical and methodological guidance, reflexive dialogue, and intellectual and editorial support in crafting the work for publication.

Dedication

This work is dedicated in memory of my father, Martin McGrath, who passed away during the writing of this thesis. He taught me to love, to laugh, to persevere, and most importantly to dream. Without his unwavering support, I would not be the person I am today.

Acknowledgements

To say these past four years have been an independent journey would be a gross understatement and would not do justice to the many people who have helped me along this journey and have helped shape the work presented herein.

I must begin with an expression of sincere gratitude to my supervisor, Dr. Debbie Laliberte Rudman. This thesis would not have been possible without your patience, brilliance, and keen ability to challenge me to always apply my critical lens. You have helped me to find my critical voice and I am forever indebted to you for that. Your feedback, perspectives, and insightful questions provided throughout this process have helped me develop a thesis that I am truly proud of.

I would also like to extend my thanks to all of my supervisory committee members including Drs. Jan Polgar, Barry Trentham, and Marlee Spafford. I would not have been able to complete this doctoral thesis without your ongoing support and guidance. You have each contributed endless hours engaging in committee meetings, peer debriefing, and reviewing thesis drafts. The thoughtful discussions I have had with each of you has shaped this research and helped to make this a meaningful learning process. I would also like to thank those who sat on my thesis defence committee including Drs. Jan Polgar, Carri Hand, Paula Gardner, and Ingrid Connidis. Thank you for your time and interest in this work.

To my family. I cannot express how grateful I have been to have you by my side over these last four years. To my parents, Martin and Sylvia McGrath, words cannot express how appreciative I am for your unconditional love and support during this journey. Your confidence in me was unwavering which was a great source of strength and motivation. To my father, who passed away as I was writing this thesis, I thank you for being my biggest fan. I wish you could have seen me to the finish line, but I finally made it! To my sister Megan and my brother-in-law Dave, I thank you for making me laugh whenever I needed it and keeping me well fed during those many times when I thought soup constituted a complete and balanced diet. Thank you also for always showing a genuine

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Last, but certainly not least, my sincerest thanks to each of the participants in this study who gave freely of their time, insights, and enthusiasm. You have taught me so much about how your environments influence your daily engagement in occupation and for that I am truly indebted to each of you.

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List of Abbreviations

- ARVL** – Age-related vision loss
- CAG** – Canadian Association on Gerontology
- CNIB** – Canadian National Institute for the Blind
- HAC** – Haldimand Abilities Centre
- HCoA** – Hamilton Council on Aging
- EG** – Environmental gerontology
- AMD** – Age-related macular degeneration
- ADL** – Activities of daily living
- IADL** – Instrumental activities of daily living
- CAOT** – Canadian Association of Occupational Therapists
- CMOP-E** - Canadian Model of Occupational Performance and Engagement
- CMOP**- Canadian Model of Occupational Performance
- OHIP** – Ontario health insurance plan
- ADP** – Assistive devices program
- WHO** – World health organization
- LVRS** – Low vision rehabilitation services
- ILS** – Independent living skills
- O&M** – Orientation and mobility
- HSREB** - The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects
- HSR** – Hamilton Street Railway
- CCB** – Canadian Council of the Blind
- VFQ** – Visual Function Questionnaire
- DCP** – Disability creation process
- CCTV** – Closed circuit television
- ICF** – International Classification of Functioning, Disability and Health
- ICIDH** - International Classification of Impairments, Disabilities, and Handicaps
- UPIAS** – Union of the Physically Impaired against Segregation
- CDT** – Critical disability theory
- AODA** – Accessibility for Ontarians with Disabilities Act

CHAPTER ONE

1 'I am not disabled. It's my environment that makes me disabled.' A critical ethnography of age-related vision loss (ARVL) in older adulthood: An introduction

1.1 Introduction

Age-related vision loss (ARVL) has been framed as an impending epidemic in Canada (National Coalition for Vision Health, 2009). For older adults, ARVL can have a significant negative impact on participation and engagement in a diversity of daily activities that they need, want, or are expected to do. Drawing on occupational therapy and occupational science terminology, such activities are encompassed in the term 'occupation' which includes elements of self-care, leisure, and productivity (Townsend & Polatajko, 2007). The pervasive impact of low vision on occupational engagement, a term that encompasses both the performance of occupation and the meaning associated with it (Townsend & Polatajko, 2007), has been linked to a variety of negative outcomes including social isolation, depression, and compromised quality of life (Harada et al., 2008; Laitinen et al., 2007; Laliberte Rudman & Durdle, 2008). Although research, to date, has explored psychological, physical, social, functional, and emotional challenges and outcomes associated with restricted occupational engagement, how the environment influences occupational engagement for older adults with ARVL as well as how disability is shaped by environments has been scarcely addressed. Framed within a critical paradigm, this dissertation aimed to add to the existing ARVL literature by shifting the focus onto the ways in which the environment, particularly in relation to how it is shaped and structured on the basis of ageist and ableist assumptions, serves to restrict the occupational engagement of older adults with ARVL. This work also aimed to raise awareness of the ways in which the environment is implicated in the shaping and perpetuating of disability for older adults with ARVL. In doing so, this research challenged taken-for-granted assumptions that inform how environments are constructed while further deconstructing the ageist and ableist assumptions inherent therein.

The work presented in this dissertation accomplished a series of objectives. First, it synthesized current research that has addressed demographic, emotional, behavioral, diagnostic, and environmental influences on the occupational engagement of older adults with ARVL. Second, it outlined a methodological approach for using critical ethnography to address how disability is experienced and shaped for persons with age-related vision loss. Third, it established theoretical justification for drawing upon elements of critical gerontology, environmental gerontology, a critical occupational perspective, and critical disability theory to not only further understandings of environmental influences in low vision, but also to raise awareness of how disability is produced through complex transactions between impairment and context. Lastly, it provided empirical findings regarding those attributes that older adults with ARVL perceive as being the markers of a 'good old age.' Additionally, it focused on how disability is located not solely within the functions of the body, but also within the broader context in which older adults with age-related vision loss are embedded. Collectively this body of work achieved three main objectives aligned with critically-located research including: 1) deepening our understanding of the complex interplay between the individual experience of impairment and the environment both of which are implicated in the shaping and perpetuating of disability for older adults with ARVL; 2) breaking down 'taken for granted' assumptions regarding how the environment is structured on the basis of ageist and ableist assumptions and; 3) making recommendations to inform social change to increase opportunities for meaningful occupational engagement for older adults with ARVL.

I begin this chapter with an overview of ARVL as well as the presence of ARVL conditions within Canada and the resulting implications of ARVL on occupational engagement within current environmental conditions. I then provide an overview of the study purpose as well as the two key objectives informing the research study. Next, I situate the research by explaining how issues of positionality, influenced the research process and how I, as the primary investigator, came to study this topic area. As this thesis has been written in an integrated-article

format with manuscripts intended for different disciplinary audiences, at times the language used is more aligned with occupational therapy and occupational science (see chapters 1, 2, 3 and 8), and at other times it aligns more with language commonly used within critical gerontology and critical disability theory (see chapters 4, 5, 6 and 7). Thus in this chapter, I provide definitions of key terms including: occupation, occupational engagement, environment, disability, older adults, and culture as they have been used within the context of this research study. Lastly, I include a detailed description of the structure of the thesis by outlining the chapters included within this dissertation.

1.2 Study Purpose

This critical ethnographic study addressed an identified research gap, both empirically and methodologically, thus adding to the existing ARVL literature. Empirically, it addressed a gap in research by focusing on how various aspects of environments shape the disabling effects of ARVL within the lives of older adults. Methodologically, it added to existing research focused on ARVL by employing a critical ethnographic approach. By drawing on critical gerontology, environmental gerontology, a critical occupational perspective, and critical disability theory, this thesis aimed to re-think how disability associated with ARVL is understood, shifting away from a dominant tendency to locate such disability at the level of the individual with ARVL towards conceptualizing disability as resulting from interactions with various socio-political forces. Specifically, the two primary research objectives of this research included:

- i) To critically examine the role of the physical, social, cultural, political, and institutional environment in supporting as well as detracting from the occupational engagement of older adults with ARVL and;
- ii) To raise awareness of how primary barriers older adults with ARVL face in relationship to various physical, social, cultural, political, and institutional environmental factors are embedded in ageist and ableist assumptions.

The ultimate emancipatory goal of this critical ethnographic study, which was carried out in Hamilton, Ontario, was to raise awareness of how environmental forces, including physical, social, cultural, political, and institutional, shape the disability experience for older adults with ARVL. By critically deconstructing these environmental barriers, in relationship to their ageist and ableist assumptions, my research aims to support the future development and sustainment of age and vision-friendly environments designed to more fully support the occupational engagement of older adults with ARVL, thereby decreasing its disabling effects.

1.3 Background and Significance

The following section will help set the context of this dissertation. I provide a definition of age-related vision loss, an overview of the three most common causes of ARVL--age-related macular degeneration (AMD), glaucoma, and diabetic retinopathy--and describe its prevalence and occupational implications. I then set the demographic stage, by describing Canada's current aging population trends and the presence of ARVL in Canada.

1.3.1 Defining ARVL

Age related vision loss, or low vision, refers to a permanent loss of vision that cannot be corrected by eyeglasses, contact lenses, medication or surgical intervention and interferes "with the performance of common age-appropriate seeing tasks" (VREBR, 2005, p. 10). In industrialized countries, older adults constitute the fastest growing segment of the population with low vision (Watson, 2001), including AMD, glaucoma, and diabetic retinopathy, with such conditions often collectively referred to as ARVL (Watson, 2001).

1.3.1.1 Age-related macular degeneration

AMD is the leading cause of blindness or partial sight in Canada, affecting approximately one million Canadians (Buhrmann, Hodge & Beardmore, 2007; CNIB, 2009). AMD is a disease of the macula at the back of the eye; the macula is the central part of the retina and responsible for distinguishing fine detail needed

for tasks such as reading and seeing faces (The National Coalition for Vision Health, 2009). There are two types of macular degeneration, wet and dry AMD. The dry form is the most common and accounts for approximately 90% of all cases of AMD (CNIB, 2007). It is caused when the retinal photoreceptor cells gradually dry out and atrophy. Vision loss from dry AMD is generally gradual and happens over several years; however, it can progress to wet AMD without warning (CNIB, 2007). Dry AMD is characterized by the following symptoms: blurred central vision, blank spots in the vision field, sensitivity to light, as well as difficulty recognizing faces or focusing on fine details (CNIB, 2007). There are no effective treatments for dry AMD (CNIB, 2007). Wet AMD, although rarer, is the more serious form of AMD because of the degree of vision loss. In the case of wet AMD, hemorrhages in sub-retinal blood vessels are associated with damaged cells in the macula, resulting in central vision loss and blurred vision (CNIB, 2007; Spence, 1999). Wet AMD can lead to sudden loss of vision within weeks or months. There are treatments that may help to slow down the vision loss including intraocular (anti-VEGF) injections, laser photocoagulation therapy, and photodynamic therapy (CNIB, 2007).



Courtesy: National Eye Institute, National Institutes of Health (NEI/NIH)

Figure 1.1- Comparing "normal vision" with age-related macular degeneration

1.3.1.2 Glaucoma

Glaucoma is the second most common cause of blindness or partial sight among Canadians over 65 years of age, with over 250,000 Canadians affected by the disease (Buhmann et al., 2007; CNIB, 2009). Although glaucoma typically affects older adults, it exists in a number of forms and can develop at any age

(The National Coalition for Vision Health, 2009). Glaucoma results from excessive pressure within the eye to maintain a healthy optic nerve; the damaging pressure results from insufficient drainage of aqueous humor, relative to its production, in the anterior cavity of the eye (Spence, 1999). Over time, the disease damages the optic nerve at the back of the eye, causing a permanent loss of peripheral vision that can advance to a complete loss of vision (CNIB, 2007). The two main types of glaucoma are primary open-angle and closed-angle glaucoma. Primary open-angle glaucoma is the most common form of the disease, accounting for 90% of all cases in Canada; in this type, the fluid in the eye passes too slowly through the meshwork that connects the cornea to the iris causing pressure buildup within the eye that damages the optic nerve over a period of years (CNIB, 2007). In closed-angle glaucoma, the meshwork between the cornea and iris closes off completely, stopping the fluid from being able to drain from the eye, and causing a sudden increase in pressure within minutes or hours (CNIB, 2007). Primary open-angle glaucoma is typically painless and has no obvious symptoms, including no immediate vision loss. As a result, most people do not know that they have glaucoma until the damage is significant (CNIB, 2007). Early detection and treatment, however, is essential to prevent severe vision loss. Treatments may include: reducing aqueous production using eye drops or increasing aqueous drainage via eye drops, laser therapy, or surgery (CNIB, 2007).

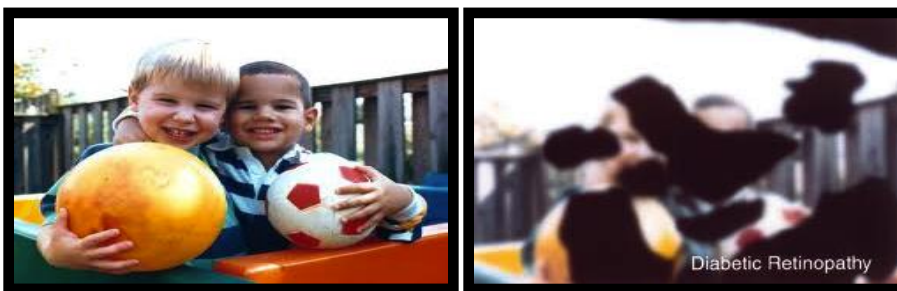


Courtesy: National Eye Institute, National Institutes of Health (NEI/NIH)

Figure 1.2- Comparing "normal vision" with glaucoma

1.3.1.3 Diabetic retinopathy

Diabetic retinopathy affects approximately 500,000 Canadians and is the leading cause of blindness or partial sight among Canadians under 50 years of age (Buhrmann et al., 2007; CNIB, 2009). People with type 1 and type 2 diabetes are at an increased risk of developing diabetic retinopathy (CNIB, 2007). It is caused when contractile cells in the wall of the retinal capillaries swell and rupture, weakening the vessels and allowing them to dilate and form small pouches called micro-aneurysms (Spence, 1999). As the blood travels through the dilated capillaries, adjacent capillaries carry less blood and eventually some areas of the retina will be deprived of blood while other areas experience hemorrhages (Spence, 1999). There are four stages of diabetic retinopathy, ranging from mild non-proliferative retinopathy, moderate non-proliferative retinopathy, severe non-proliferative retinopathy and, proliferative retinopathy (CNIB, 2007). At any of these stages, the macula can become edematous, causing loss of central vision. In the early stages of the disease, there are often no symptoms and vision may not be noticeably affected. There are treatments that can help to prevent the vision loss from getting worse; however, it will not restore vision lost as a result of diabetic retinopathy (CNIB, 2007). Treatment may include: retinal laser treatment, vitrectomy, or intraocular (anti-VEGF) injections. Without treatment, diabetic retinopathy may result in uncorrectable vision loss or blindness, usually in both eyes (CNIB, 2007).



Courtesy: National Eye Institute, National Institutes of Health (NEI/NIH)

Figure 1.3- Comparing "normal vision" with diabetic retinopathy

1.3.2 The presence of ARVL in Canada

The global population is aging. Worldwide, there are 58 million people who turn 60 each year, which corresponds to two people every two seconds (International Federation of Ageing, 2013). In 2006, 11% of the world's population was aged 60 years and older (Weinberger, 2007). By 2050, that number will triple to nearly 2 billion persons, making up for approximately 22% of the world's population (Weinberger, 2007). Within Canada, seniors now constitute the fastest growing segment of the population. In 2001, it was estimated that approximately 3.92 million Canadians were 65 years and older (Division of Seniors, 2002) or one in eight persons (Health Canada, 2002). The proportion is expected to increase to 6.7 million in 2021 and approximately 9.2 million by 2041 (Health Canada, 2002). Vision loss is already the leading cause of age-related disability and these demographic changes will result in an ever-increasing number of older adults affected by vision loss (International Federation on Ageing, 2013).

Despite its overwhelming presence, ARVL continues to be under-treated, partly because ARVL is too frequently accepted as a typical part of the aging process (International Federation on Ageing, 2013). In fact, older adults with ARVL commonly wait between 5 to 7 years after losing their vision before seeking vision rehabilitation services (CNIB, 2009). However, accessing services at an earlier point has the potential to prevent several of the negative effects on occupational engagement that ARVL may otherwise have (Heyl & Wahl, 2001; Lapointe, 2006).

There are more than 817,000 Canadians living with blindness or partial sight (CNIB, 2009) and every 12 minutes someone in Canada is affected by vision loss (CNIB, 2009; CNIB, 2009b). Age-related eye conditions, including macular degeneration, glaucoma, cataracts, and diabetic retinopathy are the leading causes of blindness and partial sight in Canada (CNIB, 2009). In fact, there are over 3.43 million Canadians living with some form of AMD, diabetic retinopathy, glaucoma, or cataracts (CNIB, 2009). This number is projected to double between 2006 and 2031 (National Coalition for Vision Health, 2009). Of the ARVL conditions that are the focus of this study, 11% of blindness or partial sight

in Canada is caused by AMD, 4% by diabetic retinopathy, and 3% by glaucoma. After age 75, the number of people experiencing blindness or partial sight triples (The National Coalition for Vision Health, 2009) with 1 in 4 Canadians developing irreversible vision loss (National Coalition for Vision Health, 2009). According to the National Coalition for Vision Health (2009), given population aging, Canada is "on the brink of an epidemic of age-related eye disease" (p. 1).

1.3.3 The occupational implications of ARVL

Participation in everyday occupation is a vital component of the human condition, providing purpose and meaning to life (Law, 2002). In the present low vision literature, there has been a strong focus on highlighting the challenges faced by older adults with ARVL as it pertains to participation in everyday occupation. Research specifically focuses on those occupational performance challenges older adults with ARVL experience in relation to self-care (Berger & Porell, 2008; Crews & Campbell, 2004; Grue et al., 2008; Knudtson, Klein, Cruickshanks, & Lee, 2011; Travis, Boerner, Reinhardt & Horowitz, 2004; West et al., 2002;), leisure (Boerner & Wang, 2010; Crews & Campbell, 2004; Desrosiers et al., 2009) and productivity (Alma et al., 2011; Lamoureux, Hassell, & Keeffe, 2004). Such a pervasive impact on occupational engagement strongly contributes to experiences of disability for older adults with age-related vision loss.

The degree to which older adults with ARVL experience restrictions to occupational engagement is of particular concern considering that participation in occupations that promote social engagement, physical involvement, and leisure enjoyment can be related to increased quality of life (Gabriel & Bowling, 2004), increased longevity (Seeman & Crimmins, 2001), decreased rates of depression (Glass et al., 2006), enhanced happiness and wellbeing (Menec, 2003; Van Willigen, 2000) as well as an increased ability to cope with new life circumstances (Duke, Leventhal, Brownlee, & Leventhal, 2002; Silverstein & Parker, 2002). Alternatively, the impact of ARVL on occupational engagement has been associated with a variety of negative outcomes including an increased

risk of falls and premature death, greater likelihood of medication errors, social isolation, depression, social dependence, compromised health-related quality of life, and premature admission to nursing homes (CNIB, 2009; Harada et al., 2008; Hooper, Jutai, Strong, & Russell-Minda, 2008; Laitinen et al., 2007; Laliberte Rudman & Durdle, 2008; Lin et al., 2004; Markowitz, 2006).

Prior research has extensively studied the physical, functional, and psychological implications of ARVL as well as the impact of ARVL on self-care, productivity, and leisure. However, the influence of environmental factors on occupational engagement and how the disability experience is shaped by these environmental influences has not fully been explored. Theoretical models in gerontology, such as Lawton and Nahemow's Competence-Press Model (see section 4.2.1), and in occupational therapy, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (see section 1.4.3), emphasize that the performance and meaning assigned to activities, that can be seen as part of occupational engagement, is influenced not just by personal factors, but by transactions of personal, occupational, and environmental factors (Townsend & Polatajko, 2007). This substantiates the need for research that explores the influence of environmental influences on occupational engagement for older adults with age-related vision loss.

Of the 22 articles included as part of the literature review for this study, as detailed in chapter three, only nine articles addressed environmental influences on occupational engagement (Girdler, Packer, & Boldy, 2008; Laliberte Rudman & Durdle, 2008; Laliberte Rudman, Huot, Klinger, Leipert, & Spafford, 2010; MacLachlan, Laliberte Rudman, & Klinger, 2007; Stevens-Ratchford & Krause, 2004; Teitelman & Copolillo, 2005; Wahl, Oswald, & Zimprich, 1999; Wang & Boerner, 2008; Wong, Guymer, Hassell, & Keeffe, 2004). The manner in which these articles addressed environmental influences contrasted from my own critical ethnographic study in three primary ways:

- 1) I primarily focused data generation and analysis on the various ways in which environments shape the occupational engagement of older adults with ARVL. This is in contrast to previous research in which environmental influences, when addressed, have tended to emerge as secondary to the primary objectives and results of the study.
- 2) I took a more holistic and dynamic view of the environment by acknowledging the influence of physical, social, cultural, political, and institutional environmental features, and acknowledging the dynamic nature of environments. This was in contrast to previous research in which the primary focus has been on the immediate physical and social environment of individuals, and static conceptualizations of environments have tended to dominate.
- 3) I applied a critical ethnographic methodology informed by critical gerontological, environmental gerontological, critical occupational and, critical disability scholarship. This is in contrast to previous qualitative research in low vision which has typically assumed a phenomenological (Laliberte Rudman et al., 2010; Laliberte Rudman & Durdle, 2008; MachLachlan et al., 2007; Moore, 2000; Moore & Miller, 2003; Spafford, Laliberte Rudman, Leipert, Klinger & Huot, 2010), grounded theory (Wong et al., 2004) or generic methodological approach (Copolillo & Teitelman, 2005; Girdler et al., 2008; Stevens-Ratchford & Krause, 2004; Teitelman & Copolillo, 2005; Wang & Boerner, 2008; Weber & Wong, 2010). In many cases, this research has not been explicit in relation to paradigm positioning, with the exception of Laliberte Rudman et al., (2010) and by extension Spafford et al., (2010) whereby an interpretive paradigm was adopted. As such, adopting a critical ethnographic methodology was a novel approach which enabled me to view older adults with ARVL not just as individuals but as part of a collective or 'culture' whose lives are shaped in particular ways through environmental elements.

1.4 A Clarification on Language

I acknowledge that a single word may have multiple meanings depending on the context in which it is used. For this reason, in this section I define a number of terms that are used throughout this dissertation that warrant clarification including: occupation, occupational engagement, environment, disability, older adults, and culture. When defining the abovementioned terms, I make reference to the theoretical perspectives that guided my research study including critical gerontology, environmental gerontology, a critical occupational perspective, as well as critical disability theory. First, however, I describe the influence of my positionalities on the language I used throughout this dissertation.

1.4.1 Positionality and its influence on language

In addition to the multiple positionalities later articulated in section 1.5.1, my roles as an occupational therapist, researcher, and an employee with the Canadian National Institute for the Blind (CNIB) served to influence the research process, specifically as it pertained to my use of language. Trained as an occupational therapist in 2006-2008, I was instructed to adopt person first terminology, such as 'person who is blind or partially sighted' instead of 'blind or partially sighted person.' Given my adoption, however, of critical disability theory, I felt that this use of person-first terminology was at odds with the theoretical underpinnings of a critical framework. For example, social disability theorists argue that person-first language can actually serve to further oppress 'disabled people' by placing the onus for disability on the person, not society (Titchkosky, 2001). Given that my dissertation sought to take a critical frame in considering the environmental shaping of disability, I choose to adopt the terminology supported by my critical positioning in lieu of the person-first language that has long been a part of my occupational therapist persona. My employment with CNIB further influenced not only the language I used throughout this dissertation to describe vision loss, but also the attitudes I developed that have been informed by my experiences with CNIB, as further described in section 1.5.1. As it pertains specifically to

language, I have chosen to use the following three terms interchangeably: blind or partially sighted, ARVL, or low vision as these are the terms I have been exposed to in the Canadian-based academic literature and through CNIB publications.

1.4.2 Occupation

In this section, I introduce a critical occupational perspective and describe how my adoption of a critical occupational perspective shaped how I conceptualized the term 'occupation' in this thesis. A critical occupational perspective combines critical social theory with occupational science (Njelesani, Gibson, Nixon, Cameron, & Polatajko, 2013). It takes an occupational perspective, which is focused on the "form, function, and meaning of human occupations" (Njelesani et al., 2013, p. 12; Yerxa et al., 1989), and combines it with critical social theory, which aims to question the often taken-for-granted systems and structures of power that cause or perpetuate social injustice (Given, 2008). The resulting critical occupational perspective views occupation as transient, dynamic, context-dependent and, most importantly, "an active political site where meaning is generated and contested" (Njelesani et al., 2013, p. 12).

The term occupation is derived from the Latin 'occupare' meaning to seize or occupy space or time (Yerxa et al., 1989). Occupation represents a basic human need to which all humans engage in one form or another (Yerxa et al., 1989). Although there is recognition that occupation is complex, there is no consensus regarding its definition. For the purposes of this dissertation, I have used the following definition of occupation as provided by the Canadian Association of Occupational Therapists (CAOT):

"Occupation refers to groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)" (Townsend & Polatajko, 2007, p. 369).

I have chosen four primary assumptions, which I feel underlie the definition of occupation used in this thesis. These assumptions include:

- **Occupation is embedded within a particular environmental context**

I believe that occupation is embedded within the physical, social, cultural, political, and institutional environment and that the environment interacts with the individual in complex ways that support as well as restrict occupational engagement. I do not believe that occupation is solely a subjective individual experience or purely a socio-political construct. As such, I acknowledge both the individual experience of occupation as well as the influence of political, social, and cultural forces in shaping occupational choice and subsequent engagement (Laliberte Rudman, 2013; Laliberte Rudman, 2014).

- **Occupation develops and changes over time based on personal interest and values, in interactions with broader social and cultural values**

This assumption is consistent with my belief that people develop occupational patterns based on personal interests, values, as well as the cultural and social context in which they exist (Townsend & Polatajko, 2007). Further, individuals perform occupation in their own way, which may or may not be consistent with how others perform the same occupation.

- **Occupation is shaped by social relations of power**

I believe that occupation is “shaped within social relations of power” (Laliberte Rudman, 2014, p. 4). In this way, social relations of power are seen to legitimize occupation and privilege some groups while marginalizing others (Laliberte Rudman, 2013; Mumby, 2004), such as older adults and disabled persons.

- **Occupation provides a sense of meaning and purpose to life**

This assumption reinforces the idea that individuals derive a particular sense of value and/or meaning from occupation. This assumption is consistent with my belief that the manner in which an occupation is carried out and the meaning derived therein, is specific to the individual as well as the context in which the occupation occurs. As such, within a different socio-political context, the value and meaning ascribed to the same occupation may differ. This is congruent with my critical occupational perspective, which would argue that occupation has meaning and that it must be understood within the particular socio-political context in which that occupation is embedded (Njelesani et al., 2013).

1.4.3 Occupational engagement

Occupational engagement is a term that encompasses both the performance of an occupation and the meaning associated with it (Polatajko et al., 2007). The shift to occupational engagement from a primary focus on occupational performance was formalized within Canadian occupational therapy with the introduction of the Canadian Model of Occupational Performance and Engagement (CMOP-E) in 2007. The CMOP-E (see Figure 1.4) describes the dynamic interaction between persons, environments, and occupations whereby occupational engagement results from this transaction (Polatajko et al., 2007). In the three-level model, the person is situated as the innermost level and includes: affective, cognitive and physical performance components with spirituality at the core of the individual. The environment is depicted as the outermost circle and includes four components: physical, institutional, social, and cultural. Lastly, occupation is represented as the inner circle and classified into three categories: self-care, productivity, and leisure. The CMOP-E provides an extension of the 1997 conceptual framework, the Canadian Model of Occupational Performance (CMOP) that was developed by the Canadian Association of Occupational Therapists (CAOT). The CMOP-E moves beyond just occupational performance, that is, the behavioural aspects of occupation, to encompass engagement as well.

Occupational engagement is an important construct in understanding human occupation. Occupational engagement includes not only the performance of the occupation but also the level of meaning, importance, and satisfaction that occupation holds for the individual (Polatajko et al., 2007). As it pertained to my research, 'occupational engagement' was used as opposed to 'occupational performance' because I was interested not only in the manner in which participants performed their occupations, but also the meaning and satisfaction derived from it.

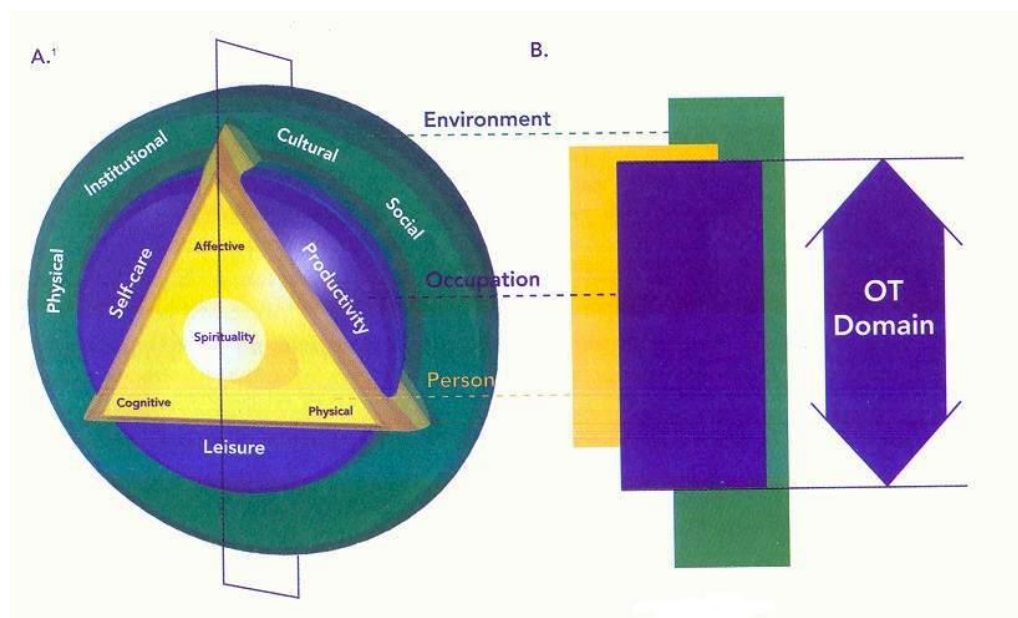


Figure 1.4- The Canadian Model of Occupational Performance and Engagement (CMOP-E).

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1.4.4. Environment

In this section, I introduce environmental gerontology (EG) and describe how my adoption of an EG perspective shaped how I conceptualized the term 'environment' throughout this critical ethnographic study. Environmental gerontology, a guiding theoretical framework of this dissertation, is primarily focused on understanding the relationship between aging persons and their physical-social environment (Wahl & Lang, 2003; Wahl & Oswald, 2010; Wahl & Weisman, 2003). As defined within EG, the social environment includes

components such as social networks, supports, and relationships (Antonucci, 2001; Lang, 2001) and focuses on how individuals socially interact within their daily lives. Conversely, the physical environment is linked to material space as well as the natural and built environment, including home environments, neighbourhoods, and long-term care institutions (Lawton, 1985; Wahl, 2001). In order to more fully understand how the environment shapes and perpetuates disability, as experienced by older adults with ARVL, it is vital to incorporate a critical sensibility to this traditional approach to the environment, as supported by key scholars such as Rowles and Bernard (2013). The incorporation of a critical sensibility to EG, as argued for in chapter four of this thesis, encourages an expansion beyond a micro-level focus towards the greater incorporation of macro-level elements of environments. This expansion incorporates long-standing attention to physical and social components of the environment, but more critically attends to these and also addresses cultural, political, and institutional elements. The incorporation of a critical sensibility is also described in chapter four as encompassing a shift from a static to a more dynamic environmental conceptualization. These fundamental changes to the field of EG underpin the conceptualization of the environment that I have adopted for this research study. Overall, this incorporation was designed to enable me to raise questions about how and why environments are organized in the way they are, and the implications such organization poses for the aging process and for the social conditions in which aging occurs.

In conceptualizing the various inter-acting elements or facets of the environment, I combined literature from occupational therapy, EG, and critical gerontology. In adopting the perspectives of each of these disciplines, I acknowledged that the environment is dynamic, inter-related, and socially constructed; thereby making it differentially experienced (Letts, Rigby & Stewart, 2003). By taking a critically infused perspective of the physical environment, I attempted to question why spaces have been designed in such a manner as to meet the needs of those members of society considered 'productive' while simultaneously restricting access for disabled persons as well as older adults. I also aimed to deconstruct

how physical environments are shaped around various ageist and ableist assumptions. My critically-oriented view of the social environment led me to consider the influence of social structures and how particular social groups are afforded varying degrees of power and access to resources over others (Giddens, 1987; Layder, 1994). The critically aligned view I assumed of the cultural environment, caused me to question how the socio-cultural environment shapes the experience of aging and the meaning and value assigned to later life. Lastly, by taking on a critical perspective of the political/institutional environment, I began to question how power ultimately serves to influence how resources are distributed within society, leading to mistreatment of marginalized populations. As well, I questioned whose needs are served by policy and how legislation can actually serve to fuel marginalization or neglect of certain social groups, such as older adults as well as disabled persons.

For the purposes of my dissertation, I analyzed the environmental influences described by my research participants, using this critical perspective on environmental facets. This approach to understanding the environment was congruent with my positioning as an occupational therapist. In occupational therapy the environment is seen to include physical, social, cultural, and institutional components which act as either enablers or barriers to occupational engagement (Letts et al., 2003). By pushing this critical conception of the environment, my research aimed to further understandings of the inter-relationship between aging persons and their environments and the dynamic nature of occupational engagement and environmental contexts.

1.4.5 Disability

The term disability can be interpreted or understood from multiple viewpoints. The biomedical model of disability is the dominant discourse on disability within Western societies (Smart, 2006-2007). Entrenched within a positivist methodological approach, the biomedical model understands disability primarily as individual pathology, meaning that there is something 'wrong' with the

individual's body resulting from disease, trauma, or an accident (Albrecht, 1992). Disability is seen as needing medical intervention or rehabilitation in order to 'fix' the disability (Devlin & Pothier, 2006) or otherwise bring the individual to as close a state of 'normal' as possible (Mitra, 2006). By viewing disability as existing within the individual, the biomedical model suggests that it is the person that must be treated, modified, or fixed in order to meet the demands of Western society. This medicalization of disability, locates disability within the individual instead of the social structures which serve to disable people (Stone, 2013). For the purposes of this thesis, I have resisted the tendency within the ARVL literature, to adopt a biomedical perspective. Instead, I have adopted critical disability theory. Similar to other theories that comprise the critical social theory family, critical disability theory aims for progressive and emancipatory social change (Meekosha & Shuttleworth, 2009) by looking "below the surface of the status quo and seek[ing] the potentiality for, or desirability of, things being other than they are" (p. 16). Using critical disability theory as a grounding framework, I have adopted the following three understandings of the term disability which I have then applied to my research study. First, I believe that disability is not solely the result of a biological characteristic nor should it only be understood as a socio-political construct. Rather, I believe that disability occurs in the interaction between components of the individual and the physical, social, cultural, political, and institutional environment. In this sense, I believe that disability cannot be separated from the context, including the environment, in which it exists. Secondly, I believe that ableist assumptions permeate our social consciousness, influencing how structures and practices are organized in ways that serve to privilege those considered able-bodied or 'normal' while oppressing and marginalizing disabled persons. I disagree with the notion that being able-bodied means being 'normal' but rather advocate for the valuing of diversity in abilities. Lastly, I believe that disability is often equated with helplessness, dependency, loss, tragedy, and inadequacy (Hammell, 2006). I reject these comparisons, and as part of a critical disability framework, I aim to work towards developing critically informed research that supports inclusion, equality, and autonomy for

older adults with ARVL while further recognizing the strengths of disabled persons and their contributions made to the community.

1.4.6 Older Adults

There is considerable dialogue surrounding what terminology to use in describing the older adult cohort. I considered one of the guiding theoretical frameworks of my research study, critical gerontology, when making my choice in terminology. I consulted a sample of critical gerontology literature to determine the terminology most commonly used by the authors as well as the older adult participants in the studies. These terms included: older persons (Grenier, 2005), older people (Holstein & Minkler, 2003; Minkler & Holstein, 2008), older individuals (Katz, 2000), older adult(s) (Martinson & Halpern, 2011; Martinson & Minkler, 2006; Putnam, 2002), and seniors (Katz, 2000). The terms, as articulated above, will be used interchangeably throughout this thesis as they all bear in mind my desire to convey older adults with ARVL as active, contributing members of society with rights and responsibilities.

1.4.7 Culture

Given that the purpose of ethnography is to describe a cultural or social group, it is important that researchers describe the definition of culture that is intended to guide their work. For my critical ethnographic work, I did not assume one single representation of culture, but rather acknowledged multiple and valid perspectives (Angrosino, 2005). I adopted the following three components of a definition of culture for this study as a means of guiding my thinking. First, I believe that culture involves shared beliefs and/or values which dictate learned social behaviours of a particular group (Thomas, 1993). Second, culture ascribes meaning to life and ultimately shapes or affects our values and behaviours (Poland, Lehoux, Holmes & Andrews, 2005). Lastly, culture is made up of the manners, customs, language, norms, and belief systems that define a particular social group (Jary & Jary, 1995) that become meaningful when they are used (Chaney, 1994).

The definition of culture that I assumed fits within a critical approach in the sense that I did not see culture as static or necessarily bound by a particular place or space. In essence, as it pertains to my research participants, I constructed older adults with ARVL as a marginalized group that share concerns and issues, which are shaped within a particular social, political, and cultural context. As part of this critical ethnography, I have constructed older adults with ARVL as a culture in order to understand how this collective is positioned within society. Although older adults with ARVL may not perceive themselves as part of a vision loss culture, I have positioned them as such in order to understand how older adults with ARVL are collectively positioned within contemporary contexts.

1.5 Situating the Research

This section will begin by describing the various positionalities I held throughout the course of this research process, in relationship to my research participants. I then situate my research within the geographic, socio-cultural, and political-institutional context in which this critical ethnographic study is embedded.

1.5.1 Situating myself as researcher

Consistent with a critical paradigmatic position (Given, 2008), I maintain that my values and lived experiences cannot, and should not, be separated from the research process. As such, I did not try to eliminate these influences; instead I acknowledge that my positionality informed this work (Guba & Lincoln, 1994). In this next section, I will describe who I am as researcher in relation to the thesis topic and my participants, and I will reflect on those personal experiences that led me to choose my research focus.

I held multiple positionalities in relation to my primary sample of research participants, who identified both as older adults and as disabled. Drawing upon critical disability and gerontological scholars, I begin with the assumption that both the identity of being older and of being disabled are marginalized in society and subject to various inequalities on account of those ageist and ableist

assumptions which permeate social consciousness, practices, and constructions. In contrast to this lived experience, at the time of writing this, I am a twenty-nine year old Caucasian female in the Rehabilitation Sciences (Health and Aging) program at Western University in London, Ontario, Canada. I own my own home in a safe rural community. I do not self-identify as having a disability nor is my occupational engagement significantly restricted by virtue of environmental constraints. Since 2008, I have been a registered occupational therapist who completed her Masters of Science in Occupational Therapy at McMaster University in Hamilton, Ontario, Canada. My interest in ARVL began during the second year of my occupational therapy training. I had an opportunity to complete an independent study course on an area of occupational therapy practice I was unfamiliar with. My passion throughout my undergraduate (Honors Bachelor of Arts in Gerontology) and graduate school training had been in geriatrics and so I knew I wanted the focus to be on older adults. After considerable self-reflection, I identified a lack of personal knowledge as it pertained to vision loss in older adulthood. I also came to realize that this was an under-researched area of occupational therapy practice in Canada with only two occupational therapist researchers, Drs. Laliberte Rudman and Packer, that I was able to identify, who were consistently publishing on the topic area (Laliberte Rudman & Durdle, 2008; Laliberte Rudman et al., 2010; MacLachlan et al., 2007; Packer, Girdler, Boldy, Dhaliwal & Crowley, 2009; Packer, Simpson, Drury, Sim, Periera & Re, 2009). It was through this learning experience that my passion for contributing meaningful research, relevant to ARVL, first emerged. After working clinically for two years in private practice, with individuals who had been involved in motor vehicle accidents, I returned to school to begin my doctoral studies in 2010 to more fully explore this passion.

My position within society, as articulated above, relative to my research participants, is one of privilege and power. This privileged position ultimately influenced each decision I made during the research process including how I chose my research topic, how I negotiated my entry into the field, how I developed my data generation methods, how I analyzed my data including what I

saw and did not see in the data sets, and finally what information I chose to include, and by extension exclude, in the published manuscripts. I acknowledge this influence on the research process. As a result, I engaged in conscious reflexivity about those decisions and assumptions I made throughout the process and how those were influenced by my various positionalities. This conscious reflexivity was intended to help maintain my critical engagement with the research process (Finlay, 2006). I also engaged in collective reflexivity by discussing my evolving coding with my supervisor and sharing my writing with committee members in an effort to push me to challenge my assumptions as well as transform my understandings and perspectives over time.

I also acknowledge that my prior research experience on a grounded theory study about ARVL (see section 3.3.2), my employment with CNIB (see section 3.3.2) and my clinical occupational therapy background shaped what I anticipated finding in my research study. Coming into this dissertation work, I held three primary assumptions including:

- 1) I assumed the research participants would address those physical environmental barriers which restricted their occupational engagement. I did not, however, anticipate that the research participants would address as many cultural, social, political, or institutional barriers. However, as demonstrated in chapter seven, the research participants spoke in great detail of the myriad of environment restrictions to their occupational engagement.
- 2) I did not presume that the older adult research participants would speak to their experiences of low vision from the perspective of critical disability theory or critical gerontology. Yet, rich and detailed experiences emerged on topics related to risk, independence, ageism, ableism, and stigma throughout the empirical findings. As the researcher, operating within a critical theory paradigm, I was then able to interpret the findings within the context of these two guiding theoretical perspectives.

- 3) I did not anticipate such variability in terms of the occupations the participants choose for their observation visit. I was surprised as to the degree of community travel I participated in as I journeyed to malls, grocery stores, pharmacies, and banks with participants either by walking or taking public transportation. These unexpected experiences spoke to my own pre-supposition that my research participants would be more occupationally withdrawn, perhaps stemming from my embeddedness in the literature that has tended to focus on what seniors with ARVL cannot or do not do versus what occupations they continue to be actively engaged in.

I engaged in reflexive practices (as further described in section 3.9), such as journaling, in an effort to forefront these pre-suppositions and how they were influencing the research process, specifically during data collection and analysis.

1.5.2 Geographic context

According to the City of Hamilton website (www.hamilton.ca) Hamilton, which is situated in the geographic centre of the Golden Horseshoe, is approximately midway between Toronto and Buffalo and covers over 112,314 hectares. Hamilton is broken up into several areas that are distinctly unique in terms of the people, culture, and economy. These communities include: Downtown, Central, West (or the west end), East (or the east end) and North (or the north end). Since 2001, five additional neighboring municipalities became a part of Hamilton including, Ancaster, Dundas, Flamborough, Glanbrook, and Stoney Creek. These communities have maintained their names within this now amalgamated city. As a result of amalgamation, Hamilton is now the tenth largest city in Canada, with a population of more than 500,000. By choosing Hamilton as the geographic focus for my dissertation, I was able to obtain results that included a mix of both urban as well as rural environments.

1.5.3 Socio-cultural context

Hamilton's population is comprised of a higher-than-average proportion of seniors as well as disabled persons as compared with provincial and national averages. Within Hamilton, every three out of twenty residents are 65 years of age and older. The number of Hamiltonians over the age of 65 will continue to rise and, by 2016, it is anticipated that seniors will account for 17% of Hamilton's population (Population Health Profile: Hamilton Niagara Haldimand Brant LHIN, 2013). Hamilton also has a statistically high proportion of disabled persons. In 2010, there were 138,245 disabled persons in Hamilton, representing 20% of the total population during that time period, which is greater than the provincial (19%) and national (17.6%) averages. Of the 138,245 disabled persons in Hamilton, 38.2% were 65 years of age and older and approximately 54.3% were female. Specifically in terms of type of disability, vision loss was ranked as fifth out of eleven, in terms of frequency of disability type, for adults aged 15 years and older (The City of Hamilton, Disability Demographics, 2010).

1.5.4 Political-Institutional context

There are a number of key players involved in low vision rehabilitation in Canada including optometrists, opticians, ophthalmologists, occupational therapists, social workers, nurses, orientation and mobility trainers, low vision clinics, as well as organizations such as the CNIB. Within the geographic region of this study, as of June 2014, there were approximately 27 Optometrists within a 15km radius of Hamilton (including Stoney Creek, Ancaster, Dundas, and Waterdown) according to the Ontario Association of Optometrists. There were an additional 12 Ophthalmologists within Hamilton according to the Royal College of Physicians and Surgeons of Canada. In terms of low vision clinics, no such facility exists within Hamilton; however, the closest centres include the Centre for Sight Enhancement in Waterloo and the Ivey Eye Institute in London. Lastly, within Hamilton the CNIB is located in the east end of the city at 115 Parkdale Avenue South. CNIB is a charity that "provides community based support, knowledge, and

a national voice to ensure Canadians who are blind or partially sighted have the confidence, skills and opportunities to fully participate in life" (www.cnib.ca). Hamilton also has a number of committees focused on addressing the needs of both seniors and disabled persons including; the Age Friendly Cities initiative through the Hamilton Council on Aging (HCoA) as well as the Seniors Advisory Committee and the Advisory Committee for Persons with Disabilities, both through the City of Hamilton.

As it relates to the provision of low vision services, ophthalmologists are mostly involved in the prescription of vision aids, opticians in the dispensing of visual aids, and optometrists in both the prescription as well as dispensing of low vision devices (Lapointe, 2006). Gold, Zuvella and Hodge (2006) conducted a telephone/mail survey across Canada with ophthalmologists, optometrists, and opticians (N=26; N=25; N=10 respectively) and found that optometrists spend a higher percentage of their time devoted to low vision services. When the authors asked participants to define the amount of time they spent on providing listed low vision services, however, the majority of all groups reported less than 10% of their practice time was spent in this way. Ophthalmologists and optometrists most frequently mentioned three primary reasons for not providing low vision services including; too much time required to provide low vision services, inadequate compensation provided from the provincial health plan, and a lack of appropriate equipment to provide such services. The same survey found that waiting times to see an ophthalmologist versus an optometrist differed. For example, approximately 90% of the ophthalmologists reported an average wait time of three months for their patient's first consultation, whereas the majority of both optometrists and opticians reported a less than one month average wait time.

A further consideration, as it pertains to low vision rehabilitation services, concerns the relative cost of services. As of November 1, 2004 routine eye examinations provided by either an optometrist or a physician, for those patients aged 20 to 64 years of age, were no longer covered by the Ontario Health Insurance Plan (OHIP). At present, OHIP coverage for eye care services is

available only for children (aged 0 to 19 years) and seniors (aged 65 years and older) to receive one full eye examination annually. Some vision assessment, for seniors, is also covered for routine monitoring of cataracts, macular degeneration, and/or glaucoma. For those seniors who require a low vision assessment, however, there is a fee for this service.

Another cost associated with low vision has to do with the purchase of assistive devices. The assistive devices program (ADP) exists for a permanent resident of Ontario whose disability has persisted for at least 6 months and who has a visual acuity of 20/70 (6/21) or less in the better seeing eye or a significant field loss. ADP will cover 75% of the cost of a device that costs a minimum of \$25 with the remaining 25% owed by the individual. All eligible persons are allowed three aids every five years unless their vision changes. If the vision decreases further, then the person is entitled to three new aids for another five years. ADP-registered professionals include ophthalmologists, optometrists, and occupational therapists.

The number of Canadians with vision loss is projected to double within the next 25 years. Thus, low vision rehabilitation providers may not have the necessary resources to continue to provide rehabilitation support to all Canadians who are experiencing vision loss. In a 2009 report entitled, "The cost of vision loss in Canada", the CNIB and the Canadian Ophthalmological Society, argued that there is an urgent need for Canada to develop a national vision plan in order to deal with this "vision loss crisis" (CNIB, 2009). In 2003, the Canadian government was an instrumental partner in the development of the Global Initiative for the Elimination of Avoidable Blindness (also known as Vision 2020: The Right to Sight) at the World Health Assembly. As part of this resolution, Canada made a commitment to the World Health Organization (WHO) to develop a national vision plan by 2005 and begin with its implementation in 2007. Although many other countries, including the United Kingdom, India, and Australia made the same commitment and have begun developing and implementing this plan, Canada has neither established a nation-wide vision health strategy nor demonstrated a

“commitment to follow through on the exploding epidemic of ARVL” (The National Coalition for Vision Health, 2009).

The National Coalition for Vision Health, which was established in 1998, is made up of representatives from the Canadian Association of Optometrists; Canadian Ophthalmological Society; The Foundation Fighting Blindness; Institute of Neurosciences, Mental Health and Addiction; and the Vision Health Research Council. The coalition provides national leadership on Canada’s vision health issues and in the development of related public policy. The coalition has advocated for the development of a national vision health plan. The coalition argues that without a national vision health plan, vision loss in Canada will continue to pose the greatest direct health-related costs of any disease category, costing approximately \$15.8 billion each year (The National Coalition for Vision Health, 2009). Every year that Canada waits, another 43,800 Canadians lose their vision (CNIB, 2009). With the implementation of a national vision plan, Canada would be able to move vision rehabilitation away from its large dependence on a not-for-profit model, to a national health priority (The National Coalition for Vision Health, 2009). Moving forward, the National Coalition for Vision Health would propose a national vision plan which would commit to the funding of vision rehabilitation services as part of the Canadian health care system, including the provision of all proven treatments and prevention strategies for eye disease under public health care plans. A national vision plan would also lead to the assigning of a department within the Public Health Agency of Canada, devoted to promoting vision health. Such a department would be responsible for the development of a coordinated public health campaign along similar lines as the Canadian Diabetes Strategy or the Tobacco Control Strategy. Lastly, a national vision plan would support the introduction of a nationwide ADP compared to the present climate, whereby only four Canadian provinces, including Ontario, have an assistive devices program.

1.6 Plan of Presentation

This thesis is presented in manuscript style. The thesis consists of eight chapters, reflecting a combination of conceptual, theoretical, and empirical thinking. Although intended to stand alone as distinct papers for publication, each of the chapters presented herein build upon each other in order to work towards the ultimate goal of increasing understandings of the various ways in which environments shape the occupational engagement of older adults with ARVL and to raise critical awareness of how the shaping of disability for older adults with age-related vision loss occurs within and through the physical, social, cultural, political, and institutional environments. In those chapters where I am the sole author (including chapters 1, 3 and 8) I have chosen to use singular pronouns, such as “I” or “my”, in order to substantiate my role as lead investigator and to demonstrate ownership over the ideas presented. In contrast, I have chosen to use plural pronouns, such as “we” or “our”, in those chapters (including chapters 2, 4, 5, 6 and 7) where I am both the lead investigator and author, but in which authorship is shared with members of my thesis committee. The content of each of these chapters will be described now.

In this chapter, I introduced the thesis as a whole, outlining the study purpose, research objectives, and study significance. Particular attention was paid to defining the terms used throughout the dissertation that warranted clarification. This chapter also situated the research within current demographic trends related to both aging and vision loss, and was able to provide a critical exploration of my positionality in relationship to both the research topic as well as my research participants.

Chapter two, a scoping review, explored the various factors, including demographic, emotional, behavioral, diagnostic, and environmental components, which serve to influence the occupational engagement of older adults with ARVL. The scoping review provided evidence of the knowledge gap in the low vision

research specific to environmental influences, which then became the focus of this thesis.

Chapter three provided a comprehensive overview of the methods and methodology adopted for my study. Specifically, I outlined the ontological and epistemological location of this study within a critical theory paradigm. I provided a rich description of the critical ethnographic methodology adopted for this study, including a description of the research field, a detailed account of my immersion into the field of low vision, the sample recruited for this study, as well as the methods adopted for data collection, management, and analysis.

Chapter four and five outlined the key theoretical foundations for the dissertation. Specifically, chapter four focused on introducing a critical sensibility to the existing discipline of environmental gerontology, while chapter five outlined the key aims, emphases, and assumptions of critical disability theory and explored how such an approach could lead to new research foci in the study of ARVL.

Chapters six and seven presented empirical findings of my critical ethnographic study. Chapter six focused on exploring those attributes that older adults with ARVL perceived as being the markers of a 'good old age' and how these markers were situated in both ageist and ableist social assumptions regarding what it means to 'age well.' Chapter seven shifted away from dominant understandings of disability, which locate disability within the functions of the body, towards the locating of disability within the broader environmental context in which older adults with age-related vision loss are embedded. As each of these chapters are intended to stand alone for publication, there is some repetition across them as it pertains to the introduction, methodology, and literature review.

The final chapter provided a synthesis of findings and insights gained during this research. Study implications were discussed for persons with vision loss, for vision rehabilitation professionals, for researchers, for the development of vision-friendly environments, as well as for the development of inclusive social policy. The strengths and limitations of the study were addressed, as well as directions

for future research. My personal reflections on the research process were also revealed.

Each of the chapters presented in the thesis, with the exception of chapter one, three, and eight, have been written as independent papers for publication. These papers have either been published, are in review, or will be submitted for publication in a peer-reviewed journal following completion of my dissertation. See Table 1.1 for a full description of manuscript topics and their current publication status.

Table 1.1: *Manuscript Publication Status*

Chapter Number	Manuscript Title	Journal	Status
1	Introduction	N/A	
2	Factors that Influence the Occupational Engagement of Older Adults with Low Vision: A Scoping Review	British Journal of Occupational Therapy	Published
3	Methods and Methodology	N/A	
4	Enhancing Environmental Gerontology: Integrating a critical perspective	International Journal of Aging and Later Life	In review
5	Re-shaping understandings of disability associated with age-related vision loss (ARVL): Incorporating critical disability theory into research	Canadian Journal of Disability Studies	Pending submission
6	Negotiating 'positive' aging in the presence of age-related vision loss (ARVL): The shaping and perpetuation of disability	Ageing & Society	Pending submission
7	Environmental barriers and the production of disability for seniors with age-related vision loss (ARVL): A critical ethnographic study	Journal of Community and Applied Social Psychology	Pending submission
8	Discussion/Conclusion	N/A	

1.7 Conclusion

I began this chapter with an overview of ARVL, the demographic presence of ARVL conditions within Canada, and the resulting implications on occupational engagement within current environmental conditions. I then provided an overview of the study purpose as well as the two key objectives informing the research study. Next, I situated the research by explaining how issues of positionality influenced the research process and how I, as the primary investigator, came to study this topic area. I also provided a clarification of language used throughout this dissertation by defining key terms including: occupation, occupational engagement, environment, disability, older adults, and culture as they have been used within the context of this research study. Lastly, I provided a plan of presentation, including a detailed description of the chapters included within this dissertation.

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CHAPTER TWO

2 Factors that Influence the Occupational Engagement of Older Adults with Low Vision: A Scoping Review

2.1 Introduction

One definition of low vision, as proposed by the Vision Rehabilitation Evidence-Based Review (VREBR) team, refers to a permanent loss of vision that cannot be corrected by eyeglasses, contact lenses, medication or surgical intervention and interferes “with the performance of common age-appropriate seeing tasks” (2005, p. 10). Older adults constitute the fastest growing segment of the population with low vision conditions, including macular degeneration, glaucoma and diabetic retinopathy, with such conditions often collectively referred to as age-related vision loss (ARVL) (Watson, 2001). Although other terms are used to describe vision loss in older adulthood, such as age-related visual impairment or age-related sight loss, the term ARVL is used throughout this article.

The World Health Organization (WHO) estimates that approximately 314 million people worldwide have a visual impairment, an overwhelming 82% of whom are aged 50 years and older (2009). As the global population continues to age, it will be important for occupational therapists to develop and implement evidence-based services that address the occupational implications of ARVL.

The occupational performance challenges older adults with ARVL experience, specifically in relationship to self-care, leisure and productivity, have been widely documented. For example, limitations with activities of daily living (ADL) including dressing, bathing, eating, grooming, toileting and completing bed transfers (Knudtson, Klein, Klein, Cruickshanks & Lee, 2011), have been found to increase with decreasing visual acuity (Laitinen et al., 2007). Reduced participation in instrumental activities of daily living (IADL), specifically household management, managing medications, money management, and shopping, is also associated with visual impairment in later life (Grue et al., 2008). ARVL has also been shown

to impact participation in leisure activities (Boerner & Wang, 2010) as well as paid and unpaid work (Alma et al., 2011).

Participation in everyday occupation is a vital component of the human condition, providing purpose and meaning to life (Law, 2002). Although the benefits of occupational participation are well known (Duke, Leventhal, Brownlee & Leventhal, 2002; Gabriel & Bowling, 2004; Glass, DeLeon, Bassuk & Berkman, 2006; Seeman & Crimmins, 2001) the pervasive impact of low vision on occupational engagement, a term that encompasses both performance and the meaning associated with it (Townsend & Polatajko, 2007), has been associated with a variety of negative outcomes including social isolation, depression and compromised quality of life (Harada et al., 2008; Laitinen et al., 2007; Laliberte Rudman & Durdle, 2008).

To date, much of the research on low vision in older adulthood has focused on demonstrating the impact of low vision on self-care, leisure and productivity. Although such research clearly demonstrates a need for occupational therapy services, an appreciation of the multitude of factors which influence the occupational engagement of seniors with ARVL is required to optimize the design and delivery of such services. Thus, the purpose of this scoping review was to summarize what is currently known regarding the underlying factors which influence the occupational engagement of older adults with ARVL.

2.2 Method

As an alternative to a systematic review, scoping reviews focus on systematically mapping a broad area of research and aim to provide a picture of main emphases and gaps within a particular topic area (Arksey & O'Malley, 2005). Unlike a systematic review, which provides a detailed reporting of individual studies, the scoping review does not necessarily focus on evaluating the quality of included research studies (Goldner et al., 2011). In our scoping review, the focus was to broadly map the main characteristics of relevant studies, with a

particular focus on mapping the types of factors identified as influencing aspects of occupational engagement.

The authors adopted the five step framework for conducting a scoping review as proposed by Arksey & O'Malley (2005). The first step in this framework is to identify the research question. The question addressed by this scoping review was: *What are the factors that influence the occupational engagement of older adults with ARVL?*

The second and third steps include identifying publications as well as screening and selecting relevant publications. A total of 12 terms were used to search 9 electronic databases. The primary author identified relevant research studies in CINAHL, Medline, Embase, AMED, Cochrane Library, Healthstar, PsychINFO, Ageline, and Sociological Abstracts. Hand searches of retrieved articles were completed to yield additional results. Combinations of the following search terms were used: low vision, vision impairment, older adults, seniors, elderly, environment, occupation, function, activity, leisure, self-care, and productivity. This search process yielded 302 abstracts. Each abstract was read by the primary author to ascertain its relevance to the identified research question. Studies were included if they: a) were written in English; b) were published between 2000-2011; c) were available at McMaster University or The University of Western Ontario and; d) focused on factors that influence the occupational engagement of older adults with ARVL. Articles that focused on the validation of assessment tools, rehabilitation interventions, falls prevention, or otherwise did not include any relevance to carrying out and attributing meaning to an occupation, were excluded. Application of the inclusion and exclusion criteria resulted in 22 articles, including 14 qualitative articles and 8 quantitative articles.

Step four in the scoping review process involved developing an evidence table summarizing the studies included in the review. Within this table, the description of each study's methodology and methods is based on the categorization provided within the article. As well, the findings were categorized based on which

factor or factors, as identified in the results section, each study addressed (see Table 2.1 for further descriptive characteristics).

The final step, as proposed by Arksey & O'Malley (2005), calls for the elucidation of key themes. Within a scoping review, the published articles are the research data. As such, a synthesis approach to data analysis was utilized. This involved inductive analysis, in which each article was read and codes were developed to track the factors addressed as potential influences on occupational engagement. Articles were coded in an iterative process, and then codes were brought together into overall categories. This inductive analysis was conducted by the first author with results then iteratively discussed with the second author to refine codes and categories.

2.3 Findings

The authors identified five types of factors which have been identified as influences on the occupational engagement of older adults with ARVL including: demographic variables, emotional components, behavioral components, diagnostic components, and environmental aspects. Findings pertaining to these various factors are summarized below, highlighting those that cross studies as well as identifying emerging findings found in only a few studies that require further investigation. Quotes, highlighting those factors which influence the occupational engagement of older adults with ARVL, are used for illustrative purposes when relevant and available.

2.3.1 Demographic Variables

Age was found to contribute to the occupational performance challenges experienced by older adults with ARVL. The degree of difficulty older adults with ARVL experience with daily activities appears to increase with age. For example, West et al., (1997) found that 15% of older adults with ARVL reported a lot of difficulty with one or more activity of daily living tasks by 80 years of age compared to 5% of those aged 65-69 years of age. Age also appeared to be

associated with the types of occupations that were reported to be challenged by ARVL. For example, Boerner and Wang (2010) found that middle aged adults (N=44; aged 42-64) reported a greater influence of vision loss on their engagement in productivity (53% versus 6%) and family life (13% versus 2%) compared to the older adults (N=107; aged 65-94) who reported vision loss as having a greater influence on leisure participation (44% versus 66%). Alma et al., (2011) conducted a cross-sectional study through telephone interviews, which assessed the magnitude of activity restriction in a sample (N=173) of individuals with vision impairment (≥ 55 years old). After stratifying for age and self-reported general vision, results indicated that older participants (≥ 75 years) experienced greater self-reported activity restriction as compared to younger study participants (< 75 years) in the areas of heavy household activities and hobby activities.

2.3.2 Degree of Vision Loss

The degree of vision loss has also been found to influence the occupational engagement of older adults within several quantitative studies. Results from three quantitative studies indicated that activity restriction increased with decreasing visual acuity. For example, Grue et al., (2008) conducted an observational study to determine the association of hearing and vision impairment with a loss of instrumental activities of daily living in a sample of older adult patients (N= 770 older adults; ≥ 75 years old) admitted to an acute care hospital. The likelihood of experiencing IADL loss increased with moderate to severe vision impairment compared with mild vision impairment. Laitinen et al., (2007) conducted a cross sectional survey with older adults (N=3439; ≥ 55 years old) aimed at determining the effect visual acuity had on activities of daily living, instrumental activities of daily living, and mobility. Data, which was obtained through a nation-wide health and functional capacity survey, revealed that the prevalence of ADL, IADL and mobility limitations increased with decreasing visual acuity ($p < 0.001$). Owsley, McGwin, Sloane, Stalvey and Wells, (2001) aimed to identify those IADLs whose completion time was associated with visual

function in a sample (N=342) of older adults aged 56-86 years old. After controlling for age, education, depression, and general health, results indicated that poorer scores on visual acuity, contrast sensitivity and useful field of view were associated with longer visual IADL completion time, such as reading ingredients on a food can. In addition, Wong, Guymer, Hassell and Keeffe, (2004) carried out a qualitative grounded theory study, which aimed to describe the impact of age-related macular degeneration among fifteen older adults (60-85 years old). The findings, which emerged from interviews, suggested that the respondents with unilateral age-related macular degeneration experienced minimal difficulty in their daily occupations compared to those participants with bilateral advanced age-related macular degeneration.

2.3.3 Emotional Components

Emotional components, including fear and one's emotional response to vision loss, emerged as influences on how persons with ARVL managed their daily occupations.

2.3.3.1 Fear

Several qualitative studies addressed ways that fear can influence if and how older adults with vision loss engage in occupation. Many of the studies discussed the fear older adults with ARVL had of harming themselves or others (Laliberte Rudman & Durdle, 2008; Moore & Miller, 2003). For example, in an article focused on community mobility, Laliberte Rudman and Durdle (2008) discussed an underlying fear participants had of sustaining bodily harm, particularly a fear of falling when walking in the community or crossing the street. For example, when discussing her fear of walking in the community, one rural woman stated: "You have to watch it, because sometimes you feel like you're gonna go on your nose.....It's just that you're not safe, you don't feel safe and sometimes you've almost felt like you're gonna go" (p. 112). Participants also described a fear of losing their way while in the community (Laliberte Rudman & Durdle, 2008). For

example, one urban participant described “a very limited existence.....I just closed right down because it’s positively frightening to go places where you don’t know where you’re going” (p. 112). This pervasive fear, combined with feeling at risk when attempting to navigate the physical environment, often restricted the older adult’s community mobility, thereby restricting the number and type of occupations that were engaged in (Laliberte Rudman & Durdle, 2008).

Another significant fear, expressed in two articles (Moore, 2000; Moore & Miller, 2003), was centered on the uncertainty of a future with vision loss. For example, in the Moore (2000) article, older female informants described fear regarding the psychological impact of vision loss and fear of being uncertain in their physical surroundings. Describing her fear of traveling alone in an urban center, one participant stated: “I was so overwhelmed by all the traffic and noise, it’s like, it made me think of that, uh, in the Wizard of Oz, where Judy Garland says, “Lions and tigers and bears. Oh my!” I was thinking, “Cars, and trucks, and buses, oh my!” (Moore, 2000, p. 582). Participants also discussed the fear of future visual deterioration. For example, one participant stated: “I just pray it don’t, as I say, I just pray it don’t get worse. If it stays the way it is, I can live with it. It’s aggravating, but the thought of it getting worse would be more, more terrifying” (Moore, 2000, p. 581).

In four of the qualitative studies (Brennan et al., 2001; Girdler, Packer, & Boldy, 2008; MacLachlan, Laliberte Rudman, & Klinger, 2007; Moore & Miller, 2003), older adults demonstrated a strong commitment to maintaining their independence and described feelings of fear and uselessness as they increasingly became dependent on others to perform daily occupations. For example, Girdler et al., (2008) found that the threat of losing one’s independence, particularly the threat of having to give up their home and move into a nursing home, was a significant fear associated with vision loss. This fear of losing their independence often resulted in reluctance, on the part of the older adult with ARVL, to ask others for much needed assistance (Brennan et al., 2001; MacLachlan et al., 2007; Moore & Miller, 2003). Instead, older adults

commonly developed personal strategies and accepted the use of adaptive devices or aids in order to find creative ways to maintain independent involvement in their desired occupations for as long as possible, and sometimes discontinued occupations rather than ask for assistance (Girdler et al., 2008; Moore & Miller, 2003).

2.3.3.2 Emotional Response to Vision Loss

Several qualitative studies found that participants had intense, often negative, emotional responses to having ARVL that influenced their engagement in occupation. For example, older adults with ARVL often experienced an innate sense of grief and frustration in having to give up previously taken-for-granted occupations (Teitelman & Copolillo, 2005; Weber & Wong, 2010). For example, one participant stated: “I used to love to read in bed. Of course I can’t do that now. There is no way. There is nothing I can do” (p. 412). This innate sadness commonly led to feelings of low self-worth and feelings of a loss of control (Girdler et al., 2008). For example, one participant noted: “I feel so embarrassed by letting the wife do things I used to....It’s not only embarrassing, it’s a little bit demeaning too, because she says herself, “You used to do all these jobs.” I can’t even change a fuse, and it’s embarrassing, belittling” (p. 113). In another study, participants identified a sense of hopelessness and feeling as though they had no choice but to accept the inevitable progression of their vision loss, and the loss of occupations that went with this progression (MacLachlan et al., 2007).

In contrast to the more negative emotional reactions to vision loss, some older adults discussed the importance of accepting vision loss with a positive attitude (Brennan et al., 2001; Moore, 2000; Moore & Miller, 2003; Weber & Wong, 2010). For example, one participant stated: “I see the world through rose colored glasses. Life is to be lived, not cried about” (Moore, 2000, p. 578). Girdler et al., (2008) noted that having the right attitude was often the first step to dealing with vision loss, as evidenced by a participant who stated: “Well it depends on your

attitude. If you're willing to accept it you can go on.....I don't let myself feel sorry for myself" (p. 114). Amid their discussion of acceptance and adaptation, however, participants in two studies still expressed hope that they would not lose any more vision or that a cure for vision loss would be found so that occupational engagement could be maintained (Brennan et al., 2001; MacLachlan et al., 2007).

A number of coping strategies utilized by older adults with ARVL, that assisted them in maintaining engagement in valued occupations, were outlined in the qualitative articles reviewed. For example, results from three studies (MacLachlan et al., 2007; Moore, 2000; Teitelman & Copolillo, 2005), discussed how participants attempted to cope with their vision loss by comparing their situation to those perceived as worse off. For example, one participant stated: "But I thank God, see I think there's always somebody that's in worse shape than you or me" (Moore, 2000, p. 578). The articles described the importance of this "cognitive restructuring of their situation" (Teitelman & Copolillo, 2005, p. 413) as a means of dealing with the vision loss. It was further suggested by Moore (2000), that such a positive perspective helped the older adults see the value of living their lives with vision loss. Also in relation to coping strategies, both Teitelman and Copolillo (2005) and Wong et al., (2004), found that those older adults with ARVL who had supportive social networks were better able to manage the effect vision loss had on their daily activities. For example, a participant in the study conducted by Teitelman and Copolillo (2005), stated: "My biggest device I have and the best device I have, of course, is my wife" (p. 414). A further coping strategy which helped older adults adjust emotionally to vision loss was having an understanding of their vision condition, as it allowed the older adults to prepare practically for a future with vision loss (Girdler et al., 2008). As expressed by one participant: "You can prepare for the future because my macular degeneration is getting worse all the time, and if you can accept the fact that one day you're going to have a real problem, you can prepare for that" (p. 114).

2.3.4 Behavioral Components

Behavioral responses, on the part of the older adult with low vision, can directly affect the occupational performance difficulties encountered on a day-to-day basis. A series of qualitative studies addressed such behavioral responses, including refusing rehabilitation services and accepting risk.

2.3.4.1 Refusing and Delaying Rehabilitation Services

The overarching goal of low vision rehabilitation services (LVRS) is to help individuals with low vision adapt to their visual loss and maximize their occupational performance by using remaining visual capacity as well as assistive devices and adaptive strategies (MacLachlan et al., 2007). Despite the known benefits of LVRS, however, research indicates that older adults often refuse or delay rehabilitation services for a variety of reasons. For example, Laliberte Rudman, Huot, Klinger, Leipert, and Spafford, (2010) and Spafford, Laliberte Rudman, Leipert, Klinger, and Huot, (2010), both of which used the same data set, purposefully sampled older adults with AVRL who had not yet accessed any form of low vision rehabilitation. The two studies found that accepting LVRS was seen as a threat to independence and therefore was prolonged for as long as possible. Drawing upon pilot data for the study reported by Laliberte Rudman et al., (2010), MacLachlan et al., (2007) found that older adults with vision loss refused LVRS because they did not want to identify themselves as having low vision or perceived that accepting such services also meant accepting the reality of their vision loss. For example, one participant stated: “That just makes it real, as in I am really on the way to having less and less vision” (p. 56). In two qualitative studies, older adults with ARVL also described experiences with their ophthalmologists, whereby after being informed that no further medical intervention was available, the older adult would not be referred onward for LVRS or told about low vision assistive devices (Copolillo & Teitelman, 2005; Spafford et al., 2010), which acted as a significant barrier to accessing LVRS and caused the older adults’ significant feelings of disappointment (Spafford et al., 2010).

Low vision assistive devices, a form of LVRS, are often necessary in order for older adults with low vision to be able to maintain engagement in meaningful or required occupations (Laliberte Rudman et al., 2010; Moore, 2000; Moore & Miller, 2003). In fact, Horowitz, Brennan, Reinhardt, and MacMillan, (2006) found that optical device use was significantly associated with a decline in functional disability among older adults (N=438; aged 65 and older) at 6-months follow up. Despite the positive effect that assistive devices can have on occupational engagement, there remain a proportion of older adults with ARVL who reject the use of assistive devices for multiple reasons including practical factors such as the cost of assistive devices (Spafford et al., 2010) or if they were perceived as too heavy, too big or took up too much space (Copollilo & Teitelman, 2005). The rejection of an assistive device has also been linked to an older adult's acceptance of their vision loss, whereby older adults at the early stages of vision loss are less likely to use an assistive device because they have not fully accepted their diagnosis (Girdler et al., 2008). The acquisition and integration of assistive devices into one's daily routine was also found to be more seamless when older adults had a more positive experience with low vision health professionals (Copolillo & Teitelman, 2005).

2.3.4.2 Accepting Risk

Accepting risk was an emerging theme in one study that was reported on at two different points in data analysis (Laliberte Rudman et al., 2010; MacLachlan et al., 2007). Older adults living with low vision described making decisions regarding occupation based on weighing the risks of the occupation with the perceived benefits of engagement (MacLachlan et al., 2007). This struggle often resulted in the older adult giving up desired occupations as a result of the physical and/or social risks the occupation posed (Laliberte Rudman et al., 2010). For example, older adults may have made the decision to restrict their access to the physical environment in an effort to minimize risk. By setting such limits, however, older adults restricted the types of occupations available to them (Laliberte Rudman et al., 2010). In an effort to minimize risk and maximize

independence, older adults frequently limited themselves to accessing spaces that were familiar to them, while still other older adults with ARVL stopped accessing their communities altogether without the accompaniment of someone else, all of which were factors that largely restricted community-based occupational engagement (Laliberte Rudman et al., 2010). The willingness of older adults to accept risk, however, allowed them to continue to engage in meaningful occupations. In fact, there were certain factors that were used to manage risk and allow for continued occupational engagement including; “asking for help, planning ahead, using assistive devices, restricting activity to specific conditions, well-practiced methods and familiar environments” (MacLachlan et al., 2007, p. 52).

2.3.5 Environmental Components

Although not as commonly addressed as those personal factors explored above, findings from both qualitative and one quantitative study suggest that there are a variety of physical and social environmental factors which can adversely affect the occupational engagement of older adults with ARVL. This research, however, is sparse and demonstrates a significant gap within the current literature base.

2.3.5.1 The Importance of Supportive Physical Spaces

Older adult informants in the qualitative study reported by Laliberte Rudman et al., (2010) and MacLachlan et al., (2007) reported that several aspects of the physical environment influenced their abilities to maintain their independence in performing desired occupations, such as weather, season, time of day, and lighting. Such factors particularly influenced the ability to access and engage in community-based occupations (Laliberte Rudman et al., 2010). Stevens-Ratchford and Krause (2004) conducted a qualitative study and found that older adults with ARVL commonly introduced different environmental modifications within their homes to support their occupational engagement such as; the use of low vision devices, making simple home modifications, and maintaining order and structure within the home environment. Further, a quantitative study

conducted by Wahl, Oswald, and Zimprich, (1999) found that a supportive physical environment that was adapted to the needs of the older adult with ARVL (either severely visually impaired or blind) allowed for better performance on IADLs in comparison to older adults who lived in less supportive environments (Wahl et al., 1999).

2.3.5.2 Experiencing Difficulty in Social Situations

From a social environmental standpoint, in their qualitative study focused on social relationships, Wang and Boerner (2008) found that older adults with low vision commonly encountered significant challenges in social situations due to a lack of understanding from others regarding the implications of their vision loss that resulted in these others either under-estimating or over-estimating what the person with vision loss could or could not do. Informants in this study also discussed experiencing difficulties interacting with others in social situations due to their inability to respond to visual cues (Wang & Boerner, 2008). In response to these vision-related challenges, some older adults in Wang and Boerner's study chose to withdraw from social relationships altogether, thereby restricting their occupational engagement. Teitelman and Copolillo (2005) connected such social difficulties to feelings of stigma and embarrassment which were particularly prevalent for older adults when in public settings. While Girdler et al., (2008) found that relying on social support networks, such as family and friends as well as community services, were strategies used by older adults to support their adaptation to vision loss and foster inclusion in occupational participation, other studies have found that older adults with ARVL expressed not wanting to ask their social supports for help for fear of being seen as a burden (Laliberte Rudman et al., 2010; Wong et al., 2004). In fact, older adults in some qualitative studies expressed feelings of resentment associated with having to depend on family members for assistance and as a result began to limit their engagement in daily occupations rather than ask for assistance (Laliberte Rudman et al., 2010; Laliberte Rudman & Durdle, 2008). Such an emphasis on independence and a

reluctance to ask for help may result in social isolation and decreased occupational participation (Laliberte Rudman et al., 2010).

2.4 Discussion

This scoping review aimed to map those factors which have been found to influence the occupational engagement of older adults with low vision. As a profession focused on enabling participation in meaningful occupation, occupational therapy is particularly well suited to provide low vision rehabilitation services for seniors experiencing vision loss. The results of this scoping review, however, may be used to further define and expand the role of occupational therapy in low vision rehabilitation.

For example, in both occupational therapy and low vision rehabilitation, growing attention has been given to self-management approaches (Packer, 2011; Rees, Saw, Lamoureux, & Keeffe, 2007). A self-management approach both incorporates and moves beyond the more traditional approaches to vision rehabilitation, which generally involves the provision of visual aids and training in order to encourage older adults to use their residual vision (Rees et al., 2007). In contrast, self-management, involves teaching individuals with chronic conditions the skills to problem solve and manage the “practical, social and emotional consequences of their condition” (Rees et al., 2007, p. 40). In relation to the results of this review, self-management programs could be designed by occupational therapists in ways that assist clients in developing the problem solving skills needed to deal with the impact of emotional, behavioural, and environmental factors on their engagement in meaningful occupation. The efficacy of self-management interventions have already been assessed for older adults with macular degeneration with results suggesting positive outcomes in relation to improved functioning, self-efficacy and reduced emotional distress (Birk et al., 2004; Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2005; Eklund, Sonn, & Dahlin-Ivanoff, 2004).

The quantitative research included within this scoping review, largely explored how the occupational engagement of older adults with ARVL related to age and degree of vision loss. The qualitative research added further insight regarding the influence of emotional and behavioural factors on occupational engagement and also provided initial findings regarding the importance of the physical and social environment. Thus, the findings from this scoping review highlight the need for low vision rehabilitation to go beyond addressing the influence of personal factors on occupational engagement to include a broader consideration of the influence of the environment on the occupational engagement of seniors with vision loss. Given the body of knowledge regarding environmental influences on occupation, as well as the range of strategies occupational therapists employ to address environmental influences on occupation (Letts, Rigby & Stewart, 2003), this is an area where occupational therapists can contribute to the development and enhancement of low vision rehabilitation services.

At the same time, given the limited amount of studies found that addressed environmental influences on the occupational engagement of older adults with ARVL, it is apparent that further research is required to elucidate the complex ways in which various environmental features support and detract from occupational engagement. As well, beyond considerations of physical and social aspects of the environment, critically informed social aging theories point to how more macro-level aspects of the environment, including political, cultural and institutional, influence the health and activities of aging individuals (Estes, Biggs & Phillipson, 2003). Thus, to fully understand what leads to occupational restriction among seniors with low vision and to design policies, programs, and advocacy efforts that optimally enable occupational engagement for seniors with ARVL, there is a significant need for research that focuses on environmental influences that spans the various types of environments. There is also a practical and political role for occupational therapy in advocating for inclusive spaces, policies, and programs that promote the physical and social engagement of older adults with vision loss. Such a focus will raise awareness of how different aspects of the environment operate to support as well as detract from the

occupational engagement of seniors with age-related vision loss. By taking the lead in addressing this current research gap and linking findings to practice, occupational therapy will be well positioned to expand its contributions to LVRS and optimize the occupational engagement of the growing number of seniors who experience age-related vision loss.

2.5 Conclusion

Given population aging trends and the chronic nature of ARVL, occupational therapists will be increasingly likely to encounter clients with low vision in a variety of practice settings. As a profession focused on enabling participation in meaningful occupation, it is important that occupational therapists understand the factors which influence the occupational engagement of older adults with ARVL. To date, most of the research in the ARVL field has focused on the impact of low vision but not on understanding the various factors that influence the occupational engagement of older adults with ARVL. Research that has examined influences on these occupational challenges has largely focused on person-related factors, although there are some findings which address physical and social environmental components. Further research regarding the factors that shape and perpetuate the negative impact of ARVL on occupational engagement, particularly research which more broadly considers environmental influences, is needed to advance evidence-based occupational therapy practice in this practice area.

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Table 2.1: Study Descriptive Characteristics

Authors	N=	Article type	Factors addressed by results
West, Munoz, Rubin, Schein, Roche, Zeger, German & Fried (1997)	2520	Quantitative; population study	Age
Wahl, Oswald & Zimprich (1999)	84	Quantitative; experimental with control group	Physical environment
Brennan, Horowitz, Reinhardt, Cimarolli, Benn & Leonard (2001)	593	Qualitative; narrative data examined from three previous quantitative studies	Fear, emotional response to vision loss
Moore (2000)	8	Qualitative; phenomenology; interviews	Fear, emotional response to vision loss, refusing/ delaying rehabilitation services
Moore & Miller (2003)	8	Qualitative; phenomenology; interviews	Fear, emotional response to vision loss, refusing/ delaying rehabilitation services
Stevens-Ratchford & Krause (2004)	2	Qualitative; interviews	Physical environment
Wong, Guymer, Hassell & Keeffe (2004)	15	Qualitative; grounded theory; interviews	Degree of vision loss, social environment
Copolillo & Teitelman (2005)	15	Qualitative; applied ethnography; interviews	Refusing/delaying rehabilitation services
Teitelman & Copolillo (2005)	15	Qualitative; focus groups and interviews	Emotional response to vision loss, social environment
MacLachlan, Laliberte Rudman & Klinger (2007)	4	Qualitative; phenomenology; interview	Fear, emotional response to vision loss, refusing/ delaying rehabilitation services, accepting risk, physical environment

Laitinen, Sainio, Koskinen, Rudanko, Laatikainen & Aromaa (2007)	3439	Quantitative; cross sectional survey	Degree of vision loss
Girdler, Packer & Boldy (2008)	22	Qualitative; focus groups	Fear, emotional response to vision loss, refusing/delaying rehabilitation services, social environment
Wang & Boerner (2008)	58	Qualitative; cross sectional	Social environment
Grue et al., (2008)	770	Quantitative; observational	Degree of vision loss
Laliberte Rudman & Durdle (2008)	34	Qualitative; phenomenology; interviews	Fear, social environment
Laliberte Rudman, Huot, Klinger, Leipert & Spafford (2010)	34	Qualitative; phenomenology; interviews	Refusing/delaying rehabilitation services, accepting risk, physical environment, social environment
Boerner & Wang (2010)	151	Quantitative; interviews	Age
Alma, Van Der Mei, Melis-Dankers, Van Tilburg, Groothoff & Suurmeijer (2011)	173	Quantitative; cross sectional study	Age, degree of vision loss
Horowitz, Brennan, Reinhardt & MacMillan (2006)	584	Quantitative; before and after with follow up	Refusing/delaying rehabilitation services
Owsley, McGwin, Sloane, Stalvey & Wells (2001)	342	Quantitative; observational	Degree of vision loss
Spafford, Laliberte Rudman, Leipert, Klinger & Huot (2010)	34	Qualitative; interviews	Refusing/delaying rehabilitation services
Weber & Wong (2010)	30	Qualitative; survey	Emotional response to vision loss

2.7 Addendum to Chapter (completed 5/18/2014)

2.7.1 Introduction

The dissertation chapter entitled: *Factors that Influence the Occupational Engagement of Older Adults with Low Vision: A Scoping Review* was published in the British Journal of Occupational Therapy and is included here, as printed in 2013. However, to ensure an up-to-date review of the relevant low vision literature, I extended the search used for the scoping review using the same search terms, databases, and inclusion and exclusion criteria from 2011-May 2014. The search yielded three additional articles which brought the overall article count to 25 including 16 qualitative studies and 9 quantitative studies (see Table 2.2). As described below, the findings of these three studies largely supported the existing themes, although new findings related to socio-economic status (SES) also emerged.

2.7.2 Demographic Variables

2.7.2.1 Age

Age, as a contributing factor to the occupational performance challenges experienced by older adults with ARVL, was further supported by the findings of Alma, Van der Mei, Groothoff and Suurmeijer (2012). The study, which included the same data set as described by Alma et al., (2011), performed a cross-sectional study with visually impaired seniors (aged ≥ 55 years; $n=173$) to assess determinants of social participation. Results of the univariate analyses demonstrated that age was statistically significantly associated with participation in domestic life (0.30; $P<0.001$), major life areas, which was defined as paid and unpaid work (0.96; $P<0.05$), and community, social, and civic life (0.15; $P<0.05$).

2.7.2.2 Socio-economic status

Although research to date has shown a correlation between SES and prevalence of vision loss, few studies have made the link between SES and occupational

engagement in older adults with ARVL. Based on the updated literature review, however, SES was found by Alma et al., (2012) to be a contributing factor. Alma et al., (2012) conducted a cross sectional study with 173 seniors (aged ≥ 55 years) to assess factors that influence the level of social participation of older adults with vision loss. Based on univariate regression analysis, income was found to be statistically significantly associated (0.26; $P < 0.01$) with participation in community, social, and civic life which was defined as involvement in clubs or associations, hobbies, sports, going to recreational places, cultural places, and public places, going on holidays, and involvement in religious activities.

2.7.3 Emotional Components

2.7.3.1 Fear

Some of the findings associated with fear, built on those examples already identified in the initial literature review. For example, Berger (2012), in a generic qualitative research study, found that older adults (N= 26 aged ≥ 70 years) with ARVL experienced a fear of harming themselves or others when in the community, coupled with a fear of being lost or becoming disoriented in their physical environments. Other findings, however, provided new, albeit supporting, evidence of how fear can influence if and how older adults with vision loss engage in occupation. Berger (2012), for example, noted a sense of fear among older adults with ARVL that stemmed from feelings of vulnerability when out in the community. For example, one participant discussed not using his white cane in public as he felt it made him an easy target for personal attack. Another participant discussed her sense of vulnerability stemming from her inability to recognize faces. Although this participant previously enjoyed walking around her neighbourhood, her inability to recognize faces anymore caused her to feel overwhelmed and therefore restricted herself to the home with minimal spontaneous or independent travel. As a result, participants often restricted their community access to activities which they deemed as necessary, which did not typically include leisure-based occupations. Additionally, Fok, Polgar, Shaw, and Jutai (2011), through one-on-one semi-structured telephone interviews with 17

adults (M= 56 years old), found a fear of stigmatization as a reason for declining to use assistive devices, such as the white cane.

2.7.4 Behavioural Components

2.7.4.1 Refusing and Delaying Rehabilitation Services

As noted in the original review, the refusal and/or delaying of rehabilitation services may further impede occupational engagement; however, the use of assistive devices may help to mitigate this otherwise negative impact on occupational engagement. For example, Fok et al., (2011) supported the claim made by previous authors (Laliberte Rudman et al., 2010; Moore, 2000; Moore & Miller, 2003) that the use of low vision assistive devices allows older adults with ARVL to be able to maintain engagement in meaningful and/or required occupation.

2.7.5 Environmental Components

2.7.5.1 Experiencing Difficulty in Social Situations

Alma et al., (2012) provided a further supporting example of the influence of social network on the occupational engagement of older adults with ARVL. Based on univariate regression analysis, Alma et al., (2012) found that social network size, which was determined by counting the number of individuals within the person's social network of children, friends, relatives, and neighbours, was found to be statistically significantly associated with participation in interpersonal interactions and relationships, which included meeting relatives, friends, or neighbours in person and by telephone or e-mail (0.26; $P < 0.01$), participation in major life areas, which included paid and unpaid work (1.03; $P < 0.05$), and participation in community, social, and civic life (0.22; $P < 0.01$).

2.7.6 Conclusion

The findings included in this addendum largely built on the existing examples provided in the original literature review, with the exception of Alma et al., (2012)

who added a further example of a demographic component, SES, and its influence on occupational engagement among older adults with ARVL. These additional three articles published since 2011, provides not only an up-to-date literature review for the purposes of this author's dissertation but also provides a more exhaustive account of the existing low vision literature regarding those underlying factors which influence the occupational engagement of older adults with ARVL. In support of the findings from 2011, there remains a need for research in the area of low vision to move beyond addressing the influence of personal factors on occupational engagement to include a broader consideration of the influence of the environment on the occupational engagement of seniors with vision loss.

2.7.7 References

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Table 2.2: Addendum Study Descriptive Characteristics

Authors	N=	Article type	Factors addressed by results
Berger (2012)	26	Qualitative; semi-structured interviews	Fear, physical environment, social environment
Fok, Polgar, Shaw & Jutai (2011)	17	Qualitative; semi-structured telephone interviews	Refusing/delaying rehabilitation services
Alma, Van der Mei, Groothoff & Suurmeijer (2012)	173	Quantitative; cross sectional study	Age, socio-economic status (SES)

CHAPTER THREE

3 Methodology and Methods

3.1 Introduction

In this chapter, I review the ontological and epistemological location of this study within a critical theory paradigm. Secondly, a description of the critical ethnographic methodology adopted for this study is provided, including a description of the research field, a detailed account of my immersion into the field of age-related vision loss (ARVL), the sample recruited for this study, as well as the methods adopted for data collection, management, and analysis of the research data. Lastly, I explore the quality criteria applied to this study to ensure rigour of the data collected.

3.2 Positioning of the Researcher

3.2.1 Paradigmatic location

This research was guided by a critical theory paradigm position. Critical theory, an umbrella term which encompasses a range of specific theories, is primarily concerned with issues of power and justice and the ways in which matters of race, social class, ethnicity, age, and gender interact to construct social systems in ways that privilege or advantage some groups while disadvantaging others (Carpenter & Suto, 2008; Connidis & McMullin, 2002). A critical perspective shifts attention towards the ways in which elements of the social, economic, cultural, and political environment are constructed, and is particularly interested in understanding how such constructions ultimately constrain particular groups of people (Cooney, 2006; Kushner & Morrow, 2003). This research study aligned well with a critical theory paradigm position in that it aimed to deconstruct the transactions between the older adult with ARVL and their physical, social, cultural, political, and institutional environment, in particular drawing on critical gerontological concepts to address age and critical disability theory to address ‘ability’.

Critical theory has a focus on challenging the status quo and transforming oppressive social structures that create and perpetuate the marginalization and oppression of specific social groups (Cooney, 2006; Given, 2008). It aims to create spaces for the voices of those who have predominantly been silenced and to stimulate action or social change (Given, 2008). In this way, critical theory acts as a type of social criticism (Carspecken, 1996), by questioning the often taken-for-granted systems and structures of power that result in or perpetuate social injustice. With an underlying focus on stimulating change or social action, this study aimed to learn from the experiences of older adults with age-related vision loss in order to highlight those environmental barriers imposed upon older adults which served to constrain their full occupational engagement. By questioning how physical, social, cultural, and political/ institutional environmental features disempower older adults with ARVL, I have sought to create a space in which discussions can occur regarding how a more age and vision-friendly environment could be created in the future.

3.2.2 Ontological location

Ontology asks the question: 'What is the form and nature of reality?' From an ontological position, critical theory is characterized by historical or tentative realism, meaning that there is a belief in a reality but not in the physical or material sense (Guba & Lincoln, 1994). Instead of accepting objective truths, I understand the reality of my research participants as existing within particular social structures which are shaped by social, cultural, political, and economic values and relations of power (Ponterotto, 2005). As a critical ethnographer, I assume that issues of social oppression represent the nature of reality (Thomas, 1993). In this sense, "the things that we normally believe to be "out there" come from uncritically accepted preconceived assumptions about the world" (Thomas, 1993, p. 34). A critical ethnographer acknowledges the ontological assumption that there is 'more to know' that falls beneath the surface level which will ultimately reveal a more oppressive view of social life (Thomas, 1993). By framing my research participants' realities through the theoretical lens of critical

disability theory and critical gerontology, I seek to more critically situate their daily interactions within an often ageist and ableist physical, social, cultural, and political/institutional environment. As an example, many of my participants discussed the challenges faced with crossing the road at a busy intersection because of the limited time provided to them at the crosswalk. Although this could be accepted at face value, my ontological positioning encouraged me to question the ageist and ableist assumptions inherent therein as it relates to social norms, for example, which are predicated on promoting such desired traits as independence and efficiency as well as normative standards for walking speed based on able-bodied assumptions.

3.2.3 Epistemological positioning

Epistemology asks the question: ‘What is the nature of the relationship between the knower and what can be known?’ As it relates to critical theory, there is a fusion between ontology and epistemology in the sense that what can be known is intimately intertwined with the interaction between the investigator and the participant (Guba & Lincoln, 2004). My epistemological positioning reflects an acknowledgement that research is transactional, subjectivist, and value mediated (Lincoln & Guba, 2003). As a critical theorist, I also understand that knowledge is co-constructed, resulting from the interaction between myself and the study participants (Lincoln & Guba, 2003). In line with this critical epistemological viewpoint, is the adoption of a dialogic and dialectical methodological approach (Lincoln & Guba, 2003). By engaging actively with participants, both myself, as the investigator, and those being investigated are assumed to be interactively linked, with my values inevitably influencing the process of inquiry (Lincoln & Guba, 2003). A critical ethnography fits with this epistemological positioning because it represents a collaborative process of meaning-making between myself and participants (Manias & Street, 2001).

3.2.4 Theoretical positioning

Sanjek (2002) states that ethnographers should identify the significant theoretical bases on which their research is premised. My study was guided by critical gerontology, a critical occupational perspective (as described in chapter one), environmental gerontology, as well as critical disability theory. Critical gerontology, a critical occupational perspective, and critical disability theory are already inherently 'critical' whereas in the case of environmental gerontology, I proposed infusing a critical sensibility to the existing field, as described in chapter three. My application of critical disability theory to the examination of disability and ARVL is explicated in chapter four. My choice of theoretical frameworks is complementary to my paradigmatic positioning and is in line with how I view the world as it relates to aging, occupation, and disability.

3.3 Defining the research field

This section presents my rationale for choosing to focus on the Hamilton-Haldimand-Niagara-Brant region and further provides a description of my immersion into the field of age-related vision loss.

3.3.1 Geographic Context

This study took place within the Hamilton-Haldimand-Niagara-Brant region, specifically within the communities of; Hamilton, Burlington, Dundas, Dunnville, and Stoney Creek. I chose this region for a variety of reasons. First, the region has a higher proportion of seniors aged 65+ (14.6%) as compared to the rest of Ontario (12.8%) as demonstrated in the Population Health Profile for the Hamilton-Niagara-Haldimand-Brant local health integration network (LHIN). Second, the region includes both large urban centres as well as smaller rural regions which enabled a diverse sample distribution. For example, while Hamilton (population 519,949), which includes both Stoney Creek and Dundas after an amalgamation by the province in 2001, and Burlington (population 175,779) are considered medium-sized cities, Dunnville (population 12,000) is a smaller incorporated rural community in Haldimand county. This provided participant diversity as it related to geographic distribution. Lastly, I live in the

region, and as a result, I have developed relationships with key organizations such as the Canadian National Institute for the Blind (CNIB), the Haldimand Abilities Centre (HAC) and the Hamilton Council on Aging (HCoA), which allowed for greater immersion into the field and a more seamless process related to participant recruitment. A discussion of my immersion into the research field will follow. My immersion began prior to beginning data collection and continued well after data generation was completed.

3.3.2 CNIB and HAC

In March 2011, I began working as a research assistant on a grounded theory study funded by the Drummond Foundation in partnership with the CNIB. The research was conducted in both London and Toronto. The study aimed to understand the processes of participation and social inclusion experienced by older adults with ARVL. This project was my first immersion into the field of low vision and provided a unique opportunity to work alongside research staff at CNIB. At the same time, I was providing placement supervision to occupational therapy candidates from McMaster University at the HAC. This supervision occurred on three separate occasions from June-August 2012, November-December 2012, and in July-August 2013. HAC is a partnership between the Hamilton Alzheimer's Society, Brain Injury Services, and CNIB Outreach and provides programs and services to individuals aging with a chronic disability. This placement supervision experience provided me with the opportunity to work alongside regional CNIB staff. These experiences supported my immersion within the low vision literature as well as provided me with an opportunity to practice my interviewing skills while learning about the experiences of older adults with vision loss. At the time when I was ready to begin recruitment for my study, I had established contacts with both the research department at the national CNIB office as well as the regional staff located within Hamilton-Haldimand-Niagara-Brant and was able to negotiate their assistance in the recruitment of five older adult participants (P1-P5).

During the process of data collection, I was offered a position with CNIB for a part-time one-year contract beginning June 2013. The position was for a government grant writer position in the Foundation Relations department. Working part-time with CNIB allowed for further immersion into the field as I was responsible for developing government grant proposals to support CNIB programs and services offered to blind or partially sighted Canadians, including older adults with ARVL. The position exposed me to a variety of documents which helped to support my learning. These documents, which were included within the document analysis portion of my data collection, included: *Paying the Price: What Vision Loss Costs Canadians and What We Should Do About It (2009)*, *You and Your Vision Health (2007)*, *Clearing our Path: Universal design recommendations for people with vision loss (2009)*, and *The National Coalition for Vision Health Environmental Scan of Vision health and Vision Loss in the Provinces and Territories in Canada (2009)*. Specifically, the documents consulted, provided me with a better understanding of the funding of vision rehabilitation services in Canada and the role of CNIB, as a charitable organization, in the provision of core vision rehabilitation for blind or partially sighted Canadians. The position further exposed me to a number of organizations such as the *National Coalition for Vision Health*, the *Foundation Fighting Blindness* and the *Alliance for Equality of Blind Canadians* which are advocacy organizations that I had not previously been aware of. In addition, I was provided with an opportunity to shadow a variety of professionals including an independent living skills (ILS) specialist, an orientation and mobility (O&M) specialist, a deaf-blind intervener, and a low vision assessment specialist. These shadowing opportunities served a number of key functions. First, it supported my learning of the key services offered by CNIB. Secondly, it allowed me to have a fuller appreciation of the impact of vision loss on one's ability to interact with their environment. Lastly, it provided me with exposure to various techniques, strategies, and assistive technologies designed to make daily tasks easier for the blind or partially sighted person. In addition to the organized shadowing opportunities, working in the CNIB office environment enhanced my learning as a

number of my co-workers were blind or partially sighted. This allowed me to learn a great deal about communication techniques and the importance of providing rich descriptions as a means of familiarizing individuals with their environment. It also provided me with an opportunity to practice some of my skills, such as Braille and sighted guide. In fact, CNIB provided me with a training opportunity to learn Braille and I subsequently obtained my level one certification. These experiences helped to further immerse myself in the low vision field and gain a wider appreciation of the socio-political context in which ARVL is situated.

3.3.3 HCoA

In September 2012, I became involved with the HCoA which is a non-profit, senior-driven organization dedicated to enhancing the quality of life of all seniors in Hamilton. Specifically, I joined the HCoA's Age-Friendly Hamilton sub-committee. Through my involvement with the HCoA, I was exposed to a number of documents which were included as part of the document analysis portion of my data collection. These documents included: *Adequate, Suitable and Affordable? Report on Housing in Hamilton (2010)*, *Profile of Vulnerable Seniors in Hamilton (2011)*, *Hamilton: A City for ALL Ages (2010)*, as well as *Hamilton: A City for ALL Ages Three Years On (2013)*. Through my involvement with the HCoA, I was also exposed to community programming including the Let's Take the Bus campaign in which workshops were held across the city to teach seniors how to take public transportation. Through my involvement with this project, I was introduced to one older adult participant (P6). The HCoA also introduced me to a variety of important organizations that I was not previously aware of including the *City of Hamilton-Senior's Advisory Committee*. It was also through the HCoA that I was introduced to the Recreation Coordinator of an affordable senior's apartment in downtown Hamilton. From this introduction, I was invited to speak both with the staff regarding my research study but also to the residents of the apartment complex about ARVL and where they could access low vision services in the community. From these two presentations, and through the word of mouth

that followed, I was able to recruit three additional older adult participants (P8, P9, and P10) from across the city.

3.4 Participant recruitment process

This section provides an overview of my participant recruitment process including a description of inclusion and exclusion criteria for study participation. Both the older adult participants as well as the community organization representative participants will be discussed within the following section.

This critical ethnography sought to include the perspectives of both older adults with ARVL as well as community organization representatives. The older adults represented the primary participant group while the community organization representatives were intended to help me better understand the socio-political context in which the experiences of the older adult participants were embedded. Data generation did not occur concurrently as the community organization representatives were identified through the interviews with the older adult participants. As such, full data sets were collected with the first five older adult participants followed by four interviews with community organization representatives. Once this preliminary data was collected and analyzed, data collection with the remaining five older adults participants were completed followed by the final three community organization representative interviews. In total, ten older adult participants and seven community organizations participated in the research study.

Older adults with low vision were purposively sampled for this critical ethnography because of their rich experience living with vision loss (Thomas, 1993). Eight to ten older adult participants were originally estimated for this study. Throughout the process of data collection, however, it was iteratively decided to stop after data was collected with ten older adults with ARVL given the richness of the data collected at that point. This decision was further supported through multiple discussions with my supervisor as well as my committee members. In recruiting the older adult participants, individuals needed

to be 65 years of age and older, have received a diagnosis of ARVL (including; age-related macular degeneration (AMD), glaucoma, and/or diabetic retinopathy), self-identify as experiencing functional limitations due to ARVL, and be able to communicate effectively in English. Although this represented the original inclusion criteria, following the recruitment of the first five older adults, it was decided to increase the minimum age requirement to 75 years old in order to capture the experiences of an older cohort of seniors with ARVL given that each of the first five informants had been over this age. In addition, the inclusion criteria were modified to require each participant to have, at minimum, age-related macular degeneration. This modification was applied to ensure one level of homogeneity among the research participants experience of vision loss. Given that macular degeneration is the most common ARVL condition, this added inclusion criteria did not exclude any participants who inquired about participating in the study. Participants were excluded from the study if they experienced significant cognitive challenges which impaired their ability to engage meaningfully in the data collection process. I determined a participant's cognitive capacity to engage in a conversational interview during the initial telephone contact that occurred as part of the recruitment process. No participants were excluded from the study based on this criterion. In addition, seniors who lived in an assisted living facility, where community access and occupational participation was restricted due to facility rules and policies, were to be excluded from the study. Three of the participants in the study lived in assisted care. Two of the participants did not experience any restrictions in terms of their community engagement and so were not excluded from the study based on this criterion. For the one remaining participant, he expressed having experienced attempts by the institution to restrict his community engagement on account of his vision loss. As a result, the participant had to continually negotiate the terms of his community engagement. During those times, however, when this constant need for negotiation caused the participant frustration, he would simply "run-away." Although the institution aimed to restrict the participant's occupational engagement, the individual continued to engage with his community, albeit with

difficulty. Due to this continued engagement and persistence to engage in his community, the participant was not excluded from the study.

Older adult participants were recruited through a variety of means. My first recruitment strategy was to enlist the assistance of CNIB. As detailed in section 3.3.2, I had a relationship with CNIB prior to beginning data generation, which helped during the participant recruitment process. After receiving permission by The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) (see Appendix A) and internally from CNIB (see Appendix B), I identified a gatekeeper. This gatekeeper circulated a two-page recruitment information sheet (see Appendix C) to frontline staff who then informed eligible older adult clients with ARVL. This initial recruitment strategy resulted in five responses from two males and three females, all of whom were eligible and enrolled in the study (P1-P5). Data generation and analysis was completed with the first five research participants prior to further recruitment. This allowed for the purposeful sampling of the next group of older adults based on the emerging findings.

In the second wave of recruitment, I aimed to recruit only those older adults who were not currently receiving services from CNIB, were 75 years and older, and had, at a minimum, a diagnosis of age-related macular degeneration. In order to find older adults who met this more targeted recruitment criterion, I turned to local newspapers to run advertisements for the study (see Appendix D). *The North End Community Breezes* newsletter ran my advertisement in their May edition, resulting in one response from a female participant who was enrolled in the study (P7). The cost was too prohibitive to run advertisements in the other community newspapers. Instead I participated in an interview with a reporter at the *Flamborough Review* (see Appendix E) regarding my research which was published on May 13, 2013 and wrote an information piece regarding ARVL for the *Hamilton Mountain News* (see Appendix F) which was published on June 27, 2013. Although neither of these approaches assisted in the recruitment of

research participants, I am hopeful that it provided a greater sense of awareness regarding ARVL within my community.

At the same time as I was initiating recruitment through the local newspapers, I was further developing my relationship with the HCoA, as detailed in section 3.3.3. Part of my initial relationship with the HCoA was to familiarize myself with the programs offered through the Age-Friendly Hamilton sub-committee. At the time, the HCoA was running a series of "Let's Take the Bus" campaigns across the city in an effort to familiarize older adults with the public transportation system. I attended one of these sessions in Stoney Creek on March 28, 2013 where I met an attendee who was having considerable difficulty reading the bus schedule provided to her at the workshop. We began talking and she identified as having age-related macular degeneration. After informing her of my study, she agreed to participate (P6). The HCoA also introduced me to the Recreation Coordinator of a senior's subsidized apartment building in downtown Hamilton. On May 28, 2013, I was invited to speak about my study to the staff and volunteers of six seniors apartment complexes from across the city. I provided a copy of the research study advertisement to each of the attendees who offered to circulate the information in their buildings. This recruitment strategy resulted in two responses from females both of whom were eligible and subsequently enrolled in the study (P8 and P9). From this initial interaction with the Recreation Coordinator, I was also invited to complete a short presentation to the residents of the apartment complexes on June 14, 2013, to inform them about ARVL and where they can access services in the community. This presentation was attended by 13 residents and resulted in one response from a female resident who was eligible and enrolled in the study (P10). In total, nine of the older adults recruited for this study were recruited through CNIB and HCoA while one additional participant was recruited through a newsletter advertisement in the *North End Community Breezes*.

Although older adults with ARVL represented the primary participant group for this study, representatives from seven community organizations were also

recruited to better understand the socio-political context in which the experiences of the older adult participants were embedded. In total, nine respondents were recruited from seven organizations, given that one community organization requested the presence of three individuals at the semi-structured in-depth interview. The respondents included representatives from retail services, vision rehabilitation, low vision advocacy groups, housing services, transportation services, and seniors political/advocacy groups. Based on emerging findings from the older adult participants, these community organization representatives were targeted and recruited. To participate, the community organization representatives needed to work for, or be a member of a community or political organization which established policy guidelines or provided services that influenced older adults with ARVL and had to be able to participate in an interview in English. All of the community organization representatives were recruited through personal email communication. Although seven community organizations agreed to participate in the research study, an additional five organizations either declined to participate or did not respond to email communication. For those who declined participation, they noted a lack of time as the primary reason as well as feeling as though their contributions would be irrelevant to the study purpose.

Participant recruitment occurred over a period of nine months, beginning in November 2012 and ending in August 2013. A total of ten older adults with ARVL and seven community organizations participated in this research study. Although the newspaper advertisements were not a successful recruitment strategy, the relationships I was able to develop with CNIB and the HCoA allowed for a relatively seamless recruitment process.

3.5 Sample Description

Detailed demographic data was collected during the initial narrative interview for the sample of older adults with ARVL, who represented the primary participant group in this study (see Appendix G). A descriptive summary of each participant

is provided in Table 3.1. Overall, the older adult participant group included two males and eight females. The participants ranged in age from 76-91 years old with an average age of 83.8 years. None of the respondents were married at the time of the study. Seven respondents were widowed, one respondent was divorced, and two respondents were single, having never been married. With the exception of the two participants that were never married, all of the respondents had children and five of the respondents had at least one child living within twenty minutes of their home. Although all respondents identified as being Canadian, only six of the respondents were born in Canada while the remaining four respondents were born in England (2), Scotland (1), and Holland (1). Six of the respondents lived independently in their own apartment in Hamilton, one respondent lived in a retirement home in Dundas, one respondent lived independently in her own apartment in Stoney Creek, one respondent lived in a nursing home in Burlington, and one respondent lived in Dunnville in an assisted care facility where she had her own private apartment but received in-home housekeeping and self-care assistance.

All respondents were retired and only two respondents were actively involved with volunteering at the time of data collection. The level of education completed varied among the respondents with one respondent having completed grade school, three having finished some high school, three having completed high school, and three finishing some college/university. In terms of financial situation, three respondents reported their current financial situation as fair, five as good, and two as excellent.

All of the respondents had a diagnosis of age-related macular degeneration. With the exception of two participants, who had only age-related macular degeneration, all other respondents had a combination of ARVL conditions including one respondent with ARMD and diabetic retinopathy, three respondents with ARMD and cataracts, one respondent with ARMD and glaucoma, as well as three respondents with ARMD, cataracts and glaucoma. For one respondent their condition was diagnosed 0-2 years prior to data collection, one respondent

was diagnosed 3-5 years prior, four were diagnosed 6-10 years prior, and five were diagnosed more than 10 years prior to initiating data collection. Although there were only ten respondents, there are 11 time periods accounted for as one participant, with a combination of ARMD, cataracts and glaucoma, reported different onsets for the ARMD and glaucoma. Eight of the respondents reported the onset of their ARVL condition as gradual with two respondents describing the onset as sudden.

Detailed demographic data for the community organization representatives was not collected. The community organization respondents included seven females and two males affiliated with the following organizations: HCoA, Hamilton Street Railway (HSR), Canadian Council of the Blind (CCB), CNIB, City Housing Hamilton, The City of Hamilton Seniors Advisory Committee, as well as one shopping mall within the Hamilton-Haldimand-Niagara-Brant region. The interviews completed with each organizational representative represented their own viewpoint in addition to some specific questions regarding the organization with which they were affiliated. In order to protect the anonymity of the various community organization representatives, and the specific individuals interviewed therein, quotes presented in this thesis are not tied directly to any particular individual or organization.

Table 3.1: *Participant Demographic Chart*

ID	Age/Sex	Marital Status	Cultural background	Diagnosis	Living Situation	Financial Situation	Education	Volunteer
P1	Female; 79 years old	Widowed 3 children; all live within 20 minutes travel time	Canadian	ARMD Diagnosed more than 10 years ago. Began to affect functioning at 78 years old. Gradual onset	Hamilton Mountain (own apartment)	Excellent	Some college/university	No
P2	Male; 87 years	Widowed	European: Holland	ARMD, diabetic	Downtown Hamilton	Good	High-school	No

	old	5 children; 3 children live within 20 mins travel time		retinopathy Diagnosed 6-10 years ago. Began to affect function at 78 years old. Sudden onset	(own apartment)		completed	
P3	Male; 85 years old	Widowed 5 children; none live within 20 minutes travel time	Scottish	ARMD Diagnosed 6-10 years ago. Not sure at what age low vision began affect function. Gradual onset	Burlington (nursing home)	Good	High-school completed	No
P4	Female; 84 years old	Widowed 3 children; 1 child lives within 20 minutes travel time	Canadian	ARMD, cataracts (corrected) Diagnosed 6-10 years ago. Began to affect functioning at 75 years old. Gradual onset	Dunnville (assisted living facility)	Good	High-school completed	No
P5	Female; 91 years old	Single; never married No children	Canadian	ARMD, cataracts (corrected) Diagnosed more than 10 years ago. Began to affect functioning at 70 years old. Gradual onset	Dundas (retirement home)	Good	Some high school	No
P6	Female;	Widowed	European:	ARMD,	Stoney	Fair	Some high	Yes

	81 years old	2 children; 1 child lives within 20 minutes	England	cataracts (corrected), glaucoma Diagnosed 3-5 years ago. Began to affect functioning at 80 years old. Sudden onset	Creek (own apartment)		school	
P7	Female; 76 years old	Divorced 2 children; none live within 20 minutes	Canadian	ARMD, cataracts (corrected), glaucoma Diagnosed ARMD 0-2 years ago; glaucoma >10 years ago. Began to affect function 70 years old. Gradual onset	Hamilton (own apartment)	Fair	High school completed + 3 years nursing	Yes
P8	Female; 90 years old	Widowed 3 children; none live within 20 minutes	Canadian	ARMD, glaucoma, cataracts (corrected) Glaucoma and ARMD diagnosed >10 years ago. Began to affect function 9 months ago. Gradual onset	Hamilton (own apartment)	Good	Some college/ university (business college program)	No
P9	Female; 77 years old	Widowed 3 children; 2 children live within 20 mins.	Canadian	ARMD, cataracts (corrected) Diagnosed 6-10 years ago. Began affect functioning	Hamilton (own apartment)	Fair	Some high school (grade 10)	No

				within last 1-1 1/2 years.				
				Gradual onset				
P1 0	Female; 88 years old	Single; never married No children	European: England	ARMD, glaucoma Diagnosed more than 10 years ago. Began affect functioning within last 6 months. Gradual onset	Hamilton (own apartment)	Excellent	Grade school completed (+ 3 years bible college)	No

3.6 Methodology

Ethnography is a methodology that traces its beginnings to the cultural anthropological work of Boas, Malinowski, Radcliffe-Brown and Mead in the early 20th century (Creswell, 2007). Historically, ethnography is a research methodology focused on describing a cultural or social group and their way of life (Suzuki, Mattis, Ahluwalia & Quizon, 2005), whereby an ethnographer would engage in “first-hand collection of data concerning existing ‘primitive cultures’” (Creswell, 2007, p. 69) which are embedded within multiple layers of context (Suzuki et al., 2005). The shift to a more critical approach to ethnography grew out of the feminism and anti-racism movements of the 1970s (Carroll, 2004). Critical ethnography grew out of the realization that conventional ethnography was insufficient to study issues of power, inequality, oppression and hegemony, and, at times, itself was a colonial practice (Creswell, 2007; Jamal, 2005).

Conventional ethnography asks ‘what is?’ while critical ethnography asks ‘what is’ and ‘what can be done about it?’ (Cook, 2005; Madison, 2012). In this sense, critical ethnography is focused on eliciting the research participants' point of view and understanding their world, while at the same time challenging taken-for-granted assumptions and questioning the prevailing status quo and dominant

power structures within a particular culture that serve to constrict marginalized people's lives (Cook, 2005; Simon & Dippo, 1986; Thomas, 1993). This research study is focused both on understanding the day-to-day experiences of older adults with ARVL and the ways in which they actively negotiate their occupational engagement within existing systems and structures. This study seeks to situate those experiences within larger social structures to reveal the ways in which context, including underlying ageist and ableist assumptions, marginalize older adults with ARVL and create barriers to occupational engagement. These assumptions have created environments in particular ways so as to restrict the occupational engagement of older adults with ARVL.

For ethnography to be considered critical, Simon and Dippo (1986) argue that three criteria must be met including:

- **The work must include an organizing problematic that guides the data generation and analysis process in a way consistent with the project.**

The organizing problematic of my research centered on concerns regarding how physical, social, cultural, political, and institutional environments, operating within ableist and ageist assumptions, could serve to restrict the occupational engagement of older adults with ARVL. My choice of a critical ethnographic methodology to address this underlying problematic was congruent with my described ontological and epistemological positioning. This congruency is further evident in the process I adopted for data generation and analysis. For example, I maintained a commitment to tentative realism throughout the study whereby I acknowledged that reality changes over time and exists within particular social structures that are shaped and mediated by social, cultural, and political factors. This commitment to methodological consistency was further evidenced in my use of dialogical data generation methods designed to co-construct the data with my research participants.

- **The work must be the start of changing oppressive and inequitable social conditions.**

At its core, critical ethnography has an explicit emancipatory goal whereby the focus is not simply to understand culture, but to change it (Cook, 2005).

According to Carspecken (1996) "Criticalists find contemporary society to be unfair, unequal, and both subtly and overtly oppressive for many people. We do not like it and we want to change it" (p. 7). The critical ethnographer uses the knowledge acquired through studying cultures to work towards increasing social consciousness and ultimately facilitating change (Thomas, 1993). My primary role in this dissertation process was to raise awareness of how the environment imposes restrictions on older adults with ARVL and how these restrictions are informed by underlying social assumptions regarding aging and disability. Further to increasing awareness, I ultimately aim to create social change that supports more equitable environments for older adults with ARVL. This latter focus, although not within the immediate goals of this dissertation research, is particularly important given that a primary focus of a critical ethnography is to leave the culture of study more equitable than at the outset of the project.

- **The work must address the limits of its own claims.**

Congruent with my ontological position, I did not begin this critical ethnographic research with the intention to establish a singular reality nor is it my intention to generalize these research findings. That being said, the research findings may be relevant to other older adults with ARVL who are experiencing similar challenges negotiating their physical, social, cultural, political, and institutional environments. In line with the emancipatory focus of a critical ethnography, this research sought to support more inclusive and equitable environments for older adults with ARVL. Although this ultimate goal of facilitating change may not be within the immediate goals of this critical ethnographic research, this is the ultimate long-term goal that I will work towards.

Both Carspecken (1996) and Thomas (1993) have furthered the development and application of critical ethnography. For this research, I adopted a modified version of Carspecken's five-stage approach for critical ethnography, thereby allowing me to focus on how older adults' experience with ARVL was shaped by particular environmental features. Additionally, by adopting Carspecken's (1996) multi-stage approach, I was able to explain the intersection of those experiences with various socio-political concepts related to aging and disability as well as relevant theoretical frameworks. The five stages proposed by Carspecken, include: 1) building a primary record; 2) preliminary reconstructive analysis; 3) dialogical data generation and; 4&5) conducting systems analysis. The steps of his five-stage model are presented linearly, however, Carspecken supports the adoption of a loosely cyclical process in which the researcher is able to move fluidly from one stage to another and back again. Although Carspecken's model was used to focus the data collection process, I adopted a modified version of the multi-stage critical ethnographic approach as described below. Changes were made primarily to the sequence in which data was collected as opposed to changing the stages of data collection proposed.

3.7 Data collection methods

Prior to any data generation, all participants were required to review a letter of information (see Appendix H and I) and sign a supporting consent form (see Appendix J). The purpose behind a critical ethnography is not only to uncover knowledge about the cultural group, in this case older adults with ARVL, but also to uncover patterns of exclusion and social injustice (Averill, 2006). An examination of these multiple layers of context leads to the need to employ a number of data collection strategies (Averill, 2006). A variety of data generation methods was necessary to understand the experience of low vision for older adults. These methods included a narrative interview, participant observation session, and semi-structured in-depth interview (see Table 3.2). As well, document analysis and interviews with community organization representatives

were completed in order to understand the socio-political context in which the older adults' experience of vision loss was embedded.

Table 3.2: *Data collection process for each participant in the primary sample of older adults with ARVL*

Narrative interview	Observation session	Semi-structured interview
<ul style="list-style-type: none"> - First in-person data collection session. - Session to focus on eliciting the older adult's story of their vision loss. 	<ul style="list-style-type: none"> - Second in-person data collection session. - Occurred 2-3 weeks following the narrative interview. - Session to focus on the observation of an occupation chosen by the participant that is meaningful to him or her. 	<ul style="list-style-type: none"> - Third in-person data collection session. - Occurs during week 7 or 8 of the 2 month data collection round. - Session to focus on the influence of the physical, social, cultural and political/institutional environment on occupational participation.

Data collection, across all informants, began on December 7, 2012 and continued until September 7, 2013 (see Table 3.3). All meetings were scheduled on a date and time that was convenient for the participant, including daytime and evening appointments. Participants were invited to choose where interviews occurred. Each of the twenty interviews completed with the older adult participants were completed in the home. Seven of the observation visits occurred within the community while the remaining three occurred in the participant's home. Of the community organization representatives who participated in an interview, six took place at the workplace while the remaining interview took place at the participant's home.

Table 3.3: *Data Generation Schedule; Older Adult Participants*

Participant	Narrative Interview	Participant observation Session	Semi-structured in-depth interview
P1	December 11, 2012	January 11, 2013	January 24, 2013
P2	December 7, 2012	December 13, 2012	February 4, 2013

P3	January 16, 2013	January 22, 2013	February 20, 2013
P4	January 18, 2013	March 1, 2013	March 7, 2013
P5	December 17, 2012	February 8, 2013	February 20, 2013
P6	April 15, 2013	April 25, 2013	April 30, 2013
P7	May 9, 2013	May 9, 2013	May 24, 2013
P8	June 3, 2013	June 19, 2013	June 25, 2013
P9	June 12, 2013	June 26, 2013	July 18, 2013
P10	June 18, 2013	June 25, 2013	July 4, 2013

3.7.1 Stage One, Narrative Interview

During the first stage of the proposed five-stage model, Carspecken calls for the unobtrusive and passive collection of data through observation. This outsider, or ‘etic’, perspective aligns with Spradley’s (1979) recommendation that all ethnography start with a “conscious attitude of almost complete ignorance” (p. 4). Having had no prior relationship with my participants, however, a process of passive observation was not considered appropriate. Further, I aimed to be an active participant in the observation session and not a passive observer, as promoted by stage one of Carspecken’s model. Instead I chose to begin data generation with a narrative interview (see Appendix K), prior to completing ten individual participant observation sessions, which represented the second stage of my data collection process.

Prior to beginning with any formal data collection, the letter of information and consent form was reviewed with each participant. This consent process was altered so that no demands were made upon a participant to read printed material. In order to accommodate informants’ vision loss, the information letter and consent form was printed using enlarged font (Verdana 14 point font) and was read to each informant by myself. Participants who required hand-over-hand assistance with writing were directed to where they were required to sign the consent form.

Following a review of the letter of information and consent process, I engaged participants in an audio-taped narrative style interview focusing on the participant's experience with age-related vision loss. Although Carspecken recommends the interview stage be the third step in data collection, I began with a dialogic means of data collection. Because I had not met the participants prior to data collection, it seemed most appropriate to begin the process using a dialogical approach, such as a narrative interview, in order to create a space for the research participants voice to be heard in the research process. I applied Wengraf's (2001) lightly structured narrative interviewing approach in order to elicit the participant's story of their vision loss. I posed the following question during the narrative interview:

Can you tell me the story about your experience with age-related vision loss?

After asking the question, I attempted to create a space in which the participant told their story of age-related vision loss in as much or as little detail as they wished, without interrupting them. I took notes of the main events in the order in which they were told. After the participant was finished their narrative, I asked a series of follow-up questions both to clarify information presented as well as to elicit more detail regarding their story. Follow-up questions were presented in the same order as the participants' story was told. The narrative interviews ranged between 46 and 100 minutes in length with an average of 83 minutes.

Following the narrative interview, I administered the Visual Functioning Questionnaire (VFQ-25) (see Appendix L), which is a self-reported vision-related health status survey consisting of 25 questions across 11 sub-scales (global vision rating, difficulty with near vision activities, difficulty with distance vision activities, limitations in social functioning, role limitations, dependency on others, mental health symptoms, driving difficulties, limitations with peripheral vision, colour vision, and ocular pain) (Mangione et al., 2000). Although the survey indicates it takes only 10 minutes to administer, the assessment took closer to 20

minutes to administer with the older adult participants, as many of the questions would elicit further narrative. The VFQ-25 results (see Table 3.4) were used to summarize the degree of functional performance difficulties each participant had resulting from age-related vision loss. I conducted the VFQ-25 verbally with nine of the participants. One of the participants requested to complete the assessment independently in-between the time of the narrative and semi-structured interview. This participant completed the VFQ-25 independently; however, we then reviewed the responses together to ensure that the participant had an opportunity to ask the researcher any questions. The participant did not make any changes to her responses.

Table 3.4: Visual Function Questionnaire (VFQ-25) Participant Results

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Overall Mean
General health	50	50	0	75	50	75	50	75	0	25	45
General vision	20	40	0	40	40	60	40	20	60	20	34
Eye pain	88	50	100	75	87.5	100	50	25	100	100	78
Near activities	25	33	17	50	17	67	33	25	83	25	38
Distance activities	0	8	8	58	8	50	37.5	16	75	8	27
Social functioning	12.5	37.5	37.5	50	0	87.5	37.5	12.5	62.5	25	36
Mental health	56	25	31	81	69	81	44	6.25	69	50	51
Role difficulties	87.5	75	25	75	37.5	100	25	62.5	75	50	61
Dependency	50	25	17	100	42	92	83	33	83	50	58
Driving	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Colour vision	100	50	0	50	25	100	100	25	100	100	65
Peripheral vision	0	25	0	75	25	75	50	25	50	50	38
Overall Composite Score	44	37	24	65	35	81	50	25	76	48	49

*VFQ-25 scores reflect a quality of life indicator from 0 (lowest possible score) to 100 (highest possible score). The overall composite score is an average of the 11 vision-targeted subscale scores (not including general health ratings) for each participant. Overall mean scores across participants were lowest in the areas of distance activities, general vision and social functioning.

Following completion of the VFQ-25, I also collected basic demographic information through the administration of a demographic questionnaire. Questions were asked to each participant orally and responses were recorded by the researcher. Through the initial narrative interview it became clear that many of the participants had difficulties with reading and writing. My decision to complete the demographic questionnaire orally was intended to accommodate for that challenge.

By beginning data collection with a narrative interview I invited my participants to share the experiences of their age-related vision loss that were important to them, attempting to minimize the imposition of my own research agenda. The participant observation session and the semi-structured in-depth interview followed the narrative interview and therefore were used to expand the findings presented by the participants in this initial meeting. This dialogic approach to data collection coupled with my focus on a collaborative process of meaning-making between myself and the participants was congruent with the ontological and epistemological underpinnings of the research study.

3.7.2 Stage Two, Participant Observation

During the second stage of data collection, Carspecken recommends preliminary reconstructive analysis; however, I used this second stage to build my participant observation record (see Appendix M). Participant observation was key, in combination with my other methods of field immersion described previously, as a critical ethnography requires prolonged periods of time in the field in order to unravel the socio-cultural context. This stage of data collection provided a unique opportunity to observe the participants engage in a meaningful occupation within a particular environmental context, which provided me with a better understanding of how various layers of the environment influenced their ability to carry out the particular occupation.

Following the narrative interview, I asked each of the research participants to think about a possible occupation he or she would like to participate in with

myself. I called within one week of the narrative interview to discuss the occupation and set up a time and place to meet. If the participant was unable to choose an occupation, I made a few suggestions based on occupations that had been mentioned during the initial narrative interview; however, the final decision was always made by the participant. I participated in each occupation chosen by the older adult participants. Seven of the participants chose occupations that brought us into the community including: going to the mall, going for a walk, taking the bus to a craft program, grocery shopping, going out to eat at a restaurant, going to the pharmacy and going to the bank. Some of the participants engaged in a combination of these occupations during a single trip. The three remaining participants chose occupations that allowed them to remain in their homes including: attending a Braille lesson, learning to use a Daisy player (audio book player), and enjoying a home-cooked meal together. These observation visits achieved their intended purpose as they provided me with a better understanding of how older adults with ARVL negotiate their environments and how environmental influences, including physical, social, cultural, political, and institutional, ultimately shape occupational engagement.

During the participant observation sessions, I was an active member and not merely a passive observer (Adler & Adler, 1987). Due to the nature of the occupations chosen, audio recording was not feasible. Instead I took detailed field notes, which are a vital and yet often neglected component of ethnography (Wolfinger, 2002). The field notes were recorded immediately following the participant observation session in a private office to ensure that observations were immediate but also were recorded in a manner that was non-obtrusive (Groenkjaer, 2002). The field notes included my observations, conversations with the participant, as well as my key reflections. Field notes were framed within a comprehensive fieldwork guide building on the note-taking method of Emerson, Fretz, and Shaw, (1995). This note-taking method requires the systematic and comprehensive description of everything that happened at a particular point in time (Wolfinger, 2002). Specifically, I used the question format proposed by Spradley (1980) which included a critical exploration of the following questions:

- 1) What physical space or places are utilized?
- 2) Who are the people involved in the interaction?
- 3) What is the occupation being performed? Describe the environmental context. How is the researcher involved in the performance of the occupation?
- 4) Are there any physical objects present during the performance of the occupation?
- 5) What actions are being performed during the occupation? By which parties? What are people saying (include direct quotes if relevant)?
- 6) What is the sequencing of events as it pertains to the occupation?
- 7) What is the end goal that the individual is trying to accomplish?
- 8) What emotions are felt/ expressed by the individual? What emotions are felt by the researcher in relationship to the interaction?
- 9) What resources and/or services are necessary to support the occupation?

3.7.3 Stage Three, Semi-Structured Interview

As part of the third stage, Carspecken supports dialogical data generation in order to gain an insider, or ‘emic’ position. Interviews are included as part of this dialogical data generation process.

A semi-structured in-depth interview was the third, and final, data generation method for the older adult participants with ARVL (see Appendix N). During this stage of data collection, the focus was on understanding the impact of various physical, social, cultural, political, and institutional environmental factors on daily occupational engagement. In line with the inductive nature of critical ethnography, the contents of the semi-structured in-depth interview emerged from information gathered during the narrative interview and participant observation session. The semi-structured interview more specifically addressed issues related to environmental influences by asking the participants tailored questions based on their narrative and participant observation session. This

semi-structured interview also sought to clarify information obtained during the narrative interview and participant observation session. By following a dialogical interview format, I led the interview with the use of open-ended questions but also followed the lead of the participants (Manderson, Bennett & Andajani-Sutjahjo, 2006). This flexibility in the interview process, which was tailored for each individual's experience with ARVL, was directly in line with the emergent nature of a critical ethnographic study. All interviews were completed one-on-one. Interviews were audio-recorded and transcribed verbatim. The interviews ranged between 56 and 110 minutes in length with an average length of 89 minutes.

3.7.4 Stage Four, Document analysis and interviews with community representatives

Stage four and five, as established by Carspecken, calls for the conducting of systems analysis in order to relate findings to broader socio-political concepts and existing social theories. During this stage, which represented the fourth stage in my data collection process, I engaged in a critical analysis of sixteen relevant documents and completed seven semi-structured in-depth interviews with representatives of community organizations. This stage provided an opportunity to apply theoretical perspectives, including critical gerontology and critical disability theory, to inform data analysis and contextualize the research findings. This stage also provided me with a greater awareness of how the environmental context, in which older adults with ARVL were embedded, affected their ability to engage meaningfully in desired occupations and engage socially in their communities.

All of the documents or policies as well as the community organization representatives were selected based on emergent findings from the data collected with the older adult participants. For example, themes focusing on housing opportunities emerged from the primary data which led me to include a document entitled "Adequate, Suitable and Affordable? Report on Housing in

Hamilton (2010)” and supported my inclusion of City Housing Hamilton as one of the community organization representatives to participate in a semi-structured in-depth interview.

The documents included for analysis ranged in publication date from 2002-2013. All of the documents were found through internet searches and well as internally through the CNIB and the HCoA. When possible, documents that were specific to the Hamilton region were chosen given the geographic context of the study. Those documents that were included in data analysis are detailed below in Table 3.5.

Table 3.5: Documents Included for Analysis

Year	Document
2009	Paying the Price: What Vision Loss Costs Canadians and What We Should Do About It
2013	Independence, Activity and Good Health: Ontario’s Action Plan for Seniors
2010	Hamilton: A City for ALL Ages
2013	The High Cost of Low Vision
2005	Accessibility for Ontarians with Disabilities Act
2010	Adequate, Suitable and Affordable? Report on housing in Hamilton
2013	Hamilton: A City for All Ages Three Years On
2012	Limeridge Mall, Accessible Customer Service Policy
2009	The National Coalition of Vision Health Environmental Scan of Vision Health and Vision Loss in the Provinces and Territories of Canada
2012	Living Longer, Living Well: A Seniors Strategy for Ontario
2007	Global Age Friendly Cities: A Guide
2002	City of Hamilton Urban Braille System
2007	You and Your Vision Health
2006	City of Hamilton Barrier Free Design Guidelines
2011	Accessibility of Grocery Stores and Pharmacies in Eight Hamilton Neighbourhoods

2009	Clearing Our Path: Universal design recommendations for people with vision loss
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The seven community organizations each took part in a one-time audio recorded semi-structured in-depth interview (see Appendix O). The interviews ranged between 30 to 78 minutes in length with an average time of 52 minutes. All interviews had an initially broad focus, focusing on the organizational mandate and situating the organization within the larger socio-political context. After this initial broad focus, the questions became more focused in order to provide further insight into how environmental features were shaped and addressed by the organization, in an aim to contextualize the environmental enablers and barriers identified by the older adults with ARVL. The exact content of the interview was tailored to each community organization representative. For example, when speaking to the representative from the Seniors Advisory Committee, sample questions included:

- Can you describe three recent activities which the Seniors Advisory Committee was involved in?
- How does the Seniors Advisory Committee support the needs of older adults with age-related vision loss? How else do you think the Seniors Advisory Committee could support the needs of older adults with ARVL?
- Can you describe any relevant policies that affect how the Seniors Advisory Committee is able to meet the needs of older adults with ARVL?

The interviews occurred at two time points. The first set of four community representatives were interviewed in March 2013, after full data sets were collected with the first five older adult participants. Interviews with the final three organizations occurred between August-September 2013 after full data sets were collected with the final five older adult participants.

3.7.5 Stage Five, Data analysis

Stage five is focused on analysing the data collected through stages one to four as well as using existing theories and broader system features as a lens to inform the generation of findings (Carspecken, 1996). Data analysis occurred concurrently with data generation, meaning that insights gained during data analysis helped to inform further data collection. The manner, in which I interpreted the data, whether it was field notes, documents, or interviews, was based on my lens as the researcher (Gardezi, et al., 2009).

3.7.5.1 Analysis of the interviews and participant observation sessions

A consistent approach to data analysis was adopted for the text and observation data including the narrative interview (described as stage one), the observation visit (described as stage two) and the semi-structured in-depth interviews (described as stages three and four). All coding was completed by hand in order to ensure maximum immersion with the data sets. The analysis process began through immersion within “the context of the interactions” (Carspecken, 1996, p. 149) which involved reading each transcript or observation note individually to develop a rich understanding of the data before drawing comparisons between data sets or across participants. I followed an identical process, including applying both low level (open) and high level (theoretical) codes to each of the verbatim transcripts generated from the dialogical data generation methods and the field notes generated from the participant observation sessions.

I began with low level coding that was close to the data with limited abstraction. It served to highlight the more objective components of the research (Carspecken, 1996) and was ‘raw’ in the sense that no effort was “made to organize them into a tight hierarchical scheme” (Carspecken, 1996, p. 150). I went through each transcript line-by-line, pulling out statements such as: "sticks to familiar routes", "enjoys knitting", or "sees blurred outlines out of right eye". Early in the analysis process, in line with Carspecken’s recommendation, I enlisted feedback from my supervisor, who acted as a peer debriefer, in order to question my choice of particular codes. After low level coding was completed, I began a coding sheet

for each study participant. The development of the coding sheets helped to facilitate further immersion into the transcript data as well as helped facilitate the management of all data sets. Although not immediately, the low level codes were eventually brought together and organized loosely into categories such as: physical, social, cultural, political/institutional environmental features; disability perspective; aging perspective; compensatory strategies; low vision diagnosis; emotional response to vision loss; and changes in occupation/task performance.

Following low level coding, I proceeded to high level, or theoretical coding which required a greater degree of abstraction and interpretation as coding was not based on the transcripts alone. Instead, I framed my theoretical codes around other elements of data generation, such as the document analysis, the semi-structured in-depth interviews with community organizations, and the theoretical frameworks that guided my research, specifically critical gerontology and critical disability theory. The combination of these methods helped to frame this higher level coding process. Once again, all transcripts were re-read. I began to pull out higher level codes which were grounded in the participant's experiences but were also based on my interpretations of the data. Such high-level categories included topics related to: vision loss as disability; risk management; ageism; ableism; use of language to frame aging and disability; fear; stigma; independence as best; environmental enablers and barriers; as well as examples of how the environment is constructed in both ageist and ableist ways. In this sense, research findings were not purely based on the data generated through dialogical and observational means, but also by applying my own critical lens to the analysis process.

After an initial round of coding, I took an approximately four month break from the data, during which time I focused on writing my introductory thesis chapters. After refining my theoretical focus, specifically as it related to both critical gerontology and critical disability theory, I returned to the data specifically coding according to my chosen theoretical foci. For example, key concepts related to 'positive aging

discourses' were used to inform higher level coding specific to those characteristics older adults with ARVL defined as making up the 'good old age.'

3.7.5.2 Analysis of the documents

Prior to analysis, each document was read, in full. Printed copies of all documents were maintained in binders and any coding or notes made were applied directly to the paper copies of the documents. At this initial reading stage, I began to think about the document from the perspective of three distinct lenses including; a) how the document addressed issues relating to low vision; b) how the document talked about aging; and c) how the document addressed issues related to disability.

The documents were analysed differently than the interviews and participant observation data. Instead of coding each document using low and high level codes, the documents were analysed using a modified policy analysis framework as proposed by Bacchi (2009) (see Appendix P). The documents were critically examined according to the following six questions:

- 1) What is the problem represented it to be in the specific document or policy?
- 2) What presuppositions underlie this representation of the problem?
- 3) How has this representation of the problem come about?
- 4) What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?
- 5) What effects are produced by this representation of the problem?
- 6) How is this representation of the problem introduced, disseminated, and defended? How could it be questioned, disrupted, and replaced?

A document, with the answers to each of the above six questions, was then prepared for each of the sixteen documents included as part of this research study. With the exception of *Living Longer, Living Well: A Seniors Strategy for Ontario* and *City of Hamilton Barrier Free Design Guideline*, where only sections

relevant to low vision were analysed, all documents were analysed in full in order to highlight recurring ideas. The themes emerging from the document analysis, including an overwhelming focus on physical environmental features as well as a focus at the level of the individual, as two examples, provided some context regarding the experiences described by the participants. The documents also brought to light many taken-for-granted assumptions that informed how environments were organized in ways that both supported and restricted the occupational engagement of older adults with ARVL.

Both the documents as well as the interviews with the community organization representatives were used to support and supplement the findings that emerged from the data generated with the older adults with ARVL.

3.8 Data Management

All interviews were audio-recorded and transcribed verbatim. Transcripts of all interviews, observation field notes, the demographic questionnaire, and the VFQ-25 were labelled with code numbers only in order to protect the identities of my participants. The older adult participants were coded as P1, P2....P10, while the community organization representatives were labelled as S1, S2....S7.

Participants were provided with code identifications based on when they were recruited for participation and not based on when the first point of data collection occurred. Any quotes taken from the participants and community organization representatives were linked to their participant code number and not their name or the name of the organization with which they were affiliated. Any identifying information on transcripts (e.g. names of people, places, and names of organizations) were removed prior to sharing transcripts with members of the research team. All numerical, written, and audio data was stored in a locked filing cabinet in a locked office. Data from older adults and community representatives was maintained on a password protected computer and further located within password protected files that were accessible only by members of the research team. A master list linking data with identifiers as well as all signed consent forms

were stored separately from the data corresponding to the participants. This data was stored in a locked cabinet in a locked research office.

3.9 Optimizing the research rigor

In order to establish rigour of the data collected, there were a number of quality criteria strategies, as suggested by Carspecken (1996), that I employed which included:

- **Use multiple recording devices.** During the narrative and semi-structured in-depth interviews, I used an audio recorder in addition to taking detailed notes. Given the nature of the participant observation sessions, which commonly took place within the community, I was not able to audio record the sessions. Instead I took detailed notes immediately following the observation session detailing my observations, the information the participants shared, and my key reflections.
- **Use a flexible observation schedule.** The participant observation sessions occurred on the day of the week and time that was necessary for the particular occupation. Some observations were required to take place at a particular date and time (such as the Braille lesson or craft club), while other participants were more flexible in terms of when the session occurred. The participant observation sessions occurred between January and June 2013 thereby allowing observation to occur during different seasons and on different days and times of the week.
- **Practice prolonged engagement in the field and with the participants.** Data collection occurred over a period of nine months, between December 2012 to September 2013. The older adult participants engaged in three data generation sessions with P1-P5 engaging in data generation over approximately two months and P6-P10 engaging for approximately one month. The community organization representatives participated in one data generation session. In addition to the data collection methods

employed for this study, I practiced prolonged engagement in the field through my volunteer work with the HCoA as well as my research and paid work with CNIB as outlined in section 3.3.2.

- **Engage in peer debriefing.** As a quality criteria strategy, peer debriefing was engaged in with my doctoral supervisor throughout the data generation and analysis process. Engagement in peer debriefing was consistent with the dialogical approach I assumed during data generation. It allowed me to engage in a type of collective reflexivity with my supervisor regarding what I was and was not seeing in my data sets. These meetings also encouraged me to continue to push myself to apply my critical lens to the data. Peer debriefing was also used in order to ensure that I remained consciously aware of how my own beliefs and values were affecting what I was studying and also how information was being collected, analysed, and shared (Thomas, 1993). This process, which occurred prior to entering the field as well as throughout data collection, provided a means through which to discuss my research expectations in an effort to raise awareness of my own perspectives (Carspecken, 1996).
- **Interview the same research participant repeatedly.** By interviewing the same older adult study participants at three separate points in time, the research participants became “more likely to produce richer and more self-disclosing information than that produced in a single interview” (Carspecken, 1996, p. 166). This was observed first-hand, when participants in the semi-structured in-depth interview more openly shared the challenging aspects of their story of vision loss with me.
- **Encourage participants to describe their experiences using the terms they employ within naturalistic contexts.** I encouraged the older adult participants to describe their experiences of low vision using the terms and vocabulary that was familiar to them. In an effort to encourage the use of

familiar terms, I mirrored the terminology used by the participants. For example I would refer to AMD as "the macular" to coincide with the terminology used by a research participant.

In addition to employing the quality criteria listed above, I also engaged in reflexivity throughout the research process, which is integral to any critical ethnographic work, as promoted by Carspecken (1996). Prior to entering the field, I wrote a reflexive note regarding what I expected to find through my discussions with the older adults with ARVL. This process, as recommended by Carspecken (1996), helped to raise my consciousness and allowed for an exploration of key biases prior to entering the field. This type of reflexivity is particularly important in critical research as its purpose is to “expose the researchers’ personal constructions of the world, their values, beliefs, strengths, and weaknesses that mold the research journey and choices made” (Mulhall, Le-May & Alexander, 1999 as seen in Hardcastle, Usher & Holmes, 2006, p. 158). This process set the stage for continued reflexivity throughout the data generation and analysis process.

Once in the field, I maintained a reflexive journal in order to note the reactions and reflections I had in relationship to the research process and findings. I also integrated reflexive notes within the field notes for each of the participant observation sessions to note my reactions to the observations I made. Many of my reflexive journal entries spoke to the challenges I encountered both as a researcher and an occupational therapist. As an occupational therapist I felt compelled, at times, to provide recommendations to the participants to enable their success with a particular task and promote strategies for safety. Through my reflexive journaling, however, I was able to consciously work through these role challenges in addition to some of the disconnect I was beginning to feel regarding the importance of concepts such as independence and minimizing risk that are otherwise so integral to the occupational therapy profession.

Engaging in conscious reflexivity allowed me to more fully realize that representation has consequences (Madison, 2012). This was particularly important given the concept of positionality which states that the researcher needs to consider how their own act of representing a particular group is an act of domination, requiring researchers to “acknowledge our own power, privilege, and biases just as we are denouncing the power structures that surround our subjects” (Madison, 2012, p. 7). Positionality required me to turn back on myself in order to better understand why I was doing the research and how it would ultimately benefit the lives of others (Madison, 2012). By acknowledging the influence of positionality, I was able to recognize that my own cultural position, in relationship to the study, influenced what was studied, the information that was collected, and how it was interpreted. This influence, however, was necessary as there is the expectation that as a critical ethnographer I will be actively engaged in the research process and not be just a passive recorder (Thomas, 1993). To ensure that I maintained the integrity of my research participants, while also considering my own cultural position relative to the research, I asked myself the following reflexive questions (as adapted from Madison, 2012) throughout the critical ethnography including:

- 1) What is my purpose and intention behind the research I intend to do?
- 2) What is the intended benefit of the research? How will this make a difference in people's lives?
- 3) Have I evaluated my own potential to do harm?
- 4) How do I collaborate appropriately with others involved in this research project?
- 5) How are these research findings contextualized in the broader social and political environment?
- 6) How will my work make the greatest social contribution?

3.10 Conclusion

This chapter began by outlining the critical ontological and epistemological underpinnings of my research. This was followed by a description of how my ontological and epistemological position informed my choice of a critical ethnographic methodology for this research. I then provided a detailed description of the research field, which centred on the Hamilton-Haldimand-Niagara-Brant region. This description of the research field also included a discussion of my immersion in the low vision field, centering primarily on my work with the CNIB, HAC, and HCoA. The recruitment process used for this study and a detailed description of the sample, as collected through the demographic questionnaire, was then presented. Next, the particular data generation and analysis methods employed in this research study were described followed by a description of how the collected data, including numerical, textual, and audio, was managed throughout the research process. Finally, a discussion of the quality criteria used to ensure research rigour within this critical ethnographic study was presented and discussed in relation to the data collected and analysed. Although I articulated the key theoretical perspectives informing this critical ethnography, I did not explicate, in this chapter, how I drew upon and applied a critical gerontological perspective or critical disability theory. Thus, in the next two chapters, I articulate how the infusion of a greater critical sensibility within environmental gerontology (chapter four) and the use of critical disability theory (chapter five) may provide fruitful ways forward in terms of enhancing understandings of age-related vision loss.

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CHAPTER FOUR

4.0 Enhancing Environmental Gerontology: Integrating a critical perspective

4.1 Introduction

As a defined field of study, environmental gerontology (EG) has demonstrated the significance of the environment for aging persons in multiple ways. For example, research has studied the development of age-friendly communities (Clark & Glicksman, 2012; Lui, Everingham, Warburton, Cuthill, & Bartlett, 2009; Menec, Means, Keating, Parkhurst, & Eales, 2011), the meaning and attachment to place in older age (Cutchin, 2003; Zingmark, Norberg & Sandman, 1995), aging in place (Shank & Cutchin, 2010; Wiles, Leibling, Guberman, Reeves & Allen, 2012), the influence of neighbourhood design on health, wellbeing, and active aging (Mahmood et al., 2012; Michael, Green & Farquhar, 2006), migration and aging (Johansson et al., 2012), the influence of relocation in older adulthood (Ekerdt, Sergeant, Dingel & Bowen, 2004; Oswald & Rowles, 2006), the association between environment and personal identity in older adulthood (Peace, Holland & Kellaheer, 2005; Rubinstein & de Medeiros, 2005), and the association between person-environment fit and performance of activities of daily living (Hans-Werner, Oswald & Zimprich, 1999; Iwarsson, 2005).

Despite this expanse of topic areas and foci, many authors continue to argue that the field needs to diversify theoretically and empirically in order to further elucidate the ways in which environments shape the aging process and how aging persons negotiate their environments (Wahl & Weisman, 2003). For example, Gitlin (2003) has argued for the inclusion of new ways of thinking about the study of the home environment. Similarly Golant (2012) has supported the advancement of the field by proposing a holistic theoretical model to judge whether or not older adults occupy residential environments that are congruent with their needs. Additionally, Phillipson has argued that a further focus on understanding urban change (2004) and globalization (2007) would provide a vital new research dimensions to current approaches within EG.

There is recent movement in the EG field, as supported by the 2012 publication of a special EG issue by the *Journal of Housing for the Elderly*, to consider alternative ways of conceptualizing and studying the environment (Geboy, Moore & Smith, 2012; Golant, 2012; Pastalan, 2012; Scheidt & Norris-Baker, 2012; Schwarz, 2012). This shift was further supported by the 2013 publication of *Environmental Gerontology Making Meaningful Places in Old Age* edited by Graham Rowles and Miriam Bernard. Such authors have suggested the importance of attending to understudied populations such as older adult male and female prisoners (Scheidt & Norris-Baker, 2012), addressing issues of stigma in the built environment (Hrybyk et al., 2012), and exploring how the social environment is related to physical and mental health (Norstrand, Glicksman, Lubben & Kleban, 2012). By providing recommendations to expand the current empirical and theoretical foci within EG, these researchers make clear arguments for new ways of thinking about the influence of the environment in older adulthood.

The proposal presented in this article, to infuse a greater critical sensibility within EG, provides one additional and fruitful way forward. In agreement with Rowles and Bernard (2013), we argue for further attention to the expansion of a 'critical environmental gerontological sensibility'. We add to this call by outlining three significant changes to the dominant current understanding of the environment that need to happen to facilitate an expansion of the critical sensibility. First, the field needs to expand beyond the dominant tendency to focus on a micro-level view of the environment towards a fuller appreciation of the ways that social forces and actors, operating at the macro level, shape and perpetuate disabling and ageist environments. Second, the field must move beyond its primary focus on the physical environment, which at times is combined with attention to the immediate social environment of aging individuals. To more fully capture the complex and varied ways the environment is of significance in understanding aging at individual and collective levels, there is a need to take on a more holistic view which includes cultural, political, and institutional elements and the interconnectedness of various environmental elements. Third, the field will benefit

from shifting from a largely static to a more dynamic conceptualization of the environment.

4.2 Demarcating EG: Key Aims, Assumptions and Emphases

This paper focuses exclusively on the collection of work by those scholars who have demarcated the field of environmental gerontology because it is a field that would benefit from further development and change. We argue that applying core ideas from social, cultural and critical gerontology will improve environmental gerontology as a perspective that can be applied to critical multi-level analysis that questions the 'taken-for-granted'.

The evolution and naming of the field of EG occurred in 1959 with a chapter written by Kleemeier (1959) in the *Handbook of Aging and the Individual* (Michael et al., 2006; Wahl & Weisman, 2003). Since that point in time, and particularly through the 1960s and 1970s, research in this field flourished with key scholars such as Lawton, Carp, and Kahana (Wahl & Oswald, 20'10). A significant body of empirical and theoretical knowledge was developed during this timeframe, which has been termed the “golden days” of EG (Wahl & Weisman, 2003, p. 618). The early development of the field of EG was closely connected to the development of environmental psychology and although EG has also been described as interdisciplinary, it has not strayed too far from its initial roots (Cutchin, 2009). The principle aim of EG is to understand the relationship between aging persons and their physical-social environment (Wahl & Lang, 2003; Wahl & Oswald, 2010; Wahl & Weisman, 2003). Within this field, the physical environment is often conceptualized as material space including the natural and built environment, including homes, neighbourhoods, and long-term care institutions (Lawton, 1985; Wahl, 2001). The social environment is often studied in terms of components such as social networks, supports and relationships, particularly as these influence how individuals socially interact within daily life (Antonucci, 2001; Lang, 2001).

By the end of the 1980s, Lawton started to become critical of the development of EG. As early as 1990, Parmalee and Lawton, in their chapter in the *Handbook on*

the Psychology of Aging, argued that there was a need “to move the field beyond its current languishing state” (p. 483). More recently, Wahl and Weisman (2003) identified a type of research homogeneity within the field with respect to “analysis, range of research approaches, research themes and research concepts” (p. 626). They have been critical of the continuing absence of empirical and theoretical innovation in the considerable amount of research which emerged since Parmalee and Lawton described the field as languishing. This critical reflection has taken place outside the immediate field of environmental gerontology as well. For example, some geographers conceive environmental gerontology as adopting a “too circumscribed, and too uncritical, view of aging, place and space” (Cutchin, 2009, p. 440).

A new generation of environmental gerontologists have more recently come to the forefront led by such researchers as Miriam Bernard, Habib Chaudhury, Malcolm Cutchin, Simon Evans, Caroline Holland, Susanne Iwarsson, Leonie Kellaheer, Frank Oswald, Sheila Peace, Judith Phillips, Chris Phillipson, Thomas Scharf, Rick Scheidt, Hans-Werner Wahl and Gerald Weisman. By “building on the theoretical and applied work of the pioneers, this strongly inter- and multidisciplinary cadre of researchers has provided a growing level of sophistication” (Rowles & Bernard, 2013, p. 7) to the EG field. As suggested by Rowles and Bernard (2013), we are left on the threshold of a new era whereby EG has the potential to re-shape our understandings of how older adults relate and interact with their environments. Given this growing trend of research diversification, we would argue that the timing is appropriate to further commit to the expansion of a critical sensibility into the field of EG. In fact, this suggestion to embrace a critical sensibility is supported in Rowles and Bernard’s concluding chapter of their textbook *Environmental Gerontology. Making Meaningful Places in Old Age*. They advocate for the development of a critical EG sensibility as one strategy for facilitating the translation of research findings into practical application, specifically as it relates to the meaning of place in older age. By adopting a critical sensibility, research would begin to question taken-for-granted assumptions and would support a more focussed understanding of the interplay

of "structures, history, context, and experience" (Grenier, 2012, p. 35) as well as the link between the micro-level and macro-level environmental elements.

4.2.1 The remaining “standstill” in EG

Despite the existing critique of the boundaries within which EG has operated, the field remains at a standstill both in relation to theoretical and empirical development and has yet to fully embrace its articulated potential to re-imagine the study of aging as situated in environments. In relation to theory, Lawton has been termed the central figure within EG (Wahl & Weisman, 2003). In fact, the model most commonly referred to in the EG literature is Lawton and Nahemow's Competence-Press Model, also referred to as the Ecological Model of Aging (Iwarsson, 2005; Scheidt & Norris-Baker, 2003). It is a landmark within EG and although the model was first published in 1973, it continues to be one of the most re-produced diagrams in gerontology textbooks and journal articles (Wahl & Weisman, 2003). In this model, people are viewed as systems of competencies, while the environment is viewed as a series of demands (Iwarsson, 2005). The model assesses the interaction between the competence of individuals and the demands of the environment, suggesting that the higher the competence of individuals, the better the fit with the demands of the environment while less competent individuals experience greater impacts of the environment on their behaviors (Chouinard, Hall & Wilton, 2010). The degree to which the environment impacts older adults depends upon their level of ability to mediate the effects of the environment (Hooyman & Kiyak, 2008), placing problems within individuals and the aging process, rather than within the environment. Although Lawton proposed that the physical environment be only one element within this model, alongside social and institutional elements, there has been “an implicit tendency in Lawton's theoretical writings and a strong tendency in the majority of his empirical work on environmental issues to put more emphasis on the physical part of the environment” (Wahl & Lang, 2003, p. 9). These two key critiques of this model, including the location of problems in individuals and a focus on the physical environment, are repeatable within EG as a whole.

From an empirical standpoint, over the past almost fifty years, EG has taken a person-environment fit approach, explicitly or implicitly related to Lawton's foundational work, to such issues as housing arrangements and the home environment (Iwarsson, 2003; Kendig & Pynoos, 1996), the role of neighborhoods in later life (Scheidt & Windley, 1985), institutional living arrangements (Cohen & Weisman, 1991; Day, Carreon & Stumpt, 2000), home modifications (Gitlin, 1998), and the development of age-friendly communities (Wahl & Weisman, 2003). This type of approach to person-environment fit has been critiqued for placing problems of aging and functioning within individual's bodies (e.g. balance issues, vision deficits), minds (e.g. memory deficits, information processing deficits) and skills (e.g. coping skills, adaptive capacity), instead of acknowledging the role the environment plays in disabling older adults (Kitchin, 2000). Applying a critical disability lens (e.g., Oldman, 2002) to understanding the relationship between aging persons and their environments has revealed an individualistic, reductionist approach that reinforces a medical model of disability. Moving beyond the 'standstill' requires incorporating a critical perspective that turns attention towards understanding the role various environmental elements play in disabling older adults. Such a turn would enhance understanding and awareness of how various difficulties encountered by older adults in accessing and negotiating their environments result from societal failures to acknowledge or accommodate differences, including differences based on age (Kitchin, 2000; Oliver, 2004).

Another key aspect of the standstill in EG relates to a long-standing focus on the micro- and meso-levels of analysis within the physical environment, although it is recognized by authors such as Lawton (1977, 1982) that the "physical, social, organizational and cultural environment are deeply interwoven in reality" (Wahl & Weisman, 2003, p. 617). In fact, even though EG acknowledges micro- and meso-elements of the social environment, the role of the physical environment in influencing aging processes has been emphasized so much that the influence of other environmental elements have been negated, downplayed or ignored (Wahl & Weisman 2003). As articulated by Lawton (1977), and as demonstrated

through critically oriented work that has examined the ways that components of the environment are deeply interconnected (Scharf, Phillipson & Smith, 2005), it is problematic to focus almost exclusively on only one segment of the environment. A critical move forward would necessitate not only an appreciation of the other elements of the environment but also an understanding of the interconnectedness and transactions of environmental influences. A critical EG perspective would acknowledge that environments are not absolute or static, but rather they are interconnected and dynamic (Letts, Rigby & Stewart, 2003). This argument is supported by Cutchin (2003), who has reasoned that EG has a tendency to oversimplify the human-place relationship, viewing place as a static 'container.' Instead there needs to be "recognition of the complexity and interconnectedness of places, their ongoing change, and the continuous (non-dualistic) and active relationship of people and places" (Cutchin, 2009, p. 443).

Concerns have also been raised regarding the scope of research within EG. The current foci within EG neglects a series of environmental issues for aging persons within contemporary societies. For example, although the impact of globalization and urbanization on aging is a pressing issue of the 21st century, it does not appear to have been taken up critically, to date, within EG discourse despite the growing demographic presence of older adults in urban centers (Phillipson, 2010). Phillipson (2007), for example, stated that "globalization provides an opportunity to re-conceptualize issues relating to community and place in later life, and provides a vital new dimension to current approaches in the expanding field of EG" (p. 323).

Although EG has offered much to the field of gerontology, the introduction of a critical sensibility would provide further theoretical and empirical diversification. New directions are required to elucidate the ways in which environments shape the aging process, and how aging persons negotiate and shape their environments individually and collectively. Drawing on central aspects of critical gerontology provides one conceptual means to more fully expand the view of EG.

4.3 Expanding the view of EG: Integrating Critical Gerontology

Theoretical perspectives informed by critical social theory question the often taken-for-granted systems and structures of power that result in or perpetuate social injustice; these perspectives further aim to create spaces for the voices of those who have predominantly been silenced (Given, 2008). The field of critical gerontology, which emerged in the 1980s and 1990s (Estes, Biggs & Phillipson, 2003), led by key activists such as Maggie Kuhn and Tish Sommers (Ray & Cole, 2009), has integrated various critical perspectives in order to further understandings of injustice related to aging. This field builds upon the work of prominent theorists such as Karl Marx, Max Weber, Antonio Gramsci, Jurgen Habermas and Michel Foucault (Estes et al., 2003). In relation to the environment, such critical perspectives, which encompass a range of specific theories, are primarily concerned with the ways in which elements of social, economic, cultural and political environments are constructed, and is particularly interested in understanding how such constructions enact power relations and ultimately serve to constrain particular groups of people (Cooney, 2006; Kushner & Morrow, 2003).

Critical gerontology aims to question taken-for-granted assumptions about what it means to age well and “the seemingly un-reflexive ways in which gerontological knowledge is created” (Katz, 1996 as seen in Holstein & Minkler, 2003, p. 789). It aims to make the inequality of the aging process visible and highlights how older adults are disenfranchised by political and social oppressive forces, which can be conceptualized in relation to environmental elements (Estes et al., 2003; Minkler & Holstein, 2008). Work within critical gerontology attempts to achieve social change through enhancing awareness of the socio-political production of inequalities and forwarding alternatives to address such inequalities (Holstein & Minkler, 2003). Critical gerontology acknowledges the influence of power and the inter-sections of race, gender, and socioeconomic status on the experience of aging (Holstein & Minkler, 2007). By analysing how social relations of power

come into play in how environments are shaped and re-shaped through time, critical gerontology provides a new way of thinking about the environment in EG.

Critical gerontology encompasses a range of theoretical approaches intended to provide different avenues to think about aging (Holstein & Minkler, 2003).

According to Bernard and Scharf (2007), the political economy perspective and the humanities perspective are the two main theoretical streams of work within critical gerontology. The political economy perspective views age-related issues as existing within, and created through, underlying structural and societal forces (Holstein & Minkler, 2007). It rejects the notion of individuals being solely responsible for their age-related problems. Rather, it forefronts the influence of socio-structural forces, including aspects of the social, political, and economic environment, on the aging process, experienced by collectives and individuals (Holstein & Minkler, 2007). A political economy perspective stresses the importance of changing the socio-political context to meet the needs of aging citizens instead of the dominant EG perspective that demands individuals meet the demands of the environmental context (Ray & Cole, 2009). The humanities perspective focuses on the meaning or experience of aging, with an appreciation of the influence of environmental elements, including culture (Holstein & Minkler, 2007). The humanities perspective is “concerned with putting a human face—and a human body and spirit—on aging and growing old” (Minkler, 1996, p. 470). It questions how older adulthood is socially de-valued and the ways in which social meanings assigned to later life, as part of the socio-cultural environment, set parameters for the individual negotiation and enactment of aging (Martinson & Minkler, 2006). Integrating a critically informed humanities perspective into EG could push the field towards understanding how environments are continually negotiated through meaning-making processes and the inherently dynamic nature of environments, rather than seeing environments as static entities imposed on aging adults.

Placing a greater emphasis on critical social theory has been proposed by the related discipline of geographical gerontology (Andrews, Cutchin, McCracken,

Phillips, & Wiles, 2007), a discipline that dates back over three decades (Golant, 1972; Rowles, 1978; Warnes, 1982). Environmental gerontology and geographical gerontology are the two main disciplines that focus on how older adults experience and negotiate the physical and social environment (Andrews, Evans & Wiles, 2012). Although the two disciplines share a common primary objective, environmental gerontology “has become the dominant mode of geographical discourse within gerontology at the expense of a broader conception of geographical gerontology” (Cutchin, 2009, p. 440). Parallel to the arguments in this paper regarding ways forward for EG, geographic gerontologists have pointed to the need for a greater engagement in the “critical deconstruction of ageing” and greater theoretical and methodological innovation “in an effort to deepen our understanding of the experiences and processes of aging in ways that move well beyond the bio-medical” (Andrews, Milligan, Phillips, & Skinner, 2009, p. 1649).

Adding a critical sensibility to EG could enable the field to more fully integrate various elements of the environment, including the political, institutional, cultural and broader social environment, and consider how environments are shaped in relation to broader power relations and actively negotiated by aging persons. In the next section, two key examples of critical gerontological work are drawn upon to demonstrate the utility of expanding the incorporation of critical perspectives into EG; specifically, the intersections between neoliberalism, positive aging, and ageism will be examined.

4.3.1 Critical Perspectives on Positive Aging Discourses

Critical perspectives that deconstruct positive aging discourses provide an example of how critical perspectives can lead to innovative ways of understanding the environment and issues of power. Since the late 1960s, there has been an increasing emphasis on ‘positive aging’ within academic, policy, and media texts that has continued into the 21st century (Katz, 2001-2002). Overall, positive aging discourses depict “activity, autonomy, mobility, choice,

and wellbeing in defiance of traditionally gloomy stereotypes of decline, decrepitude and dependency” (Katz, 2001-2002, p. 27). In using the term ‘positive aging’, I acknowledge that numerous related terms have been used to fit under the umbrella of ‘positive’ aging—successful aging, productive aging, and healthy aging (Asquith, 2009).

Critical gerontology has critiqued how positive aging discourses have been taken up at the level of the political environment. For example, positive aging discourses, as taken-up within government policies, often re-frame the problems of population aging as an issue to be managed by individuals (Asquith, 2009; Cardona, 2008). However, critical gerontology questions the taken-for-granted positivity of positive aging discourses, pointing to various ways such discourses have been taken up and shaped to align with a broader neoliberal political environment. Neoliberal policies are characterized by “emphases on fostering individual responsibility, decreasing state dependency, and increasing privatization” (Laliberte Rudman & Molke, 2009, p. 377); these policies have dominated in many Western nations since the 1980s (Estes et al., 2003). Within this neoliberal political climate, it is argued that governments concerned with the economic influence of population aging have turned to positive aging, with its focus on individual responsibility, as a solution to the pending “aging bombshell” (Asquith, 2009, p. 255). However, there are concerning implications associated with the alignment of positive aging discourses and neoliberalism. For example, people are expected to age positively, in relation to health, finances, and the maintenance of youthful capabilities yet they are blamed if such ‘positives’ are not achieved. With this responsabilization of health and the aging process, governments are able to increasingly shift responsibilities and risks from the state towards individuals, and obscure the differential access to resources required to age ‘positively’ shaped through intersections of age, gender, educational status, and social class (Cardona, 2008).

Critical gerontologists have also critiqued how gerontological theoretical models have neglected to consider the ways in which socially produced conditions result

in differential resources and abilities to age successfully. In turn, criticism is aimed at the ways in which such models are embedded within, and reinforced by, neoliberal aspects of the political environment. The neoliberal ideal of individual as opposed to collective responsibility for health and wellbeing (Minkler & Holstein, 2008) is a prominent theme within the Rowe and Kahn model of successful aging (Rowe & Kahn, 1997). This model views older adults as responsible for their own aging process and suggests that the outcome of the aging process is dependent upon the lifestyle choices made by older adults (McHugh, 2003; Weir, Meisner & Baker, 2010). A model that focuses exclusively on individuals and their responsibility to age well is restrictive and exclusionary in its definition of the “good old age” failing to appreciate the influence of race, class, and gender inequalities on the experience of aging (Minkler & Fadem, 2002). By failing to appreciate these influences, the model of successful aging serves to influence not only how older adults perceive their own aging process, but also how “governments and communities structure their social institutions, which in turn, sustain or diminish unequal power relations” (Asquith, 2009, p. 257).

For the field of environmental gerontology, such work on positive aging discourses raises questions regarding how political elements of the environment shape how aging is understood and, in turn, what are thought of as the ideal types of environments for aging individuals. It also raises questions regarding how and why various theoretical models locate problems and solutions within individuals instead of within larger social forces. Lastly, this work questions how particular kinds of environments become shaped as the ‘best’ for aging individuals within particular contexts.

4.3.2 Critical Perspectives on Ageism

While positive aging has been espoused to counteract the negative representations of older adulthood, it has served to reinforce ageism by perpetuating and celebrating a desire for youthfulness and continuing to frame “oldness” as a negative construct (Angus & Reeve, 2006; Biggs, 2001; Dillaway

& Brynes, 2009). As a result, critical gerontologists have also critiqued the ways in which so-called “positive aging” discourses have fuelled ageism in the 21st century. As a term first coined by Robert Butler in 1968, ageism is defined as discrimination and stereotyping against people on the basis that they are old. It is a socially constructed concept which serves to reinforce the structural inequalities faced by older adults (Angus & Reeve, 2006), resulting in stigmatization, discrimination, and social exclusion (Bytheway, Ward, Holland & Peace, 2007; Calasanti, 2008; Clarke & Griffin, 2008; Katz, 2001-2002).

Critical gerontologists have critiqued how ageism has been taken up within the socio-cultural environment, pointing to how older adults are overwhelmingly devalued within a society that values economic productivity and independence (Angus & Reeve, 2006). This devaluation of the aging population, at the level of the socio-cultural environment, can be demonstrated by using an example from Eric Klinenberg’s ‘Heat Wave: A social autopsy of disaster in Chicago’ (2002). He described the Chicago heat-wave in 1995, when temperatures topped 120 degrees and approximately 600 people died in one month. Three quarters of the deaths were among seniors aged 65 years and older. Klinenberg made an argument in line with a critical gerontology perspective on ageism; he reasoned that the deaths of these seniors was not simply a result “of age or biology alone, instead they should be seen as biological reflections of social fault lines” (as seen in Phillipson, 2004, p. 967). The way in which older adults were devalued, made their deaths in the Chicago heat wave “easy to overlook and forget” (Klinenberg, 2002, p. 11).

Critical gerontology has also critiqued the way in which ageism has been taken up within the institutional and political environment, linking ageism with a political and economic emphasis on the value of productivity, narrowly defined as labour market contributions. Within market-driven economic and political environments, social value is assigned to groups of citizens based on economic contribution, thereby reducing the value assigned to the so-called ‘non-productive’ aging population (Clarke & Griffin, 2008). When older adults are no longer seen as

economically productive, they are socially defined as dependent and a burden on the economic system (Angus & Reeve, 2006; Estes et al., 2003). Ageism becomes increasingly acceptable in a social environment in which older adults are devalued on account of their lack of contribution to the economic fabric of society and, in turn, constructed as dependent, needy, and inactive (Rozanova, Northcott & McDaniel, 2006). Critical gerontologists have largely questioned the assumption that dependency is inherently a characteristic of 'oldness'. Rather, critical gerontology shifts away from viewing dependency in older adulthood as a taken-for-granted consequence of "oldness" towards an appreciation of how dependency is created and sustained by social and institutional environmental forces.

The work related to ageism highlights the importance of environmental gerontology considering elements outside the immediate physical and social environment; these elements include cultural and institutional forces, as well as a greater appreciation of how environmental forces create and perpetuate discrimination and marginalization on the basis of age. For example, physical environmental features that present challenges to aging individuals should not be viewed as taken-for-granted, static, and immutable aspects of the ways environments are or have to be. Instead, integrating a critical perspective leads to an examination of how power relations shape environmental elements in ways that can devalue, exclude, or obscure aging persons.

Positive aging discourses and ageism provide two classic examples of how critical perspectives can lead to new ways of thinking about political, institutional, social, and cultural environmental issues, providing further justification for the expansion of critical perspectives into EG. As well, they point to the importance of linking physical environments to other environmental elements; that is, rather than take physical environments as given static elements in which aging persons must adapt, this work points to the need to look at how physical environments are socially and politically produced in ways that marginalize aging persons or particular types of aging persons.

4.4 Empirical and Theoretical Expansion of the Field

To address the need for further empirical and theoretical expansion in the field of EG, critical gerontological perspectives should be further integrated as a means of encouraging innovative research development. Below, three key directions forward in integrating such a perspective are outlined. The first involves expanding beyond a micro-and meso-level approach to the environment in EG, towards greater consideration of the interconnectedness of various levels of the environment. Second, EG needs to move beyond a primary focus on the material, physical, and micro-level social environmental elements to include a view that examines the complex interactions and intersections between environmental elements and individuals or collectives. Third, EG needs to move towards a dynamic conceptualization of the environment. By addressing these three proposed changes, EG has the potential to push beyond the field's current research foci and introduce new ways of thinking about the environment.

4.4.1 Beyond a Micro-Level Focus

Integrating critical perspectives into EG would support extending the focus of the field beyond assessing person-environment fit at the level of individuals to better understand how: older people as a group are disadvantaged by the environment; older adults negotiate their environment within a broader context and; age intersects with other characteristics such as gender, disability, and ethnicity in manners that create and perpetuate further environmental disadvantage. Peace, Holland and Kellaher (2011), for example, considered the complex interaction of the micro and macro levels of the environment that generates the complexity of the person-environment fit and further argued that attachment to particular environments can be compromised both as a result of declining individual competence and/or change in the environment. At the point in which adaptive behaviour is no longer able to "re-balance the macro- and micro-environmental press" (p. 734), a number of strategic responses must be assumed such as modification of the environment and/or individual, the adoption of formal and

informal services and supports, as well as relocation. This perspective, as adopted by Peace et al., (2011), extended beyond Lawton and Nahemow's (1973) ecological model to encompass a broader appreciation of the complexity of the person-environment interaction.

The need to shift from a micro-level of analysis to a more macro-level theoretical focus in studying transactions between people, as individuals and collectives, and environments has been recognized in other fields, including geography where a shift from a focus on the individual's inability to navigate the environment towards a "socio-political construction of disability" (Chouinard et al., 2010, p. 3) can be seen. This requires a shift away from the predominant medical model of disability, which focuses on impairment at the level of the individual, towards social models of disability which critically consider the ways in which disability is socially, politically, and environmentally produced and sustained (Oldman, 2002).

A shift from a micro to a more macro-level theoretical focus requires a reconfiguration of the widely recognized Competence-Press Model towards an incorporation of alternative frameworks, such as the Disability Creation Process (DCP). The DCP is an example of a framework that focuses on the deconstruction of the social, political, and economic organization at a societal level, rather than modifying the individual (Fougeyrollas, Cloutier, Bergeron, Cote & St. Michel, 1999). It is a transactional environmental approach in that it acknowledges the interdependence and the interaction between the three primary domains of personal factors, environmental factors, and life habits (Fougeyrollas, Noreau & Boschen, 2002). The DCP is holistic by acknowledging the interaction between individuals and their environment while focusing broadly on the role of the environment in the disability process (Fougeyrollas et al., 2002; Levasseur, Desrosiers & Tribble, 2007). The model prides itself on preventing the "identification of persons as being responsible for the social consequences of their differences" (Fougeyrollas et al., 1999, p. 18). Instead, it advocates for the modification of the environment in line with a focus on human rights

(Fougeyrollas et al., 1999). This framework is in line with a critical EG perspective, as the focus is not on the older adult changing to meet the demands of the environment but rather the environment adapting to be more accommodating of difference.

4.4.2 Beyond a focus on the physical and immediate social environment

Another key expansion in EG that could evolve out of further integrating a critical perspective, would be to expand beyond a view of the environment that focuses primarily on the physical and social components, and that tends to frame such environmental components as static ‘givens’. Much of the existing research in the field has focused on the physical and immediate social environment. For example, Annear (2014) completed a Cochrane review of 83 quantitative and qualitative articles that explored the evidence of environmental influences on older adult health and activity participation. Findings espoused a variety of relevant aspects of both the physical and social environment including: climate, level of pollution, street lighting, traffic, pedestrian infrastructure, social networks, level of urbanism, and familiarity with the local environment. The authors noted the exclusive focus on the physical and social environment as a limitation of the existing literature.

A broader conceptualization of the environment would involve raising questions about why environments are organized in the way they are and the implications that arise for the aging process and for the social conditions in which aging occurs. For example, a critically infused perspective of the physical environment would question why the physical environment has been designed in such a manner as to meet the needs of “productive” members of society while simultaneously restricting access to individuals with a disability and older adults. A critically oriented view of the social environment would consider the influence of social structures and how particular social groups are afforded varying degrees of power and access to resources over others (Giddens, 1987; Layder, 1994). A critically aligned view of the cultural environment would question how

the socio-cultural environment shapes the experience of aging and the meaning and value assigned to later life. A critical perspective of the political/institutional environment would question how power serves to influence how social resources are distributed, leading to mistreatment of marginalized populations. Asking these types of critically oriented questions could contribute to re-shaping how the environment is understood within EG, opening avenues for new and innovative research directions.

Although it is acknowledged that from the beginnings of his writings in EG, Powell Lawton highlighted the importance of addressing both the physical and social components of the environment (Wahl & Lang, 2003), empirically there has not been much effort aimed at integrating the environmental context of aging (Wahl & Lang, 2003). Rather, the environment is commonly broken into subsets whereby there is a focus on either the physical environment or the immediate social environment (Wahl & Lang, 2003). As a result, these two subsets of the environment are rarely integrated but rather exist side-by-side (Wahl & Lang, 2003). Wahl and Lang (2003) proposed an integration of the social and physical environment, arguing that both elements are inseparable and dependent on each other. Integrating a critical perspective would expand this argument further, highlighting the importance of incorporating elements of the political, institutional, and cultural environment in addition to the more widely accepted physical and social components, into a new critical EG perspective. There is more recent movement in this direction as supported by a study from Hunter, Sykes, Lowman, Duncan, Satariano and Belza (2011) that noted a distinct paucity of research focussed on environmental policy intended to support healthy aging. Instead, a growing body of research continues to acknowledge the influence of social and physical environmental features on the health of older adults. However, Hunter et al., (2011) supported change, at the level of the institutional environment, by pointing to the importance of establishing environmental policy in order to support healthy aging. Such policy development is needed in order to modify those environmental factors that affect healthy aging such as access to accessible housing that supports aging in place, transportation options that promote

community access and subsequently social interaction, and policy that promotes protection from various environmental hazards.

By moving towards a critical conception of EG, other components of the environment, which have otherwise been largely disregarded by EG, would be integrated in order to better understand the inter-relationship between aging persons and the environment (Phillipson, Bernard, Phillips & Ogg, 2001). Scharf et al., (2005), in their discussion of social exclusion of older adults in deprived urban communities, provided one such example of a critical integrative approach regarding the nature of environmental influences on aging. They conceptualized social exclusion in later life as a multi-dimensional phenomenon influenced by physical, cultural, social, political and institutional environmental components. A new critical EG research perspective, as proposed by these authors, would adopt a similar integrative and holistic view of the nature of environmental influences in later life.

4.4.3 A shift from static to more dynamic conceptualizations of the environment

Another key way that integrating a critical perspective into EG will aid in broadening how the environment is understood and studied is that it will encourage further consideration of the environment as dynamic. Rather than being viewed as a static element to which older adults must adapt, environmental elements will be recognized as interconnected and dynamic entities that can be altered through individual agency, collectives, and/or societal action. Research that takes into consideration the interplay between the person and environmental context is being developed. Take, for example, a contemporary environmental issue such as aging in place, which has emerged as a focus of research efforts in the field of EG (Scheidt & Norris-Baker, 2003; Wahl & Lang, 2003). Aging in place is a policy ideal intended on “understanding and addressing place within the aging process” (Johansson et al., 2012, p. 2). It is often defined as living in the same, or familiar, place over a prolonged period rather than in residential

care (Johansson et al., 2012; Wiles et al., 2012). Much of the aging in place literature is focused on the home specifically (Iwarsson, 2005; Lawton, 1982; Nygren et al., 2007; Tanner, Tilse, & de Jonge, 2008). Yet, aging in place should also be examined through the lens of the cultural meanings of aging in place (Wiles et al., 2012), the dynamic construct of place (Johansson et al., 2012), the political and economic implications of aging in place as a policy ideal intended on reducing the costs of institutional care, and the impact of the environment on social inclusion and participation for those who do ‘age in place’.

4.5 Conclusion

Critical gerontologists have pointed to various ways contemporary environments, particularly in the ‘Western’ world, shape and perpetuate social injustices in later life. EG has been used to demonstrate the significance of the environment for aging persons in multiple ways; however, the field is in need of a more concerted shift towards integrating a critical sensibility in order to uncover new ways of thinking about aging and the environment and further address issues of inequity and injustice. By further integrating a critical gerontological perspective into EG, several key and innovative issues, related to how environments shape aging processes, could be explored.

The apparent difficulties in pushing beyond current conceptualizations of the environment may result from inadequate engagement in researcher reflexivity, at individual and disciplinary levels. Values and beliefs about aging shape the questions that are asked, how the problems are conceptualized, and the solutions offered within EG (Katz, 1996). Gerontological researchers are at the forefront of shaping societal perceptions of aging. If the goal is to re-shape how society perceives and addresses later life, then those studying aging and making recommendations regarding how to address age-related issues are the first ones who need to question how they think and subsequently write about aging in relation to environments. Making the shift towards a more critically informed EG requires members of the field to be critically reflexive regarding how their own

research may relate to societal values and views on aging. Implicit, taken-for-granted social conceptions of older adulthood, that influence theoretical and research development, need to be questioned and deconstructed as a necessary step before change can occur regarding how the environment in older adulthood is understood. Such a fundamental change would provide a new lens through which to view issues related to the environment and aging.

4.6 References

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CHAPTER FIVE

5.0 Re-shaping understandings of disability associated with age-related vision loss (ARVL): Incorporating critical disability theory into research

5.1 Introduction

Disability is an issue that can be interpreted or understood from multiple viewpoints. Hammell (2006) argues that any "discussion of the multiple viewpoints from which a given issue can be interpreted or understood demands consideration of epistemology" (p. 7). Epistemology is the theory of knowledge and deals with questions regarding the nature, scope, and sources of knowledge. Within a given field of research addressing disability, the foundational ways of understanding disability are shaped by epistemological standpoints such as biomedical determination and social construction. These identified ways of knowing play a crucial role in shaping the identification and construction of research questions, solutions, and practices (Alvesson & Sandberg, 2011; Finlay, 2006). In fact, every way of viewing disability allows certain aspects to be understood while other aspects are simultaneously de-emphasized or obscured. Thus, adopting a critically reflexive stance toward dominant views within a field enables researchers to broaden the viewpoints through which disability is understood and addressed (Alvesson & Sandberg, 2011; Hammell, 2006). Within this paper, we review the dominant epistemological frameworks used to address disability associated with age-related vision loss (ARVL) and consider alternative frameworks.

In this article, we focus on the body of research that has examined disability in relation to ARVL arguing that it has largely been informed by a biomedical view of disability and proposing greater inclusion of a critical disability perspective. The current understanding of low vision, seen largely through a biomedical lens, has focused research on the individual, whereby the disability exists within the individual's visual system. Thus, ARVL-induced disability has been framed as an individual phenomenon often at the exclusion of considering broader social,

cultural, and environmental factors that create, shape, and sustain the disability experience (Ells, 2001). By framing disability in ARVL in this manner, basic assumptions and understandings have been formed within the research arena that have ultimately shaped the questions, data collection, analysis, and dissemination of research. It is only by focusing on these basic assumptions, which are the starting point for knowledge production, that new conceptualizations regarding disability in ARVL, as well as new rehabilitation practices, can begin to be formed.

Consider, for example, two similarly worded research questions that convey very different assumptions regarding disability. First, "Does your age-related vision loss prevent you from going out into the community as often as you would like?" This question is focused at the level of the individual and as such, could lead to research being produced that is aimed at modifying 'individual flaws', such as deficits in coping skills or functional limitations resulting from particular components of vision impairment. Conversely, consider the research question that asks "Does the way in which your neighborhood is set up prevent you from going out into your community as often as you would like?" Asking the question in this manner shifts the focus to the shaping effects of environmental context. There is an abundance of research within the ARVL field that is focused on the individual; however, by focusing on the environment, researchers can add new dimensions by challenging taken-for-granted assumptions that permeate low vision research and open up new spaces and new possibilities for understanding, researching, and addressing disability. To accomplish this, a new model for thinking about disability in ARVL is required. As such, the aim of this article is to push the boundaries of low vision research to include a critical disability theory (CDT) approach. Arguing for an expansion of theoretical perspectives to include critical disability theory does not mean that biomedical-framed disability research, or its findings, should be replaced by critical disability theory. Rather, we intend to extend beyond purely biomedically informed research by encouraging new ways of conceptualizing, researching, writing about, and practicing in relation to ARVL.

To demonstrate the potential contributions of adopting critical disability theory to enhance understandings of ARVL, we begin this article by outlining the biomedical model of disability. We argue that this model, which has long been dominant in medical and rehabilitation science, has had a major influence on how disability has been conceptualized and studied within the ARVL literature. Next, we review the primary tenets of the social model of disability; a model which was proposed in opposition to the biomedical approach. While acknowledging the contributions of this oppositional model, we argue that its neglect of bodily impairment means that it provides an insufficient model for the study of ARVL. Next, we lay out the key aims, emphases, and assumptions of critical disability theory and provide examples of how such an approach could lead to new research foci in the study of ARVL. Specifically, we identify four qualities that ARVL research would embody when informed by critical disability theory. To support the adoption of critical disability theory in low vision research, an example is drawn from the field of gerontology to show how the development of critical gerontology has resulted in new ways of understanding and studying aging. Similarly, we predict that an explicit incorporation of a critical model of disability will open up new possibilities in the study of ARVL. Throughout the paper, we have made the conscious choice to use the term 'disabled person' over 'person with a disability'. In alignment with critical disability theory, as explicated below, this language is an attempt to acknowledge disability as an essential part of the disabled person's identity and to re-focus attention away from the individual and their impairment and onto society.

5.2 Key tenets of a biomedical model of disability and its application to research on ARVL

As stated by Smart (2006-2007), "models of disability provide definitions of disability, offer the explanation for the cause of disability, and present the solution or treatments based on the perceived needs of the individual with the disability" (p. 1). A biomedical model of disability, which has also been labeled as the individual

or 'personal tragedy theory of disability' (Oliver, 1990), has long dominated conceptions of disability in medical and rehabilitation science (Imrie, 1997).

Underpinned primarily by a positivist epistemology, the biomedical model understands disability as individual pathology, meaning that there is something 'wrong' with the individual's body resulting from disease, trauma, or an accident (Albrecht, 1992). Thus, it is the underlying pathology, impairment, or dysfunction that causes disability (Smart, 2006-2007). Much of the ARVL research has focused on the physiological correlates of vision loss, such as visual acuity, contrast sensitivity and visual field, during various activities and the impact of different management strategies on these correlates (Grue et al., 2008; Laitinen et al., 2007; Owsley, McGwin, Sloane, Stalvey & Wells, 2001; Wong, Guymer, Hassell & Keeffe 2004). For example, Laitinen et al., (2007) completed a cross sectional survey with older adults (N=3439; ≥ 55 years old). The study aimed to determine the effect of decreased visual acuity on activities of daily living, instrumental activities of daily living, and mobility. Data revealed that the prevalence of activities of daily living (ADL), instrumental activities of daily living (IADL) and mobility limitations increased with decreasing visual acuity ($p < 0.001$). Similarly, Owsley et al., (2001) aimed to identify those IADLs whose completion time was associated with visual function in a sample (N=342) of older adults aged 56-86 years old. Results indicated that poorer scores on visual acuity, contrast sensitivity, and useful field of view were associated with longer visual IADL completion time, such as reading medicine bottles, threading a needle, using a screwdriver, reading ingredients on a can, reading a newspaper article, and inserting a key into a lock.

In addition to understanding disability as individual pathology, the biomedical model of disability ascribes to the tenet of physical reductionism. Physical reductionism risks failing to acknowledge the influence of context in the disability experience because it frames disability in terms of the body, without considering contributing social, cultural, and environmental factors. As an example of this tenet, McGrath and Laliberte Rudman (2013), aimed to summarize, by means of

a scoping review, what is currently known regarding the underlying factors which influence the activity engagement of older adults with ARVL. The 22-article review revealed how this literature on activity engagement of older adults with ARVL has focused predominantly on the impact of personal factors such as, demographic (age, socio-economic status), emotional (fear, emotional response to vision loss), behavioral (accepting risk, refusing or delaying rehabilitation services), and diagnostic components (degree of vision loss). In contrast, the impact of environmental factors, such as social attitudes regarding vision loss or the physical accessibility of outdoor spaces, have been, for the most part, negated, downplayed, or ignored. Framing disability as resulting from bio-medical impairment, absolves society from the need to provide environmental accommodation and instead places the responsibility for managing disability largely upon the disabled individual.

Defining disability solely as a medical problem, lends 'scientific credibility' to the idea that "high levels of expertise, training, and technology" (Smart, 2006-2007, p. 2) are needed to treat, modify, or fix the disabled person so that they can meet the normative standards and demands of Western society. Although treatment of the body is a necessary component of rehabilitation, a focus on the environment is missing from this discussion. This idea is reinforced by two inter-related doctrines of the biomedical model, namely that of regimen and control and the doctrine of the mechanical analogy (Longino, 1998). For example, the doctrine of regimen and control states that if disease is thought to occur as a result of the body, then the logical focus of treatment is the body. In this sense, disability is seen as needing some form of medical intervention or rehabilitation in order to 'fix' the bodily dysfunction (Devlin & Pothier, 2006) or otherwise bring the individual to as close a state of "normal" as possible (Mitra, 2006). In order to 'treat' the disabled person, their body is viewed as "a system of functionally interdependent parts" (p. 105) meaning that the body is treated as though it operates as a machine and the healthcare provider as the mechanic. Not surprisingly, when visual impairment is detected, the eyes and the associated parts of the visual system are the first bodily structures to examine in order to

determine a cause and a cure. However, in research, this view can be seen as problematic when it is assumed that individual body parts can be treated in isolation from each other as well as from context. Viewed in this mechanistic manner, vision loss is seen as a malfunction of the body that needs to be 'fixed' in order to restore normalcy. This tenet is reflected in the ARVL literature that is focused primarily on the pathophysiology of vision loss, whereby assistive technology is conceptualized as a means to replace the functions lost and enable older adults to cope with disabling situations when a cure is neither a feasible nor realistic goal (Copolillo & Teitelman, 2005; Girdler, Packer & Boldy, 2008; Ivanoff & Sonn, 2005; Lamoureux et al., 2007; Moore & Miller, 2003; Pankow, Luchins, Studebaker & Chettleburgh, 2004; Ryan, Anas & Bajorek, 2003; Stelmack, Moran, Dead & Massof, 2007). For example, Fok, Polgar, Shaw and Jutai (2011) aimed to determine the relative importance of assistive technology devices for the performance of daily occupations among 17 adults (aged 30-89 years old). Results tabulated the mean ranking of importance of 21 assistive technologies, including both low tech (e.g., handheld magnifier) and high tech (e.g., CCTV) devices to daily activity performance. There are positive impacts to this work that assumes 'broken' body parts (i.e., the eye) require a mechanical 'fix' (e.g., lens magnification); however the research agenda can be unintentionally narrowed if it fails to consider issues such as designing everyday technologies for persons of differing abilities. In addition, the primary focus on fixing the body can mean that in situations in which a cure or fix is not possible, the end point becomes the message that 'nothing more can be done'; meaning that once they have done all that is possible to optimize the eye, biomedical professionals convey that there is nothing else that can be done for the patient with ARVL.

Researchers have long challenged the predominance of the biomedical model and critiqued the limits of its sole use as a model for understanding disability (Hosking, 2008; Hughes & Paterson, 1997; Smart, 2006-2007). In doing so, authors have advocated for the use of alternative models of disability. For example, Forhan (2009) examined the area of obesity research within the context of the medical, social, and biopsychosocial model of disability and advocated for

the use of the biopsychosocial model as a means of classifying and treating disability related to obesity. The International Classification of Functioning, Disability and Health (ICF; WHO, 2001) is one such biopsychosocial model that has received considerable research interest. It evolved from the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) and is an attempt to more broadly acknowledge that disability is influenced both by personal as well as contextual and environmental factors (Hammell, 2006). The model, however, has been subject to critique both due to its approach of classifying individuals according to their disability (Hammell, 2006; Pfeiffer, 2000), its lack of consideration of the role of the environment in the creation of impairment (Hammell, 2006), and its continued perpetuation of disability as an individualized and medical issue (Pfeiffer, 2000). As will be delineated in the following section, although the social model of disability addresses these primary critiques, it underplays the role of the body in the disability process.

5.3 Key tenets of a social model of disability and its application to research on ARVL

The social model of disability, which has its theoretical origins in the work of Michael Oliver, was developed in the UK, during the 1970s, by the Union of the Physically Impaired against Segregation (UPIAS, 1976). The social model of disability developed as an alternative to the traditional, dominant biomedical model and, in particular, it opposed the individualization of disability.

The social model of disability makes an important distinction between the terms 'impairment' and 'disability.' Impairment refers to the functional limitation(s) which affect a person's body and suggests that limitations in functioning are the direct result of that medical condition (Burchardt, 2004). In contrast, disability refers, not to one's lack of ability, but rather to those social, environmental, or attitudinal barriers that limit opportunities for full community participation (Crow, 1996; Stone, 2013). Drawing attention to these social, environmental, and attitudinal barriers as the causes of disability, rejects this idea of disability as personal

tragedy and instead locates disability within broader social, political, cultural, and environmental structures (Bricher, 2000) and re-conceptualizes it as a product of socio-political constructions (Lang, 2001). The focus of intervention then moves from a curative or rehabilitative approach—focused on the individual fitting into society—to a social justice advocacy approach—dedicated to addressing underlying extrinsic barriers that create and sustain disability (Burchardt, 2004).

In addition to shifting how causation of disability is thought about, the social model of disability situates the problem of disability “into the collective responsibility of society rather than the private arenas of particular individuals” (Clapton & Kendall, 2002, p. 988). In the context of older adults with ARVL, the problem is not that a person with macular degeneration is unable to read a restaurant menu in the community, for example, but rather the problem is that accessible menu formats are not readily available such as large print, audio, or Braille or that the menu itself is constructed on the basis of normative assumptions regarding visual functioning. The social model is then focused on changing these disabling societal barriers as opposed to focusing on changing the individual (Gilson & Depoy, 2000; Stone, 2013).

There are many noted strengths of the social model of disability. For example, it has been politically instrumental in advancing the social movement of disabled people; it provides a clear and specific agenda to promote social change; and it places the emphasis on society to remove the disabling barriers, which limit the full social participation of disabled persons. There is also, a significant downfall of the social model of disability; it neglects the individual experience of impairment, suggesting that persons are disabled only by the socio-political context and not also by their bodies (Meekosha & Shuttleworth, 2009). Consider, for example, older adults with macular degeneration, who are limited in their ability to appropriately respond to social situations because they are unable to recognize faces or read non-verbal cues (Terzi, 2004). Their inability to recognize faces cannot be explained solely by a social model of disability, because even when disabling barriers in the environment no longer exist, the challenges resulting

from their visual impairment will remain (Crow, 1996). This is where CDT comes into play. Critical disability theory acknowledges the interplay of both the individual experience of impairment and the environment. As such, it is the combined limitations of both the medical and social model of disability that has led to the consideration of the adoption of CDT, with its broader consideration of both the individual experience of impairment and the environment.

5.4 Understanding critical disability theory and its application to the study of ARVL

As a member of the critical social theory family, CDT is an evolving theoretical framework for the study of disability issues (Hosking, 2008). Theories included within the critical social theory family share a primary concern with issues of power and justice (Carpenter & Suto, 2008). Given its concern and aim, critical theory is particularly interested in raising awareness of how constructions of social, economic, cultural, and political environments ultimately serve to constrain particular groups of people, while simultaneously benefitting others (Cooney, 2006; Kushner & Morrow, 2003). Work situated in critical social theory does not claim to be objective, but instead is transparent regarding its values and intent to challenge the status quo and transform oppressive social structures that create and perpetuate the marginalization and oppression of particular social groups (Cooney, 2006; Given, 2008). In this way, critical social theory acts as a type of social criticism (Carspecken, 1996), by questioning the often taken-for-granted systems and structures of power that result in or perpetuate social injustice (Eakin, Robertson, Poland, Coburn & Edwards, 1996). At the core of all critical social theories is the fundamental aim for progressive and emancipatory social change (Meekosha & Shuttleworth, 2009) to be achieved by looking “below the surface of the status quo and seek[ing] the potentiality for, or desirability of, things being other than they are” (p. 16).

According to Hosking (2008), CDT has adopted principles of the social model of disability while being further informed by three underlying assumptions. First,

disability is a social construct rather than a direct or immediate result of impairment. The idea that disability is a social construct may be the most salient aspect of critical disability theory. According to Devlin and Pothier (2006), "persons with disabilities may experience functional limitations that non-disabled persons do not experience, but the biggest challenge comes from mainstream society's unwillingness to adapt, transform, and even abandon its 'normal' way of doing things" (p. 13). As such, it is the ableist values that permeate social consciousness, and in turn shape environments, which serve to sustain disability and cause the social disadvantage, oppression, and marginalization faced by disabled persons. Second, disability is a result of the complex interrelationships between impairment, the individual response to impairment, and the environment. In this sense, CDT differentiates itself from a social model of disability in that it argues that disability cannot be understood outside the experience of the body (Hughes & Patterson, 1997). Within the context of older adults with ARVL, CDT would acknowledge that both the impact and the experience of the low vision impairment and the disabling features of the environment have significant impacts on if and how partially-sighted older adults participate in society. Third, disability results in the marginalization and social disadvantage of disabled persons due to social, physical, attitudinal, and political/institutional environmental constraints. As a result, social conceptions of 'normalcy' are reinforced, and subsequently internalized by individuals themselves, thereby restricting or denying the abilities of disabled persons to participate fully in contemporary society. Critical disability theory aims to question and deconstruct these embedded assumptions that privilege 'normalcy' over the 'abnormal' or disabled.

Critical disability theory is "a self-consciously politicized theory" (Hosking, 2008, p. 14). The goal is not theory for the sake of theory but rather CDT is "theorization in the pursuit of empowerment and substantive, not just formal, equality. CDT is about power and 'who and what get valued'" (Hosking, 2008, p. 14-15). At its core, critical disability theory is focused on the valuing of diversity and the promotion of rights and equality for disabled persons (Devlin & Pothier, 2006; Hosking, 2008). It

recognizes the inevitability of difference and aims to promote the equality, inclusion, and autonomy of all disabled persons within “a framework of diversity” (Hosking, 2008, p. 11). In doing so, critical disability theory argues for multidimensionality as an integral component to inform understandings of disability. Multidimensionality intends to portray disabled persons as a diverse group made up of members, who exist within various social structures and positions related to their gender, ethnicity, race, age, class, and other socially defined attributes. It is the intersection of these memberships with disability that serve to influence disabled persons as they engage in their daily lives.

5.5 Key tenets of critical disability theory: Re-thinking disability and ARVL

In addition to its key underlying assumptions, CDT is characterized by four primary tenets that question dominant understandings of disability. First, critical disability theory questions the implicit assumption that independence is the key marker of successful adulthood. Instead, CDT encourages a model of care where interdependence and reciprocity are valued over traditional notions of independence. Secondly, critical disability theory questions social assumptions pertaining to 'normalcy', arguing for a broader conceptualization of what constitutes 'normal' and by extension 'abnormal.' Third, critical disability theory questions the use of language as it relates to disability issues, arguing that the language used to describe disability and/or disabled persons is inherently political. Lastly, CDT questions the biomedical conceptualization of disability as located within individuals and their bodies, instead taking up a conceptualization that emphasizes the social construction of disability (Hammell, 2006). Each of these tenets can be drawn upon to open up new possibilities for studying disability differently in research addressing ARVL and, in turn, for knowledge generation that will inform new ways of supporting older adults experiencing ARVL as they engage in society.

5.5.1 Questioning the prioritization of independence

One primary tenet of critical disability theory is the questioning of the prioritization of independence. In Western society, the independent, autonomous, and self-reliant individual is legitimated (Fitzgerald, 1997). In fact, it has been argued that disabled persons are "victims of an ideology of independence" (Reindal, 1999, p. 353). According to this ideology, independence is largely equated with the ability to perform basic daily activities without assistance, such as cooking, dressing, washing, and toileting. This conventional understanding of independence is strongly medically situated (Fine & Glendinning, 2005), whereby disabled individuals are measured against the skills necessary to perform the task (Reindal, 1999) and categorized in relation to their degree of dependence (Murphy & Perez, 2002). In contrast, critical theorists highlight studies which suggest disabled persons may gauge independence, or autonomy, by their ability to exercise control and make decisions over how an activity is performed including how assistance is used to achieve particular goals (Morris, 2001; Reindal, 1999). Independence then, according to this definition, is not "contingent upon having a 'normal' body" (Reindal, 1999, p. 354).

Independence is a prominent theme within the ARVL literature. For example, a large body of research has focused on quantifying the loss of independence resulting from ARVL, with researchers conceptualizing loss of independence as a key means to measure the severity and impact of ARVL. For example, the association between ARVL and greater dependence in activities of daily living, instrumental activities of daily living, leisure, work, and social participation has been well-established (Berger & Porell, 2008; Crews & Campbell, 2004; Desrosiers et al., 2009; Grue et al., 2008; Knudtson, Klein, Klein, Cruickshanks & Lee, 2011; Laitinen et al., 2007; Travis, Boerner, Reinhardt & Horowitz, 2004; West et al., 2002). Within this work, older adults with ARVL are problematized as at-risk of or vulnerable to dependence. Given the broader social value placed on independence, it is also not surprising that qualitative literature has found that older adults with ARVL view the loss of independence as the most "dreaded

outcome of declining vision" (Laliberte Rudman, Huot, Klinger, Leipert & Spafford, 2010, p. 92). This literature points to a range of activity losses, such as automobile driving; reading recipes, menus or books; or writing cheques, that older adults with low vision frame as leading to dependency on others (Moore, 2000; Moore & Miller, 2003). In response, the partially sighted older adult develops adaptive strategies, such as the use of visual devices, in an effort to maintain their independence for as long as possible (Moore & Miller, 2003) and the restriction of activities to familiar physical or social spaces in an effort to maximize independence (Laliberte Rudman et al., 2010). This results in older adults themselves actively working at staying independent even when it means the restriction of participation in valued activities. This idea serves to further reinforce issues of internalized ableism in which the assumption is that responsible adults are independent thereby marginalizing those disabled persons for whom assistance is necessary.

Research that exclusively supports the ideal of independence may result in the inadvertent labeling of dependency (Clapton & Kendall, 2002). Indeed, connotations surrounding 'dependency' in adults are almost always negative, such that dependence is considered shameful (Ells, 2001; Fine & Glendinning, 2005). Such a conception is so taken-for-granted within our society, that outwardly negative messages regarding impairment and disability largely go unnoticed (Morris, 2001). Critical disability theorists question the dichotomization of independence and dependence. They also challenge the assumption that all disabled persons are dependent, or at risk of dependency, whereas all able-bodied persons are self-sufficient. Instead, CDT proposes that all adults exist in varying states of dependence and independence (Clapton & Kendall, 2002). In fact, it is the very nature of humanity to be inter-dependent beings, whereby we both rely on and are relied upon by others (Ells, 2001; Morris, 2001). Fine and Glendinning (2005) argue that the concept of interdependence "has significant appeal as a social vision, and suggests a universal and positively valorized condition of humanity" (p. 611).

Low vision research, informed by CDT, would shift away from an exclusive focus on the goal of independence towards an acknowledgment of inter-dependence and the many creative ways clients with ARVL negotiate their daily activities (Clapton & Kendall, 2002; Gill, 1987). The idea of questioning the “contemporary emphasis on the goal of independence” (Laliberte Rudman & Durdle, 2008, p. 119) has been supported in a limited body of qualitative ARVL research. For example, a descriptive phenomenological study by Laliberte Rudman and Durdle (2008) and Laliberte Rudman et al., (2010), posited that emphasizing independence over “collective forms of support and capacity” (Laliberte Rudman et al., 2010), may result in situations of isolation or inactivity among partially sighted older adults because their desire to maintain independence may cause a reluctance to ask for assistance. Moving forward, future CDT-informed research should focus, not on the supposed dependence of older adults with ARVL, but rather on those meaningful contributions that partially sighted older adults make both to their families as well as to their communities.

5.5.2 Deconstructing concepts of normalcy

Deconstructing concepts of normalcy is another primary tenet of critical disability theory. Normalcy represents an ideological social construct designed to exclude disabled persons from a society that was not designed to meet their needs (Terzi, 2004). As a result, the very label of 'disabled' is an attempt by society to categorize those who have failed to meet the expectations of ability (Greco & Vincent, 2011). As applied to ARVL, the label of 'visually impaired' is used to categorize those who fail to meet the expectations of normal vision whereby impairment (in this case low vision) is defined as “a loss of visual acuity (i.e., less than 6/18 but at least 3/60) or visual field (i.e., less than 20 degrees) in the better eye, not correctable by spectacles, contact lenses, or intraocular lenses” (Spafford, Laliberte Rudman, Leipert, Klinger & Huot, 2010, p. 580).

The socio-cultural expectations of what constitutes 'normal' are established and given meaning by those social groups, who have the greatest amount of power

and privilege to enforce their perceived notion of normalcy. In this case, able-bodied persons hold the power. Dominant social groups are able to position certain groups of people, including disabled persons, as falling outside of the set norm (Fitch, 2002). In fact, ableist norms, such as the expectation of independence, permeate social consciousness resulting in a type of disablism that imposes “the projection of ‘able-bodied’ values which legitimize oppressive and discriminatory practices against disabled people purely on the basis that they have a physical and/or mental impairment” (Imrie, 1997, p. 263). Disablism refers to discrimination against disabled persons in favor of that which is perceived as ‘normal’, namely able-bodiedness. As a result of their inability to live up to the able-bodied established norms, disabled persons may be framed as “non-humans, as the menace, as waste material, as trivium, as objects of pity, as burdens of charity, as the child, as the sick and diseased organism, and as the dying” (p. 408) or more broadly as ‘the other’ (Morris, 2001; Siebers, 2006). This collective labelling of disabled persons as ‘the other’ stems from a fear among able-bodied persons of feeling different or becoming disabled themselves. For example, Fitzgerald (1997) stated that:

“The disabled are not only de-valued for their de-valued bodies, they are constant reminders to the able-bodied of the negative body-- of what the able-bodied are trying to avoid, forget and ignore. For example, if someone tells me she is in pain, she reminds me of the existence of pain, the imperfection and fragility of the body, the possibility of my own pain, the inevitability of it...Gradually I make her ‘other’ because I don’t want to confront my real body, which I fear and cannot accept” (p. 411).

The ‘normal’ body does not generally want to be reminded of its own sense of vulnerability and so there is a sense of underlying fear that one might experience the physical frailty and social vulnerability that are so often stereotypically associated with the disabled body. This fear has prompted the medicalization of vision loss whereby it becomes something that can be treated or fixed, largely through rehabilitation efforts, thereby placing disability within the individual (Siebers, 2006). This medicalization of vision loss has also led to the “pathologizing of difference” (Linton, 1998, p. 527); however, critical disability

theory seeks to embrace difference. In fact, the very foundation of critical disability theory is the valuing of diversity, in which difference is not simply tolerated but welcomed. In this sense, CDT seeks to question the social construction of normalcy and break down the false dividing line between the continuum of 'normal' versus 'disabled' thus attacking the very concept of normalcy.

The question then becomes how a deconstruction of normalcy translates into empirical research development. Part of the solution, as supported by critical disability theory, would be to provide spaces for the voices of disabled persons within ARVL research. Consider that social conceptions concerning disability are often predicated on the assumption that to be disabled means to live a life of suffering and dependency; a life without meaning or value (Hosking, 2008). Yet, research, informed by CDT, aims to privilege the stories of disabled persons by giving them an active voice in research. This is particularly important as the voices of disabled persons have been too often suppressed or silenced from the research process. As suggested by Hosking (2008), "when a disabled voice says what the able-bodied perspective wants to hear, it is heard; when it says something the able-bodied perspective does not want to hear, it can simply be dismissed as the inappropriate response of a person who has developed an unhealthy response to the impairment" (p. 12). A fundamental shift in power then needs to occur whereby the voices of disabled persons are heard in research regardless of whether they are saying what the able-bodied populace wants, or is comfortable, hearing. It is only by sharing the perspectives of the disabled that the able-bodied can begin to understand the experience of disability as faced by those who live it each day and begin to re-frame how they think about disability and how they define 'normal'.

5.5.3 The politics of language

Language is defined as "a set of symbols that describes, sorts, classifies, and provides the forum for sharing individual experience" (Rogers, 1996 as seen in Gilson & Depoy, 2000, p. 212). According to critical disability theory, language is

a powerful, and inherently political, tool in which "ideological implications" are strongly embedded (Hosking, 2008, p. 13). CDT argues that language, including the words used to describe disabled persons and disability, ultimately shapes how disability is taken up and understood at both individual and social levels (Hosking, 2008).

Language is used as a means of describing or labeling disabled persons. Although labels, in and of themselves, are not problematic, those used to describe disability are frequently negative. For example, disability is commonly associated with notions of 'deficit' or a flawed existence (Hughes, 2007). Disability is commonly interpreted as a tragedy and pitied or feared by those perceived as able-bodied (Hughes, 2007) and those labeled as 'disabled' are often equated with characteristics such as powerlessness, vulnerability, dependency, helplessness, loss, incompetence, inadequacy, frailty, and deviancy (Hammell, 2006; Hosking, 2008; Hughes, 2007). In the ARVL literature, there is an abundance of research that points to the 'losses' of partial sightedness; for example, there is the functional loss related to the performance of necessary or desired activities, the loss of emotional wellbeing and, the loss of meaningful social connections and relationships (Grue et al., 2008; Harada et al., 2008; Knudtson et al., 2011; Laitinen et al., 2007).

Critical disability theory understands that language is value-laden (Bricher, 2000). It acknowledges the impact that negative labels and language may have on social attitudes towards disabled persons. As such, it calls for what Fitch (2002) termed "divesting disability of its medicalized meaning" (p. 475). Consider, for example, the use of person-first language, such as 'person with a disability' instead of its alternative of 'disabled person.' Many rehabilitation professions argue for use of the former because it acknowledges the person before recognizing the presence of disability and further acknowledges disability as only one element of the person. Contrastingly, disability advocates prefer 'disabled person' because it acknowledges disability as an essential part of the disabled person's self-identity (Kielhofner, 2005). In fact, CDT argues that the choice to

use the term 'disabled people' stems from an attempt to 'politicize' the experience of disability. By doing so, it takes the focus off the individual and their impairments and re-focuses the responsibility onto society (Morris, 2001). The use of person-first language, although it encourages viewing the person before the disability, is proposed to be problematic because it defines disability by one's impairment (Morris, 2001). In fact, Titchkosky (2001) challenges the normalizing potential of person-first language by arguing that person-first language is "an apolitical, individualized, and inappropriate means by which to dismember disability from the self" (as seen in Devlin & Pothier, 2006, p. 3).

The struggle over how to define disability, and what is included in a definition of disability, is important if we are to move away from such binary thinking as able/disabled, normal/abnormal, and ability/disability. Such binary thinking quickly moves to the 'othering' of disabled persons, as discussed above; however, Devlin and Pothier (2006) have argued that disability "has no essential nature. Rather, depending on what is valued (perhaps overvalued) at certain socio-political conjunctures, specific personal characteristics are understood as defects and, as a result, persons are manufactured as disabled" (p. 5). In this sense, disability is context-dependent, meaning that disability will be present, or not, based on what Devlin and Pothier (2006) term 'the social organization of society' (p. 5). As the social context and social patterns evolve, so too may the parameters of what we define as disability and the language used accordingly.

Attention to the importance of language has been scarcely addressed in the ARVL literature. Bolt (2005) is one of the few researchers to discuss the evolution of the term 'blindness' to 'visual impairment' as a process informed by the adoption of a social model of disability. In an effort to build upon this limited research area, low vision researchers would benefit from a critical deconstruction of the implicit assumptions tied to language use which is inherent in most ARVL research paradigms. Areas of focus should include: the language typically used to describe ARVL; the intended and unintended implications of labeling partially sighted older adults; the framing of older adults with ARVL as 'other' or 'abnormal'; and the

resulting limits placed on their ability to be considered active agents in research, and perhaps, the rehabilitation process.

5.5.4 Questioning the individualization of disability

In critical disability theory, the environment plays a central role in how disability is understood (Kennedy & Minkler, 1998). CDT acknowledges that the environment creates as well as sustains disability as a means of marginalization and oppression, thereby supporting the idea that “disabilities are physically based but socially constructed” (Albrecht, 1992, p. 35). Through the CDT lens, the environment, including physical, social, cultural, political, and institutional elements, has been shaped and sustained around largely ableist assumptions by adapting to the needs of the predominant able-bodied population and failing to acknowledge the needs of disabled persons. For example, consider the normative social assumptions tied to an everyday social interaction such as meeting a known acquaintance in the community. Such a typical, and perhaps taken-for-granted, social interaction would not necessarily begin with an introduction of oneself by name; however, failure to do so may serve to disadvantage those who are partially sighted if facial recognition is challenging. The norms governing basic social interactions show deep-seated assumptions regarding for and by whom the environment has been designed. Thus, these assumptions exclude or minimize the needs and voices of disabled persons.

As it relates to ARVL, CDT frames an older adults’ experience of disability as tied both to the particular environmental context in which they exist as well as by the limitations caused by their impairment. In this sense, the argument is that people live each day with glaucoma, macular degeneration, or diabetic retinopathy; however, they are not truly disabled until they come across a barrier within a largely ableist environment (Bolt, 2005). For example, people with vision loss only become disabled when they are unable to: read their bank statements in standard print; identify the correct bus stop because there are no automated announcements; avoid trip hazards because outdoor surfaces are uneven and

poorly maintained; or find their food items in a grocery store where signage is limited and small. In each scenario, disability could have been avoided with some attempt at social reform (Bolt, 2005). In this sense, disability is not simply a result of the functional limitations of one's visual system; it is also shaped and sustained through the interaction of that bodily experience with the inaccessible features of the social, physical, cultural, political, and institutional environment. As a result, an older adult with ARVL is 'disabled' if the environmental context fails to acknowledge and accommodate differences from normative standards.

Within the ARVL literature, there has been a nearly exclusive focus on the individual, primarily in relation to bodily and visual functions. In turn, there has been little attention to the impact of environmental components on the activity engagement of older adults with ARVL. When environmental factors influencing activity participation are addressed, research is often centered on physical environmental features and home environments. For example, research has attended to weather, time of day, and lighting (Laliberte Rudman et al., 2010; MacLachlan, Laliberte Rudman & Klinger, 2007); the impact of environmental modifications on supportive physical environments (Stevens-Ratchford & Krause, 2004; Wahl, Oswald & Zimprich, 1999); or required items in home safety assessments specific to the low vision population (Barstow, Bennett & Vogtle, 2011). A broader research focus is needed on how environments, including physical, social, cultural, political, and institutional, create as well as sustain disability amongst older adults with ARVL. Such work would push research beyond a purely individual level to include an exploration of the socio-political context of disability as it relates to older adults with ARVL. This would be in line with the perspective of many older disabled adults who “view their functional ability as increasingly dependent on the success with which their environments can adapt and change to accommodate their changing bodies and personal needs” (Minkler & Fadem, 2002, p. 231).

Research that is focused on changes to the context or environment is warranted. For example, considering the built environment, an individual remedial-based

approach would look at addressing those individual factors limiting people's ability to access their environment, while CDT, in comparison, re-focuses the responsibility for creating inclusive environments back onto society (Meekosha & Dowse, 2007). Consider, for example, an older adult with age-related macular degeneration (AMD), experiencing difficulty crossing at a busy intersection. Interventions situated in the biomedical model of disability would focus exclusively on individual strategies aimed at enabling independence and safety with the task of crossing the street. Such strategies might include teaching the individual to ask for help, listening for traffic surges to determine when it is safe to cross, or only walking in the community with a sighted guide. However, critical disability theory would aim to deconstruct the disablist assumptions inherent within this task. It might question why audible announcements are not available at the crosswalk, or why sufficient time is not provided for older adults with a disability to cross safely. Environmentally-focused recommendations stemming from a CDT perspective would address these underlying systemic barriers. This shift in research focus would not only require a broader research focus that considers the environment, in any capacity, as an influence on the experience of ARVL, but also research that more specifically addresses such issues from a critical disability theory lens. By broadening the focus of research that locates disability within the individual to include an understanding of disability as socially created, we encourage the responsibility for addressing disability issues to shift onto the shoulders of the community, of which disabled persons are members. In addition, future research must adopt the ideals of social transformation and emancipatory social change that are defining features of critical social theory (Given, 2008). This would also require embracing participatory models of research in which researchers work with disabled persons in order to raise their own social awareness. In keeping with a focus on the environment, future ARVL research must not accept vision-related environmental barriers as static 'givens' but rather must question the existence of such barriers and further advocate for social change through the creation of vision-friendly environments.

5.5.5 Drawing an example from contemporary critical gerontology

This article aimed to put forward critical disability theory as an approach to the study of disability that could offer the particular theoretical and empirical push needed to broaden the current ARVL research foci in order to more effectively understand and address disability. To support the arguments regarding the potential of taking up a critical perspective in ARVL, an illustration of how critical gerontology has added to the study of aging is explicated. Critical gerontology, as a recognized field, emerged in the 1980s and 1990s (Estes, Biggs & Phillipson, 2003) and has succeeded in taking up critical theory to re-conceptualize aging and its relation to disability and question the taken-for-granted assumptions about what it means to 'age well' (Holstein & Minkler, 2003). Similar to the concerns articulated in this article regarding the limitations of a biomedical model in the study of disability and ARVL, critical gerontology is based within concerns regarding "the dominance of a biomedical model that construes age with decline and illness" and the associated "individual focus of the field of gerontology that paid insufficient attention to social stratification and other aspects of socioeconomic structures" (Estes et al., 2003 as seen in Grenier, 2012, p. 22).

The introduction of a critical gerontology perspective has led to an increased breadth in research foci and prompted opportunities for new perspectives and ultimately new learning, relative to contemporary aging issues. For example, Grenier (2005) aimed to demonstrate the impact of the environment on the experience of disability among twelve older urban-residing disabled women. Findings pointed to the notion that disability is not located exclusively within the functions of the body but rather context—such as home, bus, and social location—has a particularly strong influence on the experience of disability. As a result, disability is only seen to exist when the context and/or resources available to disabled persons are inadequate or inappropriate for their needs. As a further example, in regards to the topic of civic engagement or volunteerism, researchers including Martinson and Halpern (2011) and Martinson and Minkler (2006), have questioned the ethical implications inherent in the normalization of

healthy aging ideals, including the promotion of volunteerism among older adults that can lead to the "stigmatization and disempowerment of those elders who fail to meet our criteria for 'a good old age'" (Martinson & Minkler, 2006, p. 323). By cautioning against an overemphasis on civic engagement, these researchers broke down many of the normative ideals regarding what it means to 'age well'. Although this represents only a sampling of work informed by a critical gerontology perspective, it shows the unique opportunity for low vision researchers to follow the same suit as critical gerontology in order to increase the breadth of research foci with respect to age-related vision loss.

5.6 Conclusion

Harper (1991, p. 534) stated that "all too often, the way we see the problem, is the problem" thereby requiring the taking up of new explanatory paradigms through which to understand a particular issue, such as disability. Such was the aim of this article. We aimed to stimulate a critical dialogue regarding the ways in which disability has been largely conceptualized and studied in literature addressing age-related vision loss and to suggest an expansion of this largely bio-medically informed research area to include critical disability theory. To demonstrate the potential contributions of adopting a critical disability approach to enhance understandings of ARVL, we began this article by outlining the primary tenets of the biomedical model of disability. Next, we reviewed the primary tenets of the social model of disability, a model which was proposed in opposition to the biomedical approach. Lastly, the key aims, emphases, and assumptions of critical disability theory were laid out and examples were provided of how such an approach would lead to new research foci in the study of ARVL. Specifically, we argued for four primary qualities of critical disability theory that future ARVL research should ascribe to, including a focus on interdependence over traditional notions of independence, a broader conceptualization of 'normalcy', an exploration of the influence of language as a means of describing or labeling disabled persons, and a greater focus on the influence of the socio-political environment in the creation and sustainment of

disability. To support the proposed shift, an example was drawn from the field of gerontology to show how the development of critical gerontology has resulted in new ways of understanding and studying aging, thereby providing a case to justify the claim that a critical model of disability would open up new possibilities in the study of ARVL. The adoption of critical disability theory would encourage a re-focusing within ARVL research that would encourage new ways of conceptualizing, researching, writing about, and practicing in relation to age-related vision loss.

5.7 References

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CHAPTER SIX

6.0 Negotiating 'positive' aging in the presence of age-related vision loss (ARVL): The shaping and perpetuation of disability

6.1 Introduction

Over the past two decades, there has been a growing policy and research focus on how to support seniors to achieve so-called 'positive aging'. In this article, discourses of 'positive aging' are defined broadly to encompass various terms such as 'active', 'successful', 'productive', or 'healthy' aging which permeate various types of contemporary texts, ranging from popular media to policies (Asquith, 2009; Laliberte Rudman, 2006; Mendes, 2013; Raymond & Grenier, 2013). These discourses can influence how individuals and collectives come to think about what aging well is and what needs to be done in order to 'age well', by both individuals and society. Thus, it is vital to attend to such discourses.

A central characteristic of various positive aging discourses is that 'aging well' is marked by the absence or reduced probability of disability (Asquith, 2009; Raymond & Grenier, 2013). As such, it has been proposed that such positive aging discourses serve to frame disability and dependency as examples of the older adult having failed at aging (Boudiny, 2013), thus serving to exclude and further marginalize aging persons with disabilities from mainstream society (Mendes, 2013). Such unrealistic expectations may be particularly stigmatizing for those older adults aging with a disability who, as a result of their disability, may face insurmountable challenges in meeting the narrowly defined criterion for ageing well.

Although previous research has explored the meaning of positive aging discourses from the perspective of older adults (Duay & Bryan, 2006; Hsu, 2007; Knight & Ricciardelli, 2003; Stenner, McFarquhar & Bowling, 2010; Strawbridge, Wallhagen & Cohen, 2002), little research, to date, has focused on what it means to age well from the perspective of older adults with a disability.

Given the sparse research attention paid to the intersection of aging and disability within both social gerontology and disability studies, this paper aims to examine how older adults with a specific type of impairment, that is age-related vision loss (ARVL), negotiate their own aging and activities in relation to contemporary positive aging discourses. It concludes that positive aging discourses are embedded within ageist and ableist assumptions and, as such, can serve to shape and perpetuate the disability experience for older adults with ARVL. While positive aging discourses do not determine how older adults with ARVL go about negotiating their identities and activities, this study's findings demonstrate ways that such discourses create boundaries within which such negotiations occur, thereby contributing to the marginalization, social isolation, and activity restriction experienced by older adults with vision loss.

In this paper, discourses of positive aging are conceptualized as a component of the socio-cultural and political environment and are of particular contemporary relevance given the embeddedness of such discourses in various types of policy, popular, and professional texts (Dillaway & Byrnes, 2009). Embedded in power relations, such discourses convey normative messages about what it means to age well. In turn, such messages influence how individuals think about and act in relation to their own aging, as well as how societies think about and respond to aging citizens (Asquith, 2009). This article draws data from a broader critical ethnographic study focused on how the environment influences how older adults with ARVL engage in their daily lives. Within this broader study, normative messages regarding what it means to age well emerged as an important aspect of the socio-political environment, which served to shape how ARVL was experienced within the context of daily life.

6.2 Contemporary discourses of 'positive' aging

The intersection of aging and disability has been largely underexplored in both social gerontology and disability studies. For example, within social gerontology, there has been limited exploration of the experiences and issues surrounding

aging and disability, with a few exceptions (Kennedy & Minkler, 1998; Minkler & Fadem, 2002; Priestley & Rabiee, 2002; Putnam, 2002; Raymond & Grenier, 2013; Raymond, Grenier & Hanley, 2014). Similarly, disability studies has tended to overlook the impact of aging on the disability process (Jonson & Larsson, 2009), with a primary focus on the experiences of disability among the working age population (Kennedy & Minkler, 1998; Priestley & Rabiee, 2002). Given that population aging trends will result in greater numbers of older adults with disabilities (Freedman, Martin & Schoeni, 2002), there is a crucial need for studying the intersection of aging and disability, including how it relates to positive aging discourses. Additionally, it is important to begin moving beyond seeing disability as a taken-for-granted aspect of aging towards the critical consideration of disability as being both socially and politically shaped.

Since the late 1960s, the construction of aging as a period of decline, dependency, and disability (Katz, 2001-2002) has been increasingly countered with a diversity of positive aging discourses, including the seemingly more optimistic models of 'active aging' (Havighurst, Neugarten & Tobin, 1968), 'productive aging' (Caro, Bass & Chen, 1993), and the widely known 'successful aging' (Rowe & Kahn, 1998). The roots of positive aging discourses are often traced to the seminal work of Rowe and Kahn (1997), who defined successful aging by three primary components; a) low probability of disease and disease-related disability; b) high cognitive and physical functioning and; c) active engagement with life (Rowe & Kahn, 1997). Taken together, these three concepts form the "triumvirate of positive ageing" (Asquith, 2009, p. 260). At the core of these discourses are a few basic defining characteristics including: good health; independence; continued engagement in daily activity; and social connectedness (Asquith, 2009; Tulle-Winston, 1999).

Although it has been acknowledged that discourses of positive aging have established new criterion for 'aging well' that counter long-held negative stereotypes (Asquith, 2009), concerns have been raised regarding both the exclusionary potential of such discourses, particularly in relation to aging persons

who do experience illness, impairment, and disability. As well, concerns have been raised regarding the ways positive aging discourses have been shaped and promoted in relation to a broader neoliberal political agenda which involves an emphasis on fostering individual responsibility, increasing privatization, and encouraging state retreat from collective responsibilities (Laliberte Rudman & Molke, 2009). The limitations of positive aging discourses have been recognized particularly by critical gerontologists who have raised issues with how positive aging discourses have been shaped and taken up in academia, policy, and popular media (Laliberte Rudman, 2006).

One prominent line of critique has addressed how positive aging discourses often individualize both the responsibility to age well (Connidis, 2012) and the risks of aging, such as disability, social isolation, and dependency. Raymond and Grenier (2013) undertook a critical discourse analysis regarding the concept of social participation as taken up in public policy in Quebec, Canada. Their work exemplifies the various ways in which active aging policies, in alignment with neoliberal rationality, have shifted responsibility for healthy aging and participation from a collective towards an individual model (Raymond & Grenier, 2013). Politically, this shift effectively serves to transfer the crisis of population aging onto aging individuals, justifying state retreat from various types of services previously provided to aging adults (Aberdeen & Bye, 2011; Asquith, 2009; Cardona, 2008; Kemp & Denton, 2003).

In addition, the framing of aging as an individual responsibility often embeds the assumption that aging well is primarily dependent on the lifestyle choices of older adults (Laliberte Rudman, 2006; Minkler & Fadem, 2002). As summarized by Gilleard and Higgs (2000), such discourses can simultaneously induce a fear of aging while offering up the possibility of warding it off, with the adoption of particular lifestyle adjustments such as "jogging, diet, skin creams, vitamins, fashionable clothes, holidays, personal pension plans, and lifestyle magazines" (Gilleard & Higgs, 2000, p. 8-9). It has been argued, in fact, that positive aging discourses have resulted in a new form of ageism in which the generalized fear

of aging has been replaced by a fear of aging with disability (Boudiny, 2013). The framing of old age as a matter of personal responsibility is problematic (Mendes, 2013) because it both likens the obtainment of good health to "the personal responsibility of a good citizen" (Higgs et al., 2008, p. 690-1) and further serves to obscure the ways in which positive aging is shaped by socio-cultural and political forces (Carmel et al., 2007; Laliberte Rudman, 2013). Indeed, such an individual-level focus negates the significant influence of the environmental context as well as extrinsic factors such as gender, education, financial resources, or the safety of one's neighborhood, to name a few, all of which are factors that influence one's ability to age well (Cardona, 2008; Holstein & Minkler, 2003; Minkler & Fadem, 2002).

According to Mendes (2013), the attainment of positive aging is increasingly being framed as the duty of responsible aging citizens. Increasingly, messages convey that aging well equates with avoiding disability and striving to: maintain a youthful appearance, be productive, maintain independence, and be busy (Boudiny, 2013; Laliberte Rudman, 2006; Raymond & Grenier, 2013). However, there are older adults, aging with disability, for whom attaining this construction of a positive ager is not feasible or attainable. Concerns have been raised that positive aging discourses serve to blame these older adults by arguing that "if frail older adults had made the right choices and engaged in the right lifestyle, they would not be in this vulnerable situation" (Boudiny, 2013, p. 1084). In turn, those who experience disability, and potentially dependency in later life, or are otherwise unable to ascribe to these socially embedded norms, may be marginalized, receive fewer opportunities for meaningful social engagement, and are subsequently excluded from mainstream society (Laliberte Rudman, 2006; Mendes, 2013; Raymond & Grenier, 2013). In this way, positive aging discourses, while initially offered up as a means to counteract negative stereotypes of oldness, may inadvertently reinforce a stigmatizing view of disability in later life by framing disability as a matter of failed personal responsibility and a marker of oldness (Laliberte Rudman, 2006; Martinson & Minkler, 2006).

Research has begun to focus on how positive aging discourses are negotiated by older adults within the context of their everyday life. For example, Kemp and Denton (2003) drew on data from 51 semi-structured life history interviews (informants aged 45 to 91 years old; no disability mentioned) to explore how individuals think about later life including the risks associated with aging. Aligned with the principles of positive aging discourses, older adults overwhelmingly articulated sentiments of personal responsibility for later life. This included a focus on individual planning and preparation strategies to reduce the likelihood of an array of personal risks and minimize burden or dependence on others. Failure to enact these strategies was perceived as morally wrong, undesirable, and to be avoided at all costs. As another example, within the context of healthy aging policies, Cardona (2008) interviewed 25 non-disabled users and providers of anti-aging medicine. Findings revealed that the responsibility for health maintenance was measured by the capacity of individuals to remain looking young, raising concerns about the elision of youth and health within positive aging discourses. Commensurate with concerns regarding the attribution of failure associated with positive aging discourses and the focus on lifestyle choices, informants in this study equated signs of aging with a failure to exercise proper self-care and/or make correct choices regarding consumption and bodily practices.

Despite this growing literature, minimal research has focused on how positive aging discourses are interpreted and negotiated by older adults with impairments who may experience disability. As such, in an effort to better understand the complex intersection of age and disability, this paper drew on data from a broader study to examine how older adults with ARVL negotiated the normative assumptions that underlie positive aging discourses within the context of their everyday lives.

6.3 Study Purpose and Objectives

Data drawn upon in this article was generated within the context of a broader critical ethnographic study that explored how the environment is implicated in the shaping of disability for older adults with ARVL. To accomplish this goal, two primary objectives were established. First, to critically examine how the physical, social, cultural, and political/institutional environment is constructed in ways that support as well as constrain the activity engagement of older adults with ARVL and second, to raise awareness of how these various environmental factors are embedded within ageist and ableist social and cultural assumptions. Through a process of data analysis, broader discourses regarding what it means to 'age well' emerged as an important shaping influence on how older adults negotiated vision loss. As such, the specific objective of this paper was refined from the original broad objectives, to focus on exploring those attributes that older adults with ARVL perceive as being the markers of a 'good old age', to understand how these markers are situated within both ageist and ableist social assumptions regarding what it means to 'age well,' and to raise awareness of the disabling effects of such markers.

6.4 Methodology and Methods

Ethics approval was obtained through The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) in October 2012 to undertake this critical ethnographic study. A critical ethnographic approach was chosen because it is a methodology focused both on eliciting the research participants' point of view and understanding of their world, while at the same time challenging taken-for-granted assumptions and questioning the prevailing status quo and dominant power structures within a particular culture (Cook, 2005; Simon & Dippo, 1986; Thomas, 1993).

Theoretically, this study was underpinned by the key tenets of critical gerontology (Estes, Biggs & Phillipson, 2003; Minkler & Holstein, 2008; Ray & Cole, 2009) and critical disability theory (Devlin & Pothier, 2006; Hosking, 2008; Hughes & Patterson, 1997).

6.4.1 Recruitment and Participants

Participant recruitment occurred over a period of nine months. This broader critical ethnography study sought to include the perspectives of ten older adults with ARVL as well as seven community organizations. For the purposes of this article, only data from the older adult participants was utilized. Participants were recruited through in-person presentations, organizational contacts, and newspaper advertisements. To be eligible, participants had to be at least 75-years-old, had received a diagnosis of ARVL (including; age-related macular degeneration (AMD), glaucoma, and/or diabetic retinopathy), self-identified as experiencing functional impairments due to ARVL, and be able to communicate effectively in English.

The older adult participant group included two males and eight females. The participants ranged in age from 76 to 91-years-old, with an average age of 83.8 years. None of the respondents were married at the time of the study. Seven respondents were widowed, one respondent was divorced, and two respondents were single, having never been married. With the exception of the two participants that were never married, all of the respondents had children and five of the respondents had at least one child living within twenty minutes of their home. All respondents were retired and had educational levels ranging from completion of grade school to having finished some college/university. Eight of the respondents reported the onset of their ARVL condition as gradual with two respondents describing the onset as sudden. With the exception of two participants, who had age-related macular degeneration only, the respondents had a combination of ARVL conditions. The time since diagnosis was: 3-5 years (one respondent), 6-10 years (four respondents) and more than 10 years (five respondents).

6.4.2 Data Collection

A modified version of Carspecken's (1996) five-stage approach for critical ethnography was adopted for this study. A variety of data generation methods

was necessary to understand and contextualize the experience of low vision for older adults. These methods included a narrative interview, participant observation session, and a semi-structured in-depth interview.

The first data collection method involved an audio-taped narrative style interview focusing on participant stories of living with age-related vision loss. Wengraf's (2001) lightly structured narrative interviewing approach was used in order to elicit participant stories. The second stage of data collection involved a participant observation session in which the primary author participated in an activity chosen by the older adult participants. These activities ranged from community-based activities such as grocery shopping or going out to eat at a restaurant to activities done in their homes such as attending a Braille lesson or enjoying a home-cooked meal together. These observation visits provided a better understanding of how older adults with ARVL negotiated their environments and how environmental influences ultimately shaped activity engagement. A semi-structured in-depth interview was the third, and final, data generation method for the older adult participants with ARVL. During this stage of data collection, the focus was on understanding the impact of various physical, social, cultural, political, and institutional environmental factors on daily activity engagement. This was the stage of data collection during which findings more fully emerged regarding the perceptions held by older adults about what it means to 'age well'. In addition to the data collected from the older adult participants, this study also included document analysis in order to gain insight into the socio-political context in which the older adults' experience of vision loss was embedded.

6.4.3 Data analysis

Data analysis occurred simultaneously with data collection. A consistent approach to data analysis was adopted for all forms of interview and observational data. Each interview transcript and observation note was read individually to develop a rich understanding of the data before drawing

comparisons among data sets or across participants. Both low level (open) and high level (theoretical) codes were applied to each of the verbatim transcripts (Carspecken, 1996). Codes were compared within and across participant data sets to form categories and themes. All coding was completed by the primary author; however, resulting codes and categories were refined through ongoing team meetings. Team meetings enabled collective reflexivity in which the authors became aware of any presuppositions and/or values they brought to the data and challenged these through open discussion, thereby enhancing the depth and transparency of data analysis and interpretation. The documents included in this study were analysed separately, using a modified-version of Bacchi's (2009) six-question policy analysis framework.

6.5 Study context

This study took place within the Hamilton-Haldimand-Niagara-Brant region, specifically within the communities of; Hamilton, Burlington, Dundas, Dunnville, and Stoney Creek. Hamilton is a medium-sized Canadian city with a population of over 500,000 that is spread across both dense urban centers and smaller rural regions.

In relation to the local discursive context, as noted above, data collection and analysis included attention to documents addressing aging, disability, and low vision (n=16). The documents were found primarily through internet searches and organizational contacts. All documents were selected based on emergent findings from the data collected with the older adult participants and community organization representatives. Of the documents consulted, four explicitly incorporated information related to what it means to 'age well', thus providing insight into how broader positive aging discourses have been incorporated into policy and organizational texts within the local context of the study. Two of the documents, titled *Global Age Friendly Cities: A Guide (2007)* and *Hamilton: A City for All Ages (2010)*, focused on the development of age-friendly communities, arguing that the ability of older adults to age well was contingent

upon the ability of the environment to be set-up in a manner that promoted their personal wellbeing and contributions. In discussing the need to focus on elder-friendly communities, some documents referenced the need for programs and services that support seniors to live independently. For example, the priority on independence was fore fronted in a document titled *Independence, Activity and Good Health (2013)*. Other documents clearly took up normative assumptions regarding what it means to age well; these assumptions aligned with the characteristics that have been defined as key features of contemporary positive aging discourses, including: a focus on independence (*Living Longer, Living Well (2012); Independence, Activity and Good Health*), a concentration on remaining active and healthy (*Independence, Activity and Good Health; Living Longer, Living Well*), and a focus on promoting older adults to overcome barriers to healthy aging through individual level behavioural change (*Living Longer, Living Well*). Although much of the focus of these documents was at the level of the individual, the document *Living Longer, Living Well* explicitly acknowledged the role of the government in terms of promoting policies, programs, and services to maintain healthy aging.

6.6 Results

Central to the findings of this study was a focus on the meaning older adults ascribed to what it means to 'age well' within the context of living with age-related vision loss. The participants' descriptions of the markers of a 'good old age' are organized into five main themes: maintaining independence while negotiating help; responding positively to vision loss; remaining active while managing risk; managing expectations to be compliant, complicit, and cooperative and; striving to maintain efficiency. Quotes from participants are inserted throughout and are identified using the code numbers P1, P2...P10. To protect participant anonymity, the names of persons and places, including the names of streets and landmarks, have been removed.

6.6.1 Maintaining independence while negotiating help

All informants discussed the importance of ascribing to the cultural norm of maintaining independence, framing this as an essential goal of aging well in spite of vision loss. In fact, for some respondents, maintaining independence was perceived as the ultimate marker of aging well. For example, P1 stated:

Now what could you ask for more than that and you're independent. You don't owe anybody anything. You're standing on your own feet.

Because independence was regarded so highly, some informants became resentful towards those who assumed that because an informant had ARVL, they automatically needed help. For example, P10 stated:

Well I think it's because this is a building with seniors in it and they just take it for granted that because you're a senior in here you need help... [I was] getting to the office, and, and this fellow passed me and he says, "You're doing well, [name of P10]." Why, you know, why'd he say it? Why did he say that? I was just walking down the hall...As if I couldn't do it, you know? I wasn't—I wasn't capable, walking down the hall by myself...But I guess it's, it's, I guess it's ego, you know? You want to be, for people to treat you normally...Like I can do things.

Additionally, for some participants, the importance placed on being independent was so strong that they resented those older adults who they perceived as being too dependent on others. As a result, they attempted to enforce their own normative ideals of independence onto others. For example, P5 stated:

Well, if I find it hard I'll try and see if I can do it. And then if I can't do it, I'll ask for help. Some people ask for help right away, but not me. And I get uptight sometimes when I see, I said to somebody, 'Couldn't you do that yourself?' 'Oh no.' I said, 'You mean to say you couldn't pick that up and wipe your nose yourself, you had to call somebody to do it for you?'

In many situations, the participants discussed how the priority placed on independence meant they faced internal struggles if and when they encountered situations in which they needed to depend on others. This transition was often faced with feelings of fear, resentment, and frustration. For example, P3 stated:

Cause I don't want, I don't want to feel that I'm incapable of doing things myself...I haven't really accepted that there are things I cannot do. And I feel that there are things I still can do but only after experimentation or

after a while I find out I can't... That's, that's, I'll never, I'll never lose that. I'll never lose that type of independence, cause you still want to be an independent person.

For many of the informants, their desire to remain independent stemmed from their wish to not be perceived as a burden to others, particularly family members, friends, and care staff, or more broadly a burden on society. Along with the underlying idealization of independence inherent in positive aging discourses, there is a focus on self-reliance and avoidance of becoming a burden on family or society more generally. This fear of being and/or being perceived as a burden or dependent on others reinforces the socio-culturally embedded assumption that dependency is bad or undesirable and something to be avoided at all costs. Informants described how they then retreated from valued activities in order to avoid being perceived as dependent, thus demonstrating how disability is socio-politically shaped. For example, in speaking about a craft class she was now avoiding at the assisted care home where she resided, P5 stated:

But I haven't gone down...I should, I guess...But I don't like to bother people all the time. This is why I wouldn't go to the craft...If I could only do it myself without bothering. Because she [the instructor] was busy teaching the other people, you know. And I felt I was a bloody nuisance, and I said oh, you better just stay away.

Similarly, some participants, such as P9 who was adamant about her desire to remain independent, discussed an avoidance of disclosure for fear of being perceived as a burden:

No I don't, I don't...It's not like me to say, oh I can't do it myself. I don't need...I'm stubborn, I'm independent, I always had to be eh. But I won't burden them with it. That's the last thing I want is that, so.

Although a pursuit of independence led to discontinued activity involvement in some situations, in other situations the fear of further dependence led the participants to ask for help in order to ensure safe completion of a task, such as cooking or crossing a busy intersection. Even in those situations, informants maintained that they were in control of who, when, and how help was requested.

Further, help was almost always seen as a last resort after independent completion of the task was attempted. For example, P9 stated:

Oh yeah, they'll [referring to her children] help me. If I need it, I'll ask them, but not until I have to. If I'm really stuck, they know I'll call.

A steadfast belief in independence, which was a prominent study finding, is reinforced through positive aging discourses in which 'success' is framed as being within the control of individuals through the adoption of positive lifestyle choices and behaviors.

6.6.2 Responding positively to vision loss

Informants talked openly about the myriad of emotions associated with experiencing ARVL. Although negative emotional reactions were expressed, overwhelmingly informants conveyed the importance of maintaining a positive response to vision loss. Ensuring a positive emotional response to ARVL, in spite of the significant challenges participants experienced, was perceived as a marker of ageing well. For example, participants discussed accepting the changes in vision, the need to persevere, the importance of not feeling sorry for oneself, and focusing on abilities instead of limitations. For example:

Well your whole life changes. You're not a free spirit anymore just sort of doing what you want. You're kind of tied down...A self-imposed prison, basically. But you don't look at it like that because that would make you feel lousy. So I don't do that to myself. I still look at what I can do here. There are lots of things I can do. I just accepted it...I'm not going to let it ruin my life...I'm not going to whine about it and carry on and, just accept it and do the best you can, cause why me, I don't know, who knows (P1).

That's what you gotta keep in mind. You can only do the best you can with what you got left and don't keep crying about what you haven't got. Save your breath (P2).

If you start to go blind, you have to accept that too (P8).

When participants experienced negative emotions related to ARVL, many hid these feelings so as not to be perceived as a complainer, a trait that many informants stereotypically associated with older adults. For example, P8 stated:

When somebody says, "How are you?" I just say, "Oh I'm fine, thank you." I don't want to just stand there and say "Well I can't see." Yeah, I think you know if you do too much talking it is like you're complaining about your health.

For some participants, the desire to be perceived as positive was so strong that they conveyed a false sense of happiness to family, friends, and care staff when, in actuality, they felt fearful, upset, angry, and frustrated. For example P3 stated:

Some people think I'm pretty cheerful, but that's a façade, I'm really not. I'm ah, sometimes I'm hurting, but, I cry an awful lot, you know. I don't know whether I'm crying because I'm feeling sorry for myself or because I'm absolutely realizing that I can't do anything I used to be able to do.

To emotionally cope with vision loss, participants frequently discussed the use of strategies such as humor or comparing their situation to those perceived as 'worse off.' For example, P9 stated:

Yeah well we have to joke about it...You can't cry about it. What good is that gonna do? I'm not used to feeling sorry for myself. There's things you can do to pep out of it. You don't have to be miserable. There's always something you can do.

There is much research evidence both within the critical gerontology and ARVL literature to support the claim that a positive attitude is a key characteristic of aging well (Duay & Bryan, 2006; Hsu, 2007; Knight & Ricciardelli, 2003; Moore, 2000; Moore & Miller, 2003; Reichstadt, Sengupta, Depp, Palinkas & Jeste, 2010). By striving for a sense of steadfast positivism, older adults are demonstrating their desire to be perceived as positive agers; however, to do so, they must stifle any negative emotional responses towards their impairment so as not to be portrayed as a 'complainer', or as a 'burden'.

6.6.3 Remaining active while managing risk

Participants conveyed the importance of continuing to be engaged in daily activity while managing personal risk. Mitigating risk to the self was seen as an important marker of 'aging well' and reflects a deep seated expectation that older adults will practice 'responsible living' (Kemp & Denton, 2003), which includes monitoring

and minimizing risky behaviours. Embedded within this goal of individual responsibility to mitigate risk is a broader, more collective goal, of protecting society from older adults whose 'risky' behaviours might result in social strain on the system. As part of this strategy of risk management, and as a means of deciding whether to engage in a particular activity, participants described weighing potential risks of an activity with the perceived benefits. As an example, the risk of falling was a prominent fear among participants who, as a result of this fear, commonly refrained from participating in those tasks perceived as increasing this risk:

And then once a week, the girl from the [CNIB] comes to take me out walking which I appreciate very much because I can't see where I'm going and if I stumble she's there to catch me. If I wasn't such a coward I'd go out myself, but I'm afraid of falling (P5).

I watch the cracks in the sidewalk. I watch where I put my feet when I walk because I don't want to trip. It's so easy to trip. That can spoil your whole life. I've seen it happen to seniors around here (P6).

Many of the participants also discussed the importance of living defensively as a means of minimizing risk and ensuring personal safety:

They're friendly. I find it friendly. There are rough types too, you have to watch. When I go out I don't wear any rings or anything and I don't dress fancy or anything...I don't want to look like a mark (P6).

Sometimes I'm a bit nervous. It depends on how crowded the street is. I'd rather have it crowded enough that I don't think anybody's gonna knock me off...I just feel if there's more people on the street there's less chance of you being--like your purse snatched or other things (P8).

In making determinations about whether or not an activity was too risky, participants often considered environmental factors including weather, season, time of day, and lighting. For example:

I don't like going out in the winter, because I do, snow build up, probably ice and so forth, I, I try not to go out in that very much (P3).

But when the weather is bad, especially, it won't be as easy to get out. I'm more afraid of falling in the ice; I can slip without--I can fall on dry

pavement. So, when it comes to the shopping, I'm gonna have to get some help with that (P9).

I find that when I walk, I always look that I don't step on a crack that's a little bit up. If it's uneven that much, I could trip, so I find myself watching where I'm going all the time where I'm putting my feet, and I don't go out in the winter when it's icy or snowy. I won't attempt it (P6).

Participants also discussed the state of the physical environment including the availability of curb cuts and the overall shape of the sidewalks, including the presence of cracks as factoring into their decision about whether or not an activity was too risky:

I haven't the confidence in myself to go out. I go out around here. But to go out on the street...now, I might feel with my walker, if the street was up a bit, it there was a crack, I might. And if I did, I'd be careful. But if I didn't, I could trip and go down (P5).

In discussing two situations in which she fell, P10 stated:

See I thought I was at the place where they had lowered the curb. Downtown part of the curb is raised and there is a part that isn't and I thought I was at the part where the curb had been lowered and I was at the place where the curb was still high and I didn't step up over it (P10).

In an effort to remain engaged in their communities, participants discussed adaptive strategies to minimize risk such as: asking for help, being cautious/careful, concentrating, or completing the tasks more slowly. Related to asking for help, the participants' discussed using the perceived risk of an activity as the deciding factor on whether or not to ask for help:

See any jobs that I find that maybe I could fall or be risky, I leave it 'til somebody comes. And, like I would ask them (P1).

I try most things. But if I think, 'oh it's too dangerous to do that, get help', then I will (P5).

In terms of being cautious, concentrating, and completing the task more slowly, the participants stated:

I guess every move I make is with caution...Because I guess I get told so often "Be careful when you're out. Be careful when you're out"...That's the part I feel like I'm being babied I guess (P8).

I had a few falls. But the fall that broke my hip was the fall and it was, you know, like it was sight, I didn't count properly going down the stairs. I guess I wasn't, I wasn't concentrating (P4).

But eh, I just take it careful, slow. If I'm near a stove I check if it's on I don't do that in a hurry, you know. You still gotta do the same things you feel, if you're in a home working you're basically the same only much slower and much more careful (P1).

When help was not available and the task was perceived as too risky, participants simply did not engage in it for fear of jeopardizing their personal safety. For example, P7 stated:

It's still a case of I don't see well enough to say pour even boiling water into a mug to make instant coffee so I don't bother doing that anymore.

This was the only theme in which participants discussed not only their own individual responsibility for ageing well, but also discussed the necessity of an inclusive environment which either enabled or restricted their ability to mitigate risk while managing community participation. However, participants often took it upon themselves to individually manage risks and, at times, discontinued activity so as to responsibly manage personal risk while experiencing a tension between risk reduction and independence.

6.6.4 Managing expectations to be compliant, complicit, and cooperative

Overall, when discussing their involvement in daily activity, informants discussed the perceived importance of being compliant, complicit, and cooperative to what their friends, family, care staff, and service providers requested of them, as being a marker of the 'good older person'. For example, participants aimed to abide by requests made of them to not travel into the community unattended, to cease using the stove for cooking, or to only use taxi cabs for public transportation, to name a few.

Yet, there were examples where participants discussed resisting the social expectations of compliance, such as when the expectation to be compliant worked against their need or desire to be independent. For example, participants discussed the tension they felt when being compliant was not feasible because it limited their ability to complete necessary independent daily tasks. In these situations, participants were often required to act in contrast to the recommendations of service providers. For example, P8 discussed being told by a low vision specialist to not travel into the community by herself. Although she appreciated why the request was made of her, she could not comply because there was no one willing to bring her into the community to run errands:

Well their reason is I'm old, I could fall. I could, with my eyesight; I could step off of the curb at the wrong time. Just, they figure I don't see well enough to be on my own. My reason to go out, well who in the Sam Hill is going to take me if I don't go by myself? That's about it.

Similarly, P9 discussed her children's request for her to minimize the number of items she purchases when grocery shopping; however, P9 pointed to the lack of formal and/or informal support she received with grocery shopping. Thus, she felt obligated to carry home more items than she felt comfortable managing:

When I go out, I never come home without too many bags. And even carrying them, they [her children] keep giving me heck. "Mum, you shouldn't be doing this!" Well who else is gonna do it?

Both the examples from P8 and P9 reflect the idea that, at times, maintaining independence outweighs being compliant, complicit, and cooperative.

Further, some participants resisted being compliant, not solely out of a desire to be independent, but also because they felt as though inappropriate restraints were being placed upon them. For example, P3 had previously broken his nursing home's rules when he went out on an excursion because he was adamant in his desire to go into the community on his own. He stated:

I like to have control. I like to be able to control something, and I don't like to be told what to do.

P4, similarly discussed situations whereby she resisted receiving care from staff for tasks that she felt she had the ability to complete independently:

Yes. I find that, I find that each one of them has their own idea of what I'm able to do. And unfortunately, it's a bit irritating but I try to adjust. I don't totally adjust, let's face it, I'm no saint. I do not, I was...I know what I can do and I don't want to lose it. So, some things I'm pliable and I'll go along with them, and other things I will not because I know I have that ability.

This theme demonstrated the challenges older adults aging with disability face as they attempt to be independent, but may require assistance. When assistance required them to be positioned as compliant, complicit, and cooperative, they often resisted. This resistance towards being compliant, complicit, and cooperative was seen most strongly when participants felt that doing so would jeopardize their desire for independence or that the assistance was unnecessary based on inaccurate perceptions of their capabilities. As a result, a struggle can be seen within this theme whereby participants aimed to balance their desire to be a positive ager alongside their resistance to social expectations of 'oldness,' which is tied to notions of dependency and/or being incapable.

6.6.5 Striving to maintain efficiency

Another source of tension described by participants arose out of trying to live up to contemporary demands to be efficient, demands which can be seen as based in ableist normative expectations of bodily speed and capability. The desire to remain efficient was often framed within the social norm of 'keeping up' within an increasingly fast-paced society. In a similar way that participants resisted asking for help for fear of being perceived as a burden, participants strived to be efficient as they did not want to appear as a burden or nuisance or otherwise be seen as 'in the way':

People are in a hurry. Everything's got to be this way right now. Who wants to be bothered? I find you're a pain in the neck. I feel like that sometimes, that I'm just a pain in the neck, a nuisance (P1).

For P4, her desire to remain efficient and not 'hold people up' dictated the circumstances under which she would choose to count out her own money or allow a cashier to do so at her local convenience store, thus sometimes leading her to risk being seen as dependent on others. For example, P4 stated:

Sometimes it's, you know, it's crowded, people are in a hurry, and there's no sense in holding everybody up just because you want to be independent and want to do it yourself.

This perception of society as being 'too busy' caused the participants to frequently not ask for help with necessary daily tasks, further shaping disability in their everyday lives. For example, when asked why P10 does not request assistance from her neighbors, she stated:

They seem to, they always seem to be busy. Yeah, I think they see their—like if they pass me in the, in the hallway or something, they just "Hello [name of P10]," and they're on their way. You know? They don't stop...But oh they always seem to be in a hurry.

This was also true for participants who refrained from asking family members for assistance because the participants perceived their family members as too busy:

Today it's harder. People are working more, longer hours, and they don't need me burdening them (P9).

I'm going to find it's a lot more expensive as time goes on [in speaking about the future need to use taxi cabs more frequently]. I'm going to have to take—my son can't take me everywhere all the time. He lives way back on [neighborhood]. He is busy babysitting his grandchildren because those two are working like crazy to pay the mortgage. Everybody's so busy. I hate to impose on him anymore that I absolutely have to (P6).

At times, participants such as P5 felt that others, in this case assisted living care staff, had imposed their desire for efficiency onto the older adult, an ideal that could not always be lived up to. For example:

And I laughed, one girl was hurrying me and I said, 'now, now, now, I'm an old lady and I can't move as fast as you can.' She started to laugh. 'Okay, I'll slow down,' she said. I said, 'you better or you'll be picking me up off the floor.' They don't stop to think. They think, oh I have to get this done, you know. Come on, move. Sure.

When participants were not able to live up to the social expectations of efficiency, they often scaled back or discontinued meaningful activities altogether. Thus, this expectation could further lead to experiences of disability. For example, two participants discussed giving up playing cards because they were no longer able to move as quickly as the game, and other players, required of them:

We played a lot of euchre and I loved it, but I don't now. I can't. Well I guess I could, I could do the Braille. But it's pretty slow and people don't really have patience with somebody being slow at a card game (P1).

I played cards until, if you play with people who have all their sight, they want you to go faster, so I finally quit that (P8).

Although not explicitly addressed in the literature on positive aging discourses, this finding points to an important ableist expectation in which speed and efficiency are prioritized, which places unrealistic expectations on older adults with ARVL who may not be able to live up to these socially enforced norms.

6.7 Discussion

This study aimed to provide a better understanding of the complex interaction of age and disability by deconstructing the normative assumptions that underlie the meanings older adults with ARVL ascribe to ageing well. The study further aimed to speak to the tensions older adults negotiate in their attempt to maintain an identity of ageing well that is commensurate with broader messages conveyed through positive aging discourses. Findings from this study both support as well as build upon findings from previous research, thereby expanding insights into the meaning of 'ageing well' from the perspective of older adults with age-related vision loss. The study results also critically reveal a number of ways in which older adults are restricted by socio-cultural norms, such as the prioritization of independence, the normative ideals of attaining efficiency in an increasingly fast-paced world, the increasing focus on individual responsibility for managing risks, and the ageist assumptions tied to the expectations of an older adult persona in which being positive, compliant, complicit, and cooperative are held as absolutes. The data reveal tensions that arise for older adults with ARVL as they attempt to

live up to ideals of 'positive aging' , such as maintaining independence and reducing risk, which could come into conflict with each other, as well as tensions that arise when such ideals become highly challenging to achieve within particular environmental conditions.

Many of the findings of this study were well supported in both the existing positive aging research and in the ARVL literature. For example, the ultimate marker of 'ageing well' identified by our informants was that of maintaining independence while aging with vision loss. For the study participants, their desire for independence mainly stemmed from a resistance towards becoming dependent on family, friends, and care staff, a finding that is heavily reflected in existing qualitative age-related vision loss literature (Berger, 2012; Laliberte Rudman & Durdle, 2008; Laliberte Rudman, Huot, Klinger, Leipert & Spafford, 2010; MacLachlan, Laliberte Rudman & Klinger, 2007; Moore, 2000; Moore & Miller, 2003;) in which older adults openly expressed the daily struggles faced as a result of their growing dependence on others for assistance, coupled with a sense of guilt associated with needing to ask for help. In many situations, the refusal of participants to accept help was in an attempt to retain their independence, thereby rejecting taking on the construction of older adults as dependent and disabled. This finding coincides with the results of several empirical studies related to positive aging discourses that found independence to be an important self-reported marker of aging well (Hsu, 2007; Knight & Ricciardelli, 2003; Stenner et al., 2010). The prioritization of independence, conveyed by the study informants, can be tied to the predominant Westernized view of independence as being the absence or avoidance of dependence, a value "embedded in an ideology of self-reliance" (Secker, Hill, Villeneau & Parkman, 2003, p. 388). The study informants readily adopted the taken-for-granted cultural ideal that to be a 'good older person' one must be entirely autonomous, independent, or self-reliant. The informants sought to minimize their burden and dependence on others as they saw this as not only undesirable, but morally wrong. In fact, independence was so highly valued by informants, that the significant role that interdependence, or collective forms of support, could

play in their lives was dismissed altogether. Further, with the predominant focus on the individual to remain independent, the impact of the environment in either supporting or restricting independence was not fully explicated, thereby placing sole responsibility for aging independently onto the senior with vision loss. Within critical disability theory (CDT), the problematics of prioritizing independence have been raised and it has been argued that disabled people are often painted as "victims of an ideology of independence" (Reindal, 1999, p. 353). Unfortunately this often results in older adults actively working at maintaining independence even if it means restricting their participation in valued or necessary activities. This focus on independence, as argued by CDT, also supports the assumption that to be a responsible adult, one must be independent thereby further marginalizing those disabled persons, including older adults with ARVL, for whom assistance is necessary.

Approaching vision loss with steadfast positivism, acceptance, and perseverance was another important finding of this study. In fact, the desire to portray a positive image was so deeply entrenched, that some participants discussed hiding their negative emotional responses to vision loss or conveying a false sense of happiness to family, friends, and care staff. Similar to the research supporting independence as a marker of 'ageing well,' there was much empirical literature, from the perspectives of older adults, in which maintaining a positive attitude was viewed as a key strategy for positive aging (Duay & Bryan, 2006; Hsu, 2007; Knight & Ricciardelli, 2003; Reichstadt et al., 2010). Additionally, the assumption that older adults will attend to vision loss with steadfast positivism was further supported by existing ARVL literature (Moore, 2000; Moore & Miller, 2003). This focus on maintaining a positive outlook is not restricted to ARVL, but has been supported in the literature as a necessary component of successful treatment outcomes spanning diagnostic categories and age groups (LeBovidge, Lavigne & Miller, 2005; McGrath, 2004; Stewart et al., 2001). With such an overwhelming emphasis on remaining positive, seniors with vision loss are placed at an increased risk of conveying a false sense of happiness to family, friends, and care staff when, in actuality, they are experiencing a myriad of negative

emotions. Those who fail to subscribe to the socio-cultural norm of remaining steadfastly positive, may otherwise choose to struggle in silence, instead of accessing much-needed emotional health services.

Remaining active while managing risk was a prominent finding of this study and is well supported in both the literature relevant to positive aging discourses as well as ARVL. For example, there is a particular emphasis within positive aging discourses on the older adult making choices that will reduce the risks typically associated with aging (Conway & Cranshaw, 2009) and a subsequent blaming of individuals when their failure to protect themselves from the risks of aging leads to dependency, poor health, and disability (Mendes, 2013). There is also an abundance of mainly quantitative ARVL literature related to risk, in which seniors are typically constructed as 'at risk' for functional decline, dependence, injury/accidents, social isolation, and emotional distress (Campbell et al., 2005; Capella-McDonnall, 2005; Chou, 2008; Evans, Smeeth & Fletcher, 2008; Jongenelis, Pot, Elisses, Beekman, Kluiters & Ribbe, 2004; Kiata et al., 2008) as well as studies which pose older adults with ARVL as 'a risk' particularly related to economic and social risks posed to the health care system (Brennan, 2003; Jung, Coleman & Weintraub, 2007). Both areas of research reveal an increasing emphasis placed at the level of the individual to manage risk. The uptake of this discursive individualization was shown in the study findings in that adaptive strategies adopted by informants to manage risk were largely individually-devised and enacted, such as; asking for help, being cautious/ careful, concentrating, or completing a task more slowly. The study's emphasis on individual responsibility is further consistent with a techno-scientific perspective of risk such that risk is defined as an objective phenomenon, which exists outside of socio-cultural processes and context and can be identified, measured, and calculated (Ballinger & Payne, 2002; Kaufman, 1994). This approach to risk is problematic because it locates risk within the senior's body while obscuring the number of ways in which risks are socially constructed (Grenier, 2005). The implications that arise when older adults take up this discursive emphasis, needs to be critically considered. For example, this individualizing may lead to self-blame

when an event such as a fall occurs, as well as blaming by others such as health care professionals (Ballinger & Payne, 2002). Moreover, within a socio-political context in which neoliberal rationality has come to the fore, the need for state and collective efforts to address the physical, social, cultural, political, and institutional environmental structures necessary to enable active participation in a manner that helps mitigate personal risk and injury becomes either downplayed or obscured.

The final two findings of this study, regarding being efficient as well as being compliant, complicit, and cooperative, were important findings of the study though neither were found to be explicitly addressed in positive aging or ARVL literature. The 'efficiency' theme represents a new marker of 'ageing well' with vision loss. This theme identified the increasing tension experienced by older adults with ARVL when the desire to subscribe to socially constructed norms, such as being efficient, could not be matched by the abilities of individuals. This gap left informants feeling like a child, a deviant, a burden, or a nuisance. The taken-for-granted assumption that efficiency is a marker of 'ageing well' was met with challenges by those study informants who were often unable to live up to these socially-imposed expectations. For many informants, the continued desire to attain efficiency, and not be perceived as a burden, meant that they often did not ask for help with necessary daily tasks which may lead to an increased risk of social isolation. Further, by imposing this expectation of efficiency, to which few informants were able to successfully attain, seniors risked being made to feel as though they had failed to age well, raising concerns about self-blame and possible victim blaming (Lamb, 2014). As argued by Calasanti (2005), positive aging discourses, by offering up the promise of overcoming aging through lifestyle choices, can increase the "guilt for having the bodies that we have" (p.12).

The theme regarding being compliant, complicit and cooperative suggests a resistance, on the part of the informants, towards being perceived as 'old' or 'disabled', of which characteristics such as being passive, dependent, compliant,

complicit, and cooperative are often stereotypically associated (Jones & Higgs, 2010; Lamb, 2014). In actuality, informants desired to be positive agers but were restricted because they were perceived as having a disability. They aimed to resist being perceived as old, passive, and dependent because they saw these characteristics in a negative light. However, the implication is that in their attempt to not be perceived as 'old' or 'disabled', or otherwise succumb to the standing assumption of aging as a narrative of decline, informants failed to ask for help and they restricted the activities engaged in which shaped experiences of disability and may ultimately put them at greater risk of becoming dependent.

The limitations of this study point to some important directions for future research. For example, for each participant, data were collected over a period of one to three months. A prolonged study may have resulted in a more complete understanding of how the concept of 'ageing well' with vision loss changes over time. As well, a further limitation of the study is related to the demographic makeup of the older adult participants. All research participants were either born in Canada (n=6) or Western Europe (n=4) and immigrated to Canada as young adults. Ideas regarding what it means to age well are often embedded within Westernized socially-constructed norms that privilege productivity and independence. Thus, given the limited cultural diversity of the participant pool, the perceptions of what it means to 'age well' with vision loss may also have been limited. Future research, therefore, would benefit from the recruitment of more culturally diverse participants to ensure varied perspectives are captured regarding what it means to 'age well' with ARVL.

6.8 Conclusion

This critical ethnographic study explored the perspectives of ten older adults with low vision to gain new understandings of those attributes perceived as being the markers of a 'good old age' and how these markers are situated within both ageist and ableist social assumptions regarding what it means to 'age well'. The study also explored the complex interaction of aging and disability which has

been all too commonly overlooked in both social gerontology and disability studies. The results of the study indicated that older adults with ARVL describe the markers of a 'good old age' to include: maintaining independence while negotiating help, responding positively to vision loss, remaining active while managing risk, managing expectations to be compliant, complicit, and cooperative, and seeking to maintain efficiency. Such findings provide helpful insights into how disability is re-produced among older adults with ARVL and how older adults take on an identity that is consistent with many of the socially embedded norms regarding what it means to 'age well'.

6.9 References

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CHAPTER SEVEN

7.0 Environmental barriers and the production of disability for seniors with age-related vision loss (ARVL): A critical ethnographic study

7.1 Introduction

There is a strong correlation between aging and vision loss, with older adults constituting the fastest growing low vision group within industrialized countries (Watson, 2001). Unlike typical vision changes associated with aging, low vision is defined as a permanent “loss of visual acuity (i.e., less than 6/18 but at least 3/60) or visual field (i.e., less than 20 degrees) in the better eye, not correctable by spectacles, contact lenses, or intraocular lenses” (Spafford, Laliberte Rudman, Leipert, Klinger & Huot, 2010, p. 580). The most common low vision disorders include age-related macular degeneration (AMD), glaucoma, and diabetic retinopathy, with such conditions often collectively referred to as age-related vision loss (ARVL) (Watson, 2001).

An abundance of research has focused on demonstrating the association between ARVL and disability, most often operationalized as increasing difficulties or enhanced dependence in activity performance. This research suggests that ARVL negatively affects the performance of various types of activities, including self-care (Berger & Porell, 2008; Crews & Campbell, 2004; Grue et al., 2008; Knudtson, Klein, Klein, Cruickshanks & Lee, 2011; Travis, Boerner, Reinhardt & Horowitz, 2004; West et al., 2002), leisure (Boerner & Wang, 2010; Crews & Campbell, 2004; Desrosiers et al., 2009) and productivity (Alma et al., 2011; Lamoureux et al., 2007). Given that participation in meaningful activity is often proposed to be a key contributor to health and wellbeing, (Laliberte Rudman, 2006; Law, 2002), these findings are concerning and, in turn, a body of research has sought to understand the factors that contribute to the disabling effects of ARVL. For example, there is an overwhelming focus within the ARVL literature on individual-level measures of impairment, including the physiological correlates of vision loss, such as visual acuity, contrast sensitivity, and visual field as well as the impact of these correlates on activity performance (Grue et al., 2008;

Laitinen et al., 2007; Owsley, McGwin, Sloane, Stalvey & Wells, 2001; Wong, Guymer, Hassell & Keeffe, 2004). Other research has focused on those demographic variables, such as age (Alma, Van der Mei, Groothoff & Suurmeijer, 2012; Boerner & Wang, 2010; West et al., 1997) and socio-economic status (SES) (Alma et al., 2012) that are associated with increased disability amongst older adults with ARVL. Another subset of research has looked at the impact of emotional responses to vision loss, such as fear (Girdler, Packer & Boldy, 2008), grief/frustration (Teitelman & Copolillo, 2005; Weber & Wong, 2010), embarrassment (Girdler et al., 2008), and hopelessness (MacLachlan, Laliberte Rudman & Klinger, 2007), on the ability of older adults with ARVL to engage in daily activity. In an effort to manage the disabling effects of ARVL, this research has often proposed individual-level management strategies, such as the use of assistive technology to replace lost visual functions and enable older adults to cope with disabling situations (Copolillo & Teitelman, 2005; Eklund, Sjostrand & Dahlin-Ivanoff, 2008; Girdler et al., 2008; Ivanoff & Sonn, 2005; Lamoureux et al., 2007; Moore & Miller, 2003; Pankow, Luchins, Studebaker & Chettleburgh, 2004; Ryan, Anas & Bajorek, 2003; Stelmack, Moran, Dead & Massof, 2007), as well as the adoption of self-management strategies (Birk et al., 2004; Eklund & Ivanoff, 2006; Eklund et al., 2008; Eklund, Sonn, & Ivanoff, 2004; Ivanoff, 2002; Packer, Girdler, Boldy, Dhaliwal & Crowley, 2009). This research is problematic as it often serves to individualize disability by locating it within the person, instead of within interactions with the environmental context in which the individual is embedded. By doing so, it embeds implicit assumptions that impairment, such as age-related vision loss, naturally leads to disability and that the responsibility to manage the disabling effects of disability is primarily the responsibility of, and within the control of, the impaired individual.

Although evidence suggests that the environment also adversely affects the activity engagement of older adults with vision loss, this research is sparse within the ARVL field. When environmental factors are addressed, research is often centred exclusively on physical and, to a lesser degree, social environmental components. This focus is problematic in that cultural, political, and institutional

components are excluded. For example, Laliberte Rudman et al., (2010) and MacLachlan et al., (2007) revealed aspects of the physical environment, such as weather, season, time of day, and lighting, that influence the activity participation of older adults with ARVL. Other ARVL research has included the impact of home environmental modifications on supporting activity engagement (Stevens-Ratchford & Krause, 2004), the impact of supportive physical environments on successful instrumental activities of daily living (IADL) performance (Wahl, Oswald & Zimprich, 1999), and vision specific assessments regarding lighting, contrast, visual distractions, and glare that should be done when assessing home safety (Barstow, Bennett & Vogtle, 2011). From a social environmental perspective, studies have focused predominantly on social support and challenging social interactions for older adults with ARVL. For example, Girdler et al., (2008) found that relying on social support networks helped to support adaptation to vision loss and foster inclusion in activity engagement, while other studies found that older adults expressed feelings of resentment associated with having to depend on family members for assistance, choosing to limit their engagement in daily activity rather than ask for help (Laliberte Rudman et al., 2010, Laliberte Rudman & Durdle, 2008). Lastly, Teitelman and Copolillo (2005) connected the social environmental difficulties older adults with ARVL face to feelings of stigma and embarrassment that were particularly prevalent for participants when in public settings. Similar to the research focused on understanding the factors that contribute to the disabling effects of ARVL, this research is often limited by the adoption of an individualist approach in which the responsibility to mediate the effects of the environment is placed upon the individual (Hooyman & Kiyak, 2008) thereby disregarding the “configuration of sociomaterial space as an important site for the (re)production of disability” (Korotchenko & Hurd Clarke, 2014, p. 432). Such a perspective is bounded because it fails to acknowledge that older adults with ARVL often struggle to access their environments as a result of society’s prioritization of the able-body coupled with society's failure to accommodate difference, including differences based on age and disability (Kitchin, 2000; Oliver, 2004).

Moving away from this individualizing framework, critical disability theory (CDT) offers a means to re-think both the production of disability and its management. CDT is a theoretical framework for the study of disability (Hosking, 2008) that acknowledges the interplay of both the individual experience of impairment and how society is environmentally structured in ways that produce disability for those who are not able-bodied. A growing body of work has taken up CDT to counter approaches that locate disability solely within individuals; instead, CDT includes consideration of the socio-political production of disability. Within such work:

"disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have...Our society is built in a way that assumes that we can all move quickly from one side of the road to the other, that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions" (New Zealand Ministry of Health, 2001, p.1 as cited in Mertens, Sullivan & Stace, 2011, p.228).

Within the aging literature, outside of the ARVL realm, there is an emerging body of critically informed research addressing how disability is constructed through environmental contexts, as opposed to viewing it as a characteristic of age or impairment. For example, Grenier (2005) undertook narrative interviews with twelve older women with the intent of understanding how older women made meaning of frailty, disability, and decline within the context of their everyday lives. Using the examples of the home and bus, it was illustrated that understandings of disability are overwhelmingly focused on the body. In reality, however, the women's experiences of disability were connected more to the environmental context in which disability was experienced than their impairment and associated functional restrictions (Grenier, 2005). Raymond, Grenier, and Hanley (2014) explored how twelve people ageing with disabilities experienced and understood the notion of social participation, of which access to inclusive community settings was one key component. They found that the disabling impact of the environment increased the risk of community participation exclusion and they advocated for "shifting responsibility for inclusive practices to society, rather than onto the individual" (p. 57). Lastly, Korotchenko & Hurd Clarke (2014) engaged 29 older

adults (aged 51-92 years old) in qualitative interviews to understand the experience of power mobility within the context of the built environment. Participants revealed a variety of environmental barriers to mobility encountered in public spaces that served to transform “their power mobility devices into machines of disablement” (p. 438) and caused them to feel ‘out of place’ relative to their able-bodied counterparts. Thus, while assistive technology is designed to enable activity participation, environments can still create barriers that lead to experiences of disability.

This paper adds to this emerging body of critical gerontological work by addressing the socio-political production of disability for older adults with ARVL. Data was drawn from a broader critical ethnographic study that explored how the environment is constructed in ways that support as well as restrict the activity participation of older adults with ARVL. The broader study aimed to raise awareness of how the environmental barriers that older adults face, in relationship to various physical, social, cultural and political/ institutional factors, are embedded in ageist and ableist assumptions. Within this analysis, through the critical deconstruction of the identified environmental barriers, the ultimate intended emancipatory outcome of this paper was to promote the development and sustainment of vision-friendly environments that more fully support the activity engagement of older adults with ARVL. No known ARVL study to date has shifted away from dominant understandings of disability, as being located within the functions of the body, towards locating disability within the broader environmental context in which older adults with age-related vision loss are embedded.

7.2 Methodology and Methods

7.2.1 Study Design

Ethics approval to undertake this critical ethnographic study was obtained through The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) in October 2012.

Conventional ethnography asks 'what is?' while critical ethnography asks 'what is?' and 'what can be done about it?' (Cook, 2005; Madison, 2012). In this sense, critical ethnography is focused on eliciting not only the research participants' point of view but also questioning the prevailing status quo and dominant power structures present within a particular culture that serve to constrict marginalized people's lives (Cook, 2005; Simon & Dipbo, 1986; Thomas, 1993). This study focused on understanding the day-to-day experiences of older adults with ARVL and aimed to situate those experiences in larger social systems and structures in order to reveal the ways in which disability is constructed to marginalize older adults with ARVL and create barriers to full activity engagement.

7.2.2 Theoretical Underpinnings

Theoretically, this study was underpinned by the key tenets of critical gerontology (Estes, Biggs & Phillipson, 2003; Minkler & Holstein, 2008; Ray & Cole, 2009) and critical disability theory (Devlin & Pothier, 2006; Hosking, 2008; Hughes & Patterson, 1997). Critical gerontology aims to question taken-for-granted assumptions about what it means to age well and "the seemingly un-reflexive ways in which gerontological knowledge is created" (Holstein & Minkler, 2003, p. 789). It makes the inequality of the aging process visible and highlights how older adults are disenfranchised by political and social oppressive forces (Estes et al., 2003; Minkler & Holstein, 2008).

Critical disability theory emerged as an alternative to both the medical model of disability, which understands disability as individual pathology, meaning that there is something 'wrong' with the individual's body resulting from disease, trauma, or an accident (Albrecht, 1992) and the social model of disability, which locates disability within broader social, political, cultural, and environmental structures (Bricher, 2000). In fact, it is the combined limitations of both the medical and social model of disability that led to the consideration of the adoption of CDT, with its broader consideration of both the individual experience of impairment and the environment. Critical disability theory is informed by three

underlying assumptions (Hosking, 2008) including: a) disability is a social construct rather than a direct or immediate result of impairment; b) disability is a result of the complex interrelationships between impairment, the individual response to impairment, and the environment; and c) disability results in the marginalization and social disadvantage of disabled persons.

7.2.3 Primary Sample

The primary sample of the study consisted of ten older adults with ARVL. Older adults with low vision were purposively sampled for this critical ethnographic study because of their rich lived experience with vision loss. Participants were recruited through in-person presentations, organizational contacts, and newspaper advertisements. To participate, older adults needed to be 75 years of age and older, have received a diagnosis of ARVL (age-related macular degeneration, glaucoma, and/or diabetic retinopathy), self-identify as experiencing functional impairments due to ARVL, and be able to communicate effectively in English. Participants were excluded from the study if they experienced significant cognitive challenges, which impaired their ability to engage meaningfully in the data collection process. Detailed demographic data were collected during the initial narrative interview for the sample of older adults with ARVL (see Table 7.1).

7.2.4 Other data sources

Although older adults with ARVL represented the primary participant group for this study, two additional types of data sources were included to enhance understandings of the socio-political context in which the older adult participants' experiences occurred.

Seven community organization representatives were recruited, with their selection for inclusion based on findings emerging from the analysis of the older adult participants' data. For example, when the issue of bus services was raised repeatedly by the older adult participants, a representative of the region's

transportation system was recruited to participate. A diverse sample of representatives from age-friendly seniors committees (S1), vision rehabilitation (S2), low vision advocacy groups (S3), transportation services (S4), retail services (S5), housing services (S6), and seniors political/advocacy groups (S7) were included. To participate, the representatives needed to work for, or be a member of a community or political organization, which established policy guidelines or provided services that influenced older adults with ARVL, and they had to be able to participate in an interview in English.

Additionally, sixteen documents, published between 2002 and 2013, were included in the broader study. The documents were found through internet searches and well as through organizational contacts. All documents were selected based on emergent findings from the data collected with the older adult participants and community organization representatives. For example, themes emerging on accessibility legislation led to the inclusion of the policy document entitled "Accessibility for Ontarians with Disabilities Act (AODA), 2005". These documents provided a greater awareness of how the environmental context, in which older adults with ARVL were embedded, affected their ability to engage meaningfully in desired activities.

7.2.5 Data Collection

A modified version of Carspecken's (1996) five-stage approach for critical ethnography was adopted for the study. Data collection with the primary sample occurred over a period of nine months. All meetings were scheduled on dates, times, and locations that were convenient for the participants. A variety of data generation methods were necessary to understand how the environment restricted the full activity engagement of the older adults with ARVL. Older adult informants participated in a narrative interview, participant observation session, and a semi-structured in-depth interview (see Table 7.2). Additionally, basic demographic information was collected on the older adult participants through the administration of a questionnaire. The Visual Function Questionnaire (VFQ-

25), which is a widely-used, validated, self-reported, vision health status survey (Mangione, 1998), was also completed in order to quantify the degree of vision-related functional performance difficulties of each participant (see Table 7.3).

7.2.6 Data analysis

Data analysis of interview and observational data occurred simultaneously with data collection, such that emerging findings informed subsequent data collection. All interviews were audio-recorded and transcribed verbatim. Each transcript was subsequently analysed by the first author; however, resulting codes and categories were refined through ongoing team meetings. Each transcript and observation field note was coded individually, using both low level (open) and high level (theoretical) coding in order to develop a rich understanding of the data before codes were compared across participants to form categories and themes (Carspecken, 1996). Within this article, key findings, pertaining to the ways environmental features shaped the experience of disability for participants with ARVL, are presented below, using examples of three activities that commonly surfaced as challenging. Before presenting the findings, the study context is described by drawing upon results from the document analysis and the interviews with community representatives.

7.3 Study context

The documents included in this study were analysed using a modified policy analysis framework (see Table 7.4) as proposed by Bacchi (2009). The document analysis was designed to enhance understandings of the ways issues related to disability, age, and low vision was discursively framed within the study context. Combined with the data from the community representatives, the intent was to provide an in-depth description of the study context in relation to how such issues were framed and being addressed.

This study took place within a medium-sized Canadian city that had an active age-friendly cities initiative, a political awareness of AODA legislation, city-run

senior and disability advocacy committees, as well as some attention paid to addressing issues of environmental inaccessibility within the community.

Although community representative participants and reviewed documents recognized the issue of environmental barriers faced by aging persons and those with disabilities, there was an overwhelming focus on the prioritization of issues of physical accessibility with proposed and enacted solutions largely focused on physical environmental features. Of the seven relevant documents reviewed [(Global Age-friendly Cities: A Guide (2007), City of Hamilton: Barrier-Free Design Guidelines (2006), Accessibility of Grocery Stores & Pharmacies in Eight Hamilton Neighbourhoods (2011), Clearing Our Path: Universal design recommendations for people with vision loss (2009), Hamilton: A City for ALL Ages (2010), Accessibility for Ontarians with Disabilities Act (2005), and Hamilton: A City for ALL Ages Three Years On (2013)], four focused exclusively on issues of individual physical accessibility. As an example, *Clearing our Path: Universal design recommendations for people with vision loss* (CNIB, 2009) provided detailed recommendations for the improvement of physical accessibility in environmental spaces for persons with vision loss. Similarly, the *City of Hamilton Barrier-Free Design Guidelines* (2006) provided detailed recommendations to ensure the physical accessibility of city-owned facilities, parks, open spaces, and infrastructure. Among the community organization representatives, the issue of physical accessibility was also a prominent emphasis. For example, participants spoke in detail of a variety of physical environmental features necessary to support the inclusion of older adults with ARVL, including: urban Braille (S1, S3); tactile signage (S3); audible crosswalks (S1, S3); audible bus stop announcements (S1, S3, S4); non-glare lighting (S4); low bus floor access (S4); cleared pathways in public buildings and the community (S1, S3); colour-contrasted steps and curbs (S4, S5); and distributed information being available in accessible formats such as large print, Braille, and/or audible formats (S1, S4, S5).

Although the primary focus was on physical accessibility, there was some problematization of social and political/institutional environmental elements. For example, both the documents *Hamilton: A City for ALL Ages* (2010) and *Hamilton: A City for ALL Ages Three Years On* (2013) addressed social participation including the availability of meaningful opportunities for social engagement and institutional environmental elements such as affordable transit and housing. This focus on the affordability of public transportation and housing was further reinforced in the World Health Organization publication, *Global Age-friendly Cities: A Guide* (2007). Social as well as political/institutional environmental elements were also addressed by the community organization representatives. For example, several representatives discussed the importance of accessibility legislation, such as the AODA, as being a platform for more active organizational advocacy (S1, S2, S3, S4, and S5). Education and awareness-raising was also frequently discussed. For example, participants highlighted the importance of educating health care professionals on the needs of seniors with ARVL (S2), educating youth to better understand the experiences of people with vision loss (S3), and providing customer service training to retail personnel and transportation providers, regarding how to assist users with various disabilities, (S4, S5). Further, a few participants, such as S3, highlighted the importance of political advocacy in an effort to support the rights of older adults with ARVL to be included within the community. For example:

We do promote the advocacy part because we want people to know that they have rights, and they can have what everybody else has except vision...We try to advocate for people to get out and do things and be a part of the community. I mean the community is there for all of us. It's not just for the sighted people.

With the exception of *Clearing Our Path: Universal Design Recommendations for People with Vision Loss* (2009), which was specifically written to improve environmental access for persons with ARVL, there was limited attention paid to vision loss in the remaining documents. For example, *The City of Hamilton Barrier-Free Design Guidelines* (2006), briefly discussed visual accessibility, including issues of glare, lighting, and signage, while the documents *Hamilton: A City for ALL*

Ages (2010) as well as *Hamilton: A City for ALL Ages Three Years On* (2013) discussed issues of readability such as small print in newspapers, telephone books, and newsletters, for those with sight impairment. Further, *Accessibility for Ontarians with Disabilities Act* (2005) did include a reference to 'blindness/visual impediment' but only when providing a definition of disability. In addition, for many of the community organization representatives, vision loss was not at the forefront of their thinking when developing recommendations for environmental accessibility. For example, S4, a representative of the cities' transportation system spoke about the availability of training programs regarding how to safely ride the bus offered for persons with mobility devices and for those with cognitive challenges, however, no such training existed for individuals with sensory challenges such as vision loss. Further, in speaking of the attention the local age-friendly cities committee paid to issues of vision loss, S1 stated:

"Do any of our issues take into consideration the needs of people with vision problems? You know, more indirectly in that when we do walkability assessments, some of the barriers that we're looking at would affect people with vision problems. So for example, do the streets have urban braille? Do they, at the stop lights for example, do they have the sound signals that would help people with vision problems? Are the stoplights timed long enough to allow people to get across the street?"

Similarly, S7, who represented a senior's advocacy organization, stated that his organization was focused more on those seniors with mobility challenges as opposed to sensory impairment. For example:

"In our committees we've talked a lot about balance and mechanized [mobility devices] and things like that but we haven't talked a lot about vision. I think that is where we could certainly use more exposure"

7.4 Results

To illustrate the various ways that environmental elements contributed to the shaping of disability for these informants, three commonly discussed activities including shopping, eating, and community mobility were analyzed. Although the study informants discussed a variety of activities which they found challenging,

the three activities detailed here were chosen because the challenges expressed were largely shaped and perpetuated by the environment. All collected data were labeled with code numbers to protect the identities of the research participants. Older adult participants were coded as P1, P2...P10, while the community organization representatives were labeled as S1, S2...S7. All identifying information including the names of people, places, and names of organizations have been removed to protect participant anonymity.

7.4.1 Eating

Within common activities of daily living (ADL) scales (Letts & Bosch, 2005), eating is often framed as a basic ADL and the ability to engage in this task is understood as dependent on physical, sensory, cognitive, and other individual abilities. Relative to the task of eating, participants discussed a variety of challenges related to their visual impairment, including not being able to appropriately portion manageable bites; dropping food unknowingly; not being able to identify food items; and misidentifying cutlery. Related to managing appropriate bites, P10, during the observation visit, demonstrated difficulty knowing how much food was on her fork. As a result, she had to spit out some of the extra food in order to create more manageable bites. Further, in speaking about the inability to recognize food on their plates, P1 and P5 stated:

I can't see what I'm eating on my plate. My eyes have gotten worse. So I'm at the point where I can't see where the potatoes are, peas, or carrots, or the meat (P1).

The girls put a plate down, and if they don't tell me what's on it, the salmon is white, the potatoes are white, and sometimes the vegetables white...I look at the girl sitting beside me at the table and I'll say...can you tell me what's this over here? And she'll say, oh, you got potatoes there, you got fish there and you got your vegetable here. Okay, fine, I'm alright now, long as I know where things are (P5).

In addition, the informants highlighted a variety of disabling environmental features faced when engaging in the daily activity of eating. For example, as an alternative to cooking, some participants chose to eat their meals out at local

restaurants; however, this was not accomplished without challenges, including difficulty reading menus. That is, the use of small print and glossy materials on restaurant menus created and sustained the disability experience for the participants. Disability would not have occurred if the restaurants had been set up in such a way as to accommodate difference instead of reinforcing ableist assumptions, such as everyone can read small print. Congruent with critical disability theory, the participants had impairment (i.e. age-related vision loss) at all times; however, they were only 'disabled' when the environmental context was unsuitable to meet their needs.

To address this environmentally located challenge, participants did not question why materials were presented in inaccessible ways. Rather, they described the adoption of individual level strategies, such as planning where to eat based on the restaurant's daily special so that consulting a menu was unnecessary. Although such strategies were often described as effective, they also narrowed the range of possibilities in terms of where participants could engage in the activity of eating out:

And I can't read the menus, you know, so they have to read, you know, the menu or the board or whatever, wherever you are (P4).

I can't read most menus because they're on glossy paper or they have that laminated thing. So I know most of their menus now (P7).

For many participants, their challenges with eating had less to do with the physical act of feeding themselves and more to do with a fear of social embarrassment. For example, participants described feeling embarrassed about eating out in a restaurant and so adopted certain individual-level compensatory strategies such as, choosing a non-messy meal option and being cautious in order to minimize embarrassment caused to oneself or others:

I always was careful to order something that I knew I could handle when I go out, when I'm not with family (P4).

So I pick a dish that is not messy...Try not to...I never really thought that I would be embarrassing to people who'd bring me for dinner, but I have to

be a little more careful now that I don't spill it or something or knock something over. I gotta pay attention, more than before (P1).

Their fear of embarrassment was created and sustained within a social environment that discriminates against the disabled body in favour of that which is perceived as 'normal', namely being able-bodied. Importantly, the socio-cultural expectations of what constitutes 'normal' are established and given meaning by those social groups, namely able-bodied persons, who have the greatest amount of power and privilege to enforce their perceived notion of normalcy. These dominant social groups are then able to position certain groups of people, including disabled persons, as falling outside of the set norm (Fitch, 2002). Therefore, by setting the standards for 'normal' eating according to able-bodied assumptions, older adults with age-related vision loss are framed as 'disabled' for failing to meet these normative social standards.

Such feelings of perceived social embarrassment further led participants to limit their eating out at restaurants as a result. For example, P1 stated:

I don't go out much anymore because I can't see, I can't see what I'm eating on my plate, eh, and I don't want to make a mess or I'm a little embarrassed if I spill something eh, so I really don't feel as relaxed eating in a restaurant as I used to.

By limiting their social engagement, however, the participants may also be placing themselves at a greater risk of social exclusion which, in turn, serves to further lead to a sense of disablement and a heightened sense of vulnerability, marginalization, and social devaluation (Korotchenko & Hurd Clarke, 2014).

7.4.2 Shopping

Shopping was a frequently discussed activity in which the disabling organization of environmental spaces that prioritize the able body served to disable older adults with age-related vision loss. Concerning the task of shopping, some of the more frequently noted and/or observed difficulties participants encountered included: reading prices; finding items on crowded shelves; and navigating

around store displays. Instead of situating such disabling features of the environment as being within the responsibility of society to address, study participants frequently took on a personal responsibility. For example, participants discussed adapting how they completed their shopping including asking for help, using assistive devices such as a magnifying glass, and/or only shopping in familiar stores or buying familiar products. For example, P7 stated:

Well I can't read labels anymore. So I only go to shops where the owner has known me and I make a point of going to the staff and asking questions and usually they're very helpful.

I mean I have a magnifier with me when I go to the stores but it's so difficult to read that small print, even with a magnifier, that it's not worth it. So I only buy the brands that I'm used to.

Another commonly discussed challenge of shopping was managing money including using debit machines. Participants described asking family, friends, or store employees to help them distinguish bills as well as navigate the ever-changing debit machines. Due to the disabling features of the debit machines, including difficult to read print and screen glare, participants were forced to rely on others, including strangers, to help manage their private banking affairs, thereby posing a potential financial risk to the participants. During the observation visit with P4, for example, the participant requested that the first author pay the cashier at the convenience store where we had visited for our observation visit. Further examples include:

I need a lot of help...Even my debit card- I have to, they [referring to store clerk] even have to put my number in, I can't see it (P2).

And now that I can't see the screens where you put the [debit card] in, it's just one more reason for not doing it. I will go with my checkbook. I will expect them to write it. I'll use my magnifier to make sure they've written it properly. Then I'll sign the check (P7).

I can see them; it's just that, there again, every once in a while, it's a different kinda machine, and I think, "What does that mean?" I have to ask. You know, if they were all the same, it would be easy, wouldn't it? (P9).

The lack of consistency between devices was a significant source of the frustration surrounding the use of debit machines. Indeed, the importance of familiarity and consistency was discussed by participants within the context of shopping, with a great deal of frustration expressed when product layout and/or labels were changed:

I usually, I'm a creature of habit with food now especially, I have to. And I know what it is. I know by looking at the label unless they change it. That makes me angry because they keep changing the bottles (P9).

The pharmacy changed where the things are on the shelf. When you go to the drugstore, you know where the toothpaste is and now it's gone because they moved it... They seem to delight in changing things (P10).

These examples demonstrate the subtle ways in which participants were made to feel that their bodies were "out of place" (Kitchin, 1998, p, 354) in a predominantly able-bodied environment. Their feelings of distress and frustration reflected a deeper entrenched feeling of being un-welcomed in a space that did not consider the needs of older adults with vision loss. By moving items around the store, placing obstacles in aisles, changing product labels, and affixing difficult-to-read prices on store shelving, participants were 'disabled' not by the functional limitations of their vision loss, but as a result of their environment, both of which then contributed to their struggles. This further resulted in their bodies being subsequently marked as 'other' relative to the able-bodied norm.

In addition to the above-mentioned challenges with shopping, participants also discussed a deeply entrenched fear of being taken advantage of in the community when completing their daily shopping errands. In a society that values fitness, youth, health, mobility, and independence (Korotchenko & Hurd Clarke, 2014), while simultaneously devaluing older adulthood and disability, participants experienced a heightened sense of fear and vulnerability when accessing their communities on account of both their age and ARVL:

When I go out I don't wear any rings or anything and I don't dress fancy or anything...I don't want to look like a mark (P6).

Sometimes I'm a bit nervous. It depends on how crowded the street is. I'd rather have it crowded enough that I don't think anybody's gonna knock me off...I just feel if there's more people on the street there's less chance of you being--like your purse snatched or other things (P8).

If I can't see that something is coming that way, I'd be taken advantage of. Of course, I'm a sitting duck. If I can't see, they can grab it [referring to her purse] and I don't even know which way they've gone (P6).

7.4.3 Community Mobility

Although a number of environmental mobility enablers existed in the community, such as audible crosswalks, urban Braille, sidewalks outlined in yellow paint to identify the sidewalk boundary, and automated bus announcements, nearly all of the participants recounted experiences where they faced barriers to community mobility that caused them to be 'disabled.' These barriers served to "separate disabled people from their 'normal' counterparts" (Imrie & Kumar, 1998, p. 365). For example, when participants travelled outside their immediate neighbourhood, they expressed considerable fears, including the fear of crossing at busy intersections when not enough time was provided in order to cross safely. During the observation visit with P6, for example, the participant was only able to cross 3/4 of the street, walking at a brisk pace, before the hand symbol began to flash, thereby causing the participant considerable anxiety. Further examples include:

You press the thing and wait til the walking sign comes on, which I can see fine, but it doesn't stay long enough for me or for any senior or anybody with a walker or wheelchair to get from this side, to the median, to the other side before the thing starts flashing 'Don't go!' (P6).

There are such busy streets around here and they only give you just enough time to get across. As soon as the light changes you gotta be there ready to go and the cars are ready to go also when it's their time. It's really tight...They just don't give you any time and if you're just a little slow, it's gonna change before you get across (P10).

This example points to how disability is not simply a result of the functional limitations of the visual system but the interaction of that bodily experience with the inaccessible features of the environment. For example, the amount of time provided at a crosswalk is based on ageist and ableist assumptions; mainly that

all persons have the necessary capabilities to cross the road promptly. When sufficient time is not provided, older adults with ARVL are disabled on account of the environmental context failing to accommodate or support differences from normative standards (i.e. young/able-bodied).

Several participants also spoke of their fear of falling both within the community as well as when taking public transportation:

I watch the cracks in the sidewalk. I watch where I put my feet when I walk because I don't want to trip. It's so easy to trip. That can spoil your whole life. I've seen it happen to seniors around here (P6).

And if I go in with a walker, and he drives away while I'm still walking, that's a no-no, they're not supposed to do that, they have to wait until I sit down, and sometimes they don't, I'm sorry driver, you know the rules. But they are in a rush to go again. But if they go fast I can fall down. They're supposed to wait til I sit down. Especial the blind people, you know (P2).

These fears were actualized due to largely system-level issues such as poorly maintained physical infrastructure within the community including cracked sidewalks as well as bus drivers who were either poorly trained to the needs of older adults with vision loss or were more focused on maintaining their schedules than passenger safety. In fact, during the observation visits with P2, P6, and P9, bus drivers were observed to begin driving before the participants were safely seated.

Participants managed their community mobility as they did other environmentally produced challenges. For example, they discussed using a variety of individual-level compensatory strategies such as: listening for traffic surges; planning trips ahead; using landmarks; visualizing a space; counting steps; using familiar routes; concentrating and being cautious; and asking for help. During the observation visit, P7 was observed to use landmarks in order to navigate her physical space. For example, in the pharmacy, she walked until she reached the eyeglasses and then turned left down the aisle that brought her directly to the exit. However, a display had been placed in the aisle that P7 hit twice in her attempt to navigate around it. Participants also discussed their use of a white

cane and/or a 'Traveler with Vision Loss' sign affixed to their walker as a means of identifying their vision loss.

When I go out I take my cane to let people know I have a problem and to help me if I am walking on the sidewalk (P10).

Once you are blind, you have your white cane. I guess if you have your white cane with you all the time it's more obvious then to people [that you have a disability] (P6).

For some participants, the use of identifiers of vision loss also minimized the risk of confrontations with other pedestrians; in the case that the older adults with ARVL accidentally bumped into them. For example, in speaking about her friend with vision loss and a recently obtained white cane, P9 stated:

Before she got the white cane, people were rude. One guy even stopped and said "What's the matter with you lady? You blind or something?" I said, "Yes, she is!" Then, he shut up. Once she had the white cane, she said, "Boy, with this thing, I can move mountains." Oh what a difference it made. Isn't that funny? They don't stop and think; they just snap.

Similarly, P7 stated that her reason for carrying a white cane in the community was for insurance, so that if she accidentally hit someone, her visible white cane meant people could not be angry with her:

Usually they have a scowl on their face when they turn around and then they see the white cane and they're almost syrupy sweet afterwards which doesn't cut it as far as I'm concerned. They should be observant of their environment, just as much as I try to be.

The use of the white cane was described as simultaneously enabling and disabling as it related to community mobility. While for some participants, the use of the white cane promoted their independence, others noted how their use of a white cane caused their impairment to be highlighted and otherwise brought to the foreground thus marking their bodies as 'other' relative to the able-bodied norm (Korotchenko & Hurd Clarke, 2014). These latter participants remained hesitant to use such identifiers in the community not only because of the stigma associated with being 'disabled', but also because they feared it would signal

their vulnerability. For example, P1 spoke about her hesitation of affixing a 'Traveler with Vision Loss' sign on her walker, while S3 discussed his hesitation in using a white cane:

Like somebody said to me that works for [name of organization], maybe they're right but I think they're dead wrong, put a sign up on your walker, visually impaired. And that sounds good, right? So if you bump into something they know you're not drunk or stupid, that you're visually impaired. But what about all the rotten people in the world that are just waiting to put you as a victim. You're saying, look at me, I'm a victim. I'm easy to pick on, I'm easy pickings. Do I want to do that? No (P1).

I felt like the white cane gave me a target on my back. You know? They know I'm blind. They know I can't see. How am I going to recognize them if someone decides that they want to do me harm? You know, rob me or whatever (S3)?

Even with the identifiers of vision loss, participants found a general lack of understanding among the public particularly when the disability is invisible, as age-related vision loss is. This assumption of able-bodiedness meant that requests for assistance were sometimes met with skepticism. For example, P6 spoke about the difficulty she encountered, trying to have her toenails cut at a local community church, because she was not 'obviously disabled':

If you don't look as if you have a problem, you don't have a problem. That's part of it, I think. It's not obvious to people. A lot of seniors get their toenails clipped because they have arthritis or they can't bend down. Why I go is because I can't see my toenails. I told her I said, "I have to make an appointment for next time." She's like, "I'll try and fit you in." I said, "I can't see them. They won't get cut. You have to fit me in somehow." She couldn't understand somebody who can't see their toenails. She can understand people with arthritis or people in wheelchairs or something like that, which is pretty obvious; you just have to look at them. Somebody who can't see very well, I guess it's not obvious to somebody.

7.5 Discussion

In this paper, we have examined how disability was produced for older adults with age-related vision loss when they encountered environmental features that were embedded in ageist and ableist assumptions. Overall, within the findings it was difficult to disentangle issues of age and ability. Discourses of positive aging,

youthfulness, health, and functionality are often elided, with each seen as a marker of the other thus contributing to the difficulty of disentangling ageism and ableism (Caronda, 2008; Hurd Clarke & Korotchenko, 2011). Further, critical disability theory, argues for multidimensionality as an integral component to understanding disability. Using a multidimensionality approach, oppressions are shown to not operate independently but rather various social structures and positions related to gender, age, culture, dis(ability), ethnicity, social class, race and other socially defined attributes are seen to intersect in complex patterns to compound issues of oppression or social disadvantage (McGibbon & McPherson, 2011). As applied to the study findings then, it was not age or ability alone but rather the intersection of these social structures, among others, that served to influence the older adult participants as they attempted to engage with the ageist and ableist features of their environments.

Similar to the existing ARVL literature (Barstow et al., 2011; Girdler et al., 2008; Laliberte Rudman & Durdle 2008; Laliberte Rudman et al., 2010; MacLachlan et al., 2007; Stevens-Ratchford & Krause, 2004; Teitelman & Copolillo, 2005; Wahl et al., 1999), the older adults in our study spoke, in detail, of the physical and to a lesser degree the social environmental barriers that influenced their activity engagement. This parallels what was fore fronted both within the documents and by the organizational representatives interviewed. Thus, the participants' experiences appear to be both reflected in and shaped by socio-political context. Yet, with such an overwhelming focus on the physical and social environment, few participants, or documents, discussed those underlying cultural, political, and/or institutional assumptions and practices that would need to be in place in order for older adults with ARVL to feel included within an otherwise ableist world; a world that is focused predominantly on the needs of the able-bodied population while simultaneously 'othering' those who are disabled.

Participants also discussed, albeit implicitly, their feelings of being 'out of place' in a predominantly able-bodied world; a finding that has been supported by Korotchenko and Hurd Clarke (2014) who found that the environment is "socially

constructed to perpetuate the dominance of the non-impaired body, while simultaneously marginalizing and excluding those whose bodies fail to conform to rigid normative conceptions of fitness, youth, health, mobility, and independence” (p. 432). These feelings of being 'out of place' including the social embarrassment participants felt when eating out in a restaurant, the frustration experienced with ever changing product layout and labels at the grocery store, or the anxiety faced when crossing at an insufficiently timed crosswalk were all shaped via subtle ageist and ableist features of the environment, thereby serving to further perpetuate disability and a range of negative outcomes found to be associated with ARVL, including social isolation and marginalization. To move forward, we must question the concept of 'normal' as representing an ideological social construct which has the unintended consequence of excluding disabled persons, and those who do not otherwise meet youthful standards of function, from a society that was not designed to meet their needs (Terzi, 2004). In this sense, disability has resulted from the prioritization of the able body and through the inability of the environment to accommodate or support difference from able-bodied normative standards. This represents a form of disablism or able-bodiedness, in which there is discrimination against disabled persons in favour of that which is perceived as 'normal'. Our study showed how disablism can be particularly problematic, because it imposes “the projection of ‘able-bodied’ values which legitimize oppressive and discriminatory practices against disabled people purely on the basis that they have [an]....impairment” (Imrie, 1997, p. 263).

We also found that older adults with ARVL individualized their disability and took on a personal responsibility for managing their vision loss. For example, participants discussed, at length, the adoption of various individual-level compensatory strategies to mitigate the disabling effects of the environment. This finding has been reinforced within the existing ARVL literature that is focused on such individual-level management strategies as the use of assistive technology (Copolillo & Teitelman, 2005; Eklund et al., 2008; Girdler et al., 2008; Ivanoff & Sonn, 2005; Lamoureux et al., 2007; Moore & Miller, 2005; Pankow et al., 2004;

Ryan et al., 2003; Stelmack et al., 2007) and treatment approaches focussed increasingly on self-management programs (Birk et al., 2004; Eklund et al., 2004; Eklund & Ivanoff, 2006; Eklund et al., 2008; Ivanoff, 2002; Packer et al., 2009). Although such strategies can result in positive effects, what is apparent is that the types of individual-level strategies often employed cannot overcome 'disability' because it is created and sustained through the struggles that individuals with impairment encounter when met with an inaccessible environment. There has been some research to support this, including Minkler and Fadem (2002) who stated that disabled adults "view their functional ability as increasingly dependent on the success with which their environments can adapt and change to accommodate their changing bodies and personal needs" (p. 231). By moving away from the tendency to place disability within the individual, and by moving towards an understanding of disability as socially created, a shift can be encouraged, as it pertains to responsibility for addressing disability issues, from individuals to the community (Gilson & Depoy, 2000; Stone, 2013).

Although the study findings showed that disability was overwhelmingly individualized, there were some exceptions, in that the need to promote societal responsibility for ensuring accessible environments was raised by a small number of informants. For example, P7, who was a prominent aging and disability advocate in her community, stated:

"I have limitations, I am not disabled. It's my environment that makes me disabled. Well anything I do, I have learned how to do within my limitations, but if I go out and am faced with a flight of stairs, and I have to go around the block to get from A to B, then that means that society, in general, has not taken [disabled] people's needs into the scope of things."

One of the primary goals of critical theory is to facilitate social change (Cooney, 2006; Given, 2008). Our findings support a focus on change as it relates to the creation of age and vision-friendly environments that enable the full participation of older adults with ARVL. To accomplish this goal, there is a need for more inclusive social policy that shifts away from the current focus on the prioritization of issues of physical accessibility in the built environment towards a greater holistic

framework, which includes attention to physical, social, cultural, political, and institutional environmental factors. Although environmental modification is one step towards eliminating particular physical barriers, it is insufficient for addressing the deeply entrenched social exclusion faced by disabled older adults. It is also insufficient for changing policies, institutional practices, and discriminatory cultural norms that permeate social consciousness. As such, in addition to eliminating those environmental obstacles that limit accessibility, efforts must also be directed towards changing "discriminatory social practices that underlie disablist spatial organization that precludes older adults' inclusion and participation in their communities" (Korotchenko & Hurd Clarke, 2014, p. 442); and the establishment of more inclusive social policy provides one means through which to accomplish this goal. Advocacy provides another such approach to address those underlying disablist policies and unquestioned social norms that serve to disable older adults. By adopting the ideals of advocacy, social transformation, and emancipatory social change, all of which are defining features of critical social theory (Given, 2008), future research has the opportunity to reject broader environmental barriers, such as those discussed herein, as static 'givens' and instead question how such barriers are created and legitimized within a largely ageist and ableist environment. Only then can the creation and sustainment of age and vision-friendly environments be more fully realized. In addition to inclusive social policy and advocacy, a focus on education is also paramount towards the development and sustainment of age and vision-friendly environments. For example, a focus on age and vision-friendly environments could be integrated into educational curriculum for various professional programs including: optometry; ophthalmology; gerontology; environmental studies; disability studies; low vision rehabilitation; and health professional programs. In addition, educational training programs, focused on understanding the complex needs of seniors with ARVL and how best to meet those needs, could be geared towards groups such as customer service personnel or city transit officials. It is only through education that society can begin to understand the influence of environmental barriers on the full participation of older

adults with vision loss in daily life and how the presence of an age and vision-friendly environment is a key determinant in enabling their personal success.

7.6 Conclusion

In this study, which drew on data from a broader critical ethnographic study, we explored how the environment, including various physical, social, cultural and political/ institutional factors, shaped and perpetuated the disability experience for older adults with ARVL. Within the analysis and interpretation, we have aimed to critically deconstruct the ways in which identified barriers were embedded in inter-linked ageist and ableist assumptions. Results highlighted several environmental barriers faced by study participants when engaging in the meaningful activities of shopping, eating, and community mobility. Lastly, our study identified key recommendations intended to support the future development and sustainment of vision-friendly environments that more fully enable the activity engagement of older adults with ARVL.

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Table 7.1: Participant Demographic Chart (n=10)

	N=
Age (years)	
75-80	3
81-85	3
86-90	3
91-95	1
Sex	
Male	2
Female	8
Current marital/partnership status	
Married	0
Divorced	1
Widowed	7
Single; never married	2
Place of birth	
North America	6
Europe	4
Current financial situation	
Excellent	2
Good	5
Fair	3
Poor	0
Highest level of formal education completed	
Less than grade/elementary school completed	0
Grade school completed	1
Some high school	3
High school completed	4
Some college/university	2
College/university completed	0
Living situation	
Independently in house or apartment	7
Nursing home	1
Retirement home	2
Name of vision loss condition	
Macular degeneration	10
Glaucoma	4
Diabetic retinopathy	1
Cataracts	5
Age-related vision loss onset	
Gradual	8
Sudden	2

*Time since your vision loss condition was diagnosed	
0-2 years	1
3-5 years	1
6-10 years	4
More than 10 years	5
Children	
Yes	8
No	2

*Eleven time points have been noted as participant P7 noted different dates of diagnosis for the macular degeneration and glaucoma.

Table 7.2: Data collection process for the older adults with ARVL

Narrative interview	Observation session	Semi-structured interview
<ul style="list-style-type: none"> - First in-person data collection session. - Using Wengraf's (2001) lightly structured narrative interviewing approach, this session focused on eliciting the older adult's story of their vision loss. 	<ul style="list-style-type: none"> - Second in-person data collection session. - Occurred 2-3 weeks following narrative interview. - Using the observation format proposed by Spradley (1980), this session focused on the observation of an activity chosen by the participant that was meaningful to him/her. Examples included going shopping, going for a walk, going out to eat at a restaurant, or attending a Braille lesson. 	<ul style="list-style-type: none"> - Third in-person data collection session. - Occurred during week 7 or 8 of the 2 month data collection round. - Session focused on the influence of the physical, social, cultural and political/institutional environment on activity participation.

Table 7.3: Visual Function Questionnaire (VFQ-25) Participant Results

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Overall Mean
General health	50	50	0	75	50	75	50	75	0	25	45
General vision	20	40	0	40	40	60	40	20	60	20	34
Eye pain	88	50	100	75	87.5	100	50	25	100	100	78
Near activities	25	33	17	50	17	67	33	25	83	25	38
Distance activities	0	8	8	58	8	50	37.5	16	75	8	27
Social functioning	12.5	37.5	37.5	50	0	87.5	37.5	12.5	62.5	25	36
Mental health	56	25	31	81	69	81	44	6.25	69	50	51
Role difficulties	87.5	75	25	75	37.5	100	25	62.5	75	50	61
Dependency	50	25	17	100	42	92	83	33	83	50	58
Driving	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Color vision	100	50	0	50	25	100	100	25	100	100	65
Peripheral vision	0	25	0	75	25	75	50	25	50	50	38
Overall Composite Score	44	37	24	65	35	81	50	25	76	48	49

*VFQ-25 scores reflect a quality of life indicator from 0 (lowest possible score) to 100 (highest possible score). The overall composite score is an average of the 11 vision-targeted subscale scores (not including general health ratings) for each participant. Overall mean scores across participants were lowest in the areas of distance activities, general vision and social functioning

Table 7.4: *Modified Policy Analysis Framework proposed by Bacchi (2009)*

- 1) What is the problem represented it to be in the document or policy?
- 2) What presuppositions underlie this representation of the problem?
- 3) How has this representation of the problem come about?
- 4) What is left unproblematic in this problem representation? Where are the silences? Can the problem be thought about differently?
- 5) What effects are produced by this representation of the problem?
- 6) How is this representation of the problem introduced, disseminated, and defended? How could it be questioned, disrupted, and replaced?

CHAPTER EIGHT

8 Discussion and Conclusion

8.1 Introduction

This work concludes with a summary of key findings and insights gained from undertaking this critical ethnographic study. I explore multiple implications of the findings for older adults with vision loss, researchers, and low vision rehabilitation professionals. I also consider the study implications in terms of the development of vision-friendly environments and inclusive social policy. I attend to the primary strengths and boundaries of the study as well as directions for future research. I revisit some of my personal reflections, including both theoretical and methodological insights gained, as well as my reflections on the research process and my development as a researcher over the past four years.

8.2 Summary of Thesis Structure and Foci

I completed my dissertation using an integrated manuscript approach. Together, these chapters tell the story of how disability, as experienced by the study participants with age-related vision loss (ARVL), was shaped within particular physical, social, cultural, and political/institutional environmental features and how such features were often embedded within inter-linked ageist and ableist assumptions.

In chapter one, I introduced the study purpose and research objectives. I defined ARVL and the associated medical conditions including age-related macular degeneration, glaucoma, and diabetic retinopathy. I established the study significance given current demographic trends related to aging and vision loss as well as the occupational implications associated with ARVL. In this chapter, I paid particular attention to defining a number of terms used throughout the dissertation including: occupation, occupational engagement, environment, disability, older adults, and culture. Lastly, I provided a detailed critical exploration of my positionality in relationship to both the research topic as well as

my research participants and situated the research context geographically, socially, culturally, and politically.

Chapter two was published by the British Journal of Occupational Therapy in 2013; it is entitled, *Factors that Influence the Occupational Engagement of Older Adults with Low Vision: A Scoping Review*. It explored demographic, emotional, behavioral, diagnostic, and environmental factors which have been studied in relation to the occupational engagement of older adults with ARVL. The paper included a discussion regarding how the results of the scoping review may be used to further define and expand the role of occupational therapy in low vision rehabilitation. By providing evidence of the gap in low vision research specific to environmental influences, this chapter identified the knowledge gap that became the focus of this thesis.

Chapter three detailed the methodology and methods adopted for my study. I began with a comprehensive overview of my paradigmatic, ontological, and epistemological positioning followed by a discussion of the theoretical underpinnings of the study including critical gerontology, a critical occupational perspective, environmental gerontology, and critical disability theory. I described my approach to participant recruitment, which was eased tremendously through my prior immersion in the field of low vision through my involvement with the Canadian National Institute for the Blind (CNIB), the Haldimand Abilities Centre (HAC), and the Hamilton Council on Aging (HCoA). Next, I outlined my choice in adopting a critical ethnographic methodology and detailed my data collection methods which included a combination of interviews (both narrative and semi-structured), participant observation, and document analysis. Lastly, I outlined my process of data analysis and outlined the strategies I employed to ensure research rigor.

Chapters four and five were both theoretically oriented manuscripts. Chapter four is entitled, *Enhancing Environmental Gerontology: Integrating a critical perspective* and is currently being reviewed by the *International Journal of Aging and Later*

Life. Chapter five, entitled, *Re-shaping understandings of disability associated with age-related vision loss (ARVL): Incorporating critical disability theory into research* will soon be submitted for publication to the *Canadian Journal of Disability Studies*. Chapter four outlined the importance of expanding the use of a critical sensibility in environmental gerontology. In this chapter, I aimed to demonstrate the need to expand the field from a micro-and meso-level approach towards a holistic view of the environment and propose a shift from a static to a more dynamic environmental conceptualization. In chapter five, I outlined the key aims, emphases, and assumptions of critical disability theory and explored how such an approach could lead to new research foci in the study of ARVL. Both of the theoretical chapters provided the conceptual groundwork for this study. For example, my adoption of critical gerontology, a critical occupational perspective, critical disability theory, and a critical environmental gerontological sensibility influenced data collection, data analysis, and interpretation, as well as the presentation of the empirical study findings, as outlined in chapters six and seven.

Chapters six and seven presented empirical findings of the study in manuscript style. Chapter six is entitled, *Negotiating 'positive' aging in the presence of age-related vision loss (ARVL): The shaping and perpetuation of disability*. In it, I focused on exploring those attributes that older adults with ARVL perceived as being the markers of a 'good old age' and how these markers were situated in both ageist and ableist social assumptions regarding what it means to 'age well.' I also outlined the ways in which such assumptions, in turn, shaped the daily lives of older adults with ARVL. In chapter seven, entitled *Environmental barriers and the production of disability for seniors with age-related vision loss (ARVL): A critical ethnographic study*, I aimed to shift away from dominant understandings of disability, which locate disability within the functions of the body. Instead, I sought to locate disability within the broader context in which older adults with age-related vision loss are embedded, thereby highlighting the socio-political production of disability. The manuscripts will be submitted for publication to

Ageing & Society and the *Journal of Community and Applied Social Psychology* respectively.

8.3 Study Implications

The purposes underlying critical social theories are to question taken-for-granted assumptions, challenge the status quo, raise awareness, and stimulate action and social change (Given, 2008). I sought to accomplish these goals of critical scholarship and in so doing, revealed a number of study implications for persons with vision loss, vision rehabilitation professionals, and researchers, as well as for the development of vision-friendly environments and inclusive social policy. Below, these implications are organized in relationship to key issues that surfaced as vital to addressing the disabling effects of environmental influences as experienced by older adults with age-related vision loss.

8.3.1 Addressing the misperceptions of vision loss

A key finding highlighted in this thesis was the significance of social misperceptions regarding age-related vision loss. Revealing these misunderstandings allowed me to better understand how these older adults negotiated their ARVL and how these negotiations influenced their occupational engagement. As highlighted in chapter seven, study participants frequently felt that even with their identifiers of vision loss, such as a white cane or “Traveler with Vision Loss” sign, there was a general lack of understanding among the public as to their needs. For example, P6 spoke about the difficulty she encountered trying to have her toenails cut at her local community church, because she was not ‘obviously disabled.’ A further example could be drawn from the study participants’ perception that vision loss was feared because most people they encountered misunderstood what ARVL actually entailed. This was clearly articulated by S3 who stated:

“When I had my white cane and I'd walk through Wal-Mart, people would just part in front of me. And then you'd see people grabbing their kids,

'Quick get out of the way.' Look out for the blind man...There's so many times when we're out that I can tell people are still frightened of blindness."

This reaction was also noted during the observation visits, whereby store patrons were noted to immediately move out of the way of the study participants coupled with profuse apologizing if the older adult accidentally bumped into them, but only if they saw a white cane. In these situations, awareness-raising may have gone a long way towards addressing the misunderstandings of ARVL as well as reframing the taken-for-granted conceptions or outwardly negative messages regarding impairment which largely go unnoticed in society (Morris, 2001). This recommendation for awareness-raising is reinforced as a key focus of the Convention on the Rights of Persons with Disabilities (2006). Similar to recommendations proposed by the Convention, awareness-building concentrated on addressing the misperceptions of age-related vision loss would focus on:

- 1) Raising awareness throughout society regarding the complex needs of older adults with ARVL;
- 2) Fostering respect for the rights of older adults with ARVL;
- 3) Combatting stereotypes, relating to older adults with ARVL, that are embedded within ageist and ableist social assumptions;
- 4) Promoting awareness of the skills, abilities, and contributions of older adults with ARVL to their families and more broadly to their communities.

To achieve these objectives, a number of awareness-building strategies could be utilized. One such strategy, which has been supported by the National Coalition for Vision Health, would be to organize a public awareness campaign focused on enhancing understandings of vision health and the implications of ARVL on daily living. In fact, the National Coalition for Vision Health has recommended the assigning of a department within the Public Health Agency of Canada, devoted to promoting vision health. Use of the media, such as radio advertisement is one possible means through which to launch a widespread public awareness campaign. Education and awareness-building regarding vision loss could also be

promoted through all levels of the education system. For example, S3 regularly spoke to grade-school classes regarding his vision loss, the challenges he faced, and how he used assistive technology in his everyday life. The education of children should help to foster, in them, an attitude of respect and receptiveness to the rights of disabled persons over their life-course. As I articulate later in section 8.3.5, there is also a need to include low vision curriculum within Canadian professional health programs, such as occupational therapy. By understanding what age-related vision loss entails, the challenges associated with ARVL, and the strategies necessary to address these challenges, occupational therapists will be better prepared to work with this rapidly growing segment of the Canadian population. Lastly, awareness-building may take the form of training programs designed for groups such as customer service personnel or city transit officials. Gardener (2011) in her qualitative study with six older adults, sought to contextualize the neighborhood as an important place of aging. In doing so, she spoke about the important social role played by service personnel who act as everyday 'regulars' in the lives of older adults. It is particularly important that service personnel be trained in how to appropriately interact with older adults, including those with vision-disabilities. The Accessibility for Ontarians with Disabilities Act (AODA) legislated its Customer Service Standard in 2007 and so the timing is now ideal for the customer service industry to integrate educational programming focused on understanding the complex needs of seniors with ARVL and how best to meet those needs. Based on interview and observational data with the older adult participants, customer service and transportation personnel would be an ideal place to start with this education. Given their specialized training, vision rehabilitation professionals as well as national organizations such as the CNIB would be uniquely positioned to provide this education and awareness-building in order to break down some of the misunderstandings of ARVL and create a more inclusive environment for seniors. Unfortunately, the funding mechanisms that would be necessary in order to promote this type of awareness-building are not currently in place within Canada. Although Canada was an instrumental partner in the 2003 development

of the Global Initiative for the Elimination of Avoidable Blindness (also known as Vision 2020: The Right to Sight) at the World Health Assembly, we have yet to establish a nation-wide vision health strategy. As such, awareness-building geared towards government officials also appears necessary in order to demonstrate the need for vision rehabilitation to move away from its large dependence on a not-for-profit model towards a national health priority and for efforts to expand beyond rehabilitation of individuals towards the education of the broader public.

8.3.2 The importance of a broadening awareness of the environmental shaping and perpetuating of disability

A significant implication of this thesis has been the recognition of environmental factors in the creation, sustainment, and perpetuation of disability. The adoption of critical disability theory (CDT) was paramount to this shift in thinking. Critical disability theory views the environment as playing a central role in terms of how disability is understood (Kennedy & Minkler, 1998). It acknowledges that it is the ableist values that permeate social consciousness which, in turn, shape environments that serve to sustain the disability experience and further perpetuate the oppression and marginalization faced by disabled persons.

Of particular importance, CDT frames an older adults' experience of disability as tied to both the particular environmental context in which they exist as well as the limitations caused by their impairment. This thesis acknowledged that it is problematic to only focus on the body or the environment. There needs to be an appreciation for the interplay of both the individual experience of impairment and the environment in which disability occurs. As argued in chapter six, positive aging discourses typically assume an individual-level focus that negates the significant influence of the environmental context and extrinsic factors such as gender, education, financial resources, and neighborhood safety. All these factors influence the ability of people to age well (Cardona, 2008; Holstein & Minkler, 2003; Minkler & Fadem, 2002). This thesis provided space for the role played by both the environment and the limitations caused by the impairment.

Such a shift in thinking may help to alleviate some of the blame older adults with ARVL place on themselves when, for example, they associate their inability to be independent with feelings of being a burden to family, friends, and care staff; a feeling which was expressed by multiple study participants. With an increasing focus on the role that environments play in both the creation and sustainment of disability, this study sought to take the responsibility solely off the individual aging with vision loss and instead place the responsibility for creating inclusive environments onto society as well (Meekosha & Dowse, 2007).

This thesis also sought to move beyond the overwhelming tendency within ARVL research to focus on physical environmental features and home environments (Barstow, Bennett & Vogtle, 2011; Laliberte Rudman, Huot, Klinger, Leipert & Spafford, 2010; MacLachlan, Laliberte Rudman & Klinger, 2007; Stevens-Ratchford & Krause, 2004; Wahl, Oswald & Zimprich, 1999). Instead this study encouraged the adoption of a more holistic view which includes social, cultural, political, and institutional factors and the inter-connectedness of various environmental elements. Although the study did uncover that basic attention to physical infrastructure updates such as fixing cracks in the sidewalk or re-painting the yellow outline on curb cuts is necessary to support vision-friendly environments, the study findings also demonstrated that a greater push is needed to extend beyond a purely individual level to include an exploration of the socio-political context of disability as it relates to older adults with ARVL. That is not to say that environmental modification is not a necessary or beneficial step towards eliminating particular physical barriers. Rather, this study proposed that focusing on physical barriers exclusively is insufficient for addressing issues of social isolation, exclusionary policies or institutional practices, as well as discriminatory cultural norms that exist within social consciousness. This finding is particularly relevant when considering the creation of inclusive social policy. Study findings have effectively pointed to the need for more inclusive social policy that shift away from the current focus on the prioritization of issues of physical accessibility in the built environment, a finding that was highlighted

particularly in the documents consulted for this study, towards a greater holistic framework.

In order to raise awareness of the influence of the environment in shaping and perpetuating disability, a fundamental shift in thinking is also necessary; a shift that includes the adoption of a critical disability theory lens. To successfully make this shift will require the education, particularly of health and vision rehabilitation professionals, in order to change deep-seated assumptions regarding disability that have long been shaped by the biomedical model of disability that understands underlying pathology, impairment, or dysfunction as the cause of disability (Smart, 2006-2007). The real driver of disability, however, is the interaction of the individual's bodily experience with their physical, social, cultural, political, and institutional environment. As argued for in chapter five, it is only through the education and subsequent taking up of critical disability theory that new conceptualizations regarding disability in ARVL, as well as new rehabilitation practices can begin to be formed.

8.3.3 Bringing to light the intersection of aging and disability

One key study implication highlighted in this thesis had to do with the relative absence of research that brings together the intersection of aging and disability. As highlighted in chapter six, both social gerontology and disability studies pay relatively sparse attention to this intersection, with a few notable exceptions (Kennedy & Minkler, 1998; Minkler & Fadem, 2002; Priestley & Rabiee, 2002; Putnam, 2002; Raymond & Grenier, 2013; Raymond, Grenier & Hanley, 2014). This thesis uniquely and purposefully sought to interweave these concepts; this was particularly evident in the two empirical manuscripts. In so doing, new and innovative insights were gained. As it applied to positive aging discourses (chapter six), findings revealed that such discourses are embedded within both ageist and ableist assumptions which serve to shape the disability experience for older adults with ARVL. As revealed in chapter seven, the influence of environmental barriers on the production of disability for seniors with age-related vision loss were again informed by both ageist and ableist assumptions. For

example, difficulty reading restaurant menus, frustration with the ever-changing organization of store layouts, and the fear of being taken advantage of while in the community all stemmed from environmental barriers informed by ageist and ableist assumptions. It was my adoption of multidimensionality, an integral component of critical disability theory (as described in section 5.4 and 7.5), that allowed me to pull out these inter-linked assumptions. For gerontology scholars and critical disability researchers moving forward, a fuller exploration of aging and disability at its intersections will offer new insights and possibilities for future research development. The approach taken in this thesis will add value to other areas of research beyond age-related vision loss in older adults.

8.3.4 Critically revealing the limits of an individualistic approach

A recurring theme in this thesis that had important implications was the critiquing of an individualistic framework for understanding issues of aging and disability. There are a number of professionals involved in providing low vision rehabilitation in Canada including optometrists, ophthalmologists, occupational therapists, social workers, nurses, and orientation and mobility trainers (Gold, Zuvela & Hodge, 2006; Lapointe, 2006). Present vision rehabilitation for ARVL tends to centre predominantly around the provision of assistive technology to replace declining or lost visual functions (Copolillo & Teitelman, 2005; Eklund, 2008; Girdler et al., 2008; Ivanoff & Sonn, 2005; Lamoureux et al., 2007; Moore & Miller, 2003; Pankow et al., 2004; Ryan et al., 2003; Stelmack et al., 2007) as well as the adoption of self-management strategies (Birk et al., 2004; Eklund, Sonn, & Ivanoff, 2004; Ivanoff, 2002; Eklund & Ivanoff, 2006; Eklund, Sjostrand, & Ivanoff, 2008; Packer et al., 2009). Just as the experience of disability is tied both to the context in which older adults with ARVL exist as well as by the limitations caused by their impairment, so too must rehabilitation efforts include elements of individual-level management and environmental change. This has implications for low vision rehabilitation professionals who must now go beyond a sole focus on individual-level management strategies towards a broader

consideration of the influence of the environment on the activity engagement of seniors with vision loss.

As it relates to personal responsibility, this study has shown that older adults typically adopt individual level strategies in order to cope with the disabling features of their environment; strategies such as asking for help, using assistive devices, concentrating, and being cautious. That being said, this thesis argued that the focus cannot be exclusively the responsibility of the individual to mediate the inaccessible features of their environment. Rather, in such situations where disability did occur, it was often because environments were not set up in such a way as to accommodate difference. Rather, environments reinforced ableist and ageist assumptions. One of the clearest examples can be drawn from older adults crossing at a crosswalk; an example that was discussed in detail in chapter seven. When the focus is placed on the individual, strategies such as teaching the individual to ask for help, listening for traffic surges to determine when it is safe to cross, or only walking in the community with a sighted guide are recommended. This, however, does not address the underlying ableist assumptions tied to this task. Instead, this study advocated for the adoption of a critical disability theory lens that would question why audible announcements were not available at the crosswalk or why sufficient time was not provided for older adults with a disability to cross safely. A further example can be drawn from the findings of chapter six, in which older adults with vision loss pointed to a variety of conditions associated with 'aging well' such as being independent, positive, efficient, compliant, complicit, and cooperative, as well as adopting personal strategies to manage risk. All of these conditions pointed to the socio-cultural expectations placed on the individual to 'age well', while downplaying the role of society in providing the necessary supportive environments that enable personal success. Results from this study highlighted the challenges with adopting a purely individualist approach and instead pointed to the necessity of broadening beyond the level of the individual towards an acknowledgement of the environment as a site for the "reproduction of disability" (Korotchenko & Hurd Clarke, 2014, p. 432).

As it relates to inclusive social policy, these findings point to the need to break down those socio-cultural expectations of what constitutes 'normal.' As discussed in chapter five, normalcy represents an ideological social construct which has the perhaps unintended consequence of excluding disabled persons from a society that was not designed to meet their needs (Terzi, 2004). The socio-cultural expectations of what constitutes 'normal' are established and given meaning by those social groups, who have the greatest amount of power and privilege to enforce their perceived notion of normalcy. Thus, able-bodied persons position disabled persons as falling outside of the set norm (Fitch, 2002). Future social policy must provide an inclusive framework in which disabled persons, including older adults with vision loss, are not held to able-bodied norms and values.

8.3.5 Informing the creation of more age and vision-friendly places and spaces

With one of the goals of critical theory being to facilitate social change (Given, 2008), a primary goal of this thesis was to develop recommendations that would enhance the age and vision-friendliness of communities. Study findings pointed to a number of factors that must be considered in the development of optimal age and vision-friendly environments.

Although there is no universally accepted definition of what constitutes an age-friendly community, the World Health Organization's (WHO) Age Friendly Cities initiative has been widely adopted (Alley, Liebig, Pynoos, Banerjee & Choi, 2007; Lui, Everingham, Warburton, Cuthill & Bartlett, 2009). As defined by the World Health Organization, "an age friendly community is one in which policies, services, settings and structures support and enable people to age actively" (WHO, 2007, p. 5). Within the WHO framework, the domains of an age-friendly community include: outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services (WHO, 2007; Zur & Laliberte Rudman, 2013).

There have been several critiques made of the age-friendly cities initiative, thereby demonstrating the “tension between its intent and implementation” (Zur & Laliberte Rudman, 2013, p. 374). One such critique has been its narrow focus which emphasizes the physical environment (Echenberg, 2012). This was seen firsthand in the documents critiqued as part of this thesis, where there was an overwhelming focus on the prioritization of issues of physical accessibility. Overall, sixteen documents were included in analysis, of which seven were specifically relevant to the environment. Of those, four focused exclusively on issues of physical accessibility. As an example, *Clearing our Path: Universal design recommendations for people with vision loss* (CNIB, 2009) provided detailed recommendations for the improvement of physical accessibility in environmental spaces for persons with vision loss. Similarly, the *City of Hamilton Barrier-Free Design Guidelines* (2006) provided detailed recommendations to ensure the physical accessibility of city-owned facilities, parks, open spaces, and infrastructure. However, as suggested within this thesis, the development of optimal age and vision-friendly environments is contingent on environmental obstacles that limit accessibility being addressed alongside efforts aimed at changing those discriminatory social practices that give way to the “disablist spatial organization that precludes older adults’ inclusion and participation in their communities” in the first place (Korotchenko & Hurd Clarke, 2014, p. 442). In this way, a holistic approach is both ideal and necessary.

A further critique of contemporary age-friendly cities initiatives has been the individualistic focus. For example, Estes and Wallace (2010) stated: “Global Age-Friendly Cities takes a broader view of the conditions needed for active aging...the approach, none, the less continues to be individualistic and focuses on the person-environment fit, with no attention to community and societal-level issues, such as the extent of income inequality and social solidarity that impact the aging population” (p. 514). This thesis has consistently argued that an individual focus alone is insufficient to address environmental constraints. Rather the future development of age and vision-friendly environments must appreciate that disability is not simply a result of the functional limitations of one’s visual

system; it is also shaped and sustained through the interaction of that bodily experience with the inaccessible features of the physical, social, cultural, political, and institutional environment. In fact, as argued by Menec, Means, Keating, Parkhurst and Eales (2011), an individual's personal characteristics interacts with environmental conditions such that "age-friendly domains cannot be treated in isolation from intrapersonal factors such as age, gender, income, and functional status, and other levels of influence including the policy environment" (2011, p, 479). Moving forward, the scrutinizing of municipal age-friendly messaging is necessary to uncover individualistic assumptions and challenge such discourses.

In developing future age and vision-friendly environments, one issue that was highlighted in this study, is the importance of consistency and familiarity. Sudden changes to the environment as well as a lack of consistency regarding the items used within that environment caused many of the challenges faced by study participants. For example, participants readily discussed the differences in debit card machines from one store to the next, the inconsistency of urban Braille from one street corner to the next, and/or the frequency with which stores changed their product layout; all of which caused older adults a great deal of frustration and, at times, led to disability. Moving forward, the establishment of age and vision-friendly environments will only be useful in as much as they are consistent within and across cities and towns. In this sense, the approach to creating age and vision-friendly environments must be a collective and cross-community effort.

In addition to the need for policy to legislate age and vision-friendly environments, there is also space for including a focus on age and vision-friendly communities within educational curriculum including, but not necessarily limited to: optometry, ophthalmology, gerontology, environmental studies, disability studies, low vision rehabilitation, occupational therapy, physical therapy, nursing, and social work. The study findings also support, more broadly, the need to advocate for the development of age and vision-friendly environments. In particular, advocacy efforts need to be directed towards enabling those changes

that are most difficult to implement such as political/institutional environmental change over the more easily fixed physical environmental issues.

8.4 Study Strengths

There were a number of strengths of this study, the most pertinent of which are summarized here. First, the timeliness of this study is one of its particular strengths. As described in chapter one, older Canadians now constitute the fastest growing segment of the population with 6.7 million older Canadians estimated by 2021 (Health Canada, 2002). This is coupled with an estimated 3.43 million Canadians currently living with some form of macular degeneration, diabetic retinopathy, glaucoma, or cataracts (CNIB, 2009). Taken together, these projections have led to the National Coalition for Vision Health (2009), stating that Canada is "on the brink of an epidemic of age-related eye disease" (p. 1). Given these demographic trends, this study provided a timely response to ARVL and how the shaping of disability for older adults with age-related vision loss is influenced by the physical, social, cultural, political, and institutional environment. In working against viewing disabling effects of ARVL as taken-for-granted or 'natural' outcomes of vision loss, I sought to open up space for discussion of a range of possible ways to re-think research and age-related vision loss practices.

An additional study strength had to do with my prior work experiences with organizations such as the CNIB, the HAC, and the HCoA. These experiences supported my immersion within the culture of vision loss and offered me the experience to learn first-hand from older adults, including those with ARVL. From a pragmatic standpoint, my involvement with CNIB, HAC, and HCoA gained me access to documents, many of which were not otherwise available to the public. Thus, I was able to include unique papers within the document analysis portion of my data collection. These documents included: *Paying the Price: What Vision Loss Costs Canadians and What We Should Do About It (2009b)*; *The Cost of Vision Loss in Canada: A Summary Report (2009)*; *You and Your Vision Health (2007)*; *Clearing our Path: Universal design recommendations for people with vision loss (2009)*; *The National Coalition for Vision Health Environmental Scan of*

Vision health and Vision Loss in the Provinces and Territories in Canada (2009); Adequate, Suitable and Affordable? Report on Housing in Hamilton (2010); Hamilton: A City for ALL Ages (2010); as well as Hamilton: A City for ALL Ages Three Years On (2013). It also provided me with the opportunity to shadow an independent living skills (ILS) specialist, an orientation and mobility (O&M) specialist, a deaf-blind intervener, and a low vision assessment specialist; these experiences increased my understanding of low vision rehabilitation as offered by the CNIB within the region in which the study was conducted. My experiences with these organizations also exposed me to a number of advocacy organizations such as the *National Coalition for Vision Health*, the *Foundation Fighting Blindness*, the *Alliance for Equality of Blind Canadians*, and the *City of Hamilton-Senior's Advisory Committee*. All of these organizations were new to me. Lastly, through my involvement with the CNIB, I was able to seamlessly recruit five older adult participants for my study and through a contact of the HCoA, I recruited an additional three older adult participants.

A further strength of this study was methodological. My choice of a critical ethnographic approach was novel in contrast to previous qualitative research in low vision which has typically assumed a phenomenological (Laliberte Rudman & Durdle, 2008; Laliberte Rudman et al., 2010; MachLachlan et al., 2007; Moore, 2000; Moore & Miller, 2003; Spafford, Laliberte Rudman, Leipert, Klinger & Huot, 2010), grounded theory (Wong, Guymer, Hassell & Keeffe, 2004) or generic methodological approach (Copolillo & Teitelman, 2005; Girdler et al., 2008; Stevens-Ratchford & Krause, 2004; Teitelman & Copolillo, 2005; Wang & Boerner, 2008; Weber & Wong, 2010). By adopting a critical ethnographic approach I was able to not only elicit the participants' point of view and understanding of their world, but I was also able to challenge those taken-for-granted assumptions and question the dominant power structures that served to constrict the lives of older adults with ARVL (Cook, 2005; Simon & Diplo, 1986; Thomas, 1993). Further, such an approach allowed me to critically situate participants' comments and experiences as socially constructed with a particular

time, culture, and context. Further, while other studies have adopted an interpretive paradigm (Laliberte Rudman et al., 2010; Spafford et al., 2010), I adopted a critical theory approach. As previously discussed in chapter three, critical theory is focused on challenging the status quo and transforming oppressive social structures that perpetuate the marginalization and oppression of specific social groups (Given, 2008). Within this study, the adoption of a critical approach allowed me the space to deconstruct the transactions between the older adult with ARVL and their environmental context, in particular drawing on critical gerontology and critical disability theory to deconstruct issues related to age and ability respectively.

The multiple interviewing sessions with the older adult participants, which included both a narrative and semi-structured interview, helped to build rapport and thus resulted in detailed and rich data sets. It was the richness of the data collected through the observational visits; however, that was a particular strength of the study as well as a novel method of data collection. The use of observation visits not only provided a first-hand view into how the study participants negotiated environmental enablers and barriers in their communities, but it also helped to break down the typical researcher-participant relationship by allowing for joint participation in a mutually beneficial occupation. Another study strength, which provided diverse perspectives, came from interviewing community organization representatives as well as engaging in document analysis. It was the combination of perspectives including, older adult with vision loss, community organization representatives, and document analysis that brought new understandings to how older adults understand and negotiate those normative assumptions that underlie experiences of age and disability.

My choice in theoretical underpinnings, particularly the adoption of critical gerontology, critical disability theory, and a critical occupational perspective was an additional strength of the study. The adoption of these particular theoretical approaches resulted in critically-oriented empirical findings, as detailed in chapter six and seven. Such critical findings are unique to ARVL research which has

more commonly adopted a more biomedical approach (Alma, Van der Mei, Groothoff & Suurmeijer, 2012; Boerner & Wang; 2010; Grue et al., 2008; Laitinen et al., 2007; Owsley, McGwin, Sloane, Stalvey & Wells, 2001; West et al., 1997; Wong et al., 2004). By adopting a critical gerontological approach, I was able to recommend theoretical enhancements of environmental gerontology through the incorporation of a critical environmental gerontological sensibility (as outlined in chapter four). I was able to recommend the re-shaping of present understandings of disability through the incorporation of critical disability theory into ARVL research (as outlined in chapter five). Lastly, the incorporation of a critical occupational perspective brought to light how ableist and ageist assumptions shape how older adults with ARVL engage in occupation, where they engage in occupation, and what barriers they face in doing so (as outlined in chapter seven). Although it was initially challenging to develop and subsequently apply these critical approaches, it ultimately helped to develop my critical research voice and, in doing so, gave shape to findings that will be a unique addition to our understanding of ARVL.

8.4.1 Quality Criteria

A further methodological strength of this research pertains to the attention I paid to quality criteria. Carspecken (1996) provides a number of suggestions to enhance the research rigor of a critical ethnography. These examples center around more pragmatic considerations such as the use of multiple recording devices, using a flexible observation schedule, practicing prolonged engagement in the field, engaging in peer debriefing, or interviewing the same research participant repeatedly. How I addressed each of these types of suggestions was outlined in section 3.7. Within this section, I focus more specifically on the underlying issue of the quality of my work. As such, I have adopted elements primarily from Morrow (2005), Charmaz (2006), and Tracy (2010) in my discussion on quality criteria specifically as it relates to: worthiness of the topic, adequacy of the data and interpretation, resonance, sincerity, usefulness, and

coherence of the research approach. In the following section, I discuss each of these quality criteria within the context of the research that I have conducted.

8.4.1.1 Worthiness of the research topic

In order to be considered worthy, research should be “relevant, timely, significant, interesting, and evocative” (Tracy, 2010, p. 840). Further, it should offer new insights, challenge existing ideas, and offer theoretical significance (Charmaz, 2006). With the limited environmentally-focused ARVL research, this work offered new understandings of the influence of environmental factors on the occupational engagement of older adults with age-related vision loss, thereby demonstrating its significance. By employing a theoretical framework informed primarily by critical gerontological, critical occupational, and critical disability scholarship, my research also questioned taken-for-granted assumptions as it related to issues of disability and aging. For example, it questioned taken-for-granted assumptions about what it means to age positively, showing how such assumptions can work against efforts of older adults with ARVL to participate in occupations. As another example, it questioned the dominant individualist approach in which disability is viewed as a 'natural' outcome of impairment and the responsibility to mediate the effects of the environment is placed upon the individual. Thus, my study did not merely confirm existing understandings but instead generated new insights particularly in relation to the complex interactions of environmental elements and impairment in the lives of older adults with ARVL.

8.4.1.2 Adequacy of the Data

Morrow (2005) suggests that the adequacy of the data is one key means of determining quality of the research. Adequacy, however, goes far beyond the number of participants and instead has “more to do with the information-richness of the cases selected” (Patton, 1990, p. 185). Morrow’s (2005) first measure of adequacy has to do with whether or not purposive sampling procedures were utilized. For my study, I engaged in purposeful sampling based on specific inclusion and exclusion criteria in order to select participants that would provide

rich descriptions relative to the research questions. Furthermore, as outlined in section 3.5, given the iterative nature of the study, I was able to purposefully sample community representatives during the second wave of recruitment based on the emergent findings. A second recommendation to ensure adequacy of the data is to ensure adequate variety in types of evidence. For example, Polkinghorne (2005) recommends multiple interviews with the same participant in order to ensure data depth and richness. I interviewed the same older adult research participants on three separate occasions over the course of approximately three months. By interviewing the same research participants at three separate points in time, they became “more likely to produce richer and more self-disclosing information than that produced in a single interview” (Carspecken, 1996, p. 166). This was observed first-hand, when participants in the semi-structured in-depth interview more openly shared the challenging aspects of their story of vision loss with me than was discussed during the initial narrative interview. Furthermore, Morrow proposes that the interview strategy should be clearly articulated. My interviews were purposefully left open ended such that the experiences of the study participants informed subsequent data collection as well as informed which community organization representatives were interviewed and which documents were analyzed. Morrow (2005) further recommends the use of multiple data sources in order to ensure the “richness, breadth, and depth of the data gathered” (p. 264). In this study, I collected data from different types of participants using multiple data collection methods including a narrative interview, a semi-structured in-depth interview, as well as an observation visit with the older adult study participants; a semi-structured in-depth interview with community organization representatives; document analysis; and reflexive journals. Lastly, Morrow (2005) suggests the seeking out of disconfirming evidence in order to help “combat the investigator’s natural tendency to seek confirmation of her or his preliminary or emerging findings” (p. 256). My data analysis process began through immersion within “the context of the interactions” (Carspecken, 1996, p. 149) which involved reading each transcript or observation note individually to develop a rich understanding of the

data before drawing comparisons between data sets or across participants. By approaching data analysis in this manner, I was able to see both confirming and disconfirming instances related to my findings. Engaging in multiple sessions of data collection also allowed for the further exploration of disconfirming instances. I acknowledged these disconfirming instances within each of the empirical manuscripts.

8.4.1.3 Adequacy of Interpretation

In addition to adequacy of the data, Morrow (2005) proposes that adequacy of interpretation during data analysis is an essential quality measure. First, Morrow proposes that “immersion in the data is essential” (p. 256). I attempted to ensure that I immersed myself in the data by reading and re-reading each of the transcripts, observation notes, and document analyses multiple times. In addition, I listened to each of the interview recordings in order to attempt to re-live the experience. This re-immersion with the data helped to deepen my understanding of the findings. Second, Morrow (2005) proposes that an analytic framework, that is commensurate with the researcher’s methodology, should be utilized in order to enable the “investigator to systematically make meaning of or interpret the data” (p. 256). I choose to utilize the data analysis process consistent with a critical ethnography, as proposed by Carspecken (1996) and I utilized a modified policy analysis framework as proposed by Bacchi (2009) for the document analysis. A further strategy I employed in an effort to “systematically make meaning of or interpret the data” (Morrow, 2005, p. 256) was to utilize the key tenets of my guiding theoretical frameworks, including critical gerontology, a critical occupational perspective, and critical disability theory, to interpret and make meaning of the data I collected. Lastly, Morrow (2005) proposes that when writing the study findings there should be an equal balance between the investigator’s interpretations and quotations. As demonstrated in chapters six and seven, I was particularly cognizant of creating a balance between the quotations provided and my critical interpretation. By ensuring integration of relevant, illustrative quotes, I attempted to demonstrate to

the reader that my interpretations were grounded within the experiences of the study participants and elements of their context.

8.4.1.4 Resonance

As posited by Tracy (2010), resonance refers to the ability of the research to “meaningfully reverberate and affect an audience” (p. 844); ultimately referring to its ability to have a lasting impact or influence. This study discussed the practical implications, or impact, of this research in relation to a variety of stakeholders and types of practices. Further, study participants expressed their resonance with the research topic as demonstrated by the ease with which participants were recruited, their enthusiastic participation in data collection, and the lack of participant attrition despite the time demanding data collection process. The study held resonance for community organizations such as the CNIB, as demonstrated by their request to have the findings shared via a Lunch and Learn virtual presentation to regional and national staff that will occur following completion of this thesis. Lastly, once the manuscripts are published and the findings are shared through presentations, resonance will ultimately exist in the reactions of the various readers and audiences to my work.

8.4.1.5 Sincerity

As posited by Tracy (2010), sincerity in the research process refers to research that is marked by “honesty and transparency about the researcher’s biases, goals, and foibles” (p. 841). Self-reflexivity, which is considered to be “honesty and authenticity with one’s self, one’s research, and one’s audience” (Tracy, 2010, p. 842), is one element of sincerity. I strived to remain aware of issues of reflexivity throughout the research process, which is integral to any critical ethnographic work, as promoted by Carspecken (1996). Tracy (2010) purports that researchers can begin to practice reflexivity before entering the field. I adopted that practice and before entering the field, I wrote a reflexive note regarding my motivations for studying ARVL, as well as what I expected to find, as a means of raising my consciousness and identifying key biases before

entering the field. This type of reflexivity is particularly important in critical research as its purpose is to “expose the researchers’ personal constructions of the world, their values, beliefs, strengths, and weaknesses that mold the research journey and choices made” (Mulhall, Le-May & Alexander, 1999 as seen in Hardcastle, Usher & Holmes, 2006, p. 158). This process set the stage for continued reflexivity throughout the data generation and analysis process. Once in the field, I maintained a reflexive journal in order to maintain an ongoing record of my experiences, reactions, and identify any assumptions that developed over the course of the research that needed to be interrogated through data collection and analysis processes. I also integrated reflexive notes within the field notes for each of the participant observation sessions to note my reactions to my observations. Another helpful reflexive strategy is to consult with your research team (Hill et al., 2005; Hill, Thompson, & William, 1997; Morrow & Smith, 2000). I engaged in regular dialogue, or peer debriefing, with my supervisor and committee members throughout the data generation and analysis process. These sessions allowed me to work through my responses to the research process, break down my pre-suppositions, beliefs, and values (Thomas, 1993), raise awareness of my own perspectives (Carspecken, 1996), and propose alternative interpretations to those that I, as the primary investigator, had identified. Peer debriefing also occurred through the process of submitting my dissertation chapters for review to committee members. My committee members had varying disciplinary locations, including optometry and occupational therapy, as well as different areas of research expertise including qualitative research design, aging, environmental studies, assistive technology, and age-related vision loss. As such, when reviewing manuscripts, each committee member applied a different lens which ultimately served to enrich and broaden the findings shared. In addition, I re-visited a series of five reflexive questions, as adapted from Madison (2012), throughout the research process in an effort to promote my reflexive thinking. These questions included:

- 1) What is my purpose and intention behind the research I intend to do?

- 2) What is the intended benefit of the research? How will this make a difference in people's lives?
- 3) Have I evaluated my own potential to do harm?
- 4) How do I collaborate appropriately with others involved in this research project?
- 5) How are these research findings contextualized in the broader social and political environment?
- 6) How will my work make the greatest social contribution?

8.4.1.6 Usefulness and Significance of the Findings

Tracy (2010) suggests that a further quality criterion is that research should make a significant contribution, whether theoretically, heuristically, practically, or methodologically. Theoretically significant research, at its most basic level, should examine “how existing theory or concepts make sense in a new and different context” (p. 846). I have attempted to be theoretically significant, by extending existing theories through the introduction of a critical sensibility. In doing so, I have problematized current theoretical assumptions and proposed new ways forward in diversifying thinking in environmental gerontology (chapter four) and re-shaping understandings of disability in research addressing ARVL (chapter five). Heuristic significance is accomplished, according to Abbott (2004), when research invokes curiosity within the reader prompting further exploration and new discoveries. I have outlined potential areas for future research direction in order to extend and challenge existing knowledge related to the impact of environmental influences for older adults with ARVL. Practical significance means that research is useful in shedding light on a contemporary problem and provides viable solutions for change. In this final chapter I have proposed a number of implications of my research including the use of study findings to support age and vision-friendly environments and the development of inclusive social policy. Lastly, Tracy (2010) posits that research may be methodologically significant if it offers a new methodological approach for understanding a phenomenon. This study accomplished methodological significance by

introducing critical ethnography, which is a methodology that has not otherwise been used in age-related vision loss qualitative research. The significance of study results will be shared with a broader audience through journal publications as well as through presentations in an effort to increase awareness as it relates to environmental influences and ARVL.

8.4.1.7 Coherence of the Research Approach

The final quality criteria I present refers to the coherence of the research approach. To be coherent, a study must show interconnections among the research design (including methodology and methods of data collection), theoretical underpinnings, the study goals and objectives, and the paradigmatic positioning of the researcher. To be coherent, the researcher must demonstrate that the study "hangs well together" (Tracy, 2010, p. 848). For example, my epistemological positioning reflected my acknowledgement that research is transactional, subjectivist, and value mediated (Lincoln & Guba, 2003). As a critical theorist, I believe knowledge is co-constructed, resulting from the interaction between me and study participants (Lincoln & Guba, 2003). A critical ethnography is congruent with this epistemological positioning because it represents a collaborative process of meaning-making between me and the study participants (Manias & Street, 2001). As for my research objectives, they were informed by the general absence of research focused on environmental influences in the ARVL literature. Those research objectives included:

- 1) To critically examine the role of the physical, social, cultural, and institutional environment in supporting as well as detracting from the occupational engagement of older adults with ARVL and;
- 2) To raise awareness of how primary barriers older adults with ARVL face in relationship to various physical, social, cultural and institutional environmental factors are embedded in ageist and ableist assumptions.

These objectives were congruent with my adoption of a critical ethnography in that I sought not only to elicit the research participants' point of view, but also

sought to challenge taken-for-granted assumptions and question the prevailing status quo and dominant power structures within a particular culture that served to shape and perpetuate disability. I employed methods of data collection that encompassed persons with ARVL, community representatives, and policy and organizational documents to enable the research to unveil taken-for-granted social assumptions. My choice of theoretical approaches, including critical gerontology, a critical occupational perspective, and critical disability theory, was further congruent with both my study objectives and choice of methodology, in that they provided a conceptual basis for questioning how systems and structures of power perpetuate social injustice.

In addition to the measures of coherence as recommended by Tracy (2010), I also sought to be coherent with my critical theory paradigmatic positioning. As such, I aimed to adopt eight principles described by Hammell (2007) that should be present in any critically-informed research study. These key principles include (p. 366):

- a) Research should be collaborative and have, at its core, a focus on respect for the research participants;
- b) The research topic is informed by the priorities set by the disabled persons;
- c) Research has meaningful outcomes and/or knowledge produced which is then used to inform real-world decision making;
- d) Research moves beyond a bio-medical focus towards understanding the influence of social, cultural, physical, and political/institutional environmental influences which serve to disable persons;
- e) Research acknowledges the intersection of inequality resulting from disability with other examples of social inequality on the basis of gender, race, class, and age;
- f) Research acknowledges the importance of context by focusing on the interaction of person and environmental components;

- g) Research includes critical reflexivity on the part of the researcher to re-conceptualize and challenge traditional assumptions of disability and;
- h) Participants are actively involved in the evaluation of the research process and outcomes.

I met each of these criteria with the exception of those with disabilities informing the research priorities (b) and participants being actively involved in the research process and outcomes (h). With the introduction of participatory research methods, as advocated for later in this chapter, these remaining two points could be addressed in future age-related vision loss studies.

8.5 Boundaries of the Study

In addition to the study strengths, there were also a number of boundaries, or limitations, of this study. One such boundary centered on the limited demographic variability of the older adult study participants, particularly as it related to gender, cultural background, and living situation. The participants recruited for this study were predominately female (N=8), all were either of Canadian or European descent, and all participants lived on their own. Some of my findings, such as independence as a marker of 'aging well', as outlined in chapter six, may reflect a deeply embedded Westernized value that is not necessarily relevant in other cultural contexts (Torres, 2003; Torres, 2006). As such, I wonder how a broader range of cultural and ethnic backgrounds, more variability in living arrangements, as well as greater inclusion of males may have influenced the findings of this study. Future ARVL research, therefore, would benefit from the recruitment of a diverse participant sample to ensure more varied perspectives. Future research would also benefit from looking more closely at how family relationships enter into the negotiation of disability for seniors with age-related vision loss.

A further boundary of this study involved time constraints, which are inevitable with a PhD dissertation. Time constraints limited my methods of data collection. As an example, I only completed one interview each with the community

organization representatives and in doing so, I limited my ability to develop rapport. As a result, I feel I collected less rich data than I did from the older adult study participants, with whom I met on three separate occasions. Additionally, data collected with the older adult participants occurred over a period of only seven months (December 2012 to July 2013) and for each participant, their three data generation sessions occurred within the same season, which may have limited the variability in terms of environmental enablers and barriers discussed. Although I acknowledge these research boundaries, the expectation, not to mention my desire, to graduate within approximately four years limited my ability to engage in a more longitudinal approach to data collection. Moving forward, I would recommend the adoption of longitudinal research approaches to better understand how older adults with age-related vision loss manage the disabling effects of their environments over time.

An additional limitation of the study had to do with my role as a novice researcher. At the time when I began collecting my research data, I had only participated, as a research assistant, in one previous ARVL study which adopted a grounded theory methodology. I had not undertaken critical ethnographic research and my knowledge of the methodology was limited to textbooks and journal articles. Further, I had not previously been exposed to those critical approaches which would become the theoretical grounding for this study, namely critical gerontology and critical disability theory. As such, this dissertation truly was a learning process. I do wonder whether a more seasoned researcher may have been able to uncover more complex experiences of the interplay between age, disability, and the environment. That being said, being a student also afforded me perhaps more opportunity to take the risks necessary to carve out my voice as a critical gerontologist, a critical disability theorist, and a critical ethnographer.

A final limitation had to do with the challenges inherent in writing this dissertation in an integrated-article format. First, with close to 1,100 pages of transcribed data, including interviews, observation notes, and document analysis, there was

an abundance of data that was not able to be represented within the manuscripts presented in this dissertation. Decisions needed to be made regarding what data would be highlighted for the purposes of this dissertation. I chose to focus the manuscripts on those findings that were most salient in relation to my chosen theoretical grounding, and provided the richest contribution to the aging and vision loss field. Theoretically this was accomplished by introducing a critical sensibility to environmental gerontology as well as introducing critical disability theory to enhance ARVL research foci. My two empirical manuscripts built on these theoretical chapters by providing a critical deconstruction of the normative messages regarding what it means to 'age well' (chapter six) and unpacking the socio-political construction of disability and the underlying ageist and ableist assumptions that underpin the environmental barriers faced by older adults with vision loss (chapter seven). Moving forward, I intend to produce additional manuscripts based on secondary analysis of the data which will enable me to utilize more of these rich data sets. Further, I encountered challenges in writing due to the need to match my writing to the journal audience, which ultimately influenced the representation of the thesis. At times, it was challenging to integrate these different voices, particularly as it related to my use of language. For example, within chapters one, three, and eight, which will not be published, and in chapter two which was published in an occupational therapy journal, I more comfortably used the term 'occupation' which is congruent with my identity as an occupational therapist. Within the remaining chapters, however, I targeted journals outside of occupational therapy and so I used alternative descriptors such as 'activity' which would be a more meaningful, and less complicated, term to those audiences.

8.6 Future Research Directions

The findings of this study point to a number of directions for future research. The following directions are proposed as priorities as set by me; however, this list is certainly not exhaustive nor does it represent the variety of recommendations for future research as raised within the theoretical (chapters four and five) and

empirical (chapter six and seven) manuscript chapters. Yet, it does provide an important starting point.

This study represents only the beginning of a much larger discussion that is needed around the influence of environmental factors on the occupational engagement of older adults with age-related vision loss. Given the limited number of studies that have addressed environmental influences (Barstow et al., 2011; Girdler et al., 2008; Laliberte Rudman & Durdle, 2008; Laliberte Rudman et al., 2010; MacLachlan et al., 2007; Stevens-Ratchford & Krause, 2004; Teitelman & Copolillo, 2005), it is apparent that further research is required to elucidate the complex ways in which environmental features support and detract from occupational engagement. This study provides one step forward, yet further research is critical. As well, beyond considerations of physical and social environmental aspects, more critically-informed ARVL research is necessary to address those macro-level aspects of the environment, including cultural, political, and institutional factors that influence the health, wellbeing, and participation of individuals aging with vision loss. Given the scarcity of research in this area, the possibilities for future research directions are nearly endless.

This study, through the types of questions asked and experiences shared, brought to the fore examples of the influence of environmental features on everyday activities or occupations, but did not specifically address the influence of the environment on roles such as that of a parent, grand-parent, spouse, volunteer, neighbour, friend, or member of the community. Future research would benefit from expanding to include such a focus.

Future ARVL research on environmental influences would also benefit from adopting different methodologies in order to garner new understandings and perspectives. At present, much of the ARVL research has adopted a phenomenological approach (Laliberte Rudman & Durdle, 2008; Laliberte Rudman et al., 2010; MachLachlan et al., 2007; Moore, 2000; Moore & Miller, 2003; Spafford et al., 2010;) which has been helpful in elucidating the lived experience of

older adults with ARVL. Although I found critical ethnography to be a particularly useful methodology in order to answer my research objectives, I also suggest the consideration of narrative inquiry, grounded theory, and participatory action research (PAR) for future studies. In particular, I think that future research would benefit from adopting a true participatory-based community research approach in which older adults with ARVL would be active participants throughout the research process including deciding on relevant research questions, determining data collection methods, analysing study results, and communicating findings to a broader audience. Given my focus on emancipatory social change, I think that the adoption of a PAR methodology (Baum, MacDougall, & Smith, 2006) would have been particularly well suited to answer my research objectives. That being said, PAR was not feasible given time and resource constraints. Although my epistemological positioning was such that I believed research findings to be co-constructed, this dissertation remained very much researcher-driven. However, future research would benefit from more fully embracing participatory models of research. In addition to adopting different methodologies, research that is not subjected to the time and resource constraints of a PhD dissertation would benefit from the adoption of a longitudinal design to better grasp the longer-term impacts of ARVL on occupational engagement. Research conducted over a period of years, as opposed to the months of data collection permitted for this study, would likely elucidate more complex interactions of age, disability, and the physical, social, cultural, political, and institutional environment.

Future research may also benefit from the adoption of novel methods of data collection. For example, the observation visits conducted for this study provided rich first-hand perspectives into how study participants negotiated environmental enablers and barriers in their communities. For my study purposes, this was a particularly useful method of data collection and future research may benefit from expanding on this method. For example, the adoption of the 'go along' interview method that combines interviewing with participant observation (Kusenbach, 2003), as utilized in Gardner's (2011) study on the public life of older adults aging in place, would be one possible future direction.

Future research may also benefit from moving outside of a North American context. When considering the interpretation of research data, it is important to understand the context in which that research occurred, including the geographic context. This study took place within Canada and as such certain Westernized values which prioritize individualism, autonomy, and independence came to the forefront. This was perhaps best demonstrated in chapter six whereby participants described the markers of 'ageing well.' Although I am only able to represent those findings that have been brought to light in this particular study, I do think that future research would benefit from moving outside of a Westernized context in order to explicate new understandings of environmental influences in age-related vision loss.

8.7 A Return to Reflection

I began section 1.3 by describing who I was in relationship to the research that I proposed. Now having completed my study, I re-visit some key reflections both in terms of how I shaped and in turn, how I was shaped, by my research. I entered the Health and Rehabilitation Sciences program coming from an area of occupational therapy practice where I felt constrained and limited in my ability to provide meaningful occupational therapy services. My hope, in moving into a PhD program, was that I would find the space that would allow that creative intellectual freedom I so desperately sought. For me, a pivotal moment in carving out that space came with the discovery of my critical voice, as shaped primarily by critical gerontology and critical disability theory. This was a pivotal moment not only for the development of my research but also for the development of me as a researcher, as I found a theoretical backing for how I viewed the world.

The adoption of such critical perspectives, particularly CDT, also forced me to work through the tensions I felt that stemmed from my occupational therapy training; particularly tension related to the use of language. For example, throughout my occupational therapy training (2006-2008) I had been instructed to use person-first language such as 'person who is blind or partially sighted' instead of 'blind or partially sighted person.' It was suggested that the use of

person-first language prioritized the individual before the disability. My adoption of critical disability theory, however, suggested otherwise. For example, many social disability theorists have argued that person-first language may actually serve to further oppress 'disabled people' by placing the onus for disability on the person instead of society (Titchkosky, 2001). I felt at odds between my professional training and the theoretical underpinnings of my critically adopted framework. In the end, because my dissertation privileged the environment over the individual, I choose to adopt the terminology supported by CDT in lieu of person-first language. This decision, however, was not made without considerable self-reflection, discussion, and deliberation with my supervisor and advisory committee.

In addition to solidifying my critical outlook, my experience in conducting this study also bolstered my identity as a gerontologist, and reinforced my commitment to understand and enhance the lives of older adults, specifically those with ARVL. This work helped me to better understand the complex and ongoing challenges faced by older adults with ARVL in their attempts to navigate their communities. Yet, I still find myself grappling with the 'so *what*' questions. Having now identified a number of these barriers, I struggle with how to address or, at minimum, effectively manage these environmental constraints. In many cases, the environmental barriers identified cannot be fixed solely with an adaptation to the physical infrastructure, but rather they require a fundamental shift away from underlying disablist and ageist conceptions, behaviors, and practices. But where does one begin in addressing deep-seated issues of disablism? It is not so easily accomplished as painting a curb cut yellow. I think this will be a focus, and continuing area of struggle, for me as I move forward in my career.

When I began this work, I identified three primary assumptions that I brought into this research. I now re-visit those assumptions after having completed this research study. My first assumption was that study participants would only address those physical environmental components, which enabled as well as

restricted their engagement in meaningful occupation. However, through my immersion in the data collection process, I came to the striking realization that study participants were acutely aware of how their context, including physical, social, cultural, political, and institutional environmental factors influenced their daily lives. It was faulty of me to assume that my participants would have such a restricted view of their environments.

A second assumption I held was that study participants would not speak to their experiences of low vision from the perspective of critical disability theory or a critical gerontology perspective. That too was a faulty pre-supposition on my part. Although I interpreted the findings within the context of these two guiding theoretical paradigms, participants spoke critically on issues such as the medicalization and adoption of a techno-scientific perspective of risk, stigma, ageism, ableism, and the taken-for-granted cultural ideal that to be a 'good older person' one must be autonomous, independent, or self-reliant over collective forms of support.

Lastly, I assumed that for their observation visits, participants would choose occupations that took place predominately in the home. This spoke to my pre-supposition that study participants would be occupationally withdrawn. This assumption stemmed from both my experiences working as a research assistant on an ARVL grounded theory study as well as my embeddedness in the literature that focused more on what seniors with ARVL cannot do versus what occupations they continue to do. In reality, my participants engaged in a wide variety of occupations including eating out at restaurants, attending craft clubs, or journeying to malls, grocery stores, pharmacies, and banks.

I conclude this section by asking the question "*Where do I go from here?*" In terms of my future program of research, my intention is to continue to write and publish manuscripts from this study. Some of my more immediate ideas for publication include: 1) publishing an article based specifically on my observational findings that include a discussion of how participant observation can be a useful data

collection tool in ARVL research; 2) publishing a methodologically focused article regarding the use of critical ethnography as a means of understanding living with age-related vision loss; and 3) publishing an article detailing my empirical findings regarding the influence of environmental factors on older adults engagement in meaningful occupation for a Canadian occupational therapy audience. Research that looks at environmental influence on participation in daily activity has already been carried out within the context of adults and older adults with chronic health conditions (Hand, Law, Hanna, Elliott & McColl, 2012; Hand, Wilkins, Letts & Law, 2013) and children and youth with disabilities (Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo & Law, 2013). As such, the inclusion of research focused on environmental influences on participation in daily activity among older adults with ARVL would serve as a new addition to this existing area of research. This thesis only began to highlight how ableist and ageist assumptions shape how older adults with ARVL engage in meaningful occupation, thereby substantiating the need for further research that considers the transaction between environmental influences and occupational engagement. With the exception of chapter two--a scoping review published in the *British Journal of Occupational Therapy*-- none of my manuscripts will be submitted for publication in occupational therapy specific journals. Given my professional designation and the limited research being done regarding ARVL in Canadian occupational therapy, I feel this would be an important area for future publication. I also plan to present my findings to occupational therapy, aging, disability, and low vision audiences through formal presentations and public talks.

In addition to publications and presentations, I also desire to use the study results to advocate for the inclusion of low vision curriculum within Canadian occupational therapy programs, as I feel this is an often overlooked area of professional occupational therapy practice. I have had some success in my endeavors so far. For example, in March 2014 two staff members from the CNIB and I provided an interactive lecture on the role of occupational therapy in ARVL rehabilitation as part of the second year occupational therapy curriculum at McMaster University. The lecture was well received and we have been invited

back again this year. I also participated in a lecture on ARVL in November 2013 with two CNIB staff members as well as my supervisor at Western University. Further, I have introduced a clinical case study regarding a senior with macular degeneration that is now used as part of McMaster University's problem based learning (PBL) tutorials. I will continue to work towards the inclusion of age-related vision loss curriculum in Canadian occupational therapy training in an effort to expand student's awareness of ARVL and the vital role occupational therapists can play. Additionally, results of this study could be used to inform a broadening of low vision management curriculum in both optometry and ophthalmology.

8.8 Concluding Remarks

In conclusion, this chapter provided an overview of key study findings and the insights gained from undertaking this critical ethnography. The implications of the study findings for persons with vision loss, low vision rehabilitation professionals, researchers, as well as on the development of vision-friendly environments and inclusive social policy were discussed. The primary strengths and limitations of the study were identified as well as directions for future research. As one of the strengths of this study, those quality criteria such as worthiness of the topic, adequacy of the data and interpretation, resonance, sincerity, usefulness, and coherence of the research approach were discussed in order to evaluate the quality of the research undertaken.

Overall, this study sought to address two research objectives including: 1) To critically examine the role of the physical, social, cultural, and political/institutional environment in supporting as well as detracting from the occupational engagement of older adults with ARVL; and 2) To raise awareness of how primary barriers older adults with ARVL face in relationship to various physical, social, cultural and institutional environmental factors are embedded in ageist and ableist assumptions. To accomplish these goals, a critical ethnography methodology was adopted, with theoretical underpinnings drawn primarily from critical gerontology, a critical occupational perspective, and critical disability theory.

Through this work, findings extended beyond physical environmental barriers, to begin to bring awareness and criticism to normative assumptions that both influence how older adults understand and negotiate ARVL and the socio-political production of disability. Although a common thread across this study was that older adults with age-related vision loss largely framed the management of vision loss as a personal responsibility, findings pointed out various ways that socio-political forces shape the experience of age-related vision loss for older adults that cannot be overcome through individual action alone. As such, the responsibility for addressing environmental barriers in the community and to negotiate the occupations individuals want, need, or are expected to do to maintain health and well-being cannot be placed simply on aging individuals. Instead, there is a need for collective efforts to address how barriers to occupational engagement are shaped via existing social practices, systems, and structures that serve to marginalize aging adults with ARVL. Working towards the creation and sustainment of age-friendly and vision-friendly environments is not an easy task. It will require various levels and types of collaborative actions involving a diversity of stakeholders, including older adults with ARVL, low vision rehabilitation providers, community leaders, policy makers, and researchers. There are many opportunities to enhance the environmental inclusion of older adults with age-related vision loss as long as there is a collective will based in a strong conviction for inclusivity and emancipatory social change coupled with a healthy imagination for how environments can be different.

8.9 References

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Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Debbie Rudman
 File Number: [REDACTED]
 Review Level: Delegated
 Approved Local Adult Participants: 0
 Approved Local Minor Participants: 0
 Protocol Title: Environmental influences on occupational participation among seniors with low vision: A critical ethnography.
 Department & Institution: Health Sciences/Occupational Therapy,
 Sponsor:
 Ethics Approval Date: October 23, 2012 Expiry Date: December 31, 2013
 Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		
Other	Appendix A: Narrative Interview	
Other	Appendix B: VFQ-25	
Other	Appendix C: Demographic Questionnaire	
Other	Appendix D: Field Note Guidelines	
Other	Appendix E: Semi-structured in-depth interview (with older adults with ARVL)	
Other	Appendix F: Document Analysis Framework	
Other	Appendix G: Semi-structured in-depth interview (with organization representatives)	
Letter of Information	Appendix H - Letter of information for older adults with ARVL (Faculty of Health Sciences, Health & Rehabilitation Sciences letterhead)	2012/09/16
Advertisement	Appendix I: Advertisement	
Letter of Information	Appendix J - Letter of information for members of local service providers, clubs, and organizations (Faculty of Health Sciences letterhead)	2012/09/16
Other	Appendix K - Consent form	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/CH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Signature [REDACTED]

Ethics Officer to Contact for Further Information

Janice Sutherland	Grace Kelly	Shirrel Walcott
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This is an official document. Please retain the original in your files.

[REDACTED]

Appendix B: CNIB Ethics Approval

Hi Colleen,

Just to follow on your Research Intent Form request, and our discussion just now, you are formally approved to proceed with recruitment of maximum 4 older adults' clients, as indicated in your ethics submission, and on the phone to me.

I look forward to hearing the results of your research, and definitely hope you will be able to present them (in a webinar) to our front line staff, when the dissertation is done! Good luck with the research project!

Thanks for your ongoing interest in CNIB.

Deborah.

Deborah Gold, PhD
National Director, Research and Program Development, CNIB and
Associate Professor (Status-Only), Department of Occupational Science and
Occupational Therapy, University of Toronto

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Appendix C: CNIB Staff Recruitment Information Sheet

Study Title: Environmental influences on occupational participation among seniors with low vision: A critical ethnography.

What is this study about?

This study is being carried out by Colleen McGrath, who is a PhD student at Western University. This study will take place within the Hamilton-Haldimand-Niagara-Brant region and will include 8-10 older adults with age-related vision loss (ARVL). The study aims to understand the occupational participation of seniors with low vision, as a process that is influenced by environmental elements. Its specific objectives include: i) exploring how older adults with ARVL negotiate their environments within everyday life; ii) examining the role of the physical, social, cultural, political, economic and institutional environment in supporting as well as detracting from the occupational participation of seniors with ARVL and; iii) exploring the implications of occupational restriction on the identities of older adults with ARVL.

How many people do I need to recruit?

I will be using a number of recruitment approaches for this study and so the maximum number that I am able to recruit from the CNIB is 4. If these individuals could include both males and females as well as people who live in urban as well as rural settings that would be ideal!

Who can participate in the study?

CNIB clients who meet the following five criteria CAN participate in the study:

1. 65 years of age and older;
2. Have received a diagnosis of age-related vision loss (including; ARMD, glaucoma, and/or diabetic retinopathy);
3. Self-identify as experiencing functional impairments due to ARVL;
4. Be able to communicate effectively in English.
5. Must live in the Hamilton-Haldimand-Niagara-Brant region.

An individual is NOT able to participate in the study if they experience significant cognitive challenges which would impair their ability to engage meaningfully in the data collection process or if the individual lives in an assisted living facility, where community access and occupational participation may be restricted due to facility rules and policies.

So the person is eligible to participate, now what do I do?

Step 1: Identify participants who meet the eligibility criteria. If you are unsure whether or not someone would be eligible, please refer them on to myself and I will decide after speaking with them.

Step 2: Provide the participant with a letter of information about the study (see attached letter).

Step 3: If s/he is interested in participating, you will ask if his/her telephone number can be provided to the researcher. If the individual has any questions about the study, I will gladly address those during our telephone conversation.

Step 4: Provide me with the person's telephone number.

My job is to call each individual to inform them about the study and ensure that they understand what their involvement would entail. I will also screen to ensure that the individual meets the inclusion criteria and I will get consent from the individual prior to collecting any data.

Thank you in advance for your help with recruitment!

Appendix D: Newspaper Advertisement

Understanding the influence of the environment on the participation of seniors with low vision

My name is Colleen McGrath, and I am a PhD student in the Health and Rehabilitation Sciences Program at Western University. I am interested in learning about how the environment influences the ability of older adults with vision loss to engage in their daily activities. The principal investigator for this project is Dr. Debbie Laliberte-Rudman.

- Who? Women and Men who have age-related vision loss (such as glaucoma, macular degeneration or diabetic retinopathy), are 75 years of age or older, and speak English.
- What? Two individual interviews and one observation visit will occur over a 2 month period of time. The interviews will focus on how the environment has impacted your ability to engage in your daily activities.
- How Long? The two interviews will take between 1-2 hours each to complete. The observational visit will take between 1-3 hours.
- Where? In Hamilton and the outlying rural areas. The interviews will take place with the researcher in your home or at a location of your choice.
- Why? To help determine how the environment influences the ability of older adults with low vision to engage in their daily activities.

Interested? For more information please contact:
Colleen McGrath, (Email), (Telephone Number)

Appendix E: Flamborough Review Newspaper Article

Monday, May, 13, 2013 - 10:10:58 AM

Waterdown occupational therapist focuses on age-related vision loss

By Kathy Yanchus • Review Staff

A gap in services she could provide as an occupational therapist sent Colleen McGrath back to school.

“I wanted to learn more about older adults with age-related vision loss just because I saw it as a gap in terms of occupational therapy services,” said the 28-year-old Waterdown resident, currently in the third year of a four-year PhD program in health and rehabilitation sciences at Western University.

It was a subject touched upon in her previous studies at McMaster University, where she earned an undergrad degree in health studies and gerontology and a Masters in occupational therapy, but one she wanted to pursue in greater depth.

“For some reason it just prompted a real spark in me; it was something I was really interested in and that’s why I wanted to go back to school so I could focus my energies exclusively on doing that for a four year span.”

McGrath is collecting data to determine how the environment influences the ability of older adults with age-related vision loss (ARVL), to participate in their day-to-day activities. The three most common diagnoses that fall under the ARVL umbrella are age-related macular degeneration (AMD), diabetic retinopathy and glaucoma.

Her approach to environmental factors is a holistic one, including not just an older adult’s physical environment, but their social, cultural and institutional one.

In terms of physical environment challenges, she references struggles experienced in crossing a busy intersection or the necessity to take a familiar

route to the grocery shop and the difficulties faced should that route be altered, for example, due to construction.

“They talk about how important it is to take a familiar route, so going the same way to the grocery store because they know that route, and then some of the challenges when that route changes, or even in the actual grocery store, if they’ve changed the layout.”

In their social environment, for example, struggles faced by older adults with ARVL involve being able to interact with other people.

“Our ability to see someone’s face is the way that we recognize them. When you don’t have that ability that really interferes with your ability to engage socially with others. It can be a disorienting experience when you don’t recognize who you’re talking to.”

McGrath’s data collection methods include interviews with study participants. The first step is not just listening to the older adult’s experience with vision loss, but witnessing first-hand how they engage in activities, such as shopping, riding a bus or attending a social program.

“It’s just a really nice way to see what it is that people are talking about. Someone can describe it to you, and you’ll never fully understand unless you have vision loss yourself, but to hear someone talk about it, and then to see them actually engage in that activity, really gives you a good perspective in terms of how it’s influencing their day-to-day life.”

McGrath is also connecting with service providers to get their perspective on how services are being geared to older adults with ARVL, organizations such as the CNIB, the Canadian Council of the Blind, Hamilton Street Railway and the Hamilton Council on Aging.

“I also want to talk to some of the people that older adults are encountering on a day-to-day basis, so the manager of the grocery store, or the bank manager, to try and get a sense of how those services are helping to meet the needs of older adults, and perhaps some of areas where they’re falling short.”

Study subjects have been willingly providing McGrath with enough detail she can piece together where challenges, as well as supports, exist.

The third component to her research is examining documents and policies of governments and service providers, again to determine where needs are being met and where there are gaps.

Her goal is to compile all data by August so she can begin writing her thesis next year.

Once completed, she wants to present her research findings through publications and conferences, as well as directly to older adults in community settings.

With the population aging, there will be a significant increase in the prevalence of ARVL, said McGrath.

“It is becoming an increasingly more common diagnosis that older adults are having to deal with for sure,” she said. “There already are fantastic services out there and I think we need to make sure we continue to focus on older adults with vision loss, because it’s not going anywhere, other than up.”

McGrath is still looking for a few additional adults – 65 years of age or older with ARVL – to participate in her research study. If anyone is interested, email her at (Email) or call (Telephone Number).

Once her doctorate is complete, McGrath hopes to land a faculty position in an occupational therapy department.

“So I can educate future OTs and talk to them about how they can work with older adults who have vision loss. I really do love the work that I’m doing, so ideally I’d love to end up in a faculty position.”

Appendix F: Hamilton Mountain News Newspaper Article

Wednesday, June, 26, 2013 - 8:08:24 AM

COMMUNITY COLUMNIST: What you need to know about age-related vision loss

By Colleen McGrath, special to the News

Low vision refers to a permanent loss of vision that cannot be corrected by eyeglasses, contact lenses, medication or surgery. Older adults now constitute the fastest growing segment of the population with low vision conditions, including macular degeneration, glaucoma and diabetic retinopathy.

These conditions are often collectively referred to as age-related vision loss. As the Canadian population continues to age, it is expected that there will be an increasing number of Canadians with age-related vision loss. In fact, the fastest growing low vision group are older adults between the ages of 75 to 84 years old. Age-related vision loss often has negative effects on daily functioning. This may include challenges with performing daily self-care tasks, preparing meals, shopping and housework, as well as participation in leisure activities that promote social interaction and engagement with the community.

The challenges to performing one's daily activities can often result in a variety of negative outcomes including an increased risk of social isolation, functional dependence, and compromised quality of life.

Despite the growing number of older Canadians with age-related vision loss, it continues to be under-treated. In fact, older adults commonly wait five to seven years after losing their vision before seeking out vision rehabilitation services. As a person with age-related vision loss, you may benefit from help. For example, perhaps you would benefit from an assistive device, such as a magnifying glass or CCTV that will help to support your participation in everyday tasks, such as reading.

Perhaps you are having difficulty adjusting to your low vision condition and would benefit from participating in a support group for older adults. Or perhaps you are finding yourself burning your meals and would benefit from tactile labels that would help you to identify the temperatures on your stove dial that you use most frequently.

Whatever the difficulty you may be having, either in the home or in your community, there are services in Hamilton that can help. For example, the Canadian National Institute for the Blind provides community-based support for Canadians who are blind or partially sighted. For more information about the CNIB, go to www.cnib.ca or call 1-800-563-2642. Another organization is the Canadian Council of the Blind, which provides social programming for people who are blind or visually impaired, including older adults with age-related vision loss. For more information on the services provided by the CCB, call 905-528-8555 ext. 5307.

Colleen McGrath is an occupational therapist and PhD Candidate at Western University where her research is focused on older adults with age-related vision loss.

If you would like to write in this space, call editor Gord Bowes at (Telephone Number) or (Email) to discuss.

Appendix G: Demographic Questionnaire

- 1) How would you describe your current living situation?
 - Your house in a typical city/town neighbourhood
 - Your house in a rural area
 - Your house in a retirement or adult lifestyle community
 - Your apartment/condominium in a typical city/town neighbourhood
 - Your apartment/condominium in a retirement or adult lifestyle community
 - Your apartment/condominium in seniors' housing
 - An apartment/room/flat/house owned by a family member
 - Boarding with a friend in a house or apartment
 - Other:

- 2) What is your birth date? (Month and year only)

- 3) What is the name of your low vision condition?
 - Age-related macular degeneration
 - Cataracts
 - Glaucoma
 - Diabetic retinopathy
 - Other. Please describe:
 - Unknown

- 4) How long ago was your low vision condition diagnosed?
 - 0-2 years
 - 3-5 years
 - 6-10 years
 - More than 10 years

- 5) At what age did your low vision condition begin to affect your functioning?

- 6) How would you describe the onset of your low vision condition?
 - Sudden onset
 - Gradual onset

- 7) Do you have any other health problems? If yes, please list.

- 8) How would you describe your current financial situation?
 - Excellent
 - Good
 - Fair
 - Poor

9) What is the highest level of formal education you have engaged in or completed?

- Less than grade/elementary school completed
- Grade school completed
- Some high school
- High school completed
- Some college/university
- College/university degree completed

10) What is your current marital or partnership status?

- Married/common law
- Living with partner
- Separated/divorced
- Widowed
- Single

11) Which of the following best describes your cultural background?

- Canadian
- European. Please specify:
- Non-European
 - East Indian
 - Asian
 - Middle Eastern
 - Aboriginal
 - Other non-European. Please specify:

12) Do you have children? Yes/No. If yes, how many children do you have?

13) How many of your children live within 20 minutes travel time?

14) What is your retirement status?

- Preparing for retirement
- Not yet retired
- Partially retired
- Fully retired

15) Are you currently active as a volunteer? Yes/No

Appendix H: Letter of Information for Older Adult Participants

November 8, 2012

Letter of Information

Study Title: Environmental influences on occupational participation among seniors with low vision: A critical ethnography.

Study Researcher:

Colleen McGrath, PhD Candidate
Health and Rehabilitation Sciences
University of Western Ontario

Supervisor:

Dr. Debbie Laliberte Rudman PhD, OT Reg. (ON)
School of Occupational Therapy
University of Western Ontario

You are invited to take part in a research study that aims to learn from people who are 65 years and older who are experiencing age-related vision loss (ARVL). The study will explore how the environment influences the ability of older adults with ARVL to participate in the daily activities they need and want to do. I am a doctoral student in the Health and Aging field of the Health and Rehabilitation Sciences program at Western University and the information I am collecting will be used for my thesis.

I will be interviewing up to 10 older adults with ARVL and up to 8 community organization representatives. To participate in this study, you need to be 65 years of age and older, have received a diagnosis of age-related vision loss, self-identify as experiencing functional impairments due to ARVL, and be able to communicate effectively in English.

What will I have to do if I choose to take part?

You will be asked to take part in 3 meetings with the study researcher, who is a graduate student at Western University. The first meeting will focus on your story of vision loss and how your participation in activities has changed since the onset of your ARVL. This meeting will be audio-taped and will be about 2 hours long, depending on the level of detail that you would like to share. Approximately 2-3 weeks later, you will complete an observation session where you and the study researcher will engage in an occupation together that is meaningful to you (for example, grocery shopping, gardening, going to seniors' centre, cooking). This observation session should take between 1-3 hours to complete, depending on the occupation chosen. This observation session may take place in the home or in the community, depending on the occupation that you chose. Approximately 4-5 weeks after the observation session, you will participate in a second interview

which will also be audio-recorded and will last about 2 hours. During this interview, you will discuss issues concerning the environment and how that affects your ability to engage in your daily activities. Each meeting will be held in a location of your choice; for example, at your home or at the researcher's office. You will choose the time and place.

Are there any risks or discomforts?

There are no known risks associated with taking part in this research. Occasionally some people experience discomfort when they talk about health issues. You are free to choose what you will and will not discuss. This research does require you to commit time. All meetings will be scheduled at your convenience, and you can request to reschedule or shorten meetings if you experience discomfort or fatigue.

What are the benefits of taking part?

Your first-hand experience of living with low vision is important information that only you have. Information you share will be presented to others through publications and at conferences and meetings. As a result, your views can help influence the services, programs, and policies that are put in place for older adults with ARVL. Your identity will never be released in any publication or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

What happens to the information that I tell you?

The interviews will be audio-recorded. What you say will be typed out by the study researcher or a typist. The only people who will listen to the recording will be the researcher, her thesis supervisor and a typist. I will also be taking notes about the activities you are doing and the setting we are in during the observation session. Once the observation period is over, I will write additional notes from memory. All identifying information will be removed from these notes. The only people who will read the observation notes will be the researcher, and her thesis supervisor and committee members.

To protect your identity, only an identification number will be used to identify recordings, observation notes, transcripts, and interviews. You are free to request that parts of the recording be erased, either during or after the interview sessions. Quotes from your story and the interviews, and notes from the observation sessions will be included in future publications and presentations and will be identified using fictional names. Personal details will be changed to ensure your anonymity.

The consent form, notes and recordings will be locked in a secure place at the University of Western Ontario, and all information transferred into typed format and digital files will be password protected. All information will be erased after 10 years.

Voluntary Participation:

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future. Information collected prior to withdrawal will be kept, unless you ask to have it removed from the study. You do not have to be in this study if you do not wish to be. You do not have to answer any questions in the interviews. You do not have to talk about anything in the interviews that you do not want to.

You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact me: Colleen McGrath at (Email) or by telephone at (Telephone Number). You may also wish to contact Dr. Debbie Laliberte Rudman, who is the Principal Investigator for this project, at (Email) or by telephone at (Telephone Number).

If you have any questions about the conduct of this study or your rights as a research participant, you may contact: Office of Research Ethics at the University of Western Ontario: (Telephone Number).

Representatives of the University of Western Ontario Ethics Board may contact you or require access to your study related record to monitor the conduct of this research.

This letter is for you to keep.

Appendix I: Letter of Information for Community Organization Representatives

November 8, 2012

Letter of information

Study Title: Environmental influences on occupational participation among seniors with low vision: A critical ethnography.

Study Researcher:

Colleen McGrath, PhD Candidate
Health and Rehabilitation Sciences
University of Western Ontario

Supervisor: Dr. Debbie Laliberte Rudman PhD

School of Occupational Therapy
University of Western Ontario

I am a doctoral student in the Health and Aging field of the Health and Rehabilitation Sciences program at Western University. The information I am collecting will be used in my thesis. You are invited to take part in a research study that is exploring how the environment influences the ability of older adults with ARVL to participate in their daily activities. More broadly, the study aims to inform the policies and services designed for older adults with ARVL in ways that enhance environmental support. In order to participate in this study you need to: i) work for, or be a member of a community or political organization which establishes policy guidelines or provides services that influence older adults with age-related vision loss and; ii) be able to participate in an interview in English.

What will I have to do if I choose to take part?

You will be asked to take part in one meeting with the researcher, who is a graduate student at the University of Western Ontario. The interview will be about how your organization or service deals with some of the environmental enablers and barriers that will be identified by the older adults with vision loss who will be interviewed during the first phase of this research study. You can tell me as much or as little as you like, and you can decide what information you want to share. This meeting will take approximately 1 to 1½ hours and will be held in a location of your choice; for example, at your office or at the researcher's office. You will choose the time and place.

Are there any risks or discomforts?

There are no known risks associated with taking part in this research.

What are the benefits of taking part?

Information you share will be presented to others through publications and at conferences and meetings. As a result, your views may help to influence the services, programs, and policies that are put in place for older adults with ARVL. Your identity will never be released in any publication or presentation. If you want, a copy of the study results can be forwarded to you at the completion of the study.

What happens to the information that I tell you?

The interview will be audio-recorded. What you say will be typed out by the study researcher or a typist. The only people who will listen to the recording will be the researcher, her thesis supervisor and a typist.

To protect your identity, only code numbers will be used to identify your recordings, transcripts, and interviews. You are free to request that parts of the recording be erased, either during or after the interview session. Quotes from your interview will be included in future publications and presentations and will be identified using pseudonyms. Personal details and details regarding the organization or service that you represent will be changed to ensure anonymity.

The consent form, notes and recordings will be locked in a secure place at Western University, and all information transferred into typed format and digital files will be password protected. All information will be erased after 10 years.

Voluntary Participation:

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future. You do not have to be in this study if you do not wish to be. You do not have to answer any questions in the interview. You do not have to talk about anything in the interview that you do not want to.

You will be given a copy of this letter of information and consent form once it has been signed. If you have any questions or want any additional information, you may contact me: Colleen McGrath at (Email) or by telephone at (Telephone Number). You may also wish to contact Dr. Debbie Laliberte Rudman, who is the Principal Investigator for this project, at (Email) or by telephone at (Telephone Number)

If you have any questions about the conduct of this study or your rights as a research participant, you may contact: Office of Research Ethics at the University of Western Ontario: (Telephone Number).

Representatives of the University of Western Ontario Ethics Board may contact you or require access to your study related record to monitor the conduct of this research.

This letter is for you to keep.

Appendix J: Consent Form**Consent Form**

Study Title: Environmental influences on occupational participation among seniors with low vision: A critical ethnography.

I have reviewed the contents of the letter of information, I have had the nature of the study explained to me and I agree to participate. All of my questions have been answered to my satisfaction.

Signature of Research Participant

Date

Printed Name

Signature of Person
Obtaining Informed Consent

Date

Printed Name

Appendix K: Narrative Interview Guide

Can you tell me the story of your experience with age-related vision loss (ARVL)?

Please include as much or as little detail as you would like. You may begin wherever you would like. I will not interrupt until you have finished telling me your story, at which point we will break. I will then ask you a few questions for clarification, if needed.

Follow-up questions for clarification if not addressed in the narrative interview:

1. How has your ARVL impacted your everyday life? For example, what impact has it had on your ability to do the things you want to do, need to do, or are expected to do?
2. What is the name of your age-related vision condition?
3. How long have you been dealing with ARVL?

National Eye Institute
Visual Functioning Questionnaire - 25
(VFQ-25)

version 2000

(INTERVIEWER ADMINISTERED FORMAT)

January 2000

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4. The user of the NEI VFQ-25 - July 1996 will provide a credit line when printing and distributing this document or in publications of results or analyses based on this instrument acknowledging that it was developed at RAND under the sponsorship of the National Eye Institute.
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7/29/96

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Instructions:

I'm going to read you some statements about problems which involve your vision or feelings that you have about your vision condition. After each question I will read you a list of possible answers. Please choose the response that best describes your situation.

Please answer all the questions as if you were wearing your glasses or contact lenses (if any).

Please take as much time as you need to answer each question. All your answers are confidential. In order for this survey to improve our knowledge about vision problems and how they affect your quality of life, your answers must be as accurate as possible. Remember, if you wear glasses or contact lenses for a particular activity, please answer all of the following questions as though you were wearing them.

Visual Functioning Questionnaire - 25

PART 1 - GENERAL HEALTH AND VISION

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

(Circle One)

READ CATEGORIES:	Excellent.....	1
	Very Good	2
	Good	3
	Fair	4
	Poor.....	5

2. At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very poor or are you completely blind?

(Circle One)

READ CATEGORIES:	Excellent.....	1
	Good	2
	Fair	3
	Poor.....	4
	Very Poor.....	5
	Completely Blind.....	6

* Skip Question 1 when the VFQ-25 is administered at the same time as the SF-36 or RAND 36-Item Health Survey 1.0

3. How much of the time do you worry about your eyesight?

(Circle One)

READ CATEGORIES:	None of the time	1
	A little of the time	2
	Some of the time	3
	Most of the time	4
	All of the time?.....	5

4. How much pain or discomfort have you had in and around your eyes (for example, burning, itching, or aching)? Would you say it is:

(Circle One)

READ CATEGORIES:	None.....	1
	Mild.....	2
	Moderate.....	3
	Severe, or	4
	Very severe?.....	5

PART 2 - DIFFICULTY WITH ACTIVITIES

The next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity.

5. How much difficulty do you have reading ordinary print in newspapers? Would you say you have:

(READ CATEGORIES AS NEEDED)

(Circle One)

No difficulty at all	1
A little difficulty.....	2
Moderate difficulty	3
Extreme difficulty	4
Stopped doing this because of your eyesight.....	5
Stopped doing this for other reasons or not interested in doing this	6

6. How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools? Would you say:
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

7. Because of your eyesight, how much difficulty do you have finding something on a crowded shelf?
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

8. How much difficulty do you have reading street signs or the names of stores?
(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

9. Because of your eyesight, how much difficulty do you have going down steps, stairs, or curbs in dim light or at night?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

10. Because of your eyesight, how much difficulty do you have noticing objects off to the side while you are walking along?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

11. Because of your eyesight, how much difficulty do you have seeing how people react to things you say?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

12. **Because of your eyesight, how much difficulty do you have picking out and matching your own clothes?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

13. **Because of your eyesight, how much difficulty do you have visiting with people in their homes, at parties, or in restaurants ?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

14. **Because of your eyesight, how much difficulty do you have going out to see movies, plays, or sports events?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

15. Now, I'd like to ask about driving a car. Are you currently driving, at least once in a while?

(Circle One)

Yes..... 1 Skip To Q 15c

No 2

- 15a. IF NO, ASK: Have you never driven a car or have you given up driving?

(Circle One)

Never drove..... 1 Skip To Part 3, Q 17

Gave up..... 2

- 15b. IF GAVE UP DRIVING: Was that mainly because of your eyesight, mainly for some other reason, or because of both your eyesight and other reasons?

(Circle One)

Mainly eyesight..... 1 Skip To Part 3, Q 17

Mainly other reasons..... 2 Skip To Part 3, Q 17

Both eyesight and other reasons 3 Skip To Part 3, Q 17

- 15c. IF CURRENTLY DRIVING: How much difficulty do you have driving during the daytime in familiar places? Would you say you have:

(Circle One)

No difficulty at all 1

A little difficulty..... 2

Moderate difficulty 3

Extreme difficulty 4

16. How much difficulty do you have driving at night? Would you say you have: (READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Have you stopped doing this because
 of your eyesight 5
 Have you stopped doing this for other
 reasons or are you not interested in
 doing this 6

- 16a. How much difficulty do you have driving in difficult conditions, such as in bad weather, during rush hour, on the freeway, or in city traffic? Would you say you have:
 (READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Have you stopped doing this because
 of your eyesight 5
 Have you stopped doing this for other
 reasons or are you not interested in
 doing this 6

PART 3: RESPONSES TO VISION PROBLEMS

The next questions are about how things you do may be affected by your vision. For each one, I'd like you to tell me if this is true for you all, most, some, a little, or none of the time.

(Circle One On Each Line)

READ CATEGORIES:	All of the time	Most of the time	Some of the time	A little of the time	None of the time
17. <u>Do you accomplish less than you would like because of your vision?</u>	1	2	3	4	5
18. <u>Are you limited in how long you can work or do other activities because of your vision?.....</u>	1	2	3	4	5
19. How much does pain or discomfort <u>in or around your eyes</u> , for example, burning, itching, or aching, keep you from doing what you'd like to be doing? Would you say:	1	2	3	4	5

For each of the following statements, please tell me if it is definitely true, mostly true, mostly false, or definitely false for you or you are not sure.

(Circle One On Each Line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
20. I <u>stay home most of the time</u> because of my eyesight.	1	2	3	4	5
21. I feel <u>frustrated</u> a lot of the time because of my eyesight.	1	2	3	4	5
22. I have <u>much less control</u> over what I do, because of my eyesight.	1	2	3	4	5
23. Because of my eyesight, I have to <u>rely too much on</u> <u>what other people tell me...</u>	1	2	3	4	5
24. I <u>need a lot of help</u> from others because of my eyesight.	1	2	3	4	5
25. I worry about <u>doing things</u> <u>that will embarrass myself</u> <u>or others</u> , because of my eyesight.	1	2	3	4	5

That's the end of the interview. Thank you very much for your time and your help.

A4. Because of your eyesight, how much difficulty do you have figuring out whether bills you receive are accurate?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

A5. Because of your eyesight, how much difficulty do you have doing things like shaving, styling your hair, or putting on makeup?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

SUBSCALE: DISTANCE VISION

A6. Because of your eyesight, how much difficulty do you have recognizing people you know from across a room?

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1
 A little difficulty..... 2
 Moderate difficulty 3
 Extreme difficulty 4
 Stopped doing this because of your eyesight 5
 Stopped doing this for other reasons or not
 interested in doing this 6

- A7. Because of your eyesight, how much difficulty do you have taking part in active sports or other outdoor activities that you enjoy (like golf, bowling, jogging, or walking)?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1**
A little difficulty..... 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
**Stopped doing this for other reasons or not
interested in doing this 6**

- A8. Because of your eyesight, how much difficulty do you have seeing and enjoying programs on TV?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1**
A little difficulty..... 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
**Stopped doing this for other reasons or not
interested in doing this 6**

SUBSCALE: SOCIAL FUNCTION

- A9. Because of your eyesight, how much difficulty do you have entertaining friends and family in your home?**

(READ CATEGORIES AS NEEDED)

(Circle One)

- No difficulty at all 1**
A little difficulty..... 2
Moderate difficulty 3
Extreme difficulty 4
Stopped doing this because of your eyesight 5
**Stopped doing this for other reasons or not
interested in doing this 6**

SUBSCALE: DRIVING

A10. [This items, “driving in difficult conditions”, has been included as item 16a as part of the base set of 25 vision-targeted items.]

SUBSCALE: ROLE LIMITATIONS

A11. The next questions are about things you may do because of your vision. For each item, I'd like you to tell me if this is true for you all, most, some, a little, or none of the time.

(READ CATEGORIES AS NEEDED)

(Circle One On Each Line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. <u>Do you have more help from others because of your vision?</u>	1	2	3	4	5
b. <u>Are you limited in the kinds of things you can do because of your vision?</u> .	1	2	3	4	5

SUBSCALES: WELL-BEING/DISTRESS (#A12) and DEPENDENCY (#A13)

The next questions are about how you deal with your vision. For each statement, please tell me if it is definitely true, mostly true, mostly false, or definitely false for you or you don't know.

(Circle One On Each Line)

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
A12. I am often <u>irritable</u> because of my eyesight.....	1	2	3	4	5
A13. I <u>don't go out of my home alone</u> , because of my eyesight.	1	2	3	4	5

Appendix M: Field Note Guideline

Field notes will be framed within a comprehensive fieldwork guide building upon the comprehensive note-taking method of Emerson, Fretz, and Shaw, (1995). Specifically this author will use the question format of comprehensive note-taking as proposed by Spradley (1980).

Space: What physical space or places are utilized?

Actor(s): Who are the people involved in the interaction?

Activity: What is the occupation being performed? Describe the environmental context. How is the researcher involved in the performance of the occupation?

Object: Are there any physical objects present during the performance of the occupation?

Act: What actions are being performed during the occupation? By which parties? What are people saying (include direct quotes if relevant)?

Time: What is the sequencing of events as it pertains to the occupation?

Goal: What is the end goal that the individual is trying to accomplish?

Feeling: What emotions are felt/ expressed by the individual? What emotions are felt by the researcher in relationship to the interaction?

Services: What resources and/or services are necessary to support the occupation?

Researcher's overall impressions of the participant observation session:

Follow-up questions to ask (during semi-structured in-depth interview):

Appendix N: Semi-structured Interview with Older Adult Participants

The semi-structured in-depth interview guide will be modified for each participant and will be guided by findings from the narrative interview and participant observation session. Below is a sample of questions that may be asked:

1. What does it mean to you to have low vision? What does it mean to you to be an older person aging with low vision?
2. If you think about the occupation that we did together, what are some of the things that made that task easy for you? What are some of the things that made that task difficult for you?
3. What occupations are meaningful to you? What makes those occupations meaningful?
4. What places are important to you? Why? What places/spaces give you a sense of belonging? What places/spaces make you feel excluded? Are there places that you no longer go to? Why do you no longer go to these places?
5. Are there any supports available to you that help you to do the things you want to do? Social supports (family, friends, neighbors, etc...)? Government level supports (funding, programs, etc...)?
6. Do you feel that other people in your community understand low vision? Why or why not?
7. Is there anything else I have not asked you that you would like to add?

Appendix O: Semi-structured Interview with Community Organization Representatives

The semi-structured in-depth interview guide will be modified for each organization representative based on the participant's findings. The following represent sample questions that may be asked:

1. Please describe the organization that you work for? What is your mandate? What are your primary activities?
2. How does your organization view the needs of the older adults in the community that you serve?
3. How does your organization consider the needs of older adults with age-related vision loss (ARVL)? If you are involved in meeting the needs of older adults with ARVL, how does your organization support those needs? How would you describe that relationship? If you are not involved in meeting the needs of older adults with ARVL, why do you think that is the case? How could your organization be involved in meeting the needs of older adults with ARVL in the future?
4. What do you think are the primary supports that older adults with ARVL require?
5. What do you think are the primary supports older adults with ARVL face in attempting to use your organization and/or services?
6. What do you think are the primary barriers that older adults with ARVL face?
7. What do you think are the primary barriers older adults with ARVL face in attempting to use your organization and/or services?

8. Can you describe any relevant policies that affect how your organization provides services to older adults with ARVL?
9. Is there any other information that you would like to share with me that I have not asked you about?

Appendix P: Document Analysis Framework

The documents are to be analysed using a modified version of the policy analysis framework as proposed by Bacchi (2009) according to the following seven questions:

1. What is the 'problem' represented to be in the specific document?
2. What primary presuppositions or assumptions underlie this representation of the 'problem'?
3. How has this representation of the 'problem' come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?
5. What effects are produced by this representation of the 'problem'?
6. How/where is this representation of the 'problem' produced, disseminated and defended? How could it be questioned, disrupted and replaced?
7. What solution(s) is/are offered to address the underlying problem? What conditions would need to be met to achieve this solution?

Appendix Q: Copyright Permission for Publication

Factors that influence the occupational engagement of older adults with low vision: A scoping review

Dear Colleen,

Since your first enquiry the journal has transferred to SAGE Publications as its publisher. Their terms allow reuse in a publication of your own work, which is essentially what a PhD dissertation is. I'm pasting the information from their page below. 'Version 3' means the final, published version. See highlighted text.

Kind regards,

Kathrine

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From: Colleen McGrath
Sent: 04 February 2015 15:49
To: BJOTeditorial
Subject: Requet to publish my manuscript

Hello,

I am writing to you regarding a manuscript with the following reference: McGrath, C., & Laliberte-Rudman, D. (2013). Factors that influence the occupational engagement of older adults with low vision: A scoping review. *British Journal of Occupational Therapy*, 76(5), 234-241.

I would like to include this as a chapter within my PhD dissertation. I spoke to your office previously regarding this and they were agreeable as long as no changes were made to the manuscript. I needed to update the literature review and so provided an addendum within the thesis with this updated information, as your office had instructed me to do.

I require copyright for publication permission to include within my thesis. This can simply be an email providing me with the permission to include this manuscript. Would you be able to provide this? Is there any other notation I should make within that chapter of the dissertation to indicate it has been published in your journal?

Any guidance you are able to provide to me would be much appreciated.

With thanks,
Colleen McGrath

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COT: The College of Occupational Therapists Limited is a company limited by shares and registered in England (Company number 1347374). The College is also a registered charity in England and Wales (Charity number 275119) and in Scotland (Charity number SCO39573).

Colleen Erin McGrath**EDUCATION/TRAINING:**

- Started September 2010 Doctor of Philosophy; Health & Rehabilitation Sciences
University of Western Ontario, London, Ontario
Focus: Low vision rehabilitation
Anticipated date of graduation: Spring 2015
- 2006-2008 Master of Science Occupational Therapy
McMaster University, Hamilton, Ontario
Degree conferred: November 2008
- 2002-2006 Bachelor of Arts (Hon.), Gerontology & Health Studies
McMaster University, Hamilton, Ontario
Focus: OT approaches for older adults with dementia
Degree conferred: April 2006

CURRENT STATUS:

- February 2012 PhD Candidate, Health & Rehabilitation Sciences
Western University, London, Ontario
- January 2011 Professional Associate, OT Program
School of Rehab Sciences, Faculty of Health Sciences
McMaster University, Hamilton, Ontario

PROFESSIONAL ORGANIZATIONS:

- 2006-Present Canadian Association of Occupational Therapists (CAOT)
2008-Present College of Occupational Therapists of Ontario (COTO)
2010-Present Canadian Association on Gerontology (CAG)
2012-Present International Society for Low Vision Research and Rehab

ACADEMIC AWARDS and HONOURS:***Western University, Health and Rehabilitation Sciences (Health and Aging)***

- 2013/2014 Social Sciences and Humanities Research Council (SSHRC)
Scholarship; Doctoral Fellowship
Duration- 12 months; Amount- \$20,000
- 2013/2014 Ontario Graduate Scholarship- declined by applicant
Scholarship; Doctoral
Duration- 1 year; Amount- \$15,000
- 2012/2013 Naomi Grigg Fellowship for Post-Graduate Studies in Gerontology

- Scholarship; Doctoral
Duration- 1 year; Amount- \$5,000
- 2012/2013 Ontario Graduate Scholarship
Scholarship; Doctoral
Duration- 1 year; Amount- \$15,000
- 2012 The Kirshenblatt Memorial Scholarship
Scholarship; Doctoral
Duration- 1 year; Amount- \$2,000
- 2012 Canadian Association on Gerontology Donald Menzies Scholarship
Scholarship; Doctoral
Duration- 1 year; Amount- \$1,500
- 2012 Canadian Institutes of Health Research (CIHR)
Chosen representative for the Summer Program in Aging (SPA)
Vancouver, British Columbia

McMaster University, OT Program, School of Rehabilitation Sciences

- 2008 Ontario Society of Occupational Therapists Prize
Award; Masters
Duration- 1 year; Amount- \$225

McMaster University, Health Studies and Gerontology (Honors)

- 2006 Pioneer Group Inc. Gerontology Prize
Award; Undergraduate
Duration- 1 year; Amount- \$400
- 2005 McMaster Retirees Association Scholarship
Award; Undergraduate
Duration- 1 year; Amount- \$1,000

EMPLOYMENT HISTORY:

Academic/Teaching

- March- Dec 2012 Instructor, Gerontology (Continuing Education)
Mohawk College of Applied Arts and Technology
Hamilton, Ontario
- Sept 2010- Aug 2012 Teaching Assistant, OT program (Graduate)
University of Western Ontario, London, Ontario
- February 2010-July 2013 Course Instructor (1A/Course 2), OTepp program

McMaster University, Hamilton, Ontario

February 2010- July 2013 Examination Preparation Module Coordinator, OTepp
McMaster University, Hamilton, Ontario

Sept 2006-April 2008 Teaching Assistant, Health, Aging & Society
McMaster University, Hamilton, Ontario

Research

May 2014- Present Senior Advisor
Research Office Administration Development & Support
Hamilton, Ontario

June 2013-May 2014 Government Grant Writer; Foundation Relations
Canadian National Institute for the Blind (CNIB)
Hamilton, Ontario

March 2011-March 2012 Research Assistant, Seniors with ARVL study
University of Western Ontario, London, Ontario

July 2009-July 2013 e-Learning Coordinator and Practicum Lead, OTepp
McMaster University, Hamilton, Ontario

Clinical

Sept 2008-August 2010 Occupational Therapist, Auto Insurance
Functional Rehabilitation Inc., Dundas, Ontario

Educational Consultation

June 2011 Content Developer, OTA Self-Assessment Tool
Nova Scotia Community College, Dartmouth, Nova Scotia
<http://access.nsc.ca/cgi-bin/perl/OTSP/index.pl>

Jan 2010 Content Developer, OT Practice Self-Assessment Tool
Nova Scotia Community College, Dartmouth, Nova Scotia
<http://access.nsc.ca/cgi-bin/perl/CAOT/index.pl>

SCHOLARLY AND PROFESSIONAL ACTIVITIES:

Professional Organizations

September 2012-Present: Advisory Member for the Hamilton Council on Aging

External peer review- Conference Abstracts

2013 Canadian Association on Gerontology (CAG) Review Board Member
 2014 World Federation of OTs (WFOT) Abstract Review Member

AREAS OF INTEREST:

Research: Qualitative approaches to research and program evaluation, critical ethnography, occupational engagement and age-related vision loss, critical gerontology, and environmental access in later life.

Teaching: Disability theory, critical gerontology, low vision rehabilitation, environmental access in older adulthood, and advocacy in occupational therapy.

COURSES TAUGHT:

Graduate

M.Sc (OT) Programme, School of Rehabilitation Science, McMaster University, Hamilton, Ontario

2012 Tutor, Occupational Therapy Program, Problem-based tutorial-Term 1 and Term 2
 2011 Tutor, Occupational Therapy Program, Problem-based tutorial-Term 1 and Term 2

Other (Guest Instructor, Evaluator)

2014 Guest Instructor OT 9531- Low vision rehabilitation (Western University, London, ON); Guest Instructor Term 5 PREP- Age-related vision loss and the role of occupational therapy (McMaster University, Hamilton, ON).
 2013 Evaluator: Term 5 SOLE Examination (McMaster University, Hamilton, ON); Evaluator: OT Admission interviews (McMaster University, Hamilton, ON); Evaluator: Term 6 Evidence Based Practice (EBP) Symposium (McMaster University, Hamilton, ON).
 2012 Evaluator: Term 1 PREP Evaluated Interviews (McMaster University, Hamilton, ON); Course Instructor: Occupational Therapy and Examination Preparation Project (OTEpp)- Course 1 Understanding the Canadian Practice Context (McMaster University, Hamilton, ON); Course Instructor: Occupational Therapy and Examination Preparation Project (OTEpp)- Course 5 Practicum Preparation (McMaster University, Hamilton, ON).
 2011 Guest Instructor: OT 9671- Advocacy in occupational therapy (Western University, London, ON); Guest Instructor: OT 9671- Stigma and disability rights (Western University, London, ON); Course Instructor: Occupational Therapy and Examination

- Preparation Project (OTepp)- 1B Understanding the Canadian Practice Context (McMaster University, Hamilton, ON); Evaluator: Term 1 PREP Evaluated Interview (McMaster University, Hamilton, ON).
- 2010 Guest Instructor: OT 9671- Advocacy in occupational therapy (Western University, London, ON); Guest Instructor: OT 9671- Stigma and disability rights (Western University, London, ON); Course Instructor: Occupational Therapy and Examination Preparation Project (OTepp)- 1A Foundations of Professional Practice (McMaster University, Hamilton, ON); Course Instructor: Occupational Therapy and Examination Preparation Project (OTepp)- 1B Understanding the Canadian Practice Context (McMaster University, Hamilton, ON).

SUPERVISORSHIPS:

- Jan 2012- March 2014 Western University School of Occupational Therapy
Ind. research project (Co-supervised; 4 students)
Topic: A secondary analysis of qualitative research from a grounded theory age-related vision loss study.
- July-August 2013 McMaster University Rehab Sciences (Term 6)
Practicum Supervisor (2 students)
Haldimand Abilities Centre, Hagersville, Ontario
- July-August 2013 McMaster University Rehab Sciences (Term 6)
Practicum Supervisor (2 students)
Hamilton Council on Aging (HCoA)
- 2012-2013 McMaster University Rehab Sciences (Term 4/5/6)
EBP Project Supervisor (2 students)
Topic: Scoping review of interventions designed to enhance occupational engagement for older adults with low vision.
- Nov-December 2012 McMaster University Rehab Science (Term 4)
Practicum Supervisor (2 students)
Haldimand Abilities Centre, Hagersville, Ontario
- June-August 2012 McMaster University Rehab Science (Term 6)
Practicum Supervisor (3 students)
Haldimand Abilities Centre, Hagersville, Ontario

RESEARCH FUNDING:

Funding agency: Canadian Institutes of Health Research (CIHR)

Amount: \$24,500

Funding period: November 2013-October 2014

Project title: Seniors, risk, and successful aging: Towards a broader understanding for rehabilitation

Investigators: Egan, M., Ceci, C., Gardner, P., Kessler, D., King, J., Laliberte Rudman, D., Malhotra, R., & **McGrath, C.**

PUBLICATIONS:

Journal Articles (peer reviewed):

McGrath, C., & Laliberte-Rudman, D. (2013). Factors that influence the occupational engagement of older adults with low vision: A scoping review. *British Journal of Occupational Therapy*, 76(5), 234-241.

Vrkljan, B., **McGrath, C.**, & Letts, L (2011). Office based screening tools for assessing fitness to drive: A critical appraisal of the evidence. *Canadian Journal of Occupational Therapy*, 78(2), 80-96.

Letts, L., Edwards, M., Berenyi, J., Moros, K., O'Neil, C., O'Toole, C., & **McGrath, C.** (2011). Using occupations to improve quality of life, health and wellness, and client and caregiver satisfaction for persons with Alzheimer's disease and related dementias: An evidence based review. *American Journal of Occupational Therapy*, 65(5), 497-504.

Journal Articles (not peer reviewed):

McGrath, C. (2011). Low Vision and Older Adults: The Role of Occupational Therapy. *OT Now*, 13(3).

Letts, L., Edwards, M., Berenyi, J., Moros, K., O'Neil, C., O'Toole, C., & **McGrath, C.** (2009). AOTA Critically Appraised Topics and Papers Series: Alzheimer's Disease. American Occupational Therapy Association.

McGrath C., Laliberte-Rudman D. (2013). Environmental influences on occupational engagement among older adults with low vision: A critical ethnographic study. *Visibility*, 7(3), 21-22.

Unpublished Reports:

McGrath, C. (2012). Results of a National Practicum Scan for Internationally Educated Occupational Therapists. Hamilton, Ontario: Prepared for Human Resources and Skills Development Canada.

Scholarly Presentations (peer reviewed):

Vrkljan, B., **McGrath, C.**, Balsara, S., & Love, J. (2009; June). Best practices in driver assessment for persons with disabilities. Paper Presentation. 2009 CAOT National Conference. Ottawa, ON. June 4, 2010.

Steggles, E., Baptiste, S., McMahon, P., Aguto, M., Hammond, H., Kaur, P., & **McGrath, C.** (2009; June). Creating a learning culture of accessibility. Paper Presentation. 2009 CAOT National Conference. Ottawa, ON. June 6, 2010.

McGrath, C. (2011; June). Readiness for Canadian Occupational Therapy Practice: A Self-Assessment Tool for Internationally Educated Occupational Therapists. Poster Presentation. 2011 CAOT National Conference. Saskatoon, Saskatchewan. June 18, 2011.

Gold, D., **McGrath, C.**, Laliberte-Rudman, D., & Zuvela, B. (2011; October). Exploring the lived experience of older adults with vision loss. Oral Presentation. Canadian National Institute for the Blind: Perspectives 2011. Toronto, Ontario. October 21, 2011.

Dhillon, S., Dix, L., **McGrath, C.**, & McMahon, P. (2012; June). The experience of internationally-educated occupational therapists transitioning to Canadian practice. Poster Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 9, 2012.

Baptiste, S., Dix, L., **McGrath, C.**, & Dhillon, S. (2012; June). Problem based learning in an online environment. Poster Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 9, 2012.

McGrath, C., & Laliberte-Rudman, D. (2012; June). Factors that influence occupational performance amongst seniors with vision loss. Poster Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 9, 2012.

McGrath, C., Steggles, E., McKnight, K. (2012; June). An online self-assessment tool for occupational therapist support workers. Poster Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 9, 2012.

McGrath, C., Laliberte-Rudman, D., Gold, D., & Zuvela, B. (2012; June). Understanding occupational participation amongst older adults with vision loss. Oral Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 7, 2012.

McGrath, C., & Steggles, E. (2012; June). A video diary project developed for internationally educated occupational therapists. Oral Presentation. Canadian Association of Occupational Therapists. Quebec City, QC. June 8, 2012.

Spafford, M.M., **McGrath, C.**, Zuvella, B., Gold, D., & Laliberte Rudman, D. (2012). Mapping pathways to visual rehabilitation: A study of older adults with age-related vision loss. Paper presentation. American Academy of Optometry, Phoenix, Arizona.

Gold, D., Zuvella, B., **McGrath, C.**, & Laliberte-Rudman, D. (2012; July). I'm okay-I'm not okay: The lived experience of older adults with vision loss. Oral Presentation. Association for Education and Rehabilitation of the Blind and Visually Impaired. Seattle, Washington. July 19, 2012.

Gold, D., Laliberte-Rudman, D., **McGrath, C.**, & Zuvella, B. (2012; September). The lived experience of older adults with low vision-- A Phenomenological study of influences on occupational participation. Oral Presentation. Envision Conference. St. Louis, Missouri. September 14, 2012.

Carroll, S.L., McGillion, M., **McGrath, C.**, Stacey, D. , Healey, J., Browne, G., Thabane, L., Arthur, H.M. (2013; May). Application of a Delphi method to develop a patient decision aid for implantable cardioverter defibrillator candidates. Oral Presentation. Quality of Care Outcomes & Research of the American Heart Association Scientific Meeting, Baltimore, MD. May 15-17 2013.

McGrath, C., & Steggles, E. (2013; May/June). Scan of national practicum requirements for internationally educated occupational therapists. Poster presentation. Canadian Association of Occupational Therapists, Victoria, British Columbia. June 1, 2013.

McGrath, C. (2013; May/June). Using a policy analysis framework in qualitative data analysis. Poster presentation. Canadian Association of Occupational Therapists, Victoria, British Columbia. June 1, 2013.

McGrath, C., Laliberte-Rudman, D., Gold, D., & Zuvella, B. (2013; May/June). Age-related vision loss: Understanding how occupational participation changes. Oral Presentation. Canadian Association of Occupational Therapists, Victoria, British Columbia. May 30, 2013.

Media Publications:

McGrath, C. (May 13, 2013). Waterdown occupational therapist focuses on age-related vision loss. The Flamborough Review. Available at: <http://www.flamboroughreview.com/news/waterdown-occupational-therapist-focuses-on-age-related-vision-loss/>.

McGrath, C. (June 26, 2013). What you should know about age-related vision loss. The Hamilton Community News. Available at: <http://www.hamiltonnews.com/opinion/community-columnist-what-you-need-to-know-about-age-related-vision-loss/>.