Abstract

The present study sought to understand how older adults’ social networks facilitate and constrain their engagement in meaningful occupations after being diagnosed with age-related vision loss (ARVL). A constructivist paradigm and narrative inquiry methodology were used to elicit and make sense of the participants’ unique stories. The participants consisted of five older adults 60 years and older, living with ARVL, including one of the following conditions; macular degeneration, glaucoma, and diabetic retinopathy. Participants were recruited from the Canadian National Institute for the Blind (CNIB) and Society for Learning and Retirement (SLR). Data was collected through three sessions of semi-structured, audio-recorded virtual interviews (via Zoom and telephone calls). Participants were inquired about their experiences of interacting with social networks and engaging in desired occupations while living with ARVL. Thematic and structural narrative analyses (Riesman, 2008) were performed on participants’ stories which identified the following five dominant themes:

1. Maintaining Engagement in Social Occupations to Foster a Sense of Belonging;
2. Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs;
3. Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships;
4. Community Mobility as Essential for Preserving Social Relationships; and
5. Technology as a Support to Social Connectedness: Connecting via Technology versus in Person. This research expands knowledge on ARVL-related barriers and facilitators to occupational engagement and highlights the benefits of social support in maintaining visually impaired older adults’ occupational goals. The future directions and implications of the study findings on future research and vision care services are also discussed.

Keywords: occupational engagement, age related vision loss, social network, social support, older adults, gerontology, occupational science, visual impairment, narrative inquiry
Lay Summary

This study aimed to understand how the social networks of older adults influence their engagement in desired activities after losing vision. Five visually impaired older adults (60 years and older) were interviewed and they shared stories about how their social networks were involved in maintaining their occupational goals and psychosocial adaptation to vision loss. Analysis of the participants’ narrative accounts revealed five themes including: (1) Maintaining Engagement in Social Occupations to Foster a Sense of Belonging; (2) Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs; (3) Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships; (4) Community Mobility as Essential for Preserving Social Relationships; and (5) Technology as a Substitute to Support Social Connectedness. Findings from this study may inform future research as well as the development and reformation of vision care services for older adults with visual impairment.
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Chapter 1: Introduction

Imagine that you have been ‘sighted’ for the entirety of your life but suddenly you are experiencing difficulty seeing things that you were able to see before. You may feel like darkness is caving in on you, but you try to understand this experience as a ‘normal’ or ‘typical’ part of aging. However, as you age, it becomes harder to ignore the decline in your vision and you decide to take an eye exam and find out that you are diagnosed with one of the three vision loss conditions that are categorized under age related vision loss; age related macular degeneration, glaucoma, and diabetic retinopathy. You don’t want to let your new diagnosis define who you are and so you try to continue with the things you cherish. You notice, however, that your visual impairment is gradually but surely interfering with your ability to engage in the things you used to do daily; you find it difficult to drive, read the newspaper, make a phone call, recognize and communicate with people who you know, or go out into the community. You feel lost and overwhelmed by the changes that are occurring to your routines and seek help from those around you, such as friends, family, and neighbours, who provide you with mixed responses. Some of them make you feel less competent than you actually are, while others motivate and enable you to keep engaging with the activities you love. They remind you that you still have the same qualities and many of the same abilities from before you were diagnosed with vision loss, and that you are just as capable and strong.

Age-related vision loss (ARVL) is a term used to collectively describe chronic conditions of visual impairment that occurs in later life, and is characterized by one or more of the following symptoms; low contrast sensitivity that diminishes one’s spatial awareness (i.e., ability to distinguish foreground objects to background), decreased visual acuity of retinal focus on static or moving objects, and impaired visual field that reduces the total area of peripheral vision (Quillen, 1999; Roh et al. 2018). Older adults living with ARVL experience deterioration to their vision in a gradual and progressive nature, initially resulting in partial vision which may eventually lead to complete blindness (Horowitz et al., 2005). The visual impairment caused by ARVL is permanent and cannot be corrected to normal visual acuity, which is defined as 20/20 vision, even with the use
of standard optical devices such as contact lenses or glasses (World Health Organization [WHO], 2008). The three causes of ARVL in older adults include macular degeneration, glaucoma, and diabetic retinopathy, which are respectively associated with damage to the macula, elevated pressure inside the eye, and swelling of the lens due to high blood sugar (Watson, 2001; National Eye Institute [NEI], 2019a, 2019b; WHO, 2018).

1.1. Problem Statement, Significance, and Rationale

According to the WHO (2018), ARVL is currently the third leading cause of vision impairment globally and the number of older adults diagnosed with ARVL is increasing due to population aging. A projection model of global blindness presented in Bourne et al.’s (2017) research, predicts the prevalence of ARVL will elevate three-fold by 2050. The disability-adjusted life years (DALYs) of ARVL, based on the Australian Institute of Health and Welfare (AIHW), is comparable to that of coronary heart disease and osteoarthritis, where DALY is used as a metric to calculate the overall burden of disease, measuring the years of life lost due to premature death, disability, and disease (Tay et al., 2007; WHO, 2014).

Previous research on ARVL has demonstrated the inverse relationship between the presence of an ARVL condition among older adults and their occupational engagement, including engagement in various activities of daily living (ADLs) such as self-care (i.e. bathing, toileting, dressing, etc.), as well as instrumental activities of daily living (IADLs) such as preparing meals, participating in community events, and managing financial resources (Berger & Porell, 2008; Girdler et al., 2008; Mojon-Azzi et al., 2008; Rudman & Durdle, 2008). The engagement of older adults in meaningful occupation has been associated with a decreased risk of developing mental and physical illnesses, such as mood disorders, dementia, and osteoporosis (Liberman & Cheung, 2015; Rudman et al., 2010). Moreover, occupation can provide older adults with personal goals, values, financial modes of livelihood, and opportunities to stay connected with their social environment, all of which can facilitate the formation of their identities, social roles, and social relationships (Justiss, 2013; Phelan, 2012). These positive outcomes are also related to an elevated sense of satisfaction, self-rated health, and wellbeing, therefore
demonstrating that meaningful engagement in occupation can enhance older adults’ quality of life (Justiss, 2013; Pizzi, & Richards, 2017). Contrastingly, several studies show that an ARVL diagnosis is associated with greater risk of adverse psychological, physical and social outcomes, which include higher fall-frequencies, increased feelings of anxiety, depression, social isolation, and an aversion to accessing available community services. These negative outcomes may be partially attributed to changes or withdrawal in older adults’ meaningful occupations (Berger & Porell, 2008; McGrath & Corrado, 2019; Mitchell et al., 2008; Rudman et al., 2016).

According to Elder’s (1998) life-course approach, human experiences are shared with, and are interdependent upon, the lives of others. A life course theory, therefore, suggests that an older adult’s perceptions and experiences of their ARVL condition is likely to be shaped, in part, by interactions with their social networks (Elder, 1998). In addition, according to Burt (2001) and Lin (2001), social networks are intimately involved with shaping individuals’ coping mechanisms which subsequently influences how they deal with challenges and goals. However, there is limited research focused on the social networks of older adults with ARVL, addressing how these social networks inform the coping strategies or resources that they use to facilitate their occupational engagement. Instead, the majority of the ARVL-related coping strategies depicted in the literature are concerned with diagnosis oriented traits (e.g., the onset age of ARVL, the types of ARVL, and the degree of vision impairment due to the ARVL condition), and the behavioral skills of older adults (Berger et al., 2013; Justiss, 2013; McGrath & Rudman, 2013; Rudman et al., 2016; Wang & Boerner, 2008). Examples of behavioral coping strategies include: (1) altering the way certain occupations are performed; (2) reducing the types and number of occupations engaged in; (3) using optical devices, such as bio-optics, prisms, and lighting; (4) using instrumental aids that elevate non-visual senses (i.e., maximizing one’s sense of hearing through the use of hearing aids; stimulating the sense of touch by practicing Braille and using tactile paving; enhancing one’s visual memory that allows one to create and recall accurate mental pictures of people, places, and objects by using a camera to take pictures, etc.); and (5) accessing educational or training-focused programs that aim to improve individual’s resiliency.
toward vision loss (Berger et al. 2013; Cimarolli et al., 2017; Justiss, 2013; McGrath & Rudman, 2013).

Studies that address the social networks of older adults with ARVL go beyond coping strategies to also focus on how social networks improve the emotional stability of visually impaired older adults (Cimarolli, 2002; Papadopoulos et al., 2014; Reinhardt, 2001). Positively perceived interactions with social networks can act as an emotional buffer against stressful situations and is associated with improved self-confidence, desire for autonomy, and satisfaction among older adults with ARVL (Cimarolli, 2002). Social networks can also provide older adults with information and tangible resources relevant to vision loss and their desired occupations, thus increasing their level of engagement in these occupations (Reinhardt, 2001). However, the mechanism behind these influences of social networks is unclear, and therefore, there needs to be further studies on how exactly social networks shape the engagement of older adults with ARVL in their various domains of occupation. A few studies provide information on the challenges that ARVL imposes on the (re)establishment or maintenance of social networks (Papadopoulos et al., 2014; Wang & Boerner, 2008). For instance, Wang & Boerner (2008) describe the difficulties that older adults with ARVL face while recognizing and responding to visual cues during a conversation. Due to these challenges, older adults with ARVL are often misunderstood, and perceived as dependent by others (Wang & Boerner, 2008). However, such research has not focused on the interconnected roles that social networks play in sustaining the older adult's engagement with meaningful occupations after being diagnosed with ARVL.

This study will address the identified gaps in the literature by highlighting how older adults use their social networks to manage ARVL-related changes and support their occupational engagement, as well as how social networks may detract from occupational engagement. The knowledge generated from this study may significantly contribute to future research, clinical practice, and policy development focused on low vision rehabilitation services (LVRS). It may also aid in the development of client-centered rehabilitation practices that take into consideration the older adult’s unique patterns of interactions with social networks (Heyl et al., 2005).
1.2. Research Purpose and Questions

The primary purpose of this research is to understand how older adults with ARVL story and make meaning of the roles that their social networks play in both facilitating and constraining their engagement in desired occupations.

In addressing this purpose, the following sub-questions will be asked:

1. How does living with ARVL influence older adult’s engagement in various occupations?

2. Who makes up the social networks that older adults with ARVL interact with while engaging in these occupations?

3. How do social network members react or respond to older adult’s with vision loss? What types of supports do social network members offer to older adults with ARVL and how do these supports help or limit their occupational engagement?

1.3. Defining the Language Used in this Study

It is important to ensure a consistent understanding of terminology used throughout this thesis. As such, I have defined those terms that will be used consistently throughout the thesis including: age-related vision loss, occupation, occupational engagement and social network.

1.3.1. Age Related Vision Loss.

ARVL is not a diagnosis in and of itself, but rather it is an umbrella term that is used to describe three diagnoses of vision disorders, including age-related macular degeneration, glaucoma, and diabetic retinopathy. Each of these disorders can cause various degrees of visual impairment, which is defined as “a measurable loss or departure of functional capability relative to the normal variation in healthy eyes” (Leat et al., 1999, pp. 198-199). For instance, age-related macular degeneration is characterized by degeneration of the retina, which is responsible for central vision (macula) and can cause a loss of central visual field, visual acuity, and contrast sensitivity (Watson, 2001). Refer to Figure 1 to see how age-related macular degeneration affects vision (Hoffman, 2016).
Diabetic retinopathy can induce macular edema, retinal hemorrhages, and retinal detachment, which can cause blurred vision (reduced visual acuity) and scattered scotomas (blind spots) across central, mid-peripheral, and peripheral field of vision (Watson, 2001). Refer to Figure 2 to see how diabetic retinopathy affects vision (EyeDocs, 2019). Glaucoma is caused by “an increase in intraocular pressure due to an abnormal flow of aqueous fluid from the anterior chamber and results in degeneration of the optic disc and loss of peripheral visual field” (Watson, 2001, p. 319). Refer to Figure 3 to see how glaucoma affects vision (Hoffman, 2017).
Figure 1: Age-Related Macular Degeneration. Normal vision is shown on left, and the loss of central vision caused by age-related macular degeneration is shown on right.

Figure 2: Diabetic Retinopathy. Normal vision is shown on left, and the scattered scotomas caused by diabetic retinopathy is shown on right.

Figure 3: Glaucoma. Normal vision is shown on left, and the loss of peripheral vision caused by glaucoma is shown on right.
Visual impairment caused by the aforementioned vision disorders can lead to visual disability, which refers to “any diminished or absent ability to perform a task involving vision that is needed to maintain one’s desired life style” (Leat et al., 1999, p.199). When the degree of visual impairment cannot be corrected with conventional glasses, contact lenses, or medical and surgical interventions, and is sufficient enough to cause visual disability, this is defined as low vision (Leat et al., 1999; Spafford et al., 2010). For instance, individuals living with low vision resulting from the three diagnoses of ARVL may experience difficulties gauging depth and distance, recognizing color or contrast sensitivity, and adapting from light to dark environment (Leat et al., 1999; Watson, 2001). They may, therefore, face visual disabilities in various occupations, including reading, recognizing faces, participating in social activities, doing household activities, self-care, and leisure tasks, to name a few (Dahlin et al., 2000; Jin et al., 2019; Wang et al., 2012; Watson, 2001).

1.3.2. Occupation.

Within the field of occupational science, occupation is a multidimensional term that encompasses not only the performance of a certain action or activity, but also the “subjective emotions, interpretations, and personally and culturally derived meanings that are entailed within the action” (Hocking, 2009, p. 141). Examples of occupation, which involve the broad applications and constructions of ideas, labour, products, people, and spatial capacities, include, but are not limited to people’s daily activities (e.g. house chores, work, and self-care routines), community mobility (e.g. the use of public transits, walking, and driving), and leisure activities (e.g. religious and hobby events) (Justiss, 2013; Rudman et al., 2010). Many, but not all, of these examples of occupations can be categorized as ADLs and IADLs. Here, ADLs refer to basic functions of everyday life such as toileting and feeding that are typically solitary in nature which can be done automatically without requiring complex thinking (Berger & Porell, 2008). On the other hand, IADLs such as preparing meals, driving or using public transportations, and caregiving are not necessarily needed for basic functioning, but are closely interrelated with quality of life as they enable individuals to live independently in the community (Berger & Porell, 2008). IADLs involve the use of several skills simultaneously and
hence require higher visual functioning to accomplish than ADLs (Berger & Porell, 2008). Occupation can also be considered as either performance or form, whereby “performance refers to the process of doing something”, and form refers to the “circumstances that elicit, guide and structure that performance” (Hocking, 2009, p. 141). Occupational form includes the sociocultural, geographical, historical, political, and temporal context that exists independent and external from the individuals who are involved in the occupation (Hocking, 2009). More specifically, occupational forms can structure the rules, resources, languages, cultural meanings, expectations, and people associated with the occupation, and can inform the individual of what an occupation entails, when and where it is appropriate to perform an occupation, and how it should be done (Hocking, 2009).

1.3.3. Occupational Engagement.

Occupational engagement refers to the degree to which a person is deeply immersed, involved, and committed to an occupation such that their attention, will, efforts, and physical body are occupied (Kennedy, & Davis, 2017; Morris & Cox, 2017; Reid, 2011). Occupational engagement lies on a continuum as there are degrees of greater or lesser engagement with any occupation at a specific point of time, where low to high degrees of engagement are ordered as disengagement, partial engagement, everyday engagement, and full engagement respectively (Bejerholm, & Eklund, 2006; Sutton et al., 2012). This degree of occupational engagement depends on various factors such as: (1) the nature of an occupation (2) the physical and mental competency of an actor engaging in certain occupations, and (3) the spatial, temporal, and social contexts in which the occupational engagement occurs (Kennedy & Davis, 2017; Lin et al., 2009; Morris & Cox, 2017; Townsend & Polatajko, 2007). For instance, an occupation may take place during a specific life stage (e.g. retirement, marriage, education, and etc.), in a particular environmental context, and may or may not involve actors other than oneself (Kennedy & Davis, 2017; Lin et al., 2009; Morris & Cox, 2017; Townsend & Polatajko, 2007).

Occupational engagement is partially driven by a personal value or interest, and results in perceived consequences which may be either positive or negative (Morris &
Cox, 2017; Reid, 2011). For instance, a person may place a positive value on eating a highly fat-saturated diet but engaging in such an occupation may have negative consequences on their health. Occupational engagement is also dynamic in nature as these personal interests and perceived consequences of engagement can fluctuate over time, being influenced by external and internal factors such as the sociocultural and physical environments, as well as the emotional and bodily state of the engaged person (Morris & Cox, 2017). External factors in particular can alter an individual's perception about the significance or meaning of an occupation. For instance, individuals may disengage from an occupation due to external or social expectations and stigmas associated with specific population groups (race, age, gender, class, individuals with disabilities, etc.) (Gendron et al., 2016). Social expectations can define and shape the various institutional policies and programs offered/available to certain groups of people at micro, meso, and macro levels of social structures, and thereby set social constraints on what occupations individuals can engage in (Gendron et al., 2016; Lin et al., 2009).

It is important to note that engagement in occupation is distinct from participation (Kennedy, & Davis, 2017; Morris & Cox, 2017). Here, participation is akin to taking part or sharing in the performance of an occupation (Morris & Cox, 2017). Engagement, however, refers to a broader involvement with the occupation, and does not necessarily equate to the mere performance of an occupation (Kennedy & Davis, 2017). Instead, engagement is much more meaning-oriented, thus a person engaging in an occupation would ascribe greater value and importance to that occupation than to one that they merely participate in. For example, the extent to which the occupation influences their personal purpose, goal, roles, identity, and well-being is more significant (Townsend & Polatajko, 2007). Therefore, it is possible to participate but not engage in an occupation. For instance, a person who attends a group discussion, but does not actively contribute or gain anything from the discussion may be seen as participating without engaging. It is also possible that engagement can occur in physically inactive forms (Morris & Cox, 2017). For instance, “a man pushing his son’s wheelchair round a marathon course, [may perceive his] son as engaging, but not actively participating, in marathon running” (Morris & Cox, 2017, p. 156).
1.3.4. Social Networks.

Social network is made up of various members of society and sets of ties existing between them, and such social structure can be classified by type, quality, and quantity of relationships (Ayalon, & Levkovich, 2019). Here, type refers to the composition of social actors making up the social network; quality depends on a wide range of factors, including but not limited to social support, emotional intelligence, perceived well-being, affection, self-enhancement, validation, intimacy, and interaction patterns; and quantity refers to the size of one’s social networks as well as the frequency of contact with those members (Antonucci, 2001; Ayalon & Levkovich, 2019; Fiori et al., 2007). According to Fiori et al. (2007), previous studies on older adults’ social network have “identified four relatively robust network types” (p. 322) including diverse, family-focused, friend-focused, and restricted networks. The diverse network type consists of both proximal (friends and families) and non-proximal members (non-kin members who are also not close friends, such as acquaintances, healthcare providers, far neighbours, colleagues, etc.) with the latter taking up a larger proportion of the network size (Fiori et al, 2007). A family-focused network includes frequent contact with family members such as spouses, children, siblings, and parents (Adams & Bliesznr, 2016; Antonucci, 2001; Ayalon & Levkovich, 2019). A friend-focused network type may include peers in groups of age, ethnicity, gender, social status, disability, religion, and other interests (Adams & Bliesznr, 2016; Antonucci, 2001; Ayalon, & Levkovich, 2019). The restricted social network type refers to a small network size, and infrequent contact with both proximal and non-proximal members (Fiori et al., 2007).

The formation of these social relationships are dependent on multiple factors across an individual’s life course, and one’s social networks can change throughout different stages of life (Ayalon, & Levkovich, 2019). For instance, individuals may experience different cultural, economic, political, and social environments as they age (Ayalon, & Levkovich, 2019). As a result, they may interact with shifting demographics and develop novel interests and preferences across their life stages (Ayalon, & Levkovich, 2019). These factors may, in turn, influence the composition of the members.
of their social networks, as well as the nature of the network’s relationships (Cornwell et al., 2015).

These social networks can function in multidimensional ways to moderate the quality of life and well-being of its members (Fiori et al., 2007). For instance, social networks can provide individuals with social support by enabling its members to learn and exchange specific knowledge about the norms of social behaviours, identities, places, and occupations, such as the appropriate attire to wear, language to use, and cultural customs to expect in specific circumstances (Cornwell et al., 2015). Social networks can equip individuals with access to material goods and services that they need and can foster a sense of belonging amongst its members to their social environment, thereby decreasing feelings of loneliness and social isolation (Cornwell et al., 2015). Certain social network types are associated with particular functions, in that they can provide individuals with specific types of social support, which in turn, can regulate an individual’s health to varying degrees (Fiori et al., 2007). Previous gerontology literature, for example, has identified that the diverse social network type is associated with subjective well-being, low mortality and morbidity rates, low depressive symptoms among older adults, and provides members with high levels of both emotional and instrumental support (Litwin, 2001; Wenger, 2008). Family and friend-focused networks provide more emotional support than instrumental support, and restricted network types are generally correlated with the lowest well-being and poorest quality of both emotional and instrumental support (Litwin, 2001; Wenger, 2008). In addition, Fiori et al. (2007) demonstrated that an individual’s wellbeing is not only correlated with the typology of networks (member composition), but are also related to the individual’s age group which can mediate how much support one requires. For instance, compared to individuals in the old-old age group (ages 85 to 89), individuals in the young-old age group (ages 65 to 74) received less instrumental support from their friend-focused networks, but reported having highest sense of satisfaction with their friend-focused social networks and greater self-rated wellbeing than those from the old-old age group (Adams & Blieszznr, 2016; Fiori et al., 2007; Litwin, 2001). An explanation for this may be that older individuals (aged 85 years and older) are often functionally impaired to a greater degree than young-old individuals, and therefore require greater instrumental support. This greater reliance on support may
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subsequently contribute to a lower sense of self-control, which is correlated with higher depression and decreased wellbeing (Fiori et al., 2007).

1.4. Researcher Positionality and Reflexivity

Reflexivity involves engaging in critical appraisal of our own process of doing research, namely how and why we frame issues in certain ways and investigate those using specific methods (Hardy et al., 2001; Holland, 2016; Tracy, 2010). It entails recognizing and criticizing what we know (ontology), and how we know it (epistemology) by exploring possible alternative methodological approaches and interpretations of research data (Hardy et al., 2001). At the initiation phase and then throughout a research study, engaging in reflexivity regarding one’s research topic is important as it influences what we decide to investigate, how we design or conduct our study, and acknowledges the rationale behind the choices we make throughout the research process (Holland, 2016). In other words, reflexive thinking foreshadows how our pre-understandings and the particular methodological or interpretational choices we make shape the research outcomes. Therefore, it allows us to provide a transparent account of why we have reached a particular version of reality as opposed to other possible conclusions (Hardy et al., 2001).

My reflexive process allowed me to come to terms with who I am as a researcher prior to meeting the participants; a Korean-Canadian female Master's student in her early 20s with an educational background in Human Biology and Health and Aging. My research topic of social networks and its influence on the occupational engagement of older adults with ARVL intrigued me, due to my personal experience of living with low vision as well as my long-term exposure to the field of gerontology. Throughout my life (since I was four), I have relied on glasses to support my participation in daily occupations such as engaging in school, hanging out with my friends and family, pursuing my hobbies in visual arts and music, taking care of my pets, and volunteering. I have also been working and volunteering at long-term care homes, mental health organizations, and rehabilitation centers, and during these experiences, I met and interacted with several older adults who had various degrees of visual impairment. Here,
I aided older adults while they participated in a variety of activities offered at these centers, including reading, writing, engaging in arts and crafts projects, exercising, and playing board games. Furthermore, growing up in two distinct cultures has enabled me to consider some of the similarities and differences between Korean and Canadian aspects of society, particularly as it relates to cultural norms regarding ageing and caregiving for older adults at micro, meso and macro levels between, and within, each respective country. Thus, I was particularly interested in investigating how different compositions of social networks, and the quality of ties and social supports exchanged within these networks, shaped the occupational engagement of older adults with ARVL. In addition to my personal experiences, my review of literature on the study topic also shaped my reflexive thinking process, which involved a careful consideration of my presuppositions regarding my study topic. The following statements demonstrate the preunderstandings I had as they relate to my research topic prior to meeting my participants including: 1) ARVL is associated with changes to older adult's personal and social identities; 2) changes to personal and social identity is partially mediated by the changes simultaneously occurring with their occupational engagement and social networks; and (3) these changes are assumed to be largely negative challenges. There are different types of social networks that older adults interact with after losing vision, each of which can provide different intensity, type, and variation of social support, which can also be perceived differently and have various influences on their beliefs, values, and actions towards the self and others. These social supports can either positively or negatively act on the psychosocial wellbeing of older adults and their adaptation to vision loss, including how they engage in desired occupations. Based on my preunderstandings, the following assumptions were made throughout the study process: 1) each participant was the expert of their own diagnosis of vision loss and knowledgeable about the influence their social networks had on their occupational engagement and; 2) participants were sharing and describing their experiences of engaging in occupations and interacting with social networks while living with ARVL condition as authentically as possible. The aforementioned presuppositions were then reflected in the selection of questions I chose to ask the participants during the interview sessions.
1.5. Thesis Outline

This chapter provided rich background information regarding my research question and established the rationale behind my choice to study this topic. I provided working definitions of the key terms that will be used throughout this thesis including age-related vision loss, occupation, occupational engagement, and social network. Lastly, I discussed my positionality as a researcher, including my motivations and presuppositions as it relates to my research focus. In chapter two, a literature review of the works most closely related to my research purpose and questions will be detailed. In chapter three, my methodological approach will be described including my chosen paradigm, ontology, epistemology, and guiding theoretical framework. In addition, I will detail the methods of participant recruitment, data collection, and analysis. In chapter four, the narrative accounts of each participant will be presented, and in chapter five, the results stemming from my thematic analysis will be detailed. In the final chapter, I will discuss the study limitations, future directions, and implications of the study findings, by establishing where this study fits within the existing ARVL literature and discuss the significance of its contributions within the context of research, policy, and vision rehabilitation.
Chapter 2: Literature Review

The purpose of this chapter is to provide an overview of research conducted at the intersection of occupational engagement and the social networks of older adults with ARVL, as well as identify gaps in the literature. This chapter first provides an in-depth discussion of studies relating to the influence of vision loss on older adults’ occupational engagement. Next, it presents how social networks of visually impaired older adults (i.e., formal, informal, and peer networks) shape older adults’ occupational engagement and psychosocial wellbeing after losing vision. In particular, this chapter distinguishes between positively and negatively perceived social supports provided by social networks and describe how the exchanges of these supports influence older adults’ adaptation to vision loss.

2.1. The Influence of Vision Loss on the Occupational Engagement of Older Adults

Several studies have established that there exists a significant association between ARVL and the occupational engagement of older adults (Jin et al., 2019; Lino et al., 2019; Nastasi, 2018). In fact, the onset of visual impairment can be a pivotal transition point in older adults’ lives; restricting their participation in various occupations (Girdler et al., 2008). Older adults with ARVL attach specific meaning to each occupation they engage in (Dahlin Ivanoff et al., 2000; Girdler et al., 2008) whether it is related to leisure (i.e., hobbies and interests such as sports, arts and crafts, music, etc.), instrumental activities of daily living [IADLs] (i.e., shopping, banking, managing household chores, being mobile within a community, administering prescribed medications, etc.), activities of daily living [ADLs] (i.e., self-care tasks such as bathing or showering, dressing, toileting, transferring, continence, feeding, etc.), or social interactions (Girdler et al., 2008; Lin et al., 2009; Lino et al., 2019; Swanson & McGwin, 2004). Findings from empirical studies within gerontology which focus on ADLs and IADLs, rather than the broader concept of occupation, suggest that the presence of low vision among older adults increases the difficulty level they perceive in completing their ADLs and IADLs, and indicate that the impact of vision loss is approximately twice as more significant for IADL functioning (Lino et al., 2019; Swanson & McGwin, 2004). In
addition, ARVL is associated with adverse physical outcomes such as increased imbalance, frequency of falls, greater risk of hip fracture, higher mortality rate, and a higher probability of being placed in a nursing home rather than aging in place (Crews & Campbell, 2001; Horowitz et al., 2005; Mitchell & Bradley, 2006). These ARVL-related adverse physical outcomes can further interfere with older adults’ ability to perform ADLs and IADLs, without external help, and thereby restrict the occupational choices that older adults with ARVL can pursue (Girdler et al., 2008). Restricted occupational choices, in turn, can decrease the opportunities in which older adults can demonstrate their “skills and competencies that they have developed over life time” (Girdler et al., 2008, p. 117).

Therefore, when individuals lose their vision in older adulthood, and older adults experience the restriction, abandonment, or the need to alter the ways in which they complete occupations that were previously taken for granted, it can significantly influence individual’s identity, daily routines, and roles (Blair, 2000). Such transformations can affect how older adults with ARVL define their sense of self, for instance, their unique strengths and weaknesses as well as their life priorities and personal value system (Morris & Cox, 2017). Limitations participating in meaningful occupations or disruptions to daily routines can then lead to feelings of decreased self-control and a restricted sense of independence amongst older adults with ARVL (Girdler et al., 2008). With discontinued engagement in occupation, older adults may also struggle to find other means to fill their time, and this may be contributing to findings that ARVL is associated with increased feelings of sadness, boredom, anger, and a feeling of a loss of purpose (Blair, 2000; Girdler et al., 2008; Teitelman & Copolillo, 2005). In other words, transitions in occupations due to vision loss appear to be associated with decreases in older adults’ overall well-being and can lead to negative psychological impacts including increased risk of major depressive disorders, social anxiety, loneliness, avoidant behaviours, and greater levels of emotional distress (Crews & Campbell, 2001; Horowitz, et al., 2005; Mitchell & Bradley, 2006).

Research also suggests that many older adults with ARVL also experience challenges maintaining interpersonal interactions, as well as engaging in new
relationships and social occupations including: (1) family or friendship activities outside the household; (2) sports or physical activities that involve other people; (3) educational and cultural activities involving other people such as attending courses, concerts or visiting museums; (4) volunteer or charity work; and (5) any other recreational activities involving other people, including hobbies, bingo and other games (Girdler et al., 2008; Jin et al., 2019). Such challenges are partly explained by older adults facing increased difficulty recognizing facial expressions and body language which are important social skills that allow individuals to determine “established norms and patterns of interaction” in social settings (Girdler et al., 2008, p. 117). Older adults may therefore lose faith in their social skills and associate engaging in social occupations with high risks rather than benefit, such as being embarrassed, misunderstood, or humiliated during social interactions for not being able to correctly assess situations or recognize people, and missing key information or feeling left out of the conversation (Girdler et al., 2008; Mick et al, 2018). Older adults with ARVL may also face increased difficulties with community mobility, particularly in unfamiliar environments. For example, older adults may not be aware of, or readily have access to, transportation systems or other services that can address the specific needs of visually impaired older adults (Gallagher et al., 2011; Jin et al., 2019; Swenor et al., 2015). Due to ARVL-related restrictions to community mobility, older adults may, therefore, experience heightened feelings of fear, anxiety, risk, loneliness, and distress when interacting with others while navigating unfamiliar environments, and thus try to scale down the types of occupations they engage into only sedentary or familiar tasks that require minimal social participation (Hong et al., 2014; Jin et al., 2019; Mick et al., 2018; Wang et al., 2012). The compounding effects of ARVL can thus significantly reduce older adult’s engagement in social occupations, particularly those outside their homes (Girdler et al., 2008; Mick et al, 2018; Teitelman & Copolillo, 2005).

Although compromised occupational engagement (as a result of ARVL) can negatively influence older adults’ physical, psychological, and social dimensions of health (Crews & Campbell, 2001; Horowitz et al., 2005; Lin et al., 2009), engagement in meaningful occupations may be a protective mechanism to cope with difficult challenges and buffer against psychological and physical stressors (Dahlin Ivanoff et al., 2000; Lin
et al., 2009). Several studies noted that older adults with ARVL who continue to engage in desired occupations show higher motivation to persevere through challenges in life after vision loss than those who cease their occupational engagement after losing vision (Erlandsson, 2013; Nastasi; 2018; Smith et al., 2009; Tay et al., 2014). It has also been shown in existing literature that finding new occupations to engage in after vision loss provides older adults with new goals and aids in the reformation of new roles, identities, and social relationships, as well as reduces the need for utilization of vision rehabilitation services (Girdler et al., 2008; Lin et al., 2009). In addition, according to Nastasi (2018), the occupation itself (e.g. preparing meals, making phone calls to friends and families, reading newspaper articles, and driving or using public transportation to travel within community) holds person-centered meaning and purpose, and the act of doing such occupations enhances the participant’s self-confidence, self-rated wellbeing, and desire to stay independent. This motivation for occupational engagement is more strongly associated with occupations that hold greater value to the participants, and can drive the participant to problem-solve and develop their personal adaptive skills in order to accomplish the desired activities on their own (Nastasi, 2018). For instance, older adults with ARVL may use additional lighting, employ new organizing systems, and learn to depend more on their memory and sensory functions other than sight to compensate for their loss of vision when completing tasks (American Occupational Therapy Association, 2013; Nastasi, 2018; Perlmutter et al., 2013). This evidence demonstrates the centrality of meaningful occupational engagement in supporting the quality of life of older adults with ARVL.

2.2. Understanding the Connection between the Older Adult’s Social Networks, Adjustment to Age-Related Vision Loss, and Occupational Engagement

Existing research regarding social networks and ARVL describes how ARVL may impose challenges on maintaining social networks or how members of social networks can help with the individual's psycho-social adaptation to ARVL (Latham, 2013; Marques et al., 2018; Mick et al., 2018; Wang et al., 2008). Cimarolli (2002) frames favourable adaptation of older adults to ARVL as being able to thrive in the environments they are situated within, while having high life satisfaction. Reinhardt and
D’Alilura (2000) operationalize favourable adaptation as having low rates of depression and other mental health outcomes that can be detrimental to the psychological well-being and self-rated functionality of older adults with ARVL. Drawing on Latham’s (2013) framework, the prospect of how well or poorly older adults with ARVL adapt psychosocially to their low vision can be influenced by the quantitative and qualitative measures of social networks. Here, the quantitative component refers to the number of members comprising each of the different types of networks such as a friendship network, family network, and formal network, as well as the frequency of contact, the duration of time network members have known each other, and the extent of homogeneity of members within network (Berkman et al., 2000; Latham, 2013; Wang et al., 2008). The qualitative component refers to the quality of ties and supports flowing between network members; for example, how well they understand the limitations associated with vision loss, how well their support addresses the needs of the vision impaired older adult, and the extent of reciprocity in exchanges (Berkman et al., 2000; Latham, 2013). Latham’s (2013) study focuses exclusively on social support, noting that a key function of social networks is the provision and receipt of social support, and demonstrates that the impact of social support is not acute or temporary, but rather, it can last throughout the duration of the adaptation period.

2.2.1. Positively Perceived Versus Negatively Perceived Social Support.

According to Papadopoulos et al. (2014), Cimarolli (2002), and Reinhardt et al. (2001, 2009), positively perceived social support, which is the belief that the support one desires will be available when it is needed, can reduce symptoms of depression and anxiety as well as increase self-esteem and morale of older adults with ARVL. Cimarolli and Boerner (2005) suggest that this perceived availability of support may have more positive impact than actual receipt of support on older adult’s ability to adapt to chronic visual impairments. In fact, the supports that visually impaired older adults receive from their social networks are sometimes perceived negatively when it stems from unconscious discrimination against vision loss (Cimarolli & Boerner, 2005). This is because discriminatory attitudes and actions can categorize all older adults living with vision loss into a homogeneous group and thereby fail to truthfully represent and
individually address the real needs of each older adult (Chang & Schaller, 2000; Cimarolli & Boerner, 2005). There is prevailing prejudice within the community against individuals with vision impairment due to the lack of public awareness regarding this condition. The stigmatization attached to vision loss, at times, impedes social network members from correctly assessing the needs of visually impaired individuals, which can result in the person with ARVL withdrawing from seeking additional help, to avoid being further misunderstood or embarrassed (Kaldenberg, 2019; Matti et al., 2011; Pollard et al., 2003; Spafford et al., 2010). Some of the negatively perceived social supports include insensitivity to the struggles that visually impaired individuals face, ignorance of what ARVL conditions truly entails (i.e. expecting every blind individuals to be using guide dogs), and being overprotective or disregarding the autonomy of blind individuals (Chang & Schaller, 2000; Cimarolli & Boerner, 2005; Carter & Feld, 2004; Papadopoulos et al., 2014). These negative supports are associated with higher depressive symptoms of older adults with ARVL, which in turn are correlated with reduced physical and mental capacity for environmental mastery (ability to select and alter their surrounding environmental contexts under their control) (Papadopoulos et al., 2014; Reinhardt, 2001). Carter and Feld (2004) suggest that social network members who are positively regarded by others have higher probability of being sought after, and are treated with greater respect, appreciation, and superiority compared to network members who are regarded negatively. This may contribute to the finding that positively perceived members are more likely to connect with a greater number of available individuals, including older adults with ARVL, and thus have greater size and density of social networks than negatively perceived individuals.

There is mixed evidence in the gerontology literature regarding which of the positively perceived versus negatively perceived supports has the greater impact on individual's adaptation to chronic disabilities, such as ARVL. For instance, Berg et al. (2006) assert that positive exchanges of social support can exert stronger effect on individual's psychosocial wellbeing, especially depressive symptoms, while Hobfoll and Stephens (1990) and Rook (1990) state the opposite, that detrimental impact of negative support on wellbeing outweigh the beneficial impact of positive support. On the other hand, Ingersoll-Dayton et al. (1997) describe how the net effect of positive and negative
social supports are null, as the magnitude of their impacts are comparable to one another. Reinhardt (2001) also explains that “negative exchanges are most potent when elders are contending with other life stress [suggesting that] it is important to examine the impact of both positive and negative aspects of support relationships on both positive and negative outcome variables” (p. 77).

2.2.2. Social Networks and Occupational Engagement.

Existing literature on the social networks of older adults have documented the influence that social networks can have on an individual’s occupational engagement (Berkman et al., 2000; Stafford et al., 2018). According to Stafford et al. (2018), social networks can encourage older adults’ occupational engagement by providing various kinds of social support which can “increase awareness of and facilitates access to various resources, services, and materialistic goods that reduces hurdles or anxiety related to occupational engagement, and promotes a sense of personal control” (p. 438) and thereby foster a sense of belonging and connectedness with the environment that an occupation takes place within. Social networks can also create social influence through both egocentric networks, with an individual at the center of that network, as well as through networks of networks which can pull in more diverse information and resources (Berkman et al., 2000). Therefore, an older adult’s networks can determine his or her attitude and action toward an occupation “by shaping the flow of resources which determine access to opportunities and constraints on behavior” (Berkman et al., 2000, p. 845). For instance, when members of an older adult’s social networks share information on specific occupations they have engaged in with other members of the network, this can raise the older adult’s awareness of the benefits from these occupations, and can influence how he or she feels about engaging in similar occupations (Stafford et al., 2018). Older adults may therefore place higher importance, or more positive meaning, on an occupation that their social networks also engage in, and become motivated to engage in the same occupation (Stafford et al., 2018). In addition, according to Stafford et al. (2018), older adults with a small social network size or those who have low quality relationships with the members of their social network (or those who are dissatisfied with their network) engage less in occupations. However, while these works of literature touch
upon how social networks shape the occupational engagement of the general older adult population, they do not explicitly focus on those with ARVL conditions.

A study by Alma et al. (2012) is one of the few research studies that specifically addresses the influence of social networks on the occupational engagement of older adults with vision loss. Alma et al. (2012) conducted a cross-sectional study with 173 older individuals who were 55 years of age or older with “visual acuity less than 0.3 and/or visual field less than 30 degrees in the better eye who experienced problems in daily life” (p. 88). The objective of the study was to identify the determinants that impact older adult’s level of engagement in the following domains of life, as described in the International Classification of Functioning, Disability, and Health (ICF): (1) domestic life (i.e. light or heavy household activities, assisting others, and shopping); (2) interpersonal interactions and relationships (i.e. socializing with relatives, friends, or neighbors in person or via telephone/email); (3) major life areas (i.e. participating in voluntary work such as doing unpaid work in organized associations); and (4) community, social, and civic life (i.e. involvement in clubs, associations, hobbies, sports, religious activities, and going to recreational, cultural, or public places). Through a telephone interview during which older adults with vison loss were asked about their participation in the above mentioned life-activities, the researchers concluded that although vision loss restricted older adult’s engagement level, the severity and primary cause of vision loss was not significantly associated with engagement (Alma et al., 2012). In other words, different older adults had a variety of levels of engagement, but this level was not linked with specific diagnosis type or severity of vision loss. The occupational engagement of visually impaired older adults was also influenced by the size of their social networks, whereby larger social network size increased older adult’s participation in major life areas, such as volunteer work (Alma et al., 2012). In addition, “a higher perceived importance of relationships with family and friends was correlated with a higher frequency of interactions in these domains” and resulted in increased participation in interpersonal interactions, major life areas, and community, social, and civic life (Alma et al., 2012, p. 90). While this study clearly demonstrates the correlation between social networks and occupational engagement, it lacks in its explanation of the mechanism behind this phenomenon, and thus, it is unclear how exactly the social networks of
visually impaired older adults were shaping and moderating their engagement in social and domestic activities.

2.2.3. Informal Networks Versus Formal Networks.

Reinhardt (2001) states that older adults with ARVL use informal networks such as family and friends as their primary source of support, and this informal social support is perceived more positively than formal social support. Reinhardt (2001) describes how instrumental support from kin, such as family and relatives, as well as emotional support from close friends, particularly age-peers or peers experiencing health issues associated with ageing can assist individuals with ARVL in continuing to participate in the social community and engage in various occupations. The use of informal networks by older adults with ARVL, has been documented in a study by Marques et al. (2018). The author conducted in-person interviews with outpatients in Northern Portugal who had a visual acuity of 6/12 or worse, based on their Snellen score. During the interview, the Activity Inventory questionnaire, which consists of 46 items related to difficulties in occupational engagement due to vision loss, was used to evaluate visual ability, defined as the “overall ability to perform activities that depend on vision” (p. 3). Using another set of questionnaires which were validated through a pilot experiment, the researchers also assessed the cost of informal care, or the “monetary estimate of the hours spent by informal caregivers to help visually impaired persons” (Marques et al., 2018, p. 3). Cost estimates were calculated by first asking the participants about their use of informal care within a two-week time period, then extrapolating the number of hours used between two weeks to a year-long period, and finally “multiplying the number of annual hours by the mean Portuguese hourly wage rate of full-time employees in the year of 2014” (Marques et al., 2018, p. 4). Study findings demonstrated that a significant portion (approximately 40 percent) of older adults with ARVL depended on informal care to support engagement in vision-dependent ADLs and IADLs, which was similar to the percentage of informal care usage found in other studies by Schmier et al. (2006) and Ke (2010). The average annual cost of informal care consumed by each user of informal care was the equivalent of $4,759 CDN. In addition, Marque et al. (2018) demonstrated that older adults who self-reported having lower visual ability also reported heavier usage of informal care than
those who had greater self-reported visual ability, suggesting that one’s perception of difficulties associated with performing meaningful activities predicts the intensity of informal care usage.

Kaldenberg’s (2019) research further supports the notion that social networks of older adults with ARVL, and the support provided by these networks, can shape occupational engagement in various ways, both positively and negatively. Kaldenberg (2019) utilized a qualitative descriptive inquiry methodology to identify the barriers and facilitators perceived by visually impaired older adults in accessing low vision rehabilitation services (LVRS), wherein these services were intended to support older adults’ functional capability to safely and independently engage in various occupations at home and in the community. Kaldenberg (2019) used stratified purposeful sampling to recruit older adults (aged 50 and older) with self-identified visual impairment, who were members of a community-based low vision rehabilitation programs in Massachusetts. Data collection consisted of a focus group and semi-structured interviews. Through analysis, Kaldenberg (2019) identified several factors which restricted older adult’s occupational engagement, as a result of their limited access to LVRS. First, healthcare providers were not sufficiently knowledgeable about the available services for older adults with vision loss which, too often, resulted in clients not receiving referrals to LVRS (Kaldenberg, 2019; Southall and Wittich, 2012; Wittich et al., 2013). There was also a lack of coordination and communication between different agencies that provided care services for vision impairment which lead to delayed referrals (Boyce et al., 2014; Chiang et al., 2011). On the other hand, having social networks who could understand the needs of older adults with vision impairment and provide assistance without being asked for help facilitated the older adult’s access to LVRS, and increased their engagement in meaningful occupation (Kaldenberg, 2019). The idea of not having to directly seek help from network members was important for the participants as they did not want to be seen as a burden by their social network by repeatedly asking for help (Kaldenberg, 2019). Older adults with vision loss, therefore, depended more on their interactions with informal social networks such as friends, peers, and family members to engage in meaningful occupations as they could more readily recognize and support their needs
without much explanation needed, which was in contrast to formal social networks (Kaldenberg, 2019).

Findings from Wang et al. (2008) corroborate the aforementioned studies. The cross-sectional study aimed to examine how the social networks of Chinese older adults with ARVL influenced their health-related quality of life (HRQOL). Researchers conducted in-person structured interviews with Chinese older adults with ARVL who were 60 years of age or over and were recruited through convenience sampling from two hospitals located in Wuhan city. Wang et al. (2008) used the Lubben Social Network Scale to assess family network, friendship network, and reciprocated social support. Wang et al. (2008), concluded that the family and friendship networks of the participants were each associated with distinct dimensions of vision-specific HRQOL. For instance, strong connection with one’s friendship network improved the social functioning of visually impaired older adults, which subsequently enabled their engagement in ADLs and IADLs related to social tasks, and was associated with fewer limitations to their life roles such as parent, grandparent, spouse, employee, caregiver and others, as well as a greater perception of autonomy and independence (Wang et al., 2008). The family network was most prominently associated with providing emotional support that buffered against negative mental health symptoms such as depression and anxiety disorders (Wang et al., 2008). Unfortunately, Wang et al. (2008) also found that the degree of vision impairment had a greater impact on the size of friendship network as compared to family network. For example, participants with severe visual impairment (as measured by a Snellen visual acuity > 20/200 in the better seeing eye) interacted with fewer number of friends and contacted them less frequently than participants with mild vision loss, and although this pattern was also observed with interactions with family members, there was a smaller difference in family network size between severe and mild vision loss (Wang et al., 2008). The researchers also recognized that cultural difference between East Asian and Western cultures could influence “the nature and amount of social support provided to older adults [such as the] frequency of interaction with network members and the proportion of kin in a network” (Wang et al., 2008, p. 806). Chi and Chou (2016), Huang (2003), and Wang et al. (2008) described how a collectivist society, such as Chinese culture, placed stronger emphasis on filial piety and intergenerational family solidarity,
the concept of harmonious connection between young and old family members of different generations, compared to more individualistic societies. Thus, Chinese older adults with vision impairment were highly likely to exchange mutual and reciprocated kinds of assistance and care between parents and children, and were less likely than older adults from Western cultures to utilize formal institutional health services (Wang et al., 2008).

2.2.4. Peer Support.

The implications of peer support on older adults’ psychosocial and occupational adjustments to vision loss are further discussed here. For instance, Latham (2013) demonstrated both the beneficial and adverse impacts of peer network support on older adult’s visual quality of life, and described how different levels of peer support could result in different outcomes in adjustment to vision loss. Latham’s (2013) research was conducted within an organization called Cam Sight, which provides peer support to individuals with sight loss. The participants, in this study, attended six to eight sessions of Cam Sight’s support group, where they openly discussed their story of living with ARVL with their peer group (those with vision loss who matched the participant’s age) and explored topics related to psychosocial adjustment to ARVL. Latham (2013) measured how the peer support group impacted well-being and quality of life using the Vision Quality-of-life Core Measure (VCM1) questionnaire, which evaluated topics such as: concerns with safety at home, safety outside of home, eyesight getting worse, coping with daily life, and vision-related interference with general aspects of life, as well as vision-related feelings of embarrassment, loneliness/isolation, and sadness. The researchers reported that peer support significantly reduced visually impaired older adult’s fear for personal safety outside the home, as well as feelings of loneliness and sadness associated with loss of sight, by showing that the effect size comparing the VCM1 scores of participants before and after they received peer support intervention was 1.10. Here, an effect size greater than 1 indicated that participants’ well-being scores were greater after receiving peer support intervention than before intervention. In addition, the skills and strategies learned to help manage emotional distress while living with ARVL was retained at 6 months after the cessation of support services (Brody et al.,
2005; Eklund et al., 2004; Latham, 2013). Further, improvements in quality of life related to vision loss after receiving peer support services was preserved for a longer duration of time for participants who had lower quality of life at an initial stage of service provision compared to individuals who had higher initial quality of life (Latham, 2013). This finding may imply that it is crucial to provide early intervention of peer support to older adults who are suffering from depression or engaging minimally in daily and/or social occupations after vision loss in order for them to more quickly adjust to ARVL and maintain high quality of life in the long-term (Latham, 2013).

Another study on peer network support was conducted by Silverman et al. (2017). However, unlike other works investigating the correlation between sensory loss in older adults and their social networks, Silverman et al. (2017) aimed to demonstrate “how reciprocal, enduring friendships between two people with a health condition might influence well-being”, specifically those with vision loss (p. 526). The study involved 71 individuals with legal blindness (mean age was 50 years and 56% of the participants had acquired vision loss), registered with either the American Council of the Blind or the National Federation of the Blind. Participants recorded the initials of their friends, either blind or sighted, to assess the size of each friendship network. The authors measured the self-perceived wellbeing of the participants by asking them to rate their life satisfaction using the Satisfaction with Life Scale (SWLS). In addition, the severity of participant’s functional impairment in daily activities was evaluated by assessing how much difficulty each participant had with completing the activities listed on the Patient Reported Outcomes Measurement Information System (PROMIS). Results demonstrated a positive correlation between the size of the blind peer network and the subjective wellbeing of individuals with legal blindness regardless of their size of non-blind friendship network. The greater number of blind peers in a participant's friendship network, the greater their overall satisfaction with social roles, engagement in various activities, self-reported health status, and physical and psychological functionality, even if they did not have a large network of ‘normal’ sighted friends (Silverman et al., 2017). In other words, participants with greater overall friendship network size, but a smaller number of blind peers in their network, scored worse on the SWLS as compared to those with smaller
There are several possible reasons to explain the beneficial impact of peer network support on self-rated well-being and mental health related to vision loss. Cohen (2004), Jensen et al. (2013), and Silverman et al. (2017) suggest that peer network members who share the experiences of living with vision impairment may provide unique emotional, informational, and instrumental resources beyond what friends without vision loss can provide. This is because peer network members who have a similar experience of vision loss are able to understand and empathize with vision loss-related challenges on a personal level and have in-depth insider knowledge and insight, as well as coping strategies, for adjusting to unfamiliar places, spaces, or experiences. For instance, they can teach older adults with ARVL the “skills needed for daily living such as personal care, and home management, as well as how to use optical and adaptive devices, [and assist them with community mobility by demonstrating how to be] aware of oneself in relation to one’s surroundings” (Horowitz et al., 2005, p. 564).

In addition, Reinhardt (2001) states that visually impaired older adults not only benefit from receiving social support, but being able to reciprocate the emotional and instrumental support received from their close social networks can also improve their psychological well-being as they adapt to living with ARVL. Older adults with ARVL may also decide not to seek support if they are unable to respond to it in equitable terms (Reinhardt, 2001). However, “there is more tolerance for inequities in support received and provided with increasingly intimate relationships, and the closer the relationship, the greater the substitutability in the types of support that can be exchanged, thus, a disabled elder who receives increased instrumental support, but who cannot provide instrumental support to network members, may instead provide emotional support” (Reinhardt, 2001, p. 77). This is especially relevant to peer networks because people with chronic conditions, such as ARVL, are more likely to interact with individuals who they perceive as having similar resources (i.e., physical, psychological, and social functionality) or experiences as them (i.e., increased dependency on others, reduced self-confidence, and withdrawal from social interactions or other occupations) and exchange mutually
beneficial support with those peers who they feel safe and connected with, to regain their sense of autonomy and wellbeing (Berger & Porell, 2008; Dahlin-Ivanoff et al., 2000; Funk, 2016; Mitchell et al., 2008; Teitelman & Copolillo, 2005; Wilkie, 2007).

2.3. Conclusion

The literature discussed in this chapter provided an overview of how ARVL among older adults disrupted their occupational engagement, thereby reducing their quality of life in later life. This chapter also emphasized the significant roles that the different social networks of older adults with ARVL played in both supporting and constraining the psychological well-being and functional ability of older adults as they adapted to various changes that came with vision loss. It revealed that positively perceived and negatively perceived social supports of older adults with ARVL respectively enhanced and impeded their occupational engagement and psychosocial adaptation to vision loss. Previous research also recognized that positively perceived social supports were more readily provided to older adults with ARVL by their informal social networks, and especially the peer members who lived through similar experiences of vision loss than their formal networks. In addition, this chapter showed that maintaining the independence of visually impaired older adults, was a crucial component of positive support that facilitated greater occupational engagement among older adults with ARVL. Even though social support from distinct network groups have been studied separately, to date, no research has used narrative inquiry to specifically examine perspectives of older adults with ARVL on the comprehensive influences of diverse social networks for their engagement with desired occupations and psychosocial adaptation to vision loss. To address this gap in the literature, the present narrative research aims to examine the stories of older adults with ARVL to discover the meanings they attach to their specific occupations and social interactions with their social networks. Doing so may deepen our understanding of the distinct qualities that make particular social supports positive as opposed to negative, as well as how these social interactions contribute to psychosocial and occupational aspects of their experiences with ARVL. These personal stories may also elucidate how we can better facilitate and advocate for better quality of support from all social networks of older adults with ARVL, including
their formal networks. By raising awareness of the impact of social networks on older adult’s adaptation to ARVL among the public, we may be able to reduce or avoid providing negative social support to older adults with vision impairment. In turn, we can effectively improve the older adult’s ability to remain actively engaged in occupations and society and lead to a higher quality of life after losing vision.
Chapter 3: Methodology and Methods

In this chapter, I describe key features of the study’s setting, paradigmatic, theoretical, and methodological underpinnings of the study, as well as procedures involved with participant recruitment, data collection, data analysis, and data management. I also describe how ethics was taken into consideration throughout the research process to protect the rights, safety, and confidentiality of the participants, as well as the evaluative criteria that was used to assess the quality of this narrative research.

3.1. Paradigmatic and Theoretical Approach

3.1.1. Paradigm.

According to Guba and Lincoln (1994), a paradigm is a basic set of convictions about one’s ontological and epistemological worldviews, which allow the holder to navigate through the world and their research question with a specific set of principles and frameworks. This research is positioned within a constructivist paradigm, which views reality as a dynamic social construct that can evolve over time and is derived from human experiences and perceptions (Carpenter & Suto, 2008). Moreover, in constructivist research, knowledge is thought to be shaped, accumulated, and ultimately co-constructed through interdependent interactions between the researcher and the participants (Ponterotto, 2005).

3.1.2. Ontology.

Ontology questions the nature of reality, and it is often depicted on a spectrum of relativism to realism (Guba & Lincoln, 1994). The constructivist paradigm upholds a relativist approach, which believes in the co-existence of multiple realities that are equally valid, and dependent upon one’s situatedness within the multiple dimensions of social, cultural, and historical contexts (Carpenter & Suto, 2008; Ponterotto, 2005). In contrast, a realist believes in an absolute reality based on natural laws that exist separately from human perceptions and can be predicted, repeatedly measured, and validated through rigorous and objective study designs (Guba & Lincoln, 1994).
Applying a relativist ontology to my study, I focused on the perceptions that older adults with ARVL have about their life experiences related to social interactions and occupational engagement instead of confirming the objective reality or accuracy of those life events. In other words, I paid attention to the subjective psychological, emotional, and sociological meaning making processes of older adults with ARVL, understanding that the sociocultural, historical, political, and economic context that the participants are embedded within can influence their perceptions of reality.

3.1.3. Epistemology.

Epistemology is the investigation of the “nature of the relationship between the knower (or would-be knower) and what can be known” (Guba & Lincoln, 1994, p. 108). A constructivist paradigm adheres to a transactional epistemology, which involves a cooperative generation and interpretation of in-depth knowledge in specific contexts through reciprocal interactions between the participants and researchers (Ponterotto, 2005). Therefore, the epistemological role of a constructivist researcher is to invoke interactive dialogue with the participants, and to bridge the gap between the differential power dynamics between the participants and the researchers (Ponterotto, 2005). In this study, it is acknowledged that my presence influenced the information that the older adults with ARVL chose to share about their interactions with social networks and occupational engagement. To manage this, I distinguished between knowledge that is readily available, and that which is not, paying particular attention to information that is more intimate and shielded from public domains. For instance, during the research process, the participants shared stories about how their ARVL condition led them to disengage from certain occupations, which made them feel separated from others. Here, instead of framing such statement as “ARVL condition among older adults reduces occupational engagement thereby increasing social isolation,” I probed further to gain a more holistic understanding of what occurred during the disengagement: “What are the occupations that participants disengaged from or continued with after vision loss, and why did they make such decisions?”, “How are they engaging in the current activities, who are involved in these activities, what kinds of roles are these people playing, and how do they make the participant feel and behave?”, “Why do the participants feel socially...
isolated?”. In addition, I layered my own interpretative voice on the raw data of participants in order to co-construct knowledge about the interconnectivity between the social networks and occupational engagement of the older adults with ARVL.

### 3.1.4. Theoretical Framework.

Theoretical frameworks can inform research in a diversity of ways, such as providing guidance for analysis by providing the researchers with a specific lens through which to de-construct, reframe, and understand the potential meanings that may exist behind the research data (Grant & Osanloo, 2014). Social capital theory, particularly as delineated by Burt and Lin, was used within the study to inform the research questions, data collection, and analysis.

Social capital theory originated in the 19th century and was developed from multiple disciplines, including sociology, anthropology, economics, and political science (Lin, 2001). The three founders who modernized the conceptualization and popularized the application of social capital theory in broad works of research and empirical practices were Bourdieu, Coleman, and Putnam (Bourdieu & Wacquant, 1992; Coleman, 1990; Putnam, 2001). According to Claridge (2004), the dominant constituents of social capital are social norms, social trust, and social networks. Social norms refer to a collective agreement upon what constitutes acceptable social behaviours and is a product of cultural values and beliefs (Woolcock & Narayan, 2000). Social trust refers to faith in the reliability and virtue of others that motivates people to seek collaboration and civic engagement (Woolcock & Narayan, 2000). Social networks consist of different number and composition of members whom the individual interacts with at various levels of intensity and frequency to feel a sense of companionship and social integration as well as exchange diverse amounts and forms of social support (Ayalon & Levkovich, 2019; Berkman et al., 2000; Fiori et al., 2007).

More specifically this study drew upon Burt and Lin’s social network approach to social capital theory, which defines social networks as arrangements and accumulation of relationships within and between individuals, social groups, and social structures
Social networks can influence how people fulfill their goals and adapt to challenges in their lives, by providing them with different types, quality, and quantity of resources that are irregularly distributed within society (Burt, 2001; Lin, 2001). Within Burt and Lin’s approach, social networks can be categorized as bonding or bridging types of social capital, where the bonding type refers to homogenous interaction within similar groups, and the bridging type refers to heterogeneous interactions between dissimilar groups (Burt, 2001; Lin, 2001). People can access different forms of social support from these bonding and bridging networks, which include emotional, informational, instrumental, appraisal, and positive social interaction support (Berkman et al., 2000; Sherbourne & Stewart, 1991). Here, emotional support is based on empathy, compassion, affection, and trust, and aims to alleviate negative emotions of individuals (Heaney & Israel, 2008). In contrast, instrumental support refers to tangible or materialistic goods and services such as technological and financial aids (Heaney & Israel, 2008). On the other hand, informational and appraisal supports provide individuals with useful information, suggestions, and advice to assist with their problem-solving and decision-making (Heaney & Israel, 2008). Finally, positive social interaction support (PSIS) relates to companionship and having others to do activities with (Sherbourne & Stewart, 1991). I chose to apply Burt and Lin’s social capital theory to my study because it allows me to view social networks as a resource that people can utilize to have access to other forms of social support. It also focuses on how social network’s social support influences people’s engagement with desired occupations. Therefore, this framework highlights the interconnection between the social networks of older individuals with ARVL and their occupational engagement.

3.2. Methodology – Narrative Inquiry

This study adopted a narrative methodology. According to Smith & Sparkes (2008), people are “essentially a storytelling animal [who] naturally construct stories out of life” (p. 17). The process of storytelling requires the storyteller to select, sequence, and connect the events in their lives, that they perceive as essential in order to portray particular messages to specific audiences (Riessman, 2008a). People inherently engage in such actions to make sense of their internal perceptions about their self-identities, roles,
personal goals, social norms, interactions with others, and other aspects of the world (Riessman, 2008a). For instance, people commonly construct stories when they experience life-changing events or challenges in order to make sense of the experience, and find ways to cope with their present situation, as well as decide on future actions (Riessman, 2008a). With storytelling, people also engage in social comparisons of their perceptions of reality with one another, and thereby mutually exchange their knowledge on the external world (Riessman, 2008a). Therefore, the construction and internalization of people’s personal stories are often influenced by the pre-existing discourses that are ingrained within the sociocultural context that the storyteller resides within (Smith & Sparkes, 2008).

As a methodology, narrative inquiry captures the holistic stories of people as its primary source of data, and aims to interpret how people perceive and ascribe meaning to their realities (Smith & Sparkes, 2008). Narrative inquiry may aid in the discovery of knowledge beyond the superficial discourses of ARVL that are commonly depicted in society, such as the notion that vision loss among older adults inhibits their functional abilities and makes them more dependent on others. Instead, narrative inquiry aims to uncover the unique and marginalized experiences that are harder to get to (Smith & Sparkes, 2008). For instance, the use of narrative inquiry in this study enabled the older adults with ARVL to voice their perceptions of reality not only oriented towards their diagnosis but also interconnected with their social relationships and occupational engagement.

My rationale for choosing narrative inquiry for this research is because there were no prior examples of studies conducted with older adults with ARVL that investigated the ways in which they made sense of or individually understand the influence of social networks on their occupational engagement. Existing studies on ARVL, specifically focused on social networks and support, touched on particular aspects of their occupational engagement, social interactions, and biopsychosocial well-being by using quantitative outcome measures (Alma et al., 2012; Marques et al., 2018; Reinhardt, 2001). However, by applying deductive processes in their data collection, these studies did not fully take into account the personal meanings, values, and priorities
that older adults ascribed to certain occupations and social supports, and therefore failed to capture a holistic picture of the life experiences of older adults living with ARVL, including the subjective understanding of how occupational engagement is shaped in response to social support networks. In contrast, the use of narrative inquiry in this research elicited fuller extent of information related to the life experiences of older adults with ARVL, specifically relating to how they used the social support provided by their social networks to maintain and adapt to the changes in their occupational engagement. In this approach, the dialogues with participants and their stories drove the development of the overarching themes related to the research topic. Therefore, each participant was an active member of the knowledge generation process alongside the researcher, which was in alignment with my ontological and epistemological positionality.

3.3. Research Methods

3.3.1. Study Context

This study took place in London, a city in southwestern Ontario, Canada, with a population of 494,069 as of 2016, with 23.3% (115,365) of the population aged 60 years and over (Statistics Canada, 2019a). At the time of the study, I lived and studied in London and made connections with research representatives of London’s Canadian National Institute for the Blind (CNIB) and Society for Learning and Retirement (SLR). London thus became the most practical site to recruit participants and collect data for my research. As of date (May, 2021), there have been no statistics on the number of older adults with age-related vision loss dwelling in London. However, within Ontario, among the population aged 65 and over, 8.6% (207,000) reported that they have been diagnosed with age-related macular degeneration, 7% (179,300) had glaucoma, and 2.3% (54,900) had diabetic retinopathy (Statistics Canada, 2019b).

I began collecting data in mid-June of 2020 and finished in December 2020. At the time of my data collection phase, the COVID-19 outbreak (a pandemic disease caused by the novel coronavirus SARS-CoV-2, which started in late 2019) was ongoing. COVID-19 caused economic, social, and health crises for all populations but especially affected those social groups in the most vulnerable situations, such as older adults and
individuals with disabilities. Conducting research with older adults with age-related vision loss during this period influenced and determined the scope and types of responses I garnered from the participants relating to my research question. This was because participants’ interactions with social networks and occupational engagement were heavily connected to the social changes and regulations enforced because of COVID-19. For instance, participants associated COVID-19 with increased social isolation and consequently diminished care and support for their vision, lack of physical contact with their social networks (i.e., family members, friends, neighbours, healthcare providers, etc.), and cessation and changes occurring with their daily routines and other activities.

3.3.2. Participant Recruitment and Inclusion Criteria

To participate in the study, research participants needed to: (1) be 60 years of age or older; (2) have a diagnosis of ARVL (including macular degeneration, glaucoma, and/or diabetic retinopathy); (3) have lived with ARVL for a minimum of 6 months; (4) be able to communicate in English and; (5) not have any cognitive or (non-corrected) hearing impairments that would prevent the participant from engaging fully in the research process. No exclusion criteria was set on the bases of race, ethnicity, financial status, gender, or education in order to promote participant diversity, and allow marginalized voices to be heard.

This study recruited participants who met the inclusion criteria from the Canadian National Institute for the Blind (CNIB) and the Society for Learning and Retirement (SLR) using a convenience sampling method. Convenience sampling is a form of non-probability sampling that allows the researchers to base their selection of research units (e.g., organizations, individuals, and data) on the convenience of access to those samples (Merriam, 2009). Convenience sampling requires the researcher to think critically about the essential characteristics of eligible participants, and to locate the study sites that provide access to those who best match the inclusion criteria (Merriam, 2009). According to Patton (2002) and Riessman (2008a), sample size for narrative inquiry can vary depending on the research purpose, theoretical and paradigmatic frameworks, type of information being collected, and the available time and resources. In a sample of
narrative studies reviewed, the researchers recruited between one to ten individuals, and all concluded that their sample sizes were adequate to achieve elastic saturation of data, which refers to the point of redundancy in data, where no new information is gathered from further sampling (Butina, 2015; Dela, Caine, & Mill, 2016; James, 2018; Patton, 2002). For the purpose of this research, which aimed to uncover the complex influences of social networks on the occupational engagement of older adults with ARVL, three interviews with five older adults were conducted in order to allow adequate time for in-depth interactions between the participant and the researcher to cultivate deeper meanings from participant’s stories.

Before the recruitment of participants, this study was approved by the Western University Research Ethics Board (REB), as well as reviewed in accord with processes at CNIB and SLR. Participants were recruited through a recruitment email, which was sent out to the potential participants by the gatekeepers at CNIB and SLR. The recruitment email outlined the objectives, risks, and benefits of the research, as well as the contact information of myself and my supervisor so that participants, who were interested in learning more about the study, could communicate directly with the researcher. Outside of sending the initial recruitment email, and mentioning the study to potential participants, CNIB and SLR had no further involvement in the study (i.e. they did not collect interested individuals’ contact information for the research team) and were not informed with regard to the participants' level of involvement (if any) within this study. Refer to Appendix I for detailed content of the recruitment email information.

I decided to form partnerships with these two organizations because CNIB is the most prominent non-profit foundation in Canada that supports the blind and partially sighted communities, whereas SLR provides programs that are catered to older Londoners and focuses on the needs of retired individuals who are not actively working in the labour force. The above-mentioned recruitment locations also had research experience and policies around working with graduate students. Therefore, partnering with these organizations aided in connecting with potential participants during the recruitment stage of the research. By recruiting participants from these venues that supported distinct groups of older adult populations, I attempted to achieve maximum
variation sampling in participant's age, ethnicity, duration of being diagnosed with ARVL, gender, marital status, and other categories. By using maximum variation sampling, I wished to understand how interactions with social networks, and engagement with occupations were viewed and experienced among different groups of older adults diagnosed with ARVL.

Five older adults living with age-related vision loss between the ages of 67 to 91 were recruited, wherein two participants were recruited from SLR, and three participants were recruited from CNIB. Three participants (one from SLR and two from CNIB) had macular degeneration and two participants (one each from SLR and CNIB) had glaucoma. At the time of the study, four participants were living alone, either widowed or divorced, and one participant was married and living together with her husband and father. The duration of time that participants have been diagnosed with ARVL ranged between 10 to 25 years. All participants identified as Caucasian female.

3.3.3. Study Design

Informed Consent Procedures. When potential participants contacted the research team, I followed either a telephone or email script (depending on how each participant reached out to the researcher) to confirm the eligibility of the interested participants and provide more information about the study (refer to Appendix II for Telephone Script and Appendix III for Email Script). At the end of the conversation, if eligible individuals were still interested in participating in the study, I clearly read out loud the letter of information and (refer to Appendix IV) consent form to the participants over the phone and participants also received a copy via email for their reference. After providing the letter of information to the participants, I responded to any additional questions that participants still had regarding the study.

Participants were provided with the following choices to give their informed consent: (1) verbal consent with a witness, or (2) written informed consent. These choices were provided to respect the participants’ autonomy in decision-making while also acknowledging that ARVL diagnoses might interfere with the participants’ abilities to sign the written consent due to vision-related challenges (i.e., hand-eye coordination problems). In addition to written consent or verbal consent from older adults with ARVL, obtained prior to the first interview, process consent was also obtained by the study
researcher in subsequent stages of data collection (second and third interview sessions) to ensure that the participant still wished to be involved in the research study. Refer to Appendix V for Verbal Consent form, and Appendix VI for Written Consent form.

In cases where an informant chose to provide verbal agreement, I explained the study, noted that verbal consent was obtained, and then signed as the person obtaining informed consent. In addition, for those participants who were unable to read the letter of information due to their vision impairment, a witness was present to confirm that participants were adequately informed prior to providing consent, where a family member or friend of the participant acted in the witness's role. Having a witness during the consent process ensured that the Letter of Information and Consent Form has been read properly to the participant. The Consent Form was first signed by me, then later emailed to the witness, who returned it after signing and scanning the form. However, having a witness was not a requirement but rather a choice left up to the participant. Thus, for the participant who indicated that they did not wish to involve a witness during the consent process, the consent form was only signed by the participant and myself.

**Data Collection.** Data collection entailed three interview sessions (narrative, semi-structured, and feedback interviews) with each participant. Refer to Appendix VII for a detailed protocol and example questions for each interview session.

All interviews were conducted with the older adults via Zoom videoconference or telephone at a date and time of their choosing. Although originally planned to occur in person, the interviews had to be completed virtually because of social distancing requirements as a result of COVID-19, which were in effect at the time of data collection. Each interview session time ranged between one to two hours, and all sessions were audio-recorded, except for the feedback interviews. I began audio-recording each session after I exchanged greetings and introductions with the participants. I maintained a reflexive journal by taking notes on my immediate thoughts, observations, and opinions about participant responses after each interview session as well as during the transcription and data analysis processes. The reflexive journal documented my preunderstandings and my reasoning informing interpretation of certain words, phrases, and emotions, as well as my selection of specific codes and themes from the data sets.
Transcription took place immediately after each interview session and was performed by myself in order to promote immersion in the data sets. I then cleaned the transcripts by replacing the participants’ names (using a pseudonym or P1, P2, P3, etc.) and identifiable markers (such as names of places, social networks, etc.). Grammatical errors and colloquial use of filler words such as “uh”, “umm”, “like”, and “so” were also removed from the transcripts.

All five participants completed the three interview sessions, where four participants participated via telephone and one partook via Zoom. At the end of the feedback interview session (not audio-recorded nor transcribed), each participant was given a $25 Amazon e-gift card (gift card was awarded through email-delivery) as a token of appreciation for the participant’s time and contribution to the research.

**Interview 1 (Narrative interview).** At the beginning of the interview, I reviewed the letter of information with each participant and encouraged them to voice their questions, concerns, or uncertainties about the research. Following Wengraf’s (2001) Biographic-Narrative-Interpretive Method (BNIM) approach to interviewing, the participants were asked two major open-ended questions during the first interview session. For this study, the participants were asked: (1) “Can you tell me about the types of activities you participate in since being diagnosed with vision loss, and how has your participation in those activities changed since experiencing vision loss?”; and (2) “Can you tell me about a time when someone either helped or hindered your participation in those activities?” During the participants’ storytelling, I attempted to refrain from interrupting or guiding their narratives in a specific direction, but instead, took careful note of the topics raised by the participants. I also strove to provide a safe space for the participants to freely select, organize, and sequence the events of their story, to maximize the participant’s authority and influence over the flow and the parameter of topics covered in their story (Wengraf, 2001).

Despite my efforts, conducting virtual interviews posed several challenges in enabling the participants to take the lead of the interview conversations. For instance, during telephone interviews, I could not see the participants’ facial expressions. Thus, when participants stopped talking after a few sentences, it was difficult for me to gauge whether the participants were pausing because they were contemplating the next things to
say or finished speaking. During these pauses, I waited for 10 to 15 seconds to allow participants to add on to their previous thoughts, but many times, they did not expand on their responses. I suspected that two main reasons caused these pauses: (1) rapport building process was slower through Zoom or phone call interactions because we were not connecting in-person; and (2) some participants may have been overwhelmed by the broadness of my main research questions, and felt unsure of how to approach them.

Relating to (1), I used interviewing techniques such as affirmation and reflections to build rapport over a virtual conversation. First, with affirmation, I validated the participant’s experiences and emotions associated with those experiences through statements such as, “that must have been really difficult” or “sounds like you really enjoy the time you spend with your family.” Secondly, with reflections, I paraphrased participant’s responses while adding in my personal interpretation of their quotes. For example, I re-stated back to a participant, “You said that you’re living alone, but you do not feel lonely, and you often hesitate to ask others for help. It seems to me that you value independence and want to solve problems on your own.” I felt that these strategies let the participants know of my interest in their stories and become more conscious of what they have said, helping to expand on their responses. To mitigate the effects of (2), I repeatedly and separately asked about the participant’s occupational engagement and interactions with social networks throughout the interview, helping them remember the different components of my research question better. Unfortunately, such repetition simultaneously caused my narrative interview to become more structured than I initially intended.

In addition, during the interview sessions with three of my participants (one Zoom interview and two phone call interviews), there were unstable Wi-Fi and phone connections on the participants’ end. Thus, it was challenging for me to hear parts of the participants’ responses, and I had to ask them to re-state the details I missed initially. I also set my computer and phone volume in the loudest settings and listened as carefully as possible. Despite these efforts, however, the communication with these three participants was not as smooth and clear as it could have been with in-person communication. Thus, I found it challenging to formulate probing questions immediately after participants’ responses because I was in the process of deciphering what the participants said. When I could not probe the participants further about their responses
because I had missed a significant portion of the conversation, I opted to ask questions generally relating to my research topic but not specifically to their response. This again caused the interview to be guided more heavily by my questions than intended. To mitigate the effects of the Zoom and phone call disconnections and the resultant sub-par sound quality, I created summaries by collecting participants’ statements about specific topics and delivering them back to the participants. For instance, I summarized all the social support a participant received from her children (i.e., getting her groceries, paying for her personal health trainer, providing her with magnifiers, etc.) and confirmed with the participant that I had understood her story correctly. Such summaries became especially helpful when I missed out on certain parts of the conversation because of unstable connections. During the interview, I listened attentively to the key concepts, words, emotions, and phrases expressed by the participants (Wengraf, 2001). Then, after the participants have finished narrating their story, I prompted the participant to provide further detail or information on specific topics using Patton’s (2002) informal conversational interview approach which requires the interviewer to spontaneously generate and ask questions during their natural flow of conversations with the interviewees. For instance, I asked the participants questions such as: “Can you further explain about X?” or “Can you provide an example of Y?” (Patton, 2002). At the end of the first interview session, I asked the participants to answer the Demographics Questionnaire outlined in Appendix VIII. The demographic data was used to describe the background information and characteristics of recruited participants in this study.

**Interview 2 (Semi-structured interview).** The purpose of this interview session was to probe deeper regarding participant's experiences related to specific social support received from various social network members, and how this shaped the (re)formation of their identities after losing vision as well as their decision-making process related to occupational choices and degree of engagement with these occupations. In the second interview, I followed the general interview guide approach employed by Patton (2002). A general interview guide allows the researcher to ask each participant a set of pre-determined open-ended questions without a specific sequence to probe at more pertinent topics (Patton, 2002). These semi-structured and in-depth questions for the second interview were prepared following Wengraf’s (2001) BNIM approach, and therefore,
were based on participants’ ideas and responses that were generated in the first interview. For instance, if the participant mentioned social support being provided by their social network in the first interview, I focused on asking further questions about the social support and the roles it played in influencing their occupational engagement in the second interview. For example, to a participant who shared that she had a personal health trainer who helped her exercise, I asked questions such as, “Were there any times when you experienced difficulties with exercising because of your vision loss? Were there any times when your health trainer helped you overcome the barriers in exercising caused by vision loss?” The responses to the second interview questions were then used to flush out the storylines and the narratives of participants.

**Interview 3 (Final feedback interview).** Prior to the third interview, I created a draft narrative for each participant based on the first and second interviews. I then shared this draft-rendering of the participant’s narrative account with the participants prior to the third interview session by sending them an email of the draft-narrative. During the third interview, I asked them to reflect and share their perceptions of the reconstructed narratives. All five participants participated in the final interview, which took approximately 10 to 15 minutes. Three participants suggested no revisions to their narrative and one participant requested that I remove one of the quotes I presented in her draft. Another participant emailed written feedback with minor grammatical edits made to the quotes in her narrative, and the same participant pointed out my misunderstanding of her parenting experience and provided additional information about her motherhood. I had previously misunderstood that the participant had been a single teenage mother, but she explained that she was a teenage mom who stayed married for several years before she divorced at the age of 36 and became a single mother at 36. The final rendering for participants’ stories were then altered, reflecting these final comments from the participants.

### 3.4. Data Analysis

Data analysis, which was an iterative process, included both thematic and structural analysis, and began after the transcription of the first interview. Thematic analysis elucidated the “what” questions, or the content of participant’s experiences, for
instance, the shared and distinct storylines about older adults’ ARVL condition, social networks, and occupational engagement (Fraser, 2004; Rice & Ezzy, 1999; Riessman, 2008b). Structural analysis, examined “how” the participants selected, sequenced, structured, and conveyed the major life events and main messages into their narrative accounts (Fraser, 2004; Riessman, 2008c).

3.4.1. Thematic Analysis.

The initial step of thematic analysis was to actively review the audio files of the interview in order to transcribe the data and to keep reflexive journal notes aimed to uncover my preunderstandings, underlying values, and initial interpretations of the participant’s meaning-making process of their life experiences (Riessman, 2008b). The second step involved the combination of inductive and abductive coding of the transcripts by engaging with both the entirety of the text, as well as line-by-line or paragraph reading (Fraser, 2004; Riessman, 2008b). The coding process involved the labeling of essential keywords or phrases, the context in which specific life events occurred, how the participants made sense of an experience, and the kinds of self-identities that participants portrayed through their story, with my own interpretations and descriptions (Fraser, 2004; Riessman, 2008b). Here, I engaged in both open-coding and theory-informed coding based on social capital theory. The theory-informed coding focused more on how the different types of social networks of older adults were providing different forms of social support to older adults with ARVL, and how various social networks and supports were individually and collectively shaping the occupational engagement of older adults with ARVL. The open-coding captured more general concepts related to participant’s psychological, physical, and behavioral responses towards ARVL, social networks, and occupational engagement.

The coding process was completed manually via a Microsoft Word document. One Word document was dedicated to list the codes for one transcript, such that I created two Word documents per participant (first and second interviews). Whenever I identified a portion of the transcript that I found relevant to my research topic, I copy-pasted that quote onto a Microsoft Word document and labeled it with either a descriptive code (paraphrasing the content using participant’s wording) or an interpretive code (adding on my personal interpretations to participant’s quotes). Under each code, I collected and
listed all quotes pertinent to that code. An example of a code commonly noted in many participants’ transcripts is *using low-vision assistive technology to engage in desired occupations.*

The third step of data analysis aimed to identify storylines from specific cases by comparing, contrasting, unifying, and discarding codes within each narrative account (Fraser, 2004; Riessman, 2008b). For each participant, I read the coded documents (two Microsoft Word documents) from the first two interview sessions side-by-side, and combined the similar codes together to generate themes and storylines, which were then each assigned a new title that conveyed their central meaning. The storylines generated from the thematic analysis were placed within the larger social, structural, and theoretical frameworks (Rice & Ezzy, 1999; Riessman, 2008b). For instance, concepts such as ageism, gender norms, and social class were considered together with how older adults with ARVL were interacting with their informal and formal network members. These concepts were related to who the participants were interacting with, in which contexts, the diversity and quality of supports available to the participants from these interactions, and how they perceived and utilized these supports while engaging in various occupations. Therefore, as a narrative researcher, I could come to an interpretation of my research topic of interest while keeping each of the original participant stories intact (Riessman, 2008b). These three steps of the thematic analysis were part of an iterative process that was repeated until elastic saturation of knowledge was reached, wherein, no new codes, themes, or interpretations were generated from further analysis and cross-comparison between cases (Riessman, 2008b).

### 3.4.2. Structural Analysis.

The purpose of structural analysis was to analyze how the participants structured their narrative accounts, by paying close attention to vocal tones and emotions that were evoked during their storytelling (Fraser, 2004; Riessman, 2008c). The dynamicity of the story plots was also noted, distinguishing the various structures within participant narratives, such as the beginning, settings, rising actions (conflicts), climax (turning points), falling action (consequences of climax events), and the resolution (end) of the story (Fraser, 2004). The structural analysis enabled me to question how the participants conveyed the main messages of their story by examining the reasoning behind their
selection and sequencing of the major high and low plot points (Fraser, 2004; Riessman, 2008c). In re-constructing the narrative cases, I re-confirmed the critical plot points with the participant, and used creative writing to highlight the social situatedness of the narrative.

3.4.3. Reconstruction of Narratives.

The reconstruction of each participant’s narrative began after I elicited codes from the first and second interviews. The overall structure of the narratives were broken down into several sections addressing the broader themes and storylines I had identified from each participant’s transcripts. Under each storyline, the major plot points for reconstruction were loosely re-ordered in a chronological sequence, and addressed questions such as, “Who are the main characters in this story?”, “What are the main events?”, “When and where did these events take place?”, and “How has the participant positioned [oneself] in the story?” (Nasheeda et al., 2019, p. 5). Then, transcript materials such as participant quotes and excerpts were inserted back into the newly organized narrative to provide detailed examples about the major story plots and create a holistic story (Wengraf, 2001).

In addition, each participant’s narrative account was reconstructed in third-person point of view to avoid presuming the identities or voices of the participants. Presenting collected material as though the researcher has experienced them may trigger adverse emotions among participants, as it may limit their sense of ownership and control over their own story, and make them feel as though their personally lived experiences have been stolen from them (Nasheeda et al., 2019).

In addition, the storylines were layered with my interpretative voice, which was informed by my educational background, world view, motives, moral perspectives, previous life experiences, paradigmatic assumptions, and the guiding theoretical framework of social capital theory (Rice & Ezzy, 1999). The reconstructed narratives of participants then became part of the research data to be thematically and structurally analyzed, and were cross-compared between different participant cases to elicit commonly shared storylines of the participants’ experiences (Fraser, 2004).

I then emailed the reconstructed narrative draft of each participant to my supervisor and two advisory committee members. The entire research team therefore had
a chance to separately review and provide feedback on my narrative drafts. Then narratives were sent and subsequently discussed with each participant in the final feedback interview. The insightful comments from the research team helped me better articulate the connections between different storylines within each participant’s narrative, link the participant’s narrative themes to how they construct their personal identity, and rearrange specific content under one storyline to another to enable a better flow of the story.

3.4.4. Generating Overarching Themes across the Data Sets.

After I created an initial list of codes and storylines from each of the participant’s data, and reconstructed their stories, I compared the entire data sets including the transcripts of audio-recorded interviews, reflexive journal notes, and reconstructed narratives across all cases to search for patterns and dissimilarities between case-specific codes, storylines, and contexts (Fraser, 2004). The purpose of this analytic phase was to understand the association between all of the themes generated from each participant’s data sets (Braun & Clarke, 2006). The merging of these themes across stories could holistically inform about the participants' collective experiences in interacting with their social networks to manage their vision loss and the corresponding changes in occupational engagement (Braun & Clarke, 2006). To allow for a more holistic interpretation of the data, I incorporated input from my supervisor while identifying the overarching themes across participants’ data sets. First, I created a data analysis summary document for each participant, encompassing all the themes I generated by combining the codes from first and second interview transcripts, and their respective exemplar quotes. Then I emailed my five data analysis summaries to my supervisor who had previously reviewed all interview transcripts, and we separately generated overarching themes across all participants. Once we were both finished with this process, we met to discuss the overarching themes we each identified. As I convened with my supervisor, I was able to practice co-reflexivity and challenge my perspectives and assumptions to reach a broader understanding of the data. At the end of our meeting, we finalized the five overarching themes across participants, which are further discussed in Chapter 5.
3.5. Data Management

To protect participant's identity, only an identification number was used to identify recordings, notes, transcripts, and interviews. All data (including transcripts and descriptive data) was cleaned of any identifiable information which were replaced with pseudonymous words. Participants were provided with a numerical code (i.e. P1, P2, P3, etc.) which was used instead of their name.

A master list, which was only accessible by the research team, was used to keep track of the self-identifiable markers that were not essential to the core structure and interpretation of data, including but not limited to: the names of participants and their social networks, specific locations/address, age, and gender. The master list, and all hard-copies of data with identifying information (i.e. descriptive data, written notes, consent forms, and any non-cleaned audio files and transcripts) were temporarily stored in a locked fireproof box at the primary researcher's home during the period where graduate students were not permitted on Western University campus because of COVID-19 regulations. For long-term data storage, they were stored separately in two locked filing cabinet in a locked office at Western University. Electronic versions of identifiable data were downloaded to Western University’s online learning management system; OWL, where one requires Western Identity user ID and password to create and login to a project worksite. Electronic versions of de-identified data were downloaded onto my personal laptop, in password protected files. All data collected for this research will be erased after 7 years.

3.6. Ethical Consideration

Risks of participation. I acknowledged that participants might be exposed to psychological harm when they talk about the adversities and low points in their ARVL journey, which might trigger negative emotions and cause the participants to re-experience past trauma (Smythe & Murray, 2000). To minimize and mitigate the risks of participation in this research, process consent was sought from the participants throughout the research process and participants were informed for their right to withdraw from the study at any stage of the research. Also, participants could freely request that parts of the recording and the constructed narrative be erased, either during
or after the sessions. In addition, psychological crisis resources such as contact information of community psychiatric nurses and distress helplines were available so that they could be provided when participants wished to withdraw from the research or when they expressed discomfort (either verbally or through non-verbal signs) with discussing certain topics. No participant withdrew or expressed discomfort throughout the data collection process.

Confidentiality. Self-identifiable markers that were not essential to the core structure and interpretation of data, such as the names of participants and their social networks, specific locations, age, and gender, were replaced with pseudonymous words during transcription. Prior to data collection, participants were also informed that if they wished to withdraw from the study, the data they had shared up to the point of withdrawal would be retained (with their consent) and continue to influence the researcher’s direction of analysis. They were also notified that for participants who withdraw from the study, their specific quotes and excerpts of examples that they discussed during the research would not be reproduced in any forms of publications. Participants were also cautioned that the researcher had legal obligations to report concerning situations that could threaten the safety of the participants themselves or others (and other information that were required to be disclosed by law), to appropriate institutions and authorities. This information was outlined in the letter of information, and participants were reminded at the beginning of all the interview sessions.

Power Hierarchy. To mitigate the unequal power dynamics between the participants and the researcher, I respected the participant’s agency in creating their own story by encouraging the participants to take the initiative in telling their story, and allowing them to choose and convey the important aspects of their experiences in a manner that made logical sense to them. I was also transparent about the objectives, benefits, risks, and duration of the study to the participants, and avoided forming multiple relationships with the participants, such as developing a friendship outside of the research process. I prioritized the participant’s best interest above my personal interest, and never exploited or tried to deceive the power dynamics or relationships I formed with the participants in order to collect compelling data or coerce their consent.
Exiting ethics. The expected timeline of the study was repeatedly addressed from the initial to final stages of this research to ensure that the participants were aware of when I would exit the research setting. This was to ensure that the participants were not misled about the types and depths of connections they could have with the researcher, and did not become dependent on their interactions with the researcher.

Narrative ownership. The ethical dilemma of narrative ownership is that it is challenging to define who owns the rights to the participant’s stories (Smythe & Murray, 2000). In traditional research settings, it is thought to be within the researcher’s control to interpret and present the research data (Smythe & Murray, 2000). However, in narrative inquiry, the research data is difficult to separate from the participants as it is “so heavily invested with [their] personal meaning and sense of identity” (Smythe & Murray, 2000, 324). Therefore, it was my responsibility as a narrative researcher, to talk about the issue of narrative ownership with the participants before data collection to minimize any confusion or betrayal felt by the participants when their narrative accounts did not identically represent themselves. In the informed consent letter, I addressed that the final rendering of the participants’ narrative account might differ from their experienced story, but that participants were welcome to provide feedback in the final interview session to confirm the plot points, alter their responses to previous interview questions, and give feedback on the researcher’s interpretations. After the third interview, the feedback was used to inform the final revisions that I made to my renderings of each participant’s story. For instance, I addressed the feedback by rephrasing certain textual descriptions, excluding or adding specific excerpts from the transcripts, reordering story plots, and revising my interpretations about particular themes, in order to arrive at the final version of the narrative account that better reflected the essence of the older adults’ lived experiences. I also provided the final copy of participant's narrative accounts either as a physical copy (sent to their mailing address) or electronic (email).

3.7. Quality Criteria

The quality of this research can be evaluated through Tracy’s (2010) quality criteria. Tracy (2010) acknowledges that qualitative research can be guided by diverse paradigmatic and methodological frameworks and can be conducted through a large
variety of methods. Tracy (2010), therefore, provides flexible and expansive means of evaluation that are based on “universal hallmarks of quality” (p. 839), which can unify and be applied across diverse works of qualitative research. Below, I detail how Tracy’s (2010) criteria has been addressed.

**Coherence.** Evaluation of coherence aims to assess whether the researcher’s use of paradigm, methodology, methods, and literature review are well-suited to answer the objectives of the research (Tracy, 2010). Coherent research demonstrates connectivity and consistency between what it claims to be and its findings (Tracy, 2010). To achieve coherence in my study, which was situated within a constructivist paradigm, I did not make statistical inferences, nor claim causal-effect relationships or generalizations of data from the samples. Instead, I aimed to gain expansive and intimate insight into the experiences of older adults with ARVL while striving to maintain equal interactions and power dynamics with the participants to co-construct knowledge during the data collection and analysis.

**Rigor.** Rigor is linked with the researcher’s ability to employ appropriate theoretical constructs and sufficient amount of knowledge from existing literature on the research topic to help interpret collected data (Tracy, 2010). To demonstrate rich rigor, I spent sufficient time in the research field to collect comprehensive data from appropriate samples to adequately answer the research question, and highlight the complexities in the contextually situated data (Tracy, 2010). In my study, I spent approximately four months collecting data in the form of a three-phase interview to allow myself and participants to repeatedly interact and, in turn, exchange richer information and interpretations about the participant’s experiences. This time limit of data collection was decided after reviewing a sample of dissertations and theses that used narrative inquiry as their methodology, where the researchers collected data between three to six months (Arth & O’Fallon, 2009; Rivera & Tyson, 2006; Showers et al., 2015). For instance, Arth and O’Fallon (2009) posited that their data collection period of six months allowed space for the participants to story, re-story, share, and reflect on their experiences with the researcher and become more aware of their past experiences. At the same time, the length of the data collection period still allowed the researchers to achieve expediency in their research, by allowing time to complete the formalized aspects of their theses and dissertations. I also used an
established theory, namely social capital theory, to enhance the rigor of my data analysis. For instance, social capital theory was used to ensure attention to different types of social networks and social support that participants described in their narratives (i.e., instrumental, emotional, peer, informational, positive interactions support, etc.)

**Credibility.** Credibility is concerned with the plausibility of the researcher’s interpretation of the data (e.g., the case-specific storylines and reconstruction of participant narratives) (Tracy, 2010). Credible findings are supported by detailed descriptions that transparently demonstrate the complexities of the data (Tracy, 2010). For instance, in my study, I elucidated the findings with participant quotes and excerpts of interview transcripts, as well as provided specific contexts to data such as participant’s actions, emotions, and interactions. Tracy (2010) also posited that member-reflections such as the mutual exchange of feedback between the researcher and participant about the research process could also elevate the research credibility. I achieved member-reflection in this study by sharing the draft-rendering of participant narratives with the participants as well as with my supervisor and research committee, creating space for provision of feedback on the preliminary analysis of data. I then used their feedback to revise and finalize the reconstruction of narrative accounts.

**Sincerity.** “Sincerity means that the research is marked by honesty and transparency about the researcher’s biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research” (Tracy, 2010, p. 841). In order to achieve sincerity in this research, I demonstrated self-reflexivity about myself (biases, background, goals, and values), my study, and the participants, through keeping a reflexive journal throughout the study (Tracy, 2010). The reflexive journal documented how I felt about my interactions with participants (i.e., examining the participants’ reactions to the researcher) and made sense of my opinions about participant responses. In my study, I was also transparent about my decision making during the research process in an effort to practice sincerity (Tracy, 2010). For instance, I provided clear explanations of why I made particular methodological decisions, such as my choice of theory, sampling, recruitment, methodology and methods of data collection. I also disclosed when and how I dealt with any unexpected challenges during the study.
3.8. Conclusion

Chapter 3 outlined the study’s context, philosophical and theoretical frameworks, methodology, methods, and ethical considerations. Chapter four will illustrate the reconstructed narratives of the five participants.
Chapter 4: Reconstructing Participants’ Narratives

This chapter presents the narratives that participants and I have co-constructed based on the analysis of the lightly structured narrative interview and the semi-structured follow-up interview completed. The following reconstructed narrative accounts convey how participants storied how their vision loss was dynamically experienced as implicated in their interactions with social networks and occupational engagement.

4.1. Linda’s Story

I was able to connect with my first participant, Linda, through the Society for Learning in Retirement (SLR) in early June. Linda was a 68 year old divorced woman who had been living with glaucoma for 15 years at the time of the study. Linda was a mother to a son and a daughter, but was living on her own, as both of her children lived out of the province. However, Linda was capable of driving herself, and regularly visited her two children.

Throughout our interviews, Linda and I communicated online via Zoom, with each of us operating from our respective homes. I remember being both nervous and elated during our first meeting when she popped up on my computer screen and greeted me affably. After we exchanged our introductions, Linda began explaining her experiences of living with glaucoma, in which she exuded confidence as she spoke.

**Gradual Process of Vision Loss**

Linda was first diagnosed with glaucoma in her early 50s. Her vision loss progressed slowly and gradually so that in the earlier stages of being diagnosed, it went almost unnoticed by her. When it became a little more noticeable, she used several different eye drops to reduce her intraocular pressure. When these medications were not enough to keep her eye pressure low, she received laser treatments that cleaned the drainage valve blockages, which allowed the fluids from inside her eye to flow more quickly. When Linda reached a point where high pressure didn’t respond to any more laser treatments, she proceeded with getting trabeculectomy surgery, a procedure that created a new artificial valve in her eyes to help prevent the build-up of fluids. Linda
explained that currently, she had lost half the field of vision in her left eye, but her right eye was functioning well. She also described that ARVL progressed differently for each individual. For instance, she believed that the severity of how much one’s occupational engagement was affected by vision loss depended on the type of vision loss diagnosis they had and the severity of symptoms. In sharing her perspectives, Linda talked about Kelly, an older woman she met through SLR, who had lost her central vision due to macular degeneration. Linda compared between her experiences with glaucoma and Kelly’s experiences with macular degeneration as she explained how she thought each of their diagnoses influenced their driving ability differently:

“So each one [diagnosis] is a little different. And the kind of vision loss that occurs is different. You’re standing with the macular degeneration and sometimes it comes on quite suddenly and you lose your central vision... And at that point, someone like her [Kelly] relied so heavily on her husband, because he took her everywhere, she was not able to function independently. Whereas my situation is quite different because I've lost my peripheral vision on the one side. So losing central vision is far more critical and impactful because your central vision... that means you can't drive, you can't recognize faces because you can't see what's in the middle of your vision, your visual field.”

In her particular case of being diagnosed with glaucoma, she felt that her symptoms have not impacted her daily life for the most part; she did not feel drastic changes in the types of occupations she engaged in, nor was she heavily reliant on her social networks to engage in her desired occupations. At the time of the interviews, she was very socially involved and was actively participating in community events. For instance, she was engaging in volunteer work by being a long-term member of SLR, enjoying physical activities such as “Aqua Fit,” and attending several educational and cultural activities such as peer-learning based study courses at SLR. Linda was also engaging in various leisure activities such as Scrabble which she played competitively with the members of the “National Scrabble Association.” In addition, Linda was “traveling a lot” to visit her social networks such as her friends in Toronto, daughter, and son.
Maintaining and Adapting Valued Occupations over Time

While Linda continued to engage in the same occupations she previously enjoyed, she acknowledged that the ways she carried out those occupations changed after losing vision in her left eye. For instance, Linda expressed that she experienced increased difficulties with traveling and driving for longer distances as she had “greater sensitivity to light”. Thus, concentrating on watching the roads became harder, and she had to stop more often to let her eyes rest. Linda also found it burdensome on her eyes to read or work on computer monitors for a prolonged period of time (“over an hour”), as it made her eyes “blurry” and caused her to “see double images”. She expressed that the changes in her vision and the need to rest her eyes occasionally interfered with her work as a SLR board member as she had to “do a lot of work on computers”, such as conducting Zoom meetings and launching online courses. Moreover, Linda recalled retiring early, at the age of 61, from being a college professor because she found teaching to be increasingly stressful on her eyes:

“It's [Teaching] a much more intense kind of a process, you know, where you have to have things done, have to be done on time. I had classes of 30 or 35 college students and working can be hard on my eyes.”

While Linda expressed feeling “annoyed” or “frustrated”, at times, because of these challenges, she also revealed that she had been “nearsighted” since eleven and “had been wearing glasses for almost the entirety of her life” as she said, “I have a different vision, I had my whole life... I feel like my face is naked without glasses. So I want to wear glasses because that's what I've done for 60 years.” As such, the diagnosis of glaucoma didn’t come as a surprise, but rather, she accepted vision loss as a part of herself, and a normal part of aging:

“You know, when you retire, some of the members of our group [SLR] are in their 80s and even 90s. And so some vision loss is pretty normal, as you know. Even if it's not something like glaucoma or macular degeneration, everybody has some hearing loss, vision loss, and it's just the normal aging process.”
In addition, Linda stated that because her vision loss had been progressing slowly, she has had more time to develop adaptation strategies as compared to those who have lost their vision more suddenly. She expressed that she simply took longer to complete tasks:

“So some of that is challenging for me, you know, because like I said, I can’t work at the pace that I used to work. So I have to do things more slowly. I have to be careful. And I don’t see as well as I used to. Even with the best glasses that they give me, I don’t see as well as I used to.”

Linda also mentioned using lighting adjustments and various low-vision aids such as a magnifying glass, speech-to-text software on her computer, and text-enlarging display settings on her iPad to help her accomplish her goals:

“I have some difficulty with, you know, the finer fine things like, to see a thread through a needle or to see the fine print, you know, when you get those little bottles of Advil or something and the print is so tiny because the bottle is so small. Yeah. And so you need a magnifying glass. But those things, you can deal with. Like you can have a magnifying glass. You can have a brighter light. You can be you know, with the technology today on the iPad you can make the print bigger. You do whatever it takes.”

“So I was teaching myself all the different audio devices and using the microphone to dictate things, to write e-mails.”

**Negotiating Her Relationship with Ophthalmologist and Dealing with Vision Care**

Linda was grateful that, to date, her vision loss had only occurred in the left eye, and her overall vision had not been affected to a huge extent. In discussing her journey through vision loss, Linda talked about the relationship she shared with her ophthalmologist and the kinds of vision care services she received from him. Linda explained that she and her ophthalmologist shared an amiable yet impersonal (business-like) relationship as she stated:
“The function of the ophthalmologist is simply the vision, the performance of your eyes. And so, he’s concerned about testing and making sure that the intraocular pressure stays within range. Making sure after that. But no, he has nothing to do with the rest of your life. It’s just the eye, and then the rest of it, you’re on your own.”

She also expressed that she regularly visited him to check up on her eye pressure:

“The ophthalmologist, I see if things are going well, every six months, if things are looking not so good, every three months. After the surgery, it was once a week for six weeks and more frequently, if there’s a problem. So I’ve seen him a great deal and I find him very empathetic and very kind and very good at explaining things.”

Linda added that she was satisfied with the informational support he provided, relating to her vision during her check-ups. For instance, he explained to her, “that glaucoma is like a plumbing problem” with “blockages in the pipeline that prevents the normal sort of self-cleaning process inside the eye.” Linda learned from her ophthalmologist that when her drainage valve “got blocked up,” the build-up of pressure could “damage the retina, and that’s what caused the blindness.”

In addition, Linda’s ophthalmologist offered her with instrumental support, including the prescription of medications (eye drops), laser treatment, and trabeculectomy surgery. Linda explained that she has had two surgeries thus far, one on each eye, and that the most recent surgery was performed in March on her right eye to prevent it from losing vision like her left eye.

**Working to Stay Positive While Facing Uncertainty**

Linda admitted that shortly after her trabeculectomy surgery on the right eye, she felt the full impact of her vision loss as she had to “rely on her bad eye” to navigate around her surroundings, and she “couldn’t see much at all”. Thus, she couldn’t engage in her usual occupations outside of her home such as going to the grocery store, fitness
center, social gatherings at SLR, or the pharmacy. As a result, Linda felt bored and helpless and these sentiments were well illustrated in the following quotes:

“And when I had the surgery, it was very evident because then I was gone. And now with this eye, I only have peripheral vision on the outside. So that made me feel really helpless when I was kind of stuck at home.”

“Well, like I stayed on the sofa that I’m on all the time and listened to audiobooks. Or I listened and turned on the TV, but I couldn’t really see it. But you can hear most of it and you can sort of see some of it. So you can see a little bit of what’s going on, but if you’re watching those news channels or what they run on the TV, the information here and there, you can’t see any of that. I felt very constrained. That’s what I felt, because I couldn’t really navigate much except in my own house.”

During these times when she experienced an acute but abrupt and more significant impairment in her vision, she was reminded of the possibility that her eyesight could get worse, and she was fearful and worried about this uncertain future:

“Luckily, that [severe loss of vision after getting surgery] was only a few days, but it didn’t feel…. It felt scary about what’s going to happen if I started to lose vision in my right eye. So the fear of losing the good eye when the other one isn’t working, it’s that worry that is more debilitating than the actual vision itself. Sleepless nights and not planning for what if I can’t see ever again properly? And so surgery was very, very stressful.”

Linda acknowledged that while her life had its ups and downs, she had developed strategies to cope psychologically with any anxiety she may experience. For instance, Linda focused on the present and tackled things that were within her control, rather than dwelling on the past or the future that were beyond her power:

“Worrying doesn’t solve the problem, so I’ve worked really hard on just focusing more on today and tomorrow, and focusing on the things I do control and not letting the things I can’t control, control me. So, you know, fearing something
that is nebulous and you don't even know what it is, but just... You know, it's not going to help. So, I work hard at focusing on today.”

By doing so, she focused on her personal strengths and capabilities, as well as the positive aspects of her life, rather than the things she did not have:

“When you start feeling low, I have to stop myself and say, you know, ‘What do I have to be grateful for? I have many things to be thankful for.’ And so you start counting your blessings. See, and that's a little practice thing that, you know, at some point I tried writing down, but other times you just stop yourself and say, ‘OK, stop it. You have two beautiful granddaughters. So what if you can't see them right now, you will see them, you know?’ The focus is you have two beautiful granddaughters, not that you can’t see them.”

However, maintaining a positive outlook was not always easy. On days where it became particularly hard to remain positive, Linda distracted herself from her negative emotions by turning her attention to what she termed a, “mindless” occupation, such as reading a mystery novel or watching television shows, which helped her take her mind off the negative thoughts:

“But it's a struggle sometimes to keep that positivity. You have to force yourself. Sometimes, you really have to force yourself. And sometimes you just watch TV and just forget about everything. You know, read a book or get into some crazy suspense murder mystery. Sometimes you just need to escape in your head to turn everything off and do something completely mindless.”

Linda also explained that creating a routine for her life was necessary for her to feel motivated, and she established daily goals. By accomplishing planned tasks, she felt a sense of achievement and felt more in control:

“I try to structure my day in the morning when I wake up and say, you know, try to accomplish something every day. Contact at least one friend or somebody every day. I have my garden that I take care of, and it gives me a sense of achievement.”
Desire to Stay Autonomous

The one aspect of vision loss that Linda feared most was losing her independence, namely her ability to drive. Linda emphasized that driving facilitated her ability to be out in the community, letting her “pick up and go wherever [she] wants to, when [she] wants to”, and thus provided her with a sense of “autonomy”:

“If I lose my vision, and let's say I can no longer drive, that changes how you function, right? Because we’re [Linda and her friends] used to jumping in the car to go to the store, to go anywhere, right? So that would be the first sort of biggest thing [that worries me about losing vision further in the future]. If you lose the ability to drive, which of course, you might do anyways as you get older... But a lot of people are driving in their 80s and 90s and they're doing fine. But if you lose your vision, then you can't do that. That's the thing.”

Linda also expressed that her ability to drive promoted her social inclusion by allowing her to visit with her social networks who often lived a considerable distance away from her, such as her children and grandchildren:

“And like I told you, my thing with the driving is that my son lives in the United States with his family. And my daughter and her family live in [Pont-Rouge]. So until now, I've been able to see them quite often because I drive.”

Maintaining autonomy was an important aspect of Linda’s life, and she preferred to solve problems on her own as indicated when she said, “I myself don't often do that [asking help from others]. You know, I prefer to figure it out myself without causing other people to be impacted.” Thus, she was often hesitant to ask for help from her social networks unless it was necessary such as around the time of her trabeculectomy surgery when her vision was severely impaired:

“Well, I always hesitate, but before, during and after surgeries, I've needed my good friends near me.”
During these times, she was more reliant on her informal social networks, especially her friends rather than her family. Linda explained that she didn’t always have family support available to her as she did not live with, or even close to, her immediate family:

“Around the surgeries, you know, it's pretty much like any surgery, you have someone that would come to help and usually it's, you know, a family member or a close friend. And so because my kids live far away, and I have my mother but she's like way older, so she’s not much of help. She's the one who needs help from me. So I do rely on my friends.”

The Importance of Reciprocity amongst Friendship Network

As Linda further discussed her interactions with her friends, it became clear to me that Linda had cultivated close and warm relationships with her friends and knew the details of each other’s lives. Linda stated that her friends provided her with emotional support by expressing genuine concern for her well-being whenever Linda got new prescriptions for her glasses:

“But my friends who know my vision problems, they've become very solicitous. You know, they'll ask, ‘How is your eye? How are your glasses? How is it doing?’ I have a nice circle of friends that are very caring.”

They also accompanied her while she engaged in various daily occupations such as preparing for meals and getting groceries:

“When I had the eye surgery, both this one and the one three years ago, I had friends that worked with me and walked me like a blind person because I couldn’t see, you know. And they've done a lot in terms of providing me with driving services, and getting my groceries. Even a couple of times, they've cooked some meals for me, because I seemed unable to cope...and they made sure I had everything I needed. So I have some very dear friends.”
Her friends also participated in leisure occupations with Linda, including dining out or watching movies together (not only during the post-surgery period but on an ongoing basis), and thus provided Linda with positive social interaction and support:

“But I have a small circle of friends who I drive with when I can. And we do things together. I mean, like anybody, we go to theatres and dinners and visiting or whatever.”

Although Linda was grateful for her friends, she highlighted that she was not a constant recipient of support. Instead, she also provided her friends with support when they needed it, such as when one of her friends had a colonoscopy, thereby highlighting the importance she placed on reciprocity:

“They’ve [my friends] been very kind and very thoughtful and when they need something, then I'm going to, you know, I help them. When they need to get colonoscopy, I'm going with them, you know. It's that kind of a reciprocal thing, it's not so much that I need and they don't. You know, everybody has something they need.”

Linda explained that her relationships with her friends were sustained based on mutual exchange of resources and social support that equally benefitted all of them.

**Expecting Different Responses towards Vision Loss from Younger versus Older Members of Social Networks**

As my conversations with Linda deepened, her narrative began to demonstrate that she felt a greater sense of belonging among her age-peers and those with vision loss who shared similar experiences with her, rather than among younger people. For instance, when she interacted with her age peers, she automatically felt accepted because everyone had their own health challenges and as such, were generally more understanding of others’ needs:

“Like I said, because it's a peer-learning group that I'm largely involved with, everybody has their own different shortcomings. And so I find that being in that
organization, that is all senior people, that there is a lot of understanding and a lot of patience with people needing that extra time or the extra help or not being able to see something on the board.”

Linda indicated that she didn’t feel out of place when she spoke up about her own needs as someone with vision loss while engaging with older members of her social network such as her colleagues in SLR, and it was easier for her to ask for help from her peers who she felt a personal connection to:

“Those people [her colleagues in SLR] that know me better and know about my vision loss are pretty supportive about making sure that, for example, when we have some meetings [in SLR], I need to take a break after an hour because I just can't keep looking at the screen that long. And I'm not the only one. As you guys get older, you know, it's a common problem. So I guess what I can say is that if I say to someone, 'I have a problem seeing this. Could we have a larger print? Or could we, you know, move up closer or something like that?' That's never been a problem. It's always been easy to do.”

On the other hand, she stated that “in a situation when [she] was dealing with young people, there wasn’t that kind of patience for someone who needed more time and couldn’t see as well as most”. For instance, when she received support from younger people, such as her children, her problems were not always taken seriously, and she often had to justify or explain her actions and emotions, and even so, she was sometimes not understood:

‘From my own kids, when I try to tell them that, you know, I’m having this surgery and I might not be able to see well enough to drive after that, and then I’m really worried about that, my son's typical response is, ‘Oh, don’t worry, mom. You'll be fine.’ You know, that kind of glibness is perhaps his way of trying to make me feel better. But it's not helping really, you know. […] You know, as you get older, you experience more and more difficulties, sometimes serious challenges, and so you’re much more likely to understand someone when they
say, ‘Oh, you know, I just can't do it today.’ But a young person will say, 'Come on mom, you can do it. Why are you sitting around?’”

However, rather than feeling frustrated or blaming the younger members of her social networks for not providing the support she needed, she accepted that they intended to mean well and tried to understand their position by considering why they would offer such a response.

“'It's not frustrating, it's just, 'Oh, well, they're young, they don't know.' You know, other people might feel differently, but I try to be very patient. And, you know, when you're dealing with your own family and your own close friends, I mean, you love these people. You don't blame them for what they think or how they don't understand what you're saying. If you can, you try to explain. And if you can't explain, you just let it go. There's stuff like you have to learn to let things go.”

Linda thought that younger adults without vision loss, including the students whom she taught at the Thames Valley District School Board, lived a different kind of lifestyle compared to older adults with vision loss. For instance, Linda believed that her students were “usually not used to dealing with chronic health conditions” such as “high blood pressure”, “arthritis”, and impairment in “vision” or “hearing”. Linda also mentioned that older adults were more likely to be socially isolated than younger people because they often lacked on-going social commitments that would provide them with opportunities for social connection. In contrast, Linda believed younger populations (i.e., Linda’s past students, younger friends who aren’t retired yet, and children) were still dealing with concurrent social roles (i.e., being a parent, spouse, student, worker, etc.) and were obligated to fulfill the duties of each role:

“'But for younger people like yourself, you're not as isolated on the whole. I mean, not everybody, of course. Some people are. But typically you're still dealing with a work situation or a school situation. So you're interacting with classmates, with teachers, with co-workers, with you know... And so my younger friends who are still working, are still busy doing what they do. Even if they're
doing it from home, they're still doing it. You know, and interacting with other people. And they're busy. Like my kids with their little children are busy because they have to take care of the kids and have to do what they would normally do. So they're you know, their family situation is different.”

Linda alluded to the fact that having multiple roles made younger adults busier because they had more demands on their time. Therefore, Linda found it "understandable" that younger adults were less patient or less understanding of the needs of an older person with ARVL who worked at a slower pace because they were dealing with different experiences relating to old age or disability.

**Disruptions in Occupational Engagement and Social Interactions during COVID-19**

Linda conveyed that COVID-19 had directly, and rather significantly, impacted her occupational engagement and social interactions. Many of her occupations were delayed or cancelled because the public facilities (i.e., hospital, optometrist’s office, fitness center, and school board) providing the services she needed for her desired occupations (i.e., getting surgery on her eye, ordering a new prescription of glasses, exercising, and teaching) were closed during COVID-19:

“So there's no going out to meetings. There's no going out to courses, there's no Aqua-Fit, there's no gym, there's no social events. You know, we used to have social events. I used to do volunteer teaching with the Thames Valley School Board. None of that's happening. [...] Also, everything started shutting down the week before my surgery was scheduled. And you can't even get a new prescription because the optometrists are all closed.”

Linda also felt that her in-person interactions with her social networks were being substituted with meetings on online social platforms. For instance, Linda mentioned how the workshops and group discussions that used to be held in-person at SLR were replaced with online courses:

“And of course, during the COVID, we've [SLR] had to shut down. So since March, we haven't been able to do any of that [running peer learning-based
courses with groups of 20 people]. But we've started having zoom meetings and we're preparing to launch all of our forces in the fall via zoom.”

Linda also talked about how her Scrabble tournaments were now being conducted online which she found to be more “difficult” than playing in-person because it was “hard” for her “to play for two hours or three hours [of Scrabble game] on the screen”:

“And it's [playing Scrabble games] a pastime that’s a lot of fun and that's also been canceled for the last three months. So it's forced us to play online games, right? So the Montreal Scrabble club that I used to play with and on the London Scrabble Club, we're all playing online instead of going to the meeting where we usually would play each other in-person.”

Although Linda was grateful that online technology enabled her to stay connected with her social networks, she was unsatisfied with such a restricted method of social interaction. She realized how important physical connection was for her as she talked about how much she preferred in-person interactions over communicating via Zoom:

“It's a very different kind of communication when you're actually in-person than when you're looking at, you know, at a screen like this. And a lot of my friends have mentioned that too. You notice it. It's [communicating over Zoom] better than nothing, but after a while, you still miss that person like you want to touch that person. [...] You have to get past the screen to really have contact with someone, because you can’t touch them and you can’t be with them.”

Linda mentioned that “essentially until this virus pandemic gets resolved and we can renew or do something like we used to do before, perhaps in a different way, I’m still not getting out and about.” She expressed that all of the disruptions that occurred in her social occupations (i.e., not being able to hang out with her friends and visit her family freely) left her feeling lost, bored, lonely, and sad:
“There are moments when I still feel somewhat isolated, even though we are getting together maybe once a week with a friend. And, you know, we did some takeout food last week. And then when the restaurant patios opened, we went out for lunch on one patio. But, you know, you go once a week somewhere... That's not what I'm used to. And so, yeah, there are moments when you sit here and you go, ‘Okay, what am I going to do?’ [...] And like my little two year old granddaughter, she wants a kiss from me and she tries to kiss the iPad [when we chat over Zoom], and so it just makes your heart ache [that you can’t visit them].”

Linda added that her social networks were essential for the enrichment of her quality of life, and discussed how her desire to stay socially connected increased during COVID-19, and the inability to do so made her feel further socially isolated:

“I miss... I miss my people. It's hard because people are not really connecting right now. Especially a lot of the older people are not as connected with this thing [COVID-19] and everything else. So they're more isolated.”

Unfortunately, Linda conveyed that as an older person living with a chronic condition, such as vision impairment, she felt especially vulnerable to the impacts of COVID-19. Due to this fear of becoming infected with the virus, she self-isolated herself away from her close social networks:

“But you know, where I am and where a lot of my friends and people of my age and older are, even if you have the grandkids close by, during this COVID, you're not able to interact with them. Because you never know that they might be carrying that virus and you don’t want to be in that position, you know. So some of my friends felt isolated from their grandkids, even if they live around the block because they can't be with them, for fear of getting the virus.”

Furthermore, Linda compared herself to other older adults with ARVL and described how she was reminded that vision loss in older adults could interfere with their ability to use online technology, which was being heavily relied upon during COVID-19
to connect with one’s social networks. Linda mentioned how comparing herself with others supported her while she adapted to her new reality during COVID-19 crisis (lockdown) as it made her feel grateful that she still had the visual capacity to participate online. At the same time, she felt that social isolation was exacerbated for those with a more significant vision loss than herself, and that older adults with ARVL could be dealing with the double burden of COVID-19:

“But at that situation, we all have been relying on technology, so whether it's the simple phone or this kind of a Zoom thing. All of my friends that I know are Zooming or face-timing in with their friends and their family. So there is the vision thing that comes into play, if you don't have the visual capacity, then you're kind of locked out of even that technology. I'm not there yet and I’m thankful for that, but I can see where it's possible that in the future I could be really in trouble even with that.”

4.2. Brendell’s Story

Brendell is a 91-year-old widowed woman living on her own who has had macular degeneration for over 20 years. She is a mother to one daughter who is 65 years old. Her daughter lives out of the province, and Brendell visits her annually. Brendell also shares a close relationship with Mary, whom she met and took care of during the time she worked as a social worker, and now calls her step-daughter. Brendell has been volunteering with Society for Learning in Retirement (SLR) for over two decades, and it was through SLR that I was able to reach out to her to participate in my research. Brendell and I held all of our interviews over telephone because Brendell’s computer (needed for Zoom meetings) was not working when we first connected to discuss the study. From our short conversation prior to the first interview, Brendell presented as a strong-willed, independent, and decisive woman.

The Cumulative Impact of Ageing and Chronic Conditions on Occupational Engagement
Brendell recalled that when she was first diagnosed with macular degeneration, she decided to participate in a research study focused on developing a “chemical that would stop macular degeneration”. After receiving treatment, she noticed that her vision slowly improved:

“I was part of the study group, and they did my left eye, and it’s perfect. And then I didn’t have much vision in my right eye. But now I’m getting the vision back in my right eye. And I don’t know why... I can’t read yet with my right eye, but I can see all around, and you know, my side vision, peripheral vision, everything with it.”

Brendell expressed how she was confused yet content with the improvement in her vision and said, “I hope that my eyes continue and you know, I hope I never need them [additional assistive technologies for low vision].” As Brendell continued to share her thoughts on her visual impairment, at times she framed it as relatively unobtrusive, perhaps because of intersecting effects of other chronic conditions in her life:

“Honestly, I don’t think about my eyes at all. You know, I could... It’s just a part of me. I just don’t think about it. I’m so glad that I don’t have to. I can’t think of anything, you know, of times that I’ve not done something because of my eyes.”

At the same time, Brendell did indicate that she still has to regulate how she engages in a few areas of her daily occupations due to her vision, such as in driving and using computers. For instance, she expressed how she used glasses with trifocal lenses when working on monitors:

“I need trifocals because I need the center one for when I’m on the computer. When I’m on the computers, it’s the middle range that I use and it makes it so much easier to work. You know, like the reading range was too sharp before. And now I’ve got a clear picture on my computer. It’s very much better.”

She also only drove during the daytime, avoiding nighttime driving altogether:
“I find the new cars with the white headlights, like they blind me. I just don't see well. You know, there's some new cars. The headlights are very, very white. And I don't want to have an accident.”

However, her occupational engagement was more so interrupted by her other chronic health conditions, such as her arthritis, flesh-eating disease on the hip, and knee pain rather than her vision loss. For instance, regarding her knee pain, she explained, “Something was done to fix it nine years ago, and it never worked… But it’s really, really painful.” She then noted that the pain in her knees made her heavily reliant on her walker:

“Now, I use a walker more than before. You know, like I have a walker, and I use it all the time. I can walk a few, maybe ten paces without it, but that’s about the limit now with my knee. So it’s no good trying. Because if I fell over, I’d be in trouble. So I just don’t try.”

Brendell added that her restricted ability to walk interfered with her community mobility, such as when she went out shopping:

“I haven't been able to walk since, not properly. I'm wondering now... the big thing is shopping. I'm going shopping tomorrow morning and I'm just wondering if I'll be alright doing that.”

Brendell also expressed how her arthritis interfered with some of her leisure occupations, such as knitting and sewing:

“I used to do a lot of knitting and sewing, but my hands have arthritis and I can’t do that anymore.”

In addition, her arthritis caused her to stop participating in sports that involved holding onto a racket, or other sports equipment, with her hands:

“I can’t hit a tennis racket anymore. It’s just too painful. I’ve got terrible arthritis in my hands and I just can’t function.”
Despite not being able to participate in sports personally, Brendell expressed how she “still loved sports” and found different ways to “get involved in sports” by watching professional games on her television.

Brendell noted that many of her health conditions were on-going as she said, “I got this flesh-eating disease in my hip, and I had to have it scraped out and everything. And I’m still on penicillin all this time later… And that’s been three years now. So I may be on it for the rest of my life.” Due to the chronic nature of her other illnesses, her occupational engagement was not solely affected by her vision loss. As a result, Brendell was more aware of the cumulative impact of her conditions, rather than the impact of vision loss alone.

**Maintaining Positivity and Finding Joy in Daily Life during COVID-19**

When I asked Brendell whether she has experienced any changes in her interactions with her social networks since being diagnosed with macular degeneration, she responded that while her social interactions have changed recently, it wasn’t due to her vision, but rather, COVID-19. Brendell explained that she was “very strict about self-isolating” and interacted less frequently with the people she used to meet daily, such as the members of SLR whom she volunteers together with:

“I’m not going to the office [at SLR] where I would meet people [fellow volunteer members]. When I was in the office, people would drop in. But I’ve not been to the office since COVID started.”

She also interacted with fewer individuals in-person and only met up sparingly with a few of her close social network members, such as her step-daughter, granddaughter, and neighbour, in which she strictly abided to the two-meter physical distancing regulations:

“Oh, and like my granddaughter, who is a policewoman, now she is coming tomorrow morning. But I’ll make her stay well away. I don’t want to get this thing.”
Brendell added that she was “very annoyed at the moment” that many of her occupations involving social interactions with others (i.e., receiving healthcare services and visiting family members) had been delayed due to COVID-19. For instance, regarding her doctor’s appointment, Brendell mentioned that she “was booked for August the 4th [for treatment of the flesh-eating disease on her hip] and suddenly they've backed it up to October the 4th.” In regards to her family visits, she said, “I have been going every Christmas to Vancouver [to see my daughter’s family], but I'm not going this year because of the COVID. I don't think the planes are going to be ready to, you know, to feel safe. So I'm not going this year.” Brendell further illustrated how her plan to go to the hair-salon was delayed by months:

“When they first put the ban on travelling in March. The very next day, I was supposed to be getting my hair cut. So it was about March the twenty third and my hair hadn't been cut and it was looking dreadful. It was down my back. And I went for a haircut today and they just opened. I was their first customer. This was quite a thrill.”

Overall, Brendell noted that she spent an increased amount of time staying at home, and her community mobility had become very restricted since COVID-19. For instance, during COVID-19, Brendell used her car so infrequently that she had “not even used a tank of gas since the middle of March.” Brendell reckoned, that perhaps, what had changed the most about her community mobility since COVID-19 was that she planned ahead of time whenever she was going outside, whether for shopping or going to the bank to manage her finances thereby eliminating all spontaneity from her life:

“I go to Metro once a week at 7:15 in the morning to get my groceries. That was this morning, Friday. And once a month, I go to the bank because I like to pay in cash. I'm an old fashioned buddy and that's the only time I go out.”

The reduced community mobility in Brendell’s life, in turn, increased the amount of time she spent being alone. However, rather than getting “upset or bored” by this change in her routine, she maintained her composure. She has maintained a positive outlook by looking at it as having more time to enjoy leisure activities (i.e., playing
games on the computer, doing puzzles, and watching television). For instance, she stated that she had hardly ever “watched TV before COVID” but now that she had more “time to spend” in front of her television, she was able to watch the sports games that she enjoyed:

“Well, actually, it’s been quite fun because I’m a big sports fan, I think I told you. And on the sports programs, they’d been playing all the old baseball games, old tennis and curling and hockey. So I’ve been able to watch decent games. So that really makes me feel good.”

As I chatted with Brendell, her playful personality stood out to me as she expressed her appreciation of humour:

“Well, the funniest thing with them [socials held at SLR] is, twice a year, I’m telling jokes at the luncheons. I’m famous for my jokes, and that’s the big thing.”

“Actually it’s hilarious because she’s [Brendell’s daughter] now a senior citizen. So I’ve got a daughter who’s the senior citizen, which makes me roll laughing, I’m always teasing her about that.”

Her positivity was contagious and I laughed alongside Brendell several times as she told me about various ways she found joy in the more mundane things in her life:

“You know, I love the sunshine. I love the snow. You know... And I don’t care for the rain much, but it is there. And I have always had a dog, but my dog died and I can’t manage a dog anymore because I walk with a walker and I couldn’t pick the poop up, or walk him far enough. So I do miss my dog. But... I know it sounds strange, but I’m sure he’s still in my apartment somewhere because when I come in, I never feel alone. You know, I never feel lonely. That’s a good thing. And I think I’m lucky. I’m just talking and I’m thinking how lucky I am.”

She was especially grateful that she was still capable of doing things she wanted the way she wanted at her age as she said, “Well, when you’re 90, and on the 19th of July, I’ll be 91, every day is a bonus because, you know, like a lot of people are dead and
I’m not. I’m still going strong. And so that makes me happy. You know, I wake up, and I’m still here, good.”

Building Relationships Based in Reciprocity with Social Networks: Taking on the Role of Being a Helper to Other People and Receiving Forms of Support One Needs in Return

Throughout the interviews, I noticed that Brendell had a strong passion for helping others. Brendell explained that before her retirement, she worked “for the welfare department in London” and said, “I was, believe it or not, the teaching homemaker of the city of London. It took quite a while, and it was my job to teach people how to manage their money.” During her work as a social worker, she met Mary, who was a “little child” at the time, and her mother, whom Brendell thought “was a complete dipstick and just ridiculous.” Brendell went once a week to meet Mary and “dealt with her mother” until Mary became 14. When Mary turned 14, she “went back to live with her father,” which Brendell said was “even worse because he [Mary’s father] was a Dutchman who had no idea how to bring children up.” Brendell decided that she wanted to be involved with Mary even after her work as a social worker ended, and continued to watch over her growth by sharing a house with Mary and her father. Brendell said that she has “been friends ever since” with Mary, and added, “She [Mary] calls me Nana. I think she thinks I’m a grandma sort of thing”. Brendell concluded that even though Mary was not technically her stepdaughter, she thought of her as such and shared a very close relationship with Mary. Currently, Brendell was no longer living together with Mary. However, she still visited Mary once a week to have lunch together with her family as Mary lived close to Brendell’s neighbourhood:

I see her [Mary] once a week usually, or I’ll call back once a week. She has three children. I’ve seen them grow up and her husband is a delightful person. So it's a happy family. Well, you know, that’s why I go. Because it’s happy. She’s a lousy cook, but anyways, she’s happy. It's kind of hilarious because they always bring the dessert, and sometimes lunch is a grilled cheese sandwich, and I’m
thinking, ‘My God, that was an expensive blue cheese sandwich’, but I never said anything.’”

In addition to helping Mary cope with her challenging childhood, Brendell also provided emotional support to her daughter, Lisa. For instance, Brendell regularly checked up on Lisa by “talking to her every day on the phone” and provided a safe space for her daughter to take refuge from stressful situations in her life psychologically. Brendell explained that Lisa “had a rather bad life” and that she used to suffer from domestic abuse from her ex-husband:

“She had three children by him. And eventually... He was a terrible man. He was. He didn't know the truth if he stood on it. And eventually, she got rid of him. And then for some strange reason, she married this other guy who wasn't abusive physically but verbally. And she had a child by him and that’s finished.”

Brendell said that Lisa confided in her with anything, trusting her to “not repeat it to anybody.” Brendell emphasized how important the contact with her daughter was to her and believed that this contact was equally important to her daughter as well. The reciprocal appreciation of each other’s company was well illustrated in the following quote:

“We [Brendell and Lisa] just talk about anything. She tells me about her kids and I tell her about what I've been up to. It's just as if we're talking like you and I are talking and sometimes we talk for over an hour. You know, and that’s an important part of my days, that phone call. And I think it's an important part of her day, because she's always there. Like I don't need her counseling. Let's put it that way. Sometimes I have to counsel her when she's got a problem. But I just look forward to the interaction. It's very important to me. Oh, and she always says, ‘mama, I don't know what I'd do without you’. And that makes me feel good.”
Brendell revealed that communicating with her daughter over phone calls was a method of re-affirming that her daughter was doing alright:

“*If I didn't talk to her, I'd be worrying all the time and making things in my mind that aren't happening. This way, she tells me what's happening and I don't have to worry. I know she's doing all right.*”

Brendell explained that Lisa was “on a disability” and that she was “in a lot of pain all the time because she has arthritis really badly”. The phone calls allowed Brendell to correctly assess Lisa’s needs and enabled her to support her daughter during situations when she was not doing so well. For instance, Brendell supported her daughter financially as Lisa had “very little income”:

“I love my daughter and I want to know what she is up to. You know, like if she's got... I’m very good at finding out if she's got financial difficulties because sometimes something happens and she doesn't tell me. And I find out, you know, I wiggle it out of her and I'll send a bit more money. You see, I send every month... I send her three hundred and fifty dollars towards the rent money. I can afford it and it's no big deal. Other than that, she couldn't stay where she was and she's got a nice apartment. And then, to get a bike gift, I gave her 500 bucks towards it. So, you know, I can help her that way, but she doesn't ask for it. You know, she never asked for money. But, you know, I always give her a good birthday present and good Christmas presents. Just... I’m her mom, and I have the money and I just let her have it. She might as well have it whilst I’m alive, and not when I'm dead. So, you know, I'm happy that I'm able to help her.”

Apart from her daughter and step-daughter, Brendell also regularly interacted with her neighbor, Helen. When Brendell had flesh-eating disease on her hip, Helen provided Brendell with instrumental support by coming to help her with various IADLs such as cleaning and maintaining the house, as well as shopping for groceries immediately after Brendell was discharged from hospital:
“When I first had my hip done, she was absolutely marvelous. You know, she did everything that I needed when I came home... She [Helen] and another lady I know had cleaned my whole apartment, including shampooing my rug. And she went shopping for me a couple of times and just kept her eyes on me.”

Brendell added that to this day, Helen continues to visit her daily. Although Helen does not do any housework now, she provided Brendell with on-going support for occupations involving technology that she was unfamiliar with, such as setting up Zoom meetings and repairing her sewing machine:

“She's [Helen] very good with computers and mechanical things. And, you know, she's a wonder lady... She set it [ZOOM] all up for me and showed me what to do. You know, I don't know what I would have done if I hadn't had her. She was marvelous. She's very good like that with technical things. And she set the whole program up for me. And I was quite surprised how much fun ZOOM is.”

“When I was in England, married, I did a lot of sewing and I bought a sewing machine, an electric one, and I brought it over [to Canada] and had it converted to this hydro and it broke. At that time, I wasn’t really sewing much so I didn't bother, but she [Helen] took it and she repaired it. She took it all apart and repaired it. Don’t ask me how, but she did.”

However, Brendell made sure to indicate that she never forced Helen to help her with anything, nor did she receive one-sided help from Helen. Brendell explained that whenever Helen visited her, she would listen to Helen talk about “everything she’s done all day”. In doing so, she played the role of a confidant to Helen; someone that Helen could trust to talk about her worries and things that have been bothering her. Brendell believed that Helen voluntarily visited her to seek her company and found their conversations both therapeutic and enjoyable:

“She [Helen] must enjoy it [visiting Brendell] because she doesn't have to come. She knows that, you know, like she comes because she wants to. I think it's therapeutic for her [Helen] as well, because when she comes, I hear everything
she's done all day. You know, like a full resume of what she's done all day. So I'm sure it's helpful for her as well as me.”

Brendell admitted that it was important to her to be able to mutually exchange support with her social networks and “not feel like a charity case”. Thus, Brendell tried to give back the support she received from Helen by sharing goods like groceries with Helen:

“What I try to do is, if I go to the grocery store, I’ll buy like two cauliflowers instead of one and give her [Henny] one. Pretend they were on sale or whatever. So at least I’m giving her something.”

Noticing that Brendell had often taken on the role of a helper who supported others’ lives throughout her entire life, I asked Brendell whether she felt that being a helper enriched her quality of life. To my question, Brendell responded, “Yeah, definitely mine, because it makes me feel glad that I’m alive. You know, if I didn’t have that sort of thing, I think I’d die because I’ll be feeling useless.” She further explained that helping others provided “purpose” in her life and also expressed that wanting to help others was a part of her “identity that has always been there” and a quality that “just sort of passed on” from having worked as a social worker. Brendell thus viewed and portrayed herself as a helper and within the relationships she formed with those she helped, she was also able to receive reciprocal emotional and instrumental support that she needed.

Maintaining Independence to Stay Active and Create Structure in Life

As Brendell discussed how she interacted with her social networks and how they influenced her daily occupations, she noted that she desired independence in her life. She expressed that independence provided her with purpose and motivation to continue living, as demonstrated when she said, “Well, I think if I start giving up on things, my main reason for living is going. As long as I can go shopping and do things, then I don’t think about dying. I think if I couldn’t do it, I’d think, ‘why am I alive, it’s not worth it’”. Brendell also said that she structured her life around daily routines. For instance, she had her “breakfast at about eight o’clock” and then did crossword puzzles afterward. She also
did “20 minute exercises in the morning.” Brendell added that before COVID-19, when she was volunteer-working with SLR, she would be “there at 9 o’clock and stayed till about 12:00”, and said, “I’d be doing morning’s work, or I’d be in a class, you know.” Brendell further expressed that setting these routines kept her psychologically and physically occupied, which she revealed was something she desired and needed in her life to not feel “bored”:

“Well, if I didn't do them [daily routines], I don't know, I think it would be a terrible day. You know, I can't imagine just sitting doing nothing. I never do that. I'm always, you know, sort of watching or reading or, you know, like walking... Well, I do more puzzles and things now because I'm not walking. So I've got to do.... I just don't sit and do nothing. I do some old puzzle. I love puzzles and things because I think it’s keeping my brain going. You know, this is a sort of peculiar time because normally, I wouldn't be home. I’d be in the office doing stuff. So if you're home all day, you have to find things to do.”

**Negotiating between Her Desire for Independence and Accepting Help from Others**

While expressing her wish to remain independent, Brendell described how she actively managed to balance between achieving autonomy she desires and receiving social support from her social networks. Brendell was reluctant to ask for help from her social networks and called herself “a very stubborn old person” several times as she recounted how she prepared her own meals even when she had flesh eating disease on her hip:

“I did my own cooking and stuff, but I'd arranged before I went in to have frozen dinners in my freezer so that it was just a case of warming them up. I knew that if I needed anything, she [Helen] would do it, but I tried not to do so.”

Brendell said that the reason why she preferred not to ask for help from others wasn’t because she feared what her social networks would think of her if she asked for help, but rather, being independent was simply a “matter of pride” for her. She expressed
that even though her knees were hurting badly, and it was difficult to walk long distances, she still planned on going shopping for her groceries by herself:

“That's going to do it [get groceries] somehow. I went to get my haircut this morning and I went to Shoppers and I was able to stagger around Shoppers to get the stuff I needed. So, Metro's not much bigger.”

Brendell also mentioned that some of her younger social network members such as her granddaughter, Trisha, was very much willing to help Brendell. However, she also explained that Trisha was not always readily nearby or was too busy, given that she had a job and her own family to take care of:

“I have one granddaughter here who's... She lives in Stratford and she is a city of London police woman. She and I have a very good relationship. But she has three children and she doesn't have a lot of time. So we don't talk a lot. But if I needed anything, she'd come. You know, if I was stuck, she would come.”

While Brendell would much rather take matters into her own hands, she also admitted that “I wouldn’t hesitate to ask for help if I needed it.” In particular, Brendell was willing to seek help when she was using new technology that she wasn’t familiar with:

“I have to ask for help with anyone when I can't deal with my computer, you know, like if it's something new and I don't know how.”

Another area where Brendell was willing to ask for help was related to accessing public transportation to be able to move around within the community. For instance, when I asked Brendell whether she envisioned herself using vision supports such as CNIB in the future, she replied:

“If I needed them, I wouldn't hesitate to use them. You know, it's just that I don't know... I hope I never need them. I hope that my eyes continue and you know, if I can't walk so far, or I can't drive anymore, I would definitely use the transits they provide. You know, there’s different transit groups that provide rides. I would
definitely use them. I wouldn't be too proud to use them, but I wouldn't tell Helen, only because she'd be mad that I don't get her doing it. So I noticed quite a few people in this apartment building use them. I forget what it's called now, but it seems like a club that does transport for people.”

Brendell then indicated that being able to drive and use technology facilitated her ability to work in SLR:

“If I couldn’t drive there, I’d have to resign. And that would be a problem. And it wouldn’t be nice anyway. I wouldn't say it would be a problem, but it wouldn't be nice.”

This revelation was interesting to me because Brendell previously indicated that being a member of SLR was associated with her desire to help others. Brendell, therefore, demonstrated that she was willing to seek help with things that would help her structure her life, provide purpose, and enrich her quality of life.

4.3. Jenny’s Story

Jenny is a 67-year old woman who has had glaucoma for ten years. She is currently living with her husband and her father. Jenny is the caregiver for her 96-year old father who has a severe vision impairment due to cataracts. She is also a mother to two adult daughters, one who is living in another Canadian province, and another living in Australia. Both of Jenny’s daughters have glaucoma. Jenny connects regularly with her daughters via phone or social media. At the time of the study, Jenny was not visiting her daughters due to COVID-19, but prior to COVID-19, her daughters visited Jenny annually.

Jenny was the first participant I recruited from the Canadian National Institute for the Blind (CNIB), and we held all of our interviews over the telephone. Throughout our conversations, Jenny spoke with warmth and compassion, and her family-oriented personality stood out to me, as she spoke proudly and fondly of her family members.

Modifying how desired occupations are carried out over time
Jenny indicated that although her vision impairment has progressed rather slowly and gradually, she noted that her vision loss has gotten significantly worse over the last couple of years. Consequently, she has been noticing more disruptions to her leisure activities (i.e., reading and watching television), physical activities (i.e., walking), and instrumental activities of daily living (IADLs; i.e., finding lost items). For example, Jenny mentioned how she currently experienced more significant difficulties with reading and watching television for a prolonged time as she felt “more strain on [her] eyes.” As such, Jenny now took more frequent breaks in between these activities and took a longer time to complete them. In addition, at the time of the study, Jenny was watching television shows and movies on her computer instead of watching them on the television because it allowed her to watch them at a closer distance and made it easier for her to take in facial expressions, physical actions, scene changes and settings that are occurring on the screen:

“I’m more now using a computer for Netflix or things like that, instead of watching the TV because it’s easier that way, I can see them closer up.”

Moreover, Jenny spoke of placing specific items back to their designated spots after use as this was a helpful strategy that prevented her from losing her possessions and decreased the amount of time she spent looking for lost items:

“I drop a lot of things. I think my peripheral vision is not as good as it was before, and I’ve got to put things on the table or other specific places, or they just drop, and I lose things.”

In regards to walking, Jenny said, “it’s a little trickier to see where I’m walking,” and “whenever there is a step up or step down, it’s hard to gauge where it is, especially if it is in the same color.” Some of the strategies Jenny now used to overcome these barriers while walking was to put coloured tape on her stairs to differentiate them from the floor or pavement. Jenny also talked about holding onto the handrails while going up and down the stairs, especially in public spaces, as those stairs did not generally have coloured tape:

“Well, we [Jenny and her husband] put red tapes on the edge of our porch and the garage. We go to our garage, and there’re these two steps in the garage. And yeah, I experience the same challenges everywhere. So I just go slowly, take it carefully, and I try to hold on to things when going up or down.”
Incorporating Low-Vision Assistive Technology and Relying on her Husband to Overcome Challenges in Maintaining Valued Occupations

Continuing our conversation about the transitions in her occupational engagement, Jenny mentioned how for some of her leisure activities (i.e., doing puzzles, traveling, and camping), physical activities (i.e., biking), and IADLs (i.e., driving, shopping, and preparing meals), she relied on low-vision assistive technology and her husband to maintain her engagement instead of directly modifying how she carried out those occupations. At the time of the study, Jenny was using low-vision aids such as a magnifier while doing her puzzles as it made it much easier for her to read the words or see the pictures on the puzzles, and thereby expedited the time it took to find the matching pieces:

“I like doing puzzles too, and that’s also trickier when I can’t see what’s on it. So sometimes, I use the magnifier and it allows me to finish faster.”

Jenny also spoke of using her magnifier to help with IADLs, such as preparing meals. For instance, Jenny found it challenging to read recipes without holding them close to her face, and she often used a magnifier to enlarge the print of the recipes while preparing meals for her family.

“I’ve always been the primary cook in this house, and I still am. Of course, with my current vision, when you’re reading recipes, that’s a little trickier, but I just hold the instructions more closely, or again, use my magnifier.”

Jenny also mentioned that it was difficult for her to read street signs, and she now relied more on her husband to read the signs for her while walking. In addition to walking, Jenny mentioned how she does most of her activities with her husband, saying, “we’re with each other like 95 percent of the time”. For example, Jenny stated that her favourite pastime activity is camping with her husband, and mentioned how she would often “go all around Ontario” in her recreational vehicle. Sometimes, she would also go camping in larger social groups, including not only her husband, but also her father, friends, and her friends’ husbands:
“We’ve been camping, like I said, I started camping when I was to 2, but my husband and I’ve been camping for 20 years together. And we really enjoy it, that’s what we enjoy the most. So when my other friends go with us, it’s really fun. And a lot of times, we go with their husbands and my husband and my dad.”

Jenny said that she goes driving, biking, and grocery shopping with her husband. Regarding driving, Jenny mentioned that losing her peripheral vision made her field of view very narrow, and she hardly ever drives by herself anymore because she does not feel safe to do so. She only self-drives to places that are close to her house (i.e., nail salon) and pays extra attention to her surroundings while self-driving to ensure that she is safe:

“Well, if things or places are close, like my nail place where I get my nails done is just around the corner, so it’s ok for me to drive there. I’m just extra careful [when I’m driving by myself]. I look a little bit longer both ways where you take turns and things like that.”

At the time of the study, Jenny was relying on her husband and friends to drive her to destinations that were farther away from her house:

“For places that are farther away, my husband drives me. Well, both of them, my husband drives the most, and my girlfriends do too sometimes. Having my husband drive me around is pretty new to me because he didn’t do that until the last few years where my vision really got worse. So I’m spending more time with him now because he’s been giving me rides to everywhere I need to go.”

In regards to biking, when I asked Jenny how she maneuvered her bike with impairments in her peripheral vision, she replied, “I don’t go too fast. I slow down, and I follow my husband, like he goes ahead of me, and I follow him.” She then added that by allowing her husband to take the lead, she could overcome difficulties in finding routes and avoiding obstacles while biking. Despite these precautions, however, Jenny noted that she still got into an accident where she “fell off of [her] bike a couple of years ago when [she] misread a curb and received seven stitches above [her] eye.” Finally, Jenny’s vision made it more challenging for her to find items that she wanted to purchase while grocery shopping, and she now relied on her husband and staff at the grocery stores to help her with finding items:
‘I need help from my husband because I can’t read the signs. You know, the big signs in the middle? I can’t read those unless I read those right underneath them. Yeah, like the signs for where they indicate where things are. Of course, it’s harder to find the things you are looking for too. My husband helps with finding the items as well. Actually, he asks. He doesn’t look, he asks. Yeah. So we did use help from the staff.’

Jenny noted that she had always spent a lot of time with her husband, even before losing her vision. For instance, her husband often accompanied Jenny in occupations such as camping, biking, and grocery shopping, even before she was diagnosed with glaucoma. Thus, throughout the progression of her vision loss, the amount of time she spent with her husband did not change drastically, but she received more social support from her husband during these interactions to engage in her desired occupations:

‘I mean, for me, spending a lot of time with my husband is nothing new, like even before my vision went bad, I had always gone camping and biking together with him. He tagged along when I went grocery shopping too, so we were always close to each other. But of course, now, when he’s with me, he helps me with more things, like the things that are harder for me to do because of my vision. So what’s changed in our relationship [throughout Jenny’s journey through vision loss] has more to do with what he does for me when he’s with me. He helps me find grocery items and entirely takes care of setting up the campsite when we’re out camping, whereas before I lost my vision, I didn’t need help with those things.’

The Importance of Reciprocity in Social Relationships: Accepting Help from Others while Maintaining Independence

Noticing how Jenny relied on her husband and friends to engage in some of her desired occupations, I asked Jenny how she felt about asking for help from her social networks, to which she replied, “I don’t like it.” In particular, Jenny talked about how she sometimes felt apologetic when she had to rely on her friends to drive her as she stated, “It used to be, my girlfriends and I usually take turns [driving one another], right? But now, she’s [Jenny’s friends] got to take all the turns, so I kind of feel bad.” Jenny then added that she much preferred the time when she could drive by herself because she
could visit the places she wants to at her own pace without having to wait, and emphasized that “it’s all about maintaining independence.” Realizing how Jenny desired to remain autonomous, I asked her how she balanced between her desire for autonomy and accepting help from her social networks. Jenny pondered for a while before answering that she did not mind asking for help or receiving support when she truly needed it (i.e., driving to distant destinations). However, she still preferred to handle things herself for those occupations that she could perform independently. For instance, Jenny shared how she was a caregiver for her father, and she provided him with instrumental support by preparing his meals, making his bed, and writing down important messages in large fonts on a White Board for her father to read:

“Well, since my father’s 96, what I do for him is, I get up and make his meal, and then he lies down, and he goes to bed. And he wakes up at lunch, and I feed him again. And then later, he goes to bed. And then he wakes up for supper in the evening, and we feed him yet again. He’s very easy to care for as a caregiver. He sleeps a lot of the time and everything. So, all I really do is make his bed and cook and give his meal. Oh, and I bring a White Board for him because he also can’t see. So, I write down stuff on the White Board for him.”

Jenny added that being a helper enriched her quality of life, and she found it “good to be giving and got much joy from helping others.” She had been a teacher before she retired in 2008, and she mentioned how her previous career enabled her to take on a role of “always helping people” which made her value reciprocity in her relationships with her social networks. Thus, Jenny always tried to return the help she received from others (i.e., her friends) by supporting them emotionally through listening to their life problems, and sharing entertainment products and information (i.e., puzzles, novels, television shows) with them:

“It’s good to help people. And sometimes just listening is all they need. And we [Jenny and her girlfriends] share things like puzzle, books, and ideas to watch on Netflix.”

In addition, Jenny mentioned how being able to provide her social networks with mutual support made her feel less dependent on them even if she asked for help from them for specific tasks (i.e., driving to places, finding items at stores, and reading menus
in restaurants), and emphasized how helping others helped her retain her sense of independence.

**The Importance of Informal Networks in Providing Emotional, Informational, Instrumental, Peer, and Family Support**

As our conversations deepened throughout the interviews, it was clear that Jenny had very close and strong relationships with her informal social networks, including both her family and friends. With her family, Jenny spoke with adoration and proudness as she talked about her two daughters:

“I have two daughters. One is in Australia with three grandkids, and the other one is in [out of the province], and she works at CBC. She’s going to have one of her things come up over the National pretty soon, interviewing people with COVID in [out of province]. So, we’re [Jenny, her husband, and her father] looking forward to that... My daughter in Australia is a clinical psychologist, and she went to Western also. And then she went to Australia for three months and ended up living there 25 years ago.”

Jenny then shared that she had raised her two daughters as a single mom at the age of 36 for a number of years before she married her current husband. Despite all the difficulties Jenny experienced then, she was glad that she never gave up, and she felt proud of her own life, knowing that her children had grown up so well:

“But I’m really proud of all of them [Jenny’s daughters]. They’re doing really well. Yeah, they’re good. I was pregnant at 17, married at 18, and we stayed married for 18 years, and then divorced. So I raised them pretty young, and the youngest one I raised her pretty much on my own. So, they [Jenny’s daughters] did pretty well for an 18-year-old mom. It [Raising two children alone at a young age] wasn’t easy, but I think I went through... you know, well, we [Jenny and her ex-husband] were married at the time, and we all went through Western and lived in the married students’ residences. And we never regretted it, but it was hard work. And now, I wonder, ‘how did I ever go to university and have a baby? And I worked part-time as well.’ But we never really thought anything of it.”

Through her narrative, Jenny demonstrated the identity she constructed for herself; a resilient, strong, and autonomous woman who is able to succeed amidst
adversity. Such an identity was also reflected in her approach to managing vision loss. For instance, as mentioned earlier in her narrative, she did not use her vision loss as an excuse to disengage from her desired occupations. Instead, she used assistive devices and social support from her social networks to maintain her occupational engagement. In addition, while she acknowledged the support she received from her social networks, Jenny managed to problem solve many vision-related challenges she faced using the strategies she developed on her own, as well as helped others in need to the best of her abilities.

Jenny also noted that she was very family-oriented, and noted that her parenting experience as a teenage mother, and having no one but her two children in her life for a significant portion of her life, made her value family relationships greatly. Jenny emphasized how she had very close relationships with her daughters, and the siblings themselves had close relationships with one another despite the physical distance between where they each lived:

“Yeah, even though we’re [Jenny and her daughters] many miles away from each other, we’re still pretty close. I was an only child. Then I only had the two daughters. So, when they moved away, that just left my husband and myself and my dad, the three of us here. But we’re a close family, even though we’re a long ways away. And the two sisters are pretty close too. There’s ten years apart between the two sisters, and there’s like a half a world apart, but they’re pretty close too.”

Jenny said that she regularly kept in touch with her daughters through phone calls and shared each other’s lives through social media platforms, such as Facebook:

“They [Jenny’s daughters] keep me up to date through social media and news, like Daily News and Facebook activities. They also take pictures of their kids and everything, and their new dog and the cat.”

Jenny and her daughters also visited each other regularly. For instance, Jenny’s daughter, who lived out of the province, “usually came every couple of months” to London. Jenny also occasionally traveled out of the province with her husband and her father to visit her. As for her daughter, who lived in Australia, she flew to Canada annually with her children to visit Jenny:
“We don’t go to Australia, but she comes here. It’s harder for us to travel abroad because my father is 96, and we have to accommodate for his age. It’s just more convenient for my daughter to come over to our place. So, we see her about every year and a half, and my grandkids there are seventeen, fifteen, and twelve. And we’re as close to them as we can be even though they’re on the other side of the world, because they come here so often, and we see them so often.”

Jenny shared that both of her daughters had glaucoma, and they frequently discussed about the progression of their vision loss, as well as the types of medical procedures and medications they were each using to prevent further loss over their phone calls:

“She [younger daughter] just turned thirty-nine yesterday, and she got it [glaucoma] about five years ago, so she got it very young. Well, she had surgery, and I guess we [Jenny and her younger daughter] both did the eye drops... So, we talk about that every day and I worry a lot about her having glaucoma so young. And then I have another daughter in Australia that I told you about, and she is forty-nine, and she’s also got glaucoma. My mom had glaucoma. And so, we talk about it, too. She [older daughter] has never had surgery, but she takes her drops all the time. And they both say they’re very good at taking the drops. That’s really important.”

Given that Jenny and her daughters were all experiencing the same vision loss diagnosis I asked Jenny how they provided support to each other. To this question, Jenny replied that her daughters provided her with much information relating to her diagnosis that she found useful in preventing her glaucoma from getting worse, as well as emotional support:

“Having both my daughters have glaucoma... and my daughter that works at CBC, she knows everything. You can’t tell her something she doesn’t know already. And so, if I say something wrong about glaucoma, she’ll correct me. She gives me more information than anybody does about it. And I talk to the one in Australia too, and we talk about it, and she’s not all-knowing, but she’s emotional support in that. But the one in Marieville, she knows everything about it. Like I’ll do things, and she goes like, ‘oh you shouldn’t do that, it’s not good
for glaucoma. 'I can’t remember what they are now, but I’ve done a few things, and she’s like, ‘No, no that’s not good for it.’”

Here, Jenny highlighted how emotional support was not unidirectionally provided to her, but rather Jenny also provided emotional support to her daughters, as they talked about their struggles with vision loss and general life concerns (i.e., raising children, COVID-19, etc.). In addition, Jenny also provided and received emotional support from her father as well. Jenny stated that her father had more severe vision impairment than herself due to cataracts. Although Jenny and her father did not share the same diagnosis, as someone who was also experiencing adaptations in her occupations due to vision loss, Jenny could relate to her father’s decisions when he decided to disengage from previously enjoyed occupations (i.e., watching television), and felt more emotionally connected with her father as a result of their share vision loss experience:

“I can understand it [her father’s actions and thought process] better like he doesn’t want to watch TV at all anymore. I can understand why he wouldn’t now.”

From Jenny’s narrative, it seemed as though vision loss is a part of her family identity as it was evident that discussing vision loss is an important part of how Jenny spends time together with her family and provide support to each other.

Jenny also mentioned how her father was receiving instrumental support from vision rehabilitation organizations such as CNIB. For example, they provided him with an operator assistance service on his phone and supplied him with low-vision aids, such as magnifiers:

“He [Jenny’s father] has used the phone, the home phone where you dial zero, and it just starts the operator, and it puts you through the party. It’s a service with the CNIB people. They also supplied him with some magnifiers, and they are coming out November or October sometime again. And I don’t know anymore, but the phone service, it’s just a zero and then zero again, and then you tell the operator the number you want, and they connect you without you having to look it [phone numbers] up.”
Jenny added that CNIB sometimes came to visit her house, “to see if there are things to suggest” for her father to use. Through such home visits, Jenny was able to indirectly obtain informational support that was useful to herself as well:

“He’s [Jenny’s father] got CNIB coming out. So, I just kind of take in all of their explanations and apply them where I see fit”

Noticing how Jenny received a lot of support from her family, I asked whether there was any difference between the support she received from her family versus her friends. To this question, Jenny answered that her friends also provided her emotional support, however, Jenny felt that her friends and her family played different roles in her life. In particular, Jenny mentioned how her friends were both her gender and age peers, and she found socializing with women, instead of the two men in her life (her husband and her father), to be refreshing:

“I live with two men, so it’s nice to talk to women. But I never lived with men all the time. I always had women in my house. Nowadays, I live with two men, and it’s a different life. I’m not complaining, but I’d like to talk to women now and then.”

Jenny and her female friends shared details about each other’s lives. For instance, Jenny talked about her vision loss with her friends, and they talked about their troubles, and they mutually provided emotional support to one another by listening and empathizing with each other’s stories:

“They [Jenny's female friends] listen, and I sympathize, and they sympathize. Because I can’t see, and that means I can’t see well enough to drive. And it’s all these personal things, right? And I listen to their problems, right? So it’s like a reciprocal thing.”

Jenny mentioned that sometimes, there were certain topics that she was more comfortable talking to her girlfriends about rather than her husband and father. Talking with her female friends helped her de-stress because they offered her a female perspective and a different point of view on “girl problems”:

“My friends and I, for twelve years, we’ve been sticking together doing social things and to talk about our problems, and the reasons for why certain things are
happening in life. So, it’s a stress relief, and it is a different point of view that they provide me.”

Her female friends also provided her with companionship, as they participated in leisure and social activities together (i.e., going to dinners and movie theaters):

“I have a group of friends, and we go to different theater shows, and we go out for dinner at night. So, they provide with entertainment. We go and do entertainment together, like we get to go to different places that my husband and I never go to, like new restaurants and things like that. Yeah, that’s kind of like where we hang out, we always go to more different places than we do with men. Or sometimes, we get together with their husbands and do things together.”

Jenny acknowledged that although her female friends were a great source of fun and excitement in her life, her husband ultimately brought stability to her life. Her husband acted as her primary source of emotional support, and he was the one in whom she could confide:

“We [Jenny and her husband] talk about everything, I tell him everything, and he tells me mostly everything. He’s my basic and most go-to emotional support person. I had to try and keep a secret from him because my girlfriend told me not to tell anybody the other day, it was three weeks ago. And that was really hard keeping a secret from him. I finally... It finally came out, I didn’t mean it to come out, but it did. So, I tell him everything. We always confide in each other. And he hears about it [difficulties that Jenny experience because of her vision loss] all the time whether he wants to or not. And well, he’s family, so he gives family support. We don’t always see eye to eye, but we understand each other’s point of view. That’s very important. Sometimes he gets his way, and sometimes I get my way."

Jenny concluded by saying how much she appreciated having her husband around and shared that she and her husband always solved their conflicts quickly:

“We [Jenny and her husband] get along really well. Even if we do get mad at each other, we both forget about it very quickly. Some people yell and fight all the time, but we never do that. We tend to forget that we were mad at each other, and we get over it fast. Life’s too short to fight and argue. But we’ve always been
like that. We always get along. We’re very lucky. He’s pretty strong and is a hard worker, so he’d do anything for me.”

A Desire for a More Integrated Approach to Vision Care

Jenny appreciated that she could talk about her vision loss with her informal social networks and that peer support was so readily available to her. In discussing the support she received for her vision loss, she also talked about her relationship with her formal social network, including her optometrists and ophthalmologist. Throughout her narrative, Jenny compared her experiences with her current and previous optometrists and emphasized how she preferred her current optometrist, who was much more communicative with her than the first optometrist. For instance, when talking about her first optometrist, Jenny said:

“He [Jenny’s first optometrist] was OK. He wasn’t great, but he was OK all the time, right? So, I felt like he was competent enough, but he never said anything at all. He wasn’t communicative at all, and he sang everything, so, I always thought he had a stutter. So, I asked the receptionist one day, and I asked if it [singing every sentence] had something to do with stutters, and she said, ‘No, he doesn’t have a stutter he just sings to his patient.’... So, I had him for a long time, like 10, 15 years, and I always thought that was a reason. And we’ve [Jenny and her husband] been with him [first optometrist] so long, and eventually, I decided I didn’t like him. But I stayed with that one for so long because he was the one who had diagnosed me in the first place.”

On top of not providing adequate information about Jenny’s diagnosis, her first optometrist was also very directive and authoritative whenever he provided Jenny with instrumental support (i.e., giving her a referral to an ophthalmologist):

“I don’t think he recommended any support. He just told me that I had it. It’s been a while, but he just told me straight out that I had it. And he said he referred me to Dr. [Macky] at IVEY, so I should visit him, and that was it.”
Jenny stated that she sometimes felt “alienated” in her relationship with the first optometrist when he took on this directive communication style as she felt that she was told to comply without regard to her input or opinions on the healthcare directly concerning her own vision. Jenny added that she would have much preferred if he gave her more information and emotional space before communicating about a decision she needed to make so that she could decide for herself what the best course of action to take was. Another occasion when Jenny felt dissatisfied with the support he provided was when he overcharged a tonometry test for checking the pressure within her eyes. Jenny felt that the overcharging had occurred because there was a miscommunication or lack of communication between the optometrist and the other staff in the hospital as she stated:

“He charged forty-five dollars for the glaucoma test. But when I went to other guys [Jenny’s new optometrist], they haven’t charged me, so I just felt like he was only into the money, maybe. And I do pay at the hospital, the forty-five dollars [for the tonometry test]. I don’t do it anymore, but every time I go to the hospital for the same test, I paid forty-five dollars, right? And then I’m going to his place, and he wants another forty-five dollars for the same test. So, I thought, ‘well I don’t think I really need it.’”

Jenny was disappointed with the lack of communication between her previous optometrist and herself, as well as between the optometrist and other healthcare professionals; thus, Jenny decided to go to another optometrist. Jenny’s new optometrist provided much more detailed information about how her glaucoma was progressing, and when she communicated with her, she used a guiding style of support by being more receptive to Jenny’s input when she voiced particular concerns about her vision (i.e., her eyes becoming very dry):

“I really like her [Jenny’s new optometrist]. She gave me much more information than I had ever had. I told her my eyes were always hurting and dry, and she sold me a Bruder Mask, which is supposed to help with the eye drops and things like that. And she gave me a lot of really good ideas, and I thought, ‘wow, I’m gonna stick with her.’ So that’s kind of where my optometrist is at right now. I’ve only seen her once, but I was really impressed with her. Yeah,
She’s very good... She’s quite young, and what else did she tell me that the other guy didn’t? I forget, but she gave me a lot of good ideas, like she explained a lot of things about glaucoma that I hadn’t known for years.”

Jenny’s new optometrist also included Jenny more when making decisions about her treatments, and openly “discussed the pros and cons of using specific services” together with Jenny. Jenny also explained that her new optometrist was much more communicative with other healthcare professionals (i.e., ophthalmologist and family physicians) and Jenny was able to acquire referrals much faster through her new optometrist:

“She [Jenny’s new optometrist] said, ‘well, I’ll contact your own doctor [Jenny’s family physician] and then your specialist [Jenny’s ophthalmologist] at the Ivey clinic.’ And so, she wrote to them right away, and the next week, he [ophthalmologist at IVEY clinic] got it [referral letter]. So, I was like wow, that’s fast.”

Jenny advocated for integrated vision care, saying that the overall experience she had with vision care was more positive when there was a collaboration amongst vision care professionals. Jenny believed that when vision care professionals communicated with one another, they could gain information about her overall health more readily, not only relating to her vision but also her lifestyle (i.e., her diet). Consequently, they could reduce the inefficiencies in the services they offered (i.e., duplicate testing) and provide her with services that were more customized to what she needed:

“And she [the new optometrist] actually talks, so with my own doctor [Jenny’s family physician], what did she do... I forget what she did exactly, but after she [the new optometrist] called, she [Jenny’s family physician] helped me change something about my diet, and everything was just more efficient.”

Jenny ended her narrative about her journey through the vision care system by talking about her ophthalmologist, who has supported her by providing surgery and administering visual field tests on her eyes:
“Well, I met Dr. [Macky] from the Ivey clinic. I have appointments once every year, and he does a visual field test. So, I get that done every year, and he’s also done surgery on my eye for glaucoma. And with the surgery, I don’t have to use the drops anymore. I was using drops for glaucoma before, and he zapped me, so I don’t use them anymore. I guess I was getting really bad.”

When describing her ophthalmologist, Jenny said that he was a “man with a big heart,” who genuinely cared for his patients. However, similarly to her first optometrist, her ophthalmologist also failed to converse with Jenny about her diagnosis in a helpful way:

“My ophthalmologist is... what’s the word, he’s not very communicative. He’s a man of very little words. Hardly says anything. But a nice guy, because when my daughter was in [out of the province], she couldn’t get an ophthalmologist. I think hers quit or something, and she had this glaucoma, but she couldn’t get anybody to treat her, and my ophthalmologist just said, ‘Bring her here, and I’ll take care of her.’ So I thought that was really nice of him. But his receptionist said, ‘well he can’t do that; he can’t just get somebody out of Ontario.’ But well, he volunteered to do it. But anyway, she did find somebody. My daughter found someone. Yeah, but I thought, wow, he’s a nice guy, but he never smiled, well because he’s really busy. But he’s a good guy. I guess he knows what he’s doing.”

Navigating through her Vision Loss, Occupational Engagement, and Social Interactions during COVID-19

Throughout the interviews, Jenny mentioned how a lot of her social occupations had been interrupted due to COVID-19. The three types of social occupations most significantly impacted by COVID-19 were cancelled family visits, reduced frequency of social outings with her friends, and delayed healthcare appointments. Regarding her family visits, Jenny said, “things are a bit screwed up because of COVID” and that she “hasn’t seen her daughters since January.” Her daughters were mindful of Jenny, Jenny’s husband, and her father’s age, recognizing that older adults were more vulnerable to
becoming infected with COVID and developing severe health complications. Thus, both of Jenny’s daughters and grandchildren cancelled their family visit with Jenny, as they were “afraid of giving us [Jenny, her husband, and her father] COVID”:

“My daughter in [out of the province] hasn’t come here since January with the grandkids, because [out of the province] was so bad that she didn’t want to give it to my father. So, they usually come every couple of months, but they haven’t come, so we haven’t seen them in a long time. My daughter in Australia usually books her trip over here flying over, but they can’t do that without being in isolation for 14 days, and she shops every day so that would kill her. She’s a shopper when she comes.”

Jenny also had to reduce most of her regular get-togethers with her friends because she feared that if she contracted the virus by being in close physical proximity with her friends, it would put her family, who she was living with, at risk as well, especially her father who was much older than Jenny. Thus, a lot of her leisure activities that she engaged in with her friends including, going to theaters, eating out at restaurants, and hanging out at each other’s homes, were interrupted or done while taking precautionary measures (i.e., wearing masks, abiding by physical distancing rules, and always eating on restaurant patios):

“OK, and our friends, we used to do theater every month. But we can’t do grand theater anymore, so that’s down. And we used to go to each other’s houses, but now we don’t want to go into each other’s houses. And I don’t want to invite people here because of my dad, and so we’ve gone out to a restaurant just one time. And we did all go to one of my girlfriends’ house, and we ate outside, but we were all wearing masks when we had to go through the house. So, I haven’t seen my friends as often as I used to do.”

Furthermore, Jenny’s healthcare appointment with her ophthalmologist was delayed because of COVID-19:
“My ophthalmologist, or his receptionist, filed it [Jenny’s appointment for her visual field test], so I was expecting a call from them saying maybe come in, but they didn’t. So, I finally called her [the receptionist], and I said, ‘Well, can I get in to see him?’ She said, ‘well, you’re lucky to get in November.’ So, because of COVID again, they’re not taking any appointment, and I just luckily have one in November, so I’m waiting till November for another appointment.”

Jenny also mentioned that her healthcare providers were delaying appointments with older adults even more so than other age groups. For example, her optometrist explained that they were keeping separate appointment waitlists for older adults to help prevent the spread of COVID and ensure the health of older adults. Being denied access to healthcare services because of old age had a direct and negative impact on her vision, and consequently impacted her occupational engagement, including her ability to drive:

“I was losing my vision. I felt like I wasn’t able to see as well as I could. And I’ve changed glasses three times this year. And so, I wanted an appointment. But he [Jenny’s previous optometrist] said because I’m older, that they were making special appointments for older people, because of COVID, and I wanted it in June, but I couldn’t get it till August. And Oh my God, I can’t see very well. I can hardly drive now. I don’t want to wait until August.”

Amidst all of the changes Jenny was experiencing in her social occupations because of COVID-19, she found a silver lining in the fact that she could still connect with her family via social media and phone calls:

“My daughter, the one in [out of province] facetimes me every day. And I talk to the grandson, every day. And he’s always wanting to come to our place, of course. And of course, the phone, we [Jenny and her daughters] talk on the phone a lot too. And social media again with messenger, or whatever. We talk every day pretty well.”

When I asked Jenny how she felt about substituting her in-person interactions with online interactions, Jenny said that she actually “didn’t mind it” because she had
always been relying on social media platforms and phone calls to interact with her daughters even prior to COVID-19. Overall, she felt that her life had not changed as much as her friends’ because she preferred to stay at home compared to her friends. Thus, she did not feel as much need to engage in outdoor activities to feel happy:

“It really hasn’t changed our [Jenny, Jenny’s husband, and her father] life a lot concerning COVID, as much as a lot of other people. Like a lot of people, for example, my girlfriends, their life is about going to the theater and going out to lunches all the time, they do a lot of activities like that. So, she’s just deflated because she can’t do anything like that. But we’re kind of homebodies. You know, so it really hasn’t changed too much for us. We’re probably one of the few people in the world that hasn’t experienced much change. It’s also because we have my 96-year-old dad here, so we don’t really go away, right? Well, other than camping, that is. So it hasn’t changed too much other than the fact that I can’t see my grandkids as much, which I really miss. But even so, I talk a lot with them.”

Jenny also said she didn’t particularly feel isolated even during COVID-19 because she was living with her husband and her father. Thus, she had access to in-person interactions much more frequently than older adults who were living by themselves during COVID-19.

Overall, Jenny stayed true to her warm, resilient, and family-oriented character amidst COVID. During such difficult times, Jenny relied on social media to stay connected with her loved ones, and once again, demonstrated her adaptability when faced with adversities. Her ability to autonomously problem-solve through challenges shined throughout her journey through vision loss as she actively sought after integrated vision care and developed personal strategies to maintain her engagement in desired occupations. Jenny's social networks provided her with various forms of social support as she navigated through vision loss. In particular, Jenny was able to exchange emotional, instrumental, peer, and family support with her family members as they each shared about their vision loss with one another.
4.4. Joanna’s Story

Joanna is an 85-year-old widowed woman who has had macular degeneration for 20 years and is currently living alone in a senior’s apartment complex. Joanna’s brother lives near her neighbourhood and occasionally visits Joanna. She has a daughter who lives in another Canadian province and visits her bi-monthly. Joanna also keeps in touch with her daughter over the phone and on the Internet via email. Joanna is a client of the Canadian National Institute for the Blind (CNIB). She was recruited through the CNIB and showed great enthusiasm to participate in my study. Interviews with Joanna were held via phone calls, and as we chatted, she presented as an independent and resourceful person.

Transitioning from Gradual to Rapid Vision Loss: Preparing for an Uncertain Future

Joanna was born with low vision in her right eye, but her left eye had been “pretty good” for most of her life. However, in her early 60’s, she was diagnosed with macular degeneration in her left eye, and 5 years later, the same diagnosis developed in her right eye as well. Joanna stated, “I’ve always been wearing glasses since I was very young, but it hasn’t limited me that much until I’ve got the macular degeneration.” She added that her right eye “was not good to start with, and now [because of macular degeneration], it turned almost totally blind.” She then explained how she never received treatment for her right eye from an eye care professional in the past because her ophthalmologists told her to ‘just leave it’ as “it had the poor vision to start with.” As for her left eye, however, Joanna remarked that she has “regular checkups with [her] optometrist” to monitor the progression of her macular degeneration:

“Whenever I visit him, he [Joanna’s optometrist] gives me some eye drops to the left eye, and that's supposed to dilate my pupil, and so he looks inside my left eye and tells me if there are any changes in the retina.”

While discussing her journey through vision loss, during our first interview, Joanna expressed that it had been nearly 20 years since she was first diagnosed with macular degeneration and that her diagnosis had progressed “very gradually” throughout those 20 years. Thus, I was surprised in our second interview when Joanna talked about
how her vision had gotten far worse since the first interview (within just a couple of weeks):

“I don’t know if I’ve told you this or not, but since we talked, I have one eye that we haven’t treated because it’s mostly blind anyway. It’s gone completely blind, like completely black, just in the last couple of weeks, and it is hard. It’s just more noticeable now where it wasn’t as much before.”

Joanna herself seemed bewildered by such an unexpected and rapid progression of vision loss as she stated:

“There was definitely peripheral vision before, and you could see motion. But now, I can’t even see the light or motion or anything anymore, and this never happened before.”

However, rather than remaining flustered because of her abrupt vision loss, Joanna immediately called upon her resources to prepare for a future where her vision loss continues to progress rapidly. For instance, Joanna explained how she keeps a Bosch magnifier, which has greater magnification than she currently needs, in preparation for an uncertain future:

“I have a Bosch thing; it’s like a magnifying glass, only it magnifies much larger. And I haven’t needed it yet at this point, but I’m getting there, I’ll probably need it soon. So I have one to use in the future.”

Joanna added that she hasn’t reached out to her ophthalmologist yet about the sudden change in her vision because they “haven't been in touch for quite a while because of COVID-19” but she planned on “talking to him if it starts to bother [her] more in the future.”

**Using Low-Vision Assistive Technology to Adapt to Changes in Occupational Engagement**

Joanna expanded on her experiences with macular degeneration, by explaining how her diagnosis has influenced her leisure activities such as playing Bridge and reading. In regards to playing Bridge, Joanna said she is not able to participate in competitive games anymore, partly because her “mind isn’t as great as it was when [she] was younger,” but also because competitive games do not allow the use of large print playing cards:
“Well, my favorite pastime is playing Bridge, duplicate Bridge. And it’s competitive and I really enjoyed it. But it got to the point where my vision is not good enough to play in the good games. I need larger cards, and they don’t have those at the competitive bridge games. They’re all a certain size, and they stay that way. I can play better with larger cards.”

Joanna added that she “still plays [Bridge] casually and socially” with her neighbours at her senior’s apartment complex whenever they meet up for a social gathering. Here, Joanna talked about relying on her magnifying glass to read her deck of cards, as well as asking her neighbours to read her the cards that she cannot see:

“Well, I use a magnifying glass to see the cards, and people will tell me... if the cards aren’t right in my hands, and I need to see. Like, I can ask, ‘what’s that’? And they’ll tell me, they’re very good. They realize [that I have vision impairment] because usually, they are people that live in the same complex as I do. But you don’t want to do that in competitive Bridge where people are busy, and they’re involved [in the game], you know.”

In addition to reading cards, Joanna stated that she relies heavily on low-vision aids (i.e., a handheld magnifier with five times magnification) when she needs to read small prints on food labels, instructional manuals, and TV guides:

“I use my magnifying glass. I have one that’s a good size, magnifies quite a bit. I think it’s five times. Yeah, five times, that’s the size I’m going with right now. And it’s very good. I just can’t get along without it. I need it to read down. I don’t read a book or anything like that, I listen now. But for things that you do need to read, like labels and instructions and supposing I want to look up the TV Guide on my iPad, like I want to know the programs on TV, for example, that kind of stuff. I use this magnifying glass, and I use it a lot every day. I take it to grocery shopping. I remember, too, if I want to read a label on a can, for example, or the price of something on it, I have to use this.

Joanna also mentioned using an electronic desktop magnifier [CCTV] with 12 times magnification for managing her finances:

“And I have another one [secondary magnifying glass], I don’t know what you call it, but it sits on your desk, and you can put papers down on top of it, and it
magnifies up to 12 times. So it's very good. I use that for doing bank racks or visas, checking the visa, stuff like that. So, I certainly use a magnifying glass all the time.”

Joanna added that she isn’t able to read as long anymore because of her macular degeneration, and therefore she now listens to audiobooks whenever she wants to read novels. In addition, she has now replaced reading the physical newspaper to reading the news online or watching television to obtain the daily news:

“For sure, I read or rather, listen to books less than I did before, and I do that [listening to books] with audiobooks. I can’t read newspapers either, and I don’t do that [reading news articles] on the iPad. I get all the news I want on television, but I just don’t read as much overall.”

Lost Occupations after Losing Vision

In discussing the changes in her occupational engagement, Joanna stated that there were certain activities that she has given up or does not engage in as frequently because of her vision loss. For instance, Joanna mentioned how she lost her ability to drive because of macular degeneration, and how her community mobility, as a result, became more restricted:

“Well, first of all, I don’t drive, so I’m quite limited in what I do. I didn’t try my driver’s test at age 80 because I knew I wouldn’t pass because of my vision. So that’s when I gave it [driving] up, at age 80, and that’s five years ago. And it definitely limits my mobility.”

Expanding on how her ability to drive is interconnected with her community mobility, Joanna talked about how she gave up on many of her previously enjoyed pastimes (i.e., watching music concerts, going to the theater, and watching ballet performances) because she is not able to drive herself to the places that offer these forms of entertainment anymore:

“I wouldn’t go anywhere to a concert tour. Well, I went to a Michael Bublé concert, not that long ago, and that was really good. But that’s probably the last time I’d do. I think part of the reason is because I had to stop driving, and I had
to stop driving because of my vision, so it all connects together. Like when I wasn’t in London, I could drive to the theater, and my vision had a lot to do with them. But now, I don’t think, you know, I don’t think I’ll get there. I mean, if it [music concert] were here and I just had to go to the backyard, well then, that’s when I’ll see. And I used to do theaters a lot, and now I can’t see to do that. I loved the ballet, but I can’t see to do that anymore either.”

Joanna also revealed how her gradual development of macular degeneration slowly but negatively influenced her ability to travel outside of the community as she stated:

“I used to travel a lot. I’ve been all over the world and traveled a lot, particularly with my daughter. But I don’t travel now much at all because of my eyesight. And I’m eighty-five so I’m just not interested in doing it anymore.”

Joanna stated that the only times she traveled outside of London now was to visit her daughters, and she managed her current traveling by using public transportations (i.e., train). She mentioned how she was rather fond of her trips using the train as she stated:

“If I were going there [where her daughter lives], I would go by train. Well, it’s [traveling via train] quite nice. Only I have to change in [Hamilton]. I always go with the first class, or whatever they call it, and I bring my walker with me to the trip [the station does not provide a walker, it is Joanna’s personal possession]. I have a walker that I need, and it takes me to the station lounge and brings me back, and it’s a whole day’s journey, but it’s a pleasant one.”

At the time of the study, Joanna was traveling alone without needing assistance from strangers or staff at the train station:

“I can’t think of any [times when I needed help from others at the train station]. I’m pretty familiar with it [navigating through the train station area], and you know, I go by business class, so it’s pretty straight forward and made easier because they go on separate way and there’s just one car.”

Nevertheless, Joanna has visited her daughters less frequently over time because traveling became more strenuous and less exciting when she “wasn’t able to see as well”, and wasn’t able to “fully appreciate the new sights”.

**Modifying How Desired Occupations are Carried Out**
With her reduced community mobility, Joanna also experienced difficulties in managing her day to day tasks such as going to the grocery store and shopping malls as well as attending medical appointments. However, Joanna used strategies to overcome the barriers to engaging in these IADLs, such as relying on private commercial transportation (i.e., taxi) for getting to her medical appointments:

“I can take a taxi if I need to, and I do for medical things, that’s when I really have to go out. I use a taxi for things like medical and lab works or stuff like that.”

She also talked about depending on her informal social network (i.e., friends) who would offer to drive Joanna whenever they were going to the same destinations:

“I have a friend, who’s very good. She asks me to go with her if she’s going grocery shopping and so it [getting to places within the community] hasn’t been a major thing. It’s an issue for sure, but it hasn’t bothered me an awful lot.”

Furthermore, Joanna mentioned how in 2015, she moved her home to a neighbourhood where the residential and commercial areas are closer to one another, so that it is more convenient for her to go to places without having to rely on others for drives:

“Another thing [strategy for maintaining community mobility] is, I’m not sure if I told you, but I moved here because I was going to lose my driver’s license and it’s handy to turn to Masonville Mall and Loblaws here, and it’s a handy place to be. And that [moving to a new home] was because of my vision, that I wouldn’t be able to drive. So yes, after moving, I could walk to those places.”

Finally, Joanna expressed that watching television is an occupation that she enjoys greatly and when I asked her whether she used specific strategies to help with watching television, Joanna replied that she watches her TV at a very short distance:

“Well, first of all, my chair isn’t terribly far [from the TV], and that’s fine for the news and things like that. But if I want to watch a movie and see faces, I have another chair that I bring in right in front of the TV. So that I’m sitting very, very close. And I don’t sit as far away as normal people would even just to watch the news.”
Changes in Occupational Engagement at Different Stages and Severities of Vision Loss

Joanna noted that all the adaptations to her occupations mentioned above had occurred gradually over 20 years, before the recent, and more significant, deterioration to her vision that had occurred over the last three weeks. Here, I asked Joanna whether the recent changes in her vision had influenced her activities any differently than before, to which she replied, “No, not at all. I don’t think so at all.” Joanna explained that she was still able to “make use of the strategies [she had] developed over the 20 years” of having macular degeneration to engage in her desired occupations. Even though she noticed the difference in the severity of vision loss between the first and second interview sessions, that change in severity did not make a difference to her occupational engagement. Based on Joanna’s narrative, it seemed as though the way in which the severity of Joanna’s vision loss influenced her occupational engagement could be described using a plateau curve. For instance, when comparing between Joanna's occupational engagement when she had minimal vision loss (early stages of macular degeneration) versus intermediate vision loss (throughout 20 years of gradual development), Joanna's occupational engagement changed considerably in terms of the types of activities she engaged in and how she maintained her engagement. However, when comparing Joanna's occupational engagement when she had intermediate versus severe vision loss (during the recent abrupt development), her occupational engagement did not seem to be affected too significantly. In other words, the severity of Joann's vision loss only made a difference to her occupational engagement until a certain stage of vision loss, but once she reached and went past that point, the severity of her vision loss did not seem to influence her occupational engagement as drastically.

The Cumulative Influence of Ageing and Chronic Health Conditions on Occupational Engagement

Joanna’s occupational engagement was limited by other chronic health conditions that were occurring concurrently with macular degeneration. For instance, Joanna described arthritis in her back, which made it difficult for her to “stay upright” while walking. Joanna thus, “couldn’t walk very far” and she usually aimed to “walk for
20 minutes a day”. Remembering a conversation from our first interview, regarding how Joanna relied on a wheelchair and a walker in the train station to visit her daughter, I asked Joanna whether they were needed more from a mobility standpoint because of her arthritis, or whether they had to do with her vision. To this question, Joanna replied, “Oh, no. It’s mobility. Yeah, it’s mobility definitely” and added that she had reduced her traveling not only because of her vision but also because she could not walk as long because of her arthritis:

“I think it’s [cessation in traveling] happened because of my vision and age. Yeah, I can’t travel easily to [Hamilton] due to all those health conditions [related to age]. But my vision is a big problem too. So, the vision is a major part, but it’s not the only problem.”

In addition to her back, Joanna talked about how she had arthritis in her shoulders, and that this restricted how long, and how well, she could engage in hobbies, such as knitting:

“I have a shoulder problem which limits the amount of knitting I can do. That's the fun of getting old; there’s always something. Like I have a problem on my right shoulder, and once it starts to ache, then I have to stop knitting. I can’t knit a lot. Like I’d like to knit all day if I’m watching TV or just sitting around. I like to knit while I’m doing that. But I can’t. Although I can knit to a certain degree, it’s not as much as I’d like to. And I can’t knit complicated things anymore. It’s just basic easy stuff that I do now.”

**Emotionally Coping with the Restrictions to her Occupational Engagement**

Joanna expressed that accepting the changes to her occupational engagement, whether caused by vision loss or her other chronic illnesses, was not always easy. Adaptation to vision loss and arthritis “came with frustrations,” and she felt “bored at times” when she could not engage in an occupation (i.e., reading, driving, going to concerts, knitting, etc.) at the same capacity that she could before. Here, I asked Joanna how she managed her emotions during these times. To my question, Joanna replied:

“I guess I just put up with it [feeling frustrated]. I don’t have a choice, like I put up with it as much as I have to. But I’m not a patient person, so sometimes it’s pretty frustrating, but you just have to admit it, and not run away.”
Joanna chooses to accept her present situation even if some aspects of it are not to her liking. She acknowledged the negative feelings she had towards vision loss and faced her emotions head on instead of ignoring them. For Joanna, her goal was not to always stay positive, but rather, admitting when she was feeling down allowed her to come to terms with her situation and made it easier for her to move on from feeling frustrated. Joanna also talked about how she substituted the occupations that she could not as easily engage in (i.e., walking), with other occupations that she was more easily able to do and equally enjoyed (i.e., watching television and listening to audiobooks):

“I was just going to say it’s up to you what you do about it [not being able to engage in desired occupations], I guess. You know, if I could walk more, it would be good too, but you just have to substitute as much as you can with something you can do right now. Like I do a lot more indoor activities.”

When Joanna wanted to engage in a specific occupation and did not want to replace it with anything else, she engaged at her own pace, making sure to take longer breaks when she was finding it stressful on her eyes or body. For instance, with knitting, Joanna stated that she waited long enough to let her shoulder pain subside before engaging in knitting again:

“I haven’t found anything to replace knitting yet. I just wait until... I have to stop when it [shoulder] starts to hurt, and I don’t... I try to wait, and after a while, you just carry on. When you’ve waited long enough, you try again. See if you can knit a little more. Sometimes you can’t until tomorrow. But there’s nothing you can do about it, right? It’s all you can do.”

The Influence of COVID-19 on Occupational Engagement and Social Interactions

Throughout her narrative, Joanna mentioned how COVID-19 interrupted her engagement in occupations with her social networks (i.e., daughters, friends, and family physician) because she could not engage in the occupations she desired while maintaining proper social distancing. For instance, Joanna had to cancel her trip to visit her daughter because, during COVID-19, the first-class train service she had always used was not offered. Joanna preferred to use first-class over regular service as it better accommodated her mobility challenges (i.e., providing a walker at the lounge area and wheelchair at her train seat). Joanna also knew that she had plenty of room to herself in first-class seats as
they were spacious enough to fit her wheelchair, while regular seats were much closer to one another. Thus, Joanna feared that she could not practice proper social distancing while using the regular train services and thought she would put herself at risk of contracting COVID-19 if she visited her daughter:

“I would travel to [Kingston] to visit my daughter on the train, but they have canceled the business class, and I wouldn’t travel regular on the train because I’m sure there’s not proper social distancing there. So that’s [COVID-19] certainly part of it [the reason why Joanna canceled her visit to her daughter].”

In addition, Joanna mentioned how she stopped playing Bridge socially with her friends since the start of COVID-19, because of the challenges dealing and reading cards while keeping 6 feet away from one another, especially considering that she had macular degeneration and already experienced difficulties reading her cards:

“Playing bridge, social bridge, or having lunches together [with Joanna’s friends], that has stopped because you can’t do that and maintain social distancing. And with my vision especially, I can’t read all the cards by myself, so how can I do that when we’re so far apart?”

Instead of giving up on playing cards altogether, Joanna replaced in-person games with playing them online, using her computer and iPad:

“I can play [Bridge cards] on the computer as well, or on the iPad. It [computer and iPad] just provides an avenue for me to do it, that’s all, because now because of COVID, we can’t... I don’t play it socially, only because I think it’s too dangerous.”

Joanna also substituted the in-person healthcare appointments she had with phone call appointments. Luckily, even before COVID-19, Joanna did not have regular appointments with her ophthalmologist, thus the pandemic did not influence her vision care significantly, but it did affect her appointments with her family physician, who she met with more routinely:

“For my ophthalmologist, I don’t see him that often, but I don’t feel the need to, and I feel like I could if I needed to. But my general practitioner is really fully restricted in what he’ll do and see [due to COVID-19 restrictions]. So it’s [appointment] mostly by phone if there’s anything wrong. It’s quite different.”
Although Joanna expressed that she would much rather have healthcare appointments in-person, she admitted that her family physician was still easily accessible through phone calls, and provided her with the healthcare services she needed during COVID-19:

“I don’t see my doctor because of COVID. So I’d like to be able to have a physical meeting, and well, I’d much rather be there in person, but he’s [Joanna’s general practitioner] not doing that right now. It’s not terribly serious, but it’s not as good as it was. But still, he’s very good on the phone, like I can get him anytime I want, and I don’t have a real problem that way.”

The Compartmentalized Use of Different Social Networks to Support Engagement in Desired Occupations

Joanna shared that her social network was an essential part of her life, and each of them provided her with different types of support (i.e., social, emotional, and physical). For instance, Joanna’s brother provided instrumental support by setting up her doctor’s appointments and accompanying her when she had to visit an emergency room:

“Well, my brother was here today as far as having an ear problem, and he came and checked it out and got me an appointment with my doctor. I’ve had to go to emergency a few times lately, and he’s been there.”

When I asked Joanna whether she talked about her vision loss with her brother, she replied, “Not really, no I don’t think so,” and explained that her brother mostly helped her with non-vision related health challenges, such as her recent ear infection. Joanna added that her brother lived close to her senior’s apartment complex and that he was one of the first people she would ask for help if she was “going through a crisis”:

“My brother lives in the city, and he lives close. So that’s a bit of comfort. I know if I’m in trouble, I got him to contact.”

Joanna then talked about her relationship with her daughter and stated, “We’re very close. She’s a very good daughter. Unfortunately, she lives in [Kingston], so I don’t see her that much, but she phones. Especially now, with COVID, she phones almost every day. She’s very, very supportive.” Joanna added that her daughter mostly supported her emotionally, as she was not physically nearby to help her with in-person tasks.

Overall, Joanna did not seem to interact with either her brother or daughter in-person.
frequently, but she trusted them to “have her back” when she needed them, and it was clear that Joanna perceived the support she received from her family positively, as evidenced by her stating:

“My daughter’s pretty good emotionally. If I reach out, you know, she’s there, always and forever, you know? And if I’m in any trouble, my brothers is, he’s sure there, too. I don’t socialize with my brother that much, but I do see him. You know, I wouldn’t say every week or not necessarily even every month. But I know he’s there for me.”

Apart from her family, Joanna also socialized with her friends, who lived in the same apartment complex as her. In fact, her neighbour-friends were the biggest source of in-person social interactions. Joanna’s friends accompanied her on many social and leisure occupations (i.e., going out for dinner, concerts, and walks), thereby providing her with positive social support:

“I wouldn’t say it’s definitely a routine, but I have some close friends; there are these two that stay close, and one, in particular, I talk to a fair bit, and the other one joins from time to time, and we get together once a week for dinner on Saturday night. And we used to have a dining room here [at Joanna’s senior’s apartment complex] which has been closed for three months. Now, it’s going to start to open next month. So we will get together there, but there’re only two tables. And you know, I get on a walk with one of them outside when the weather’s good. And the three of us get together when there’s a group like the jazz concert.”

Her friends also provided her with peer support as they were her age peers, and some of them had arthritis or low vision. Of course, not all of her friends had the same challenges or diagnoses as Joanna, but she still felt a sense of belonging among her group of friends. Joanna mentioned how, when she and her friends gathered to socialize, the topic of their respective health conditions would frequently come up, and each of them could understand and empathize with each other’s struggles even if their diagnoses were not identical:

“We [Joanna and her friends] all talk about our ailments. Yeah, sometimes too much because we’re all in the same boat in most ways, you know. And we’ll say
‘we understand’ or something like that. So yeah, they’re supportive, and I think our support is social. You just spend time with them, and you know, if you have a problem that you want to talk about, you can sit down and do that. They’re approachable any time you need to or want to.”

As such, Joanna felt emotionally supported when she socialized with her friends. Her friends also provided informational support by sharing strategies they have used in the past to overcome the barriers they have experienced with their respective disabilities, and Joanna used this information to cope with her own challenges relating to vision loss and arthritis:

“Sometimes there’s some suggestions that come about how to deal with it [struggles Joanna and her friends have with their ailments] if there’s a specific thing you’re having a problem with. I can’t think of anything specific right now, but they’ll point something out, so I just apply that to my own case.”

Joanna also received instrumental and informational support from her formal networks, such as her family physician and ophthalmologist. For instance, her family physician provided her with referrals for non-vision related health conditions (i.e., arthritis, gastrointestinal problems, and ear infection):

“Well, he does referrals if I have serious back problems and shoulder problems with arthritis. And I have some internal gastro problems. I’m also seeing him this week for reaming out my ear, but that’s got nothing to do with vision.”

She emphasized that she never talked about her vision with her family physician. Instead, she relied solely on her ophthalmologist when she needed help for her vision. Joanna has had multiple ophthalmologists in her life, “only because they retired”, and had positive relationships with all of them:

“I’ve had several ophthalmologists. Oh, they’re very positive. I’m very happy with my second last one. I knew him personally because he was a friend of my brother’s. And the new one has been very good. I’ve liked him very much, too. No problem there at all. Yeah, I don’t recall anything negative. I am very satisfied with him. He’s personable, and I’m happy with what he does with me. I don’t have a problem there at all.”
Joanna’s ophthalmologist provided her with instrumental support by performing diagnostic tests to monitor changes in her retina. However, Joanna seemed to rely on her ophthalmologists mostly for informational support rather than instrumental support. For instance, when describing her visits to her current ophthalmologist, she explained that he communicated to her about how her vision loss is progressing but never actually prescribed her with medications or performed surgery on her eyes:

“I get my vision tested every once in a while, but they don’t provide the glasses. They just recommend that I see an optometrist to get that done. I guess he would tell me if I needed to see an optometrist. But he doesn’t do that kind of stuff. And I haven’t had surgery and no medication either. But he’s very nice, and he’s caring. When I go, he checks my eye and tells me how the disease is progressing, and well, they answer all of my questions. I don’t have a problem with that at all, with the communication.”

From listening to Joanna’s narrative, it seemed that each of Joanna’s social networks were fulfilling different needs. For example, her family members were supporting her emotionally with non-vision related health conditions, and her friends were providing peer support for her vision loss. Moreover, her family physician provided her with referrals and expert information on non-vision related health conditions, while her ophthalmologist provided informational and instrumental support for her macular degeneration.

**Maintaining Autonomy while Accepting Help from Social Networks**

While discussing her relationships with her social networks, Joanna emphasized how she views herself as an autonomous person with an independent personality. Although Joanna was living alone, she did not feel isolated, nor did she feel a constant urge to go outside and socialize with people:

“I like alone time. I don’t have to be with people all the time. I think it’s the way I am. For example, my daughter needs... She’s very different from me. She needs to be with people a lot more than I do. But for me, I meet up with my friends, but it’s not constant. I don’t see them every day or talk to them every day.”

Joanna also expressed her strong desire of not wanting to be seen as a “needy person” to others as she stated:
“I try not to be a nuisance to people unless I really need it. I try not to bug people and complain. No, I don’t want to be a nuisance.”

Joanna equated asking for help as being a nuisance, and thus, she preferred to manage occupations that she could handle on her own, such as banking and walking around the community, by herself without relying on others:

“I don’t need help with things like banking. I just go to the bank, though I don’t do that very often anymore because of COVID. And I don’t need help crossing the street or that kind of stuff.”

Although Joanna was generally reluctant to ask for help, she did not have a problem with receiving help from others when she faced situations in which their assistance was deemed necessary. For instance, she did not mind asking a stranger for help to find grocery items when she did not have her magnifying glass with her while grocery shopping:

“I was looking for something in the grocery store the other day, and I forgot to bring my magnifying glass. So I asked a stranger about something, like where this is, or that is because I couldn’t find some things. So no, I’m not hesitant about that. I don’t like to be a nuisance or anything, but every once in a while, I do that.”

Joanna noted the importance of reciprocity in her social relationships so that she would be seen as their equal, rather than a nuisance. Such reciprocity made it easier for Joanna to ask for help from her social networks as she felt that she was in a position where she could return their help when they needed her support:

“If they [Joanna’s friends] needed support, I just do it [support them]. One thing it [having reciprocal relationships with social networks] does do is, it makes you feel a little freer to ask for help from them if you needed it because it’s reciprocal, and you can always help them too.”

**Physical and Informational Barriers to Accessing Support Services from Vision Rehabilitation Organization**

Despite being a long-term client of CNIB, Joanna was not particularly fond of the organization. Joanna mentioned how CNIB provided her with low-vision aids such as her Bosch magnifying glass to improve her visual performance, and thus supported her vision
loss through the provision of assistive devices. However, Joanna did not use CNIB for any other services apart from getting these assistive devices, and expressed that she had “very limited access” to the services offered by CNIB, both because of issues with physical and informational accessibility. Relating to physical accessibility, Joanna stated that CNIB’s “office is so far away from here [Joanna’s home],” and she has difficulties going to CNIB by herself as she cannot drive. Thus, at the time of the study, Joanna had to rely on either her friends or daughter to drive her to CNIB when she wanted to access their services (i.e., getting new low-vision aids):

“I have a friend who was there [CNIB] for her own reasons this week. And they told her about the shop in Queens or Oxford, I’m not sure, but anyway, there is a shop that they can get different magnifying glasses and things. So I’m going to go there with her next week. And next time my daughter’s coming, she’s going to drive us there. But I’ve had very, very limited access to them [CNIB].”

The physical accessibility barrier was not the only aspect of CNIB that made their services unappealing to Joanna. It was also the fact that she had very little knowledge of the services being offered by CNIB, as was evident from her following statement:

“What I use from CNIB is very limited because they don’t seem to have a lot. Well, and I don’t know what they can do for me anyway. I get my eyes tested by an opthalmologist and get the glasses from an optometrist. And I just think, ‘what can CNIB do other than supply devices’? Well, that’s my take on it anyway.”

To overcome barriers in accessing information relating to CNIB’s services, Joanna felt that there needed to be more active communication and advertising from CNIB to keep their clients remain up-to-date with the services they offer:

“I guess it would be nice to know when new things [vision rehabilitation services] come out. I don’t have any communication with them [CNIB]. I have a little catalogue of theirs. I haven’t looked at it lately, but I’m sure it’s still there. But honestly, I’m not sure what they can do. I really don’t know.”
Overall, Joanna seemed to rely more heavily on her personal resources (i.e., emotional intelligence skills and practical strategies for dealing with vision loss) and support from other social networks (i.e., family, friends, family physician, ophthalmologist, etc.) than the CNIB to adapt to various challenges in her life (i.e., vision loss, arthritis, COVID-related restrictions) and engage in her desired occupations.

4.5. Grace’s Story

**Names of Social Networks**

Oldest daughter: Betty

Youngest daughter: Caroline

Son: Josh

Son-in-law: Carter

Urologist: Max

Personal health trainer: Rachel

Staff from the CNIB: Anna

Optometrist: Chris

Grace is an 82-year old widowed woman who has had macular degeneration for 27 years. She is a mother to two daughters and two sons. Both of her daughters and one of her sons live in Ontario, and her other son lives in the United States. Grace used to live in Southampton with her husband and one of her sons, but after becoming widowed in 2011, she moved to London (where her oldest daughter lives) in 2013. In London, Grace first resided at an apartment in Richmond Hill for seven years. Then, in late-September, 2020 (during COVID-19), Grace moved from Richmond Hill to a new retirement home, Fox Hollow (still in London), and at the time of the study, Grace was quarantining at home (due to COVID-19 precautions) during the first interview (October, 2020). She currently lives alone, but her oldest daughter, who lives in London, visits her weekly.
Grace also keeps in touch with her children, over the phone, daily. Grace has been using services from the Canadian National Institute for the Blind (CNIB) for close to a decade, and it was through the CNIB that I recruited Grace for my study. Grace and I held all of our interviews over the telephone, and throughout our conversations, Grace spoke with politeness, positivity, and serenity as she shared her story.

**Gradual Onset and Treatment for Vision Loss**

Grace was first diagnosed with macular degeneration in 1993. She said that when things “looked as though I was looking through water,” she knew something was wrong with her vision. However, Grace left her eyes untreated during the early stages of her vision loss because she “had never heard of macular degeneration at that point so [she] thought it would just go away.” Once she noticed that her vision was gradually becoming worse, she eventually visited an ophthalmologist and was diagnosed with macular degeneration in her left eye. Unfortunately, her eye was left untreated for too long, and she needed to receive a laser treatment by the time she visited an ophthalmologist:

“It got very bad before I went to the ophthalmologist in [Tiverton]. I had to have laser treatment, which left scar tissues on the retina. And so that eye was really bad. I see very little out of that one eye.”

Two years later, when Grace noticed the same symptoms in her other eye, she “knew exactly what it was and headed right down there [Grace’s optometrist].” Thus, in 1995, Grace became diagnosed with macular degeneration in her right eye as well, specifically wet macular degeneration. Unfortunately, in 1995, there was not much that Grace could do to treat her eyes because the angiogenesis inhibitors were not developed yet. These injections can now treat wet macular degeneration conditions by blocking fluid leakage from the abnormal blood vessel growth behind the macula (the primary cause of distorted vision). However, at the time, Grace could only opt for laser treatment for her right eye, and when the eye injections for wet macular degeneration became commercially available, both of her eyes had turned from wet to dry, leaving the injections ineffective:

“There wasn’t much he [Grace’s ophthalmologist] could do other than laser at that point because they didn’t have the injection into the eye for the wet macular
degeneration. And when it did come, then my ophthalmologist told me that mine had changed to the dry, so there was nothing they could do about it.”

Disengaging, Adapting, and Finding Alternative Occupations

Overall, Grace has noticed that her vision “has gotten a lot worse over the years.” With this gradual development, she experienced increased difficulties with various occupations, including social club and physical activities (i.e., participating in the Coffee Club at her previous apartment and group fitness classes) and hobbies (i.e., knitting and crocheting). For instance, relating to the Coffee Club, Grace described how she used to sell membership cards to residents in Richmond Hill apartment so that anyone with the cards could have free coffee. However, when she lost the ability to read small print because of her vision, it made it difficult for her to engage in her club activities, which involved documenting how many cards she sold each day and how much revenue they made. Such challenges made Grace disengage from the Coffee Club entirely:

“I used to help with the Coffee Club, but I gave it up because there was so much deterioration in my eyes that there were different things that I could not do that I used to be able to do. And so I gave it up. I used to be able to sell cards so that people didn’t have to bring money each time they came to Coffee Club. And I used to be able to fill in the forms that told what day that was and how much money we took in. And once I couldn’t fill in that form, then, I gave it up.”

Grace also stated that she is no longer able to participate in exercises as part of a larger group setting. She explained that she now has a hard time seeing the instructor’s movements if they are not near her, and therefore, cannot follow the rest of the group’s pace in exercising. Grace thus disengaged from a group-format workout and instead now has a personal health trainer who helps her exercise at her own pace.

“Well, if I had gone to a class, I would have had trouble seeing what the leader was doing, and that’s why my daughter paid for me to have a personal trainer.”

In addition, Grace described how she “used to like to knit and crochet” but she has “given up on both of them as of now because [she has] trouble reading patterns.” First, she gave up on knitting as she felt that “if [she] ever dropped a stitch, then [she] couldn’t pick it up” and would “need to start over from the start.” Grace then replaced knitting with crocheting, and she found this hobby much more comfortable to engage in
because “it just involves one stitch at a time. So if I drop the stitch, I could pick up again.” However, Grace eventually quit crocheting as well when her macular degeneration developed further because it became increasingly difficult for her to read the crochet patterns:

“Well, I did enjoy it [crocheting]. I had a lot of pattern books that my family gave to me. But I gave them all away when I left [Richmond Hill] because my vision has gone bad enough that it was too difficult for me to even crochet. So I gave my yarn and all the books to a lady in my building that does a lot of knitting and crocheting.”

Grace then moved on from crocheting and embarked on a new hobby of listening to audiobooks:

“I’ve started to use a lot of audiobooks, so I am listening to them rather than doing the knitting and crocheting exercises. And I get them from the library now, so I don’t have to pay for them.”

From Grace’s narrative, it is evident that there was a decline in her engagement with her hobbies and social occupations, which coincided with the gradual loss of her vision. However, throughout these gradual processes, Grace has managed to find several replacement activities that occupy her time and energy.

**Using Assistive Technology and Modifying How Occupations are Carried Out**

In addition to her social occupations and hobbies, Grace also experienced changes in how she engages in her religious activities (i.e., singing hymns) and instrumental activities of daily living (i.e., reading and banking). With these occupations, Grace relied on assistive technologies (i.e., digital hand-held video magnifier and CCTV desktop magnifier) to maintain her engagement. For instance, Grace expressed how singing hymns became much more difficult after losing her vision as it is hard for her to read the lyrics. Thus, she now uses an Eschenbach SmartLux (digital hand-held video magnifier) to enlarge the text. Grace particularly likes that this magnifier has multiple viewing modes that allow choices of text and background colours that facilitate her reading better:

“It’s [Eschenbach SmartLux] a magnifier, and the text will show up in different colors. I like just the black and white. So black text on the white background
shows up best for me, and well, I take it to church on Sundays, and I use it for the hymns.”

Regarding reading smaller prints, Grace also talked about how she uses a CCTV desktop magnifier, supplied to her by the University of Waterloo Optometric Clinic. Grace explained that using the CCTV makes it easier for her to find places she left off reading or signing paper forms:

“I have a CCTV that I got through the University of Waterloo. And that was five years ago, but it’s still working, and so I’m using it as well. Well, it’s a reader, and it has a tray that you can put papers on, and the tray moves, like I put the reading material on the shelf, and it shows up above [on the viewing screen]. So I can fill out forms using it. It’s getting difficult [to fill out forms] because of my vision loss. I have trouble finding out just where that mark should be or where the signing place should be.”

Grace also uses an iPad, which she bought through the assistive devices program (ADP), which is a funding program through the Ontario government that funds equipment and supplies for individuals with long-term physical disabilities. Grace explained that she used ADP funding to partially (75%) pay for her CCTV, which was assessed by the University of Waterloo low vision clinic, while her iPad was assessed by the Canadian National Institute for the Blind (CNIB):

“I got a large iPad through the ADP program, but I was assessed by the CNIB this time rather than going to The University of Waterloo for my assessment.”

Grace expressed that with her iPad, she can easily “do the online banking because [she] can use the two-finger magnification.” Grace finds her iPad to be “a big help” in managing her finances as she “does not need to physically go to the bank,” which is challenging for her as she cannot drive and is restricted in terms of community mobility.

Changing Priority on Independence Arising from the Loss of Ability to Drive
Grace revealed that her vision interferes with her ability to drive, stating: "I haven't been able to drive since 1995; that's when the second eye also went bad." Relating to losing her driving ability, she expressed, "I lost my independence when I couldn't drive anymore." Grace explained that since losing vision in both eyes, she had been "dependent on her husband" to drive her places, until he passed away in 2011 from a car accident:

"It was an accident, a car accident when he was driving the car. He went through a stop sign and was broadsided, and he had eight broken ribs, and he developed pneumonia because of that, and refused to go on the machine to help his breathing."

Grace expressed that after losing her husband, she felt even more restricted in her community mobility because there was no public transportation system in the village where she lived with her husband:

"I lived in a village in [Southampton] with a thousand people, and they didn't even have a taxi, and of course, no buses."

After the loss of her husband, Grace asked her children and friends more frequently for rides to access community services, and she felt "more dependent on family and friends for getting around." When Grace was living together with her husband, they had "similar schedules as each other." Thus, her husband was almost always available to drive her, and she could visit places she desired to go, at her own pace. However, after her husband passed away, Grace had to rely on her children and friends who weren't living with her. As a result, they did not have similar schedules, which meant that Grace was limited in terms of when and where she could go out as she had to "follow other people's plans" and could only visit places "they were willing to drive [her]." Overall, Grace experienced "increased wait-times to go to the places [she] wanted to go." Grace added that this was one of the central reasons why she "moved from [Southampton] to London in 2013" because there are "plenty of buses in London." Since moving to London, she has "thoroughly enjoyed using it (the public transportation systems)." In addition to using busses, Grace also frequently uses a private transportation system (i.e., Checker's taxi service). Grace has a Checker cab account that has her apartment address and contact information registered. Therefore she can be picked up
from her apartment and conveniently travel to places she needs to visit through this paid service:

"I can call the Checker cab, and they know, like when I lived in [Richmond Hill], I just needed to call them, and they knew that they had my phone number, and they knew that it was me that was calling, so they came to get me from my place. So it was a great service."

While talking about losing her independence, Grace spoke of how she couldn't reciprocate much of the social support she receives from her family. For instance, Grace mentioned how her family helps her with house chores, such as food preparation, and technological support, such as setting up apps and zoom meetings on her iPad. However, for Grace, her vision interferes with her ability to reciprocate. For example, Grace felt that any occupations she could undertake, her children could accomplish them better than her as they have better visual function:

"I'm not able to help them with technology at all. They [Grace's children] help me with the new technology. And I can't help them with the food preparation anymore because they all do it better than I ever can."

When I asked Grace how she felt about being reliant on her social networks, Grace responded, "I'm honestly not sure how to think about it; it's hard." She is, however, comfortable admitting that her vision makes her increasingly dependent on her social network, she is open to sharing her vision loss diagnosis with others, and generally is not hesitant to ask for help when needed. For instance, Grace often requests the tenants and staff at Fox Hollow to press her desired floor number on the elevator:

"I often tell people that I have low vision because I had to learn the elevator controls here [Fox Hollow]. And I did ask for help. A lot of times, I had to ask the person where the N is because I'm on the Nth floor. And usually, people are very helpful here, and they [residents and staff in Fox Hollow] understand when I say I have low vision."

Grace also did not hesitate to request help from strangers. For instance, Grace spoke of how she frequently relies on pedestrians to let her know the changes in traffic lights to help her cross the road safely:
"I did get some help with the gentleman at a corner because I have trouble seeing whether the walk-light is on or the not-walk light is on."

Overall, Grace still valued autonomy and was not fond of becoming more reliant on her social networks due to her vision. However, maintaining independence did not seem to be on the top of Grace’s priority list. Losing her ability to drive forced Grace to place less significance or importance on independence, and she became more able to let it go for the sake of getting things she wanted or needed to get done, accomplished. At the time of the study, Grace seemed comfortable accepting her vision loss diagnosis as part of her identity. There was no shame associated with letting others know of her vision loss, and she responded positively to any help provided by others and even welcomed their assistance.

**Family Support Encourages Self-Acceptance of One’s Vision Loss**

Grace posited that what facilitated her inner strength and enabled her to feel confident in herself, even while relinquishing her independence, was the support she received from her family members. Her children always looked out for her safety. For instance, her sons advised her to carry a white cane around to let others know that she is visually impaired and be more considerate of her circumstances. Grace’s sons also encouraged her to reach out for help when she needed it, explaining that carrying a white cane is one of the ways of signaling to people that she is willing to accept help from others:

“Well, they [Grace’s sons] both think that I should carry my cane more often, and I did take it with me yesterday when I went out for a walk... And so I guess with my cane, people then know that I might need help, and that’s what my children have said all along.”

Grace stated that her sons’ advice helped her “feel less embarrassed about her vision loss” and boosted her acceptance of her diagnosis. In acknowledging that her children emotionally supported her throughout her struggles with managing her vision loss, Grace said, “all my children are great emotional supporters. Yep, they all are; they empathize with any challenges I have.” Grace expressed that she communicates regularly
with her children who live outside of London through Facetime. Concerning her daughter in London, Grace said that she speaks with her in-person whenever her daughter visits her apartment:

“Well, my one son lives down in the States, and I Facetime with him. Well, I Facetime with all of my children other than [Betty], who is the designated caregiver, the one in London. And they only allow caregivers to visit [retirement homes] now [because of COVID]. But I do face time with all my other children. One son lives around [Southampton], where I used to live with my husband. I’m more in touch with the one in the States. But I also Facetime with [Josh], who lives near [Southampton]. And with my daughter in [Aurora], we usually Facetime each week, and she calls me by telephone when she’s coming home from work. So I usually am in touch with her each week.”

The Importance of Informal Social Support in Facilitating Advocacy and Engagement in Desired Occupations

Grace added that her children not only provide her with emotional support by listening to her talk about vision loss and empathizing with her struggles, but also provide her with instrumental support. For example, her children have helped Grace with moving houses, driving her places, providing her with financial support, supplying her with low-vision aids, and being her spokesperson. For instance, Grace described how her daughters, Betty and Caroline, and her son-in-law, Carter, helped her move from Richmond Hill senior’s apartment to Fox Hollow retirement home:

“My son in law and my daughter, who live in London, they helped me move. Well, and so did [Caroline], who lives in [Aurora], came down one day, and helped me pack for the move.

Grace added that Betty and her husband, Carter, often give rides whenever she needs to go to the grocery store or medical appointments:

“[Betty] and [Carter] also helped me with grocery shopping, especially since I’ve been quarantined [after moving to Fox Hollow]. I haven’t been able to go to
the grocery store. But they also helped with grocery shopping before COVID. When I lived at [Richmond Hill], I could walk to the Metro in the mall there, but if I wanted to go somewhere farther, like Costco, they would take me or pick up things for me there. And I am also dependent on my daughter to get to the doctor’s appointments.”

Moreover, Grace expressed that Betty provides her with financial support by paying for her groceries, Checker’s cab account, and gym membership:

“They [Betty and Carter] usually don’t charge me for the full amount of groceries they buy for me. And my daughter that lives here has supplied me with a Checker account [Taxi service app] that she pays for, and I have used that many times. I also used to have at [Richmond Hill], a personal trainer that [Betty] paid for, and we worked in the health club that was in the building across from mine.”

In addition, Grace described that her son, who lives in the United States, supports her financially by paying for her Internet:

“My son in the State is going to pay for my Internet connection. He’s so far away in [Idaho] State that he thinks that’s the only way that he can help; by paying for something.”

Furthermore, Grace mentioned how her youngest daughter, Caroline, is an optician and talked about how she can access many of her low vision aids such as her Eschenbach SmartLux magnifier through Caroline for free:

“I have a daughter who is an optician. She’s my youngest daughter, and she lives in [Aurora] and works with an optometrist in [Aurora]. She has been able to get me magnifiers; like I have Eschenbach SmartLux [digital handheld video magnifier] that I really like, and I use that for a lot of things. So she is a great help when it comes to magnification.”
Grace further noted that Caroline helps her with technological tasks, such as setting up apps on her iPad (i.e., Libby app, which she uses to borrow digital audiobooks from the public library):

“She [Caroline] was the one that put the Libby, which is the program for the libraries, and she put it on my iPad for me. So she has been a great help as far as that goes.”

Relating to playing the role of a spokesperson, Grace talked about how her daughter in London, Betty, advocated for her when she visited a urologist because of her bladder leakage. For instance, Betty communicated to the urologist that Grace has difficulties with reading small labels because of her vision, and let him know about the challenges she may face when measuring the exact dose of prescribed liquid or cream medicine using a dosing syringe:

“I have a problem with leakage in the bladder. So I have an appointment on the ninth of October to meet with Dr. [Max] at the Victoria Hospital. And [Betty] is planning on going with me to that appointment. [Betty] was there [hospital] with me before [previous appointment], and she explained to him [Grace’s urologist] that, you know, I wouldn’t be able to see a measure [on a dosing syringe].”

Grace mentioned how she had friends from her Coffee Club that would also advocate on her behalf. For instance, before Grace disengaged from the Coffee Club, her friends explained to the tenants buying the membership cards that Grace needed more time filling out the forms because of her vision and asked for their patience. They also protected Grace from the tenants who tried to take advantage of her vision loss (i.e., getting a free cup of coffee) by calling out those people and letting them know that their behaviour was unacceptable.

“I had a lot of help up until I quit [the Coffee Club]. And they [Grace’s friends] would help me fill out the forms, and the only negative thing that I can think of was when one lady put her cup on the top of her head. And of course, I couldn’t see that. So she was saying that she wanted another cup of coffee. And I didn’t
see it. And there were a lot of people who understood that I couldn’t see the cup on top of her head. They told her that she should not do that anymore when I was on the job.”

Using Formal Social Support to Engage in Instrumental Activities of Daily Living

Throughout her vision loss journey, Grace received a lot of social support from her formal social network, just as she did from her informal network. Grace described how her formal social network helped her maintain her engagement in various IADLs (i.e., managing medications, being mobile in the community, and using technological devices) and physical (non-group based) activities. For instance, Grace’s personal health trainer from Richmond Hill apartment, Rachel, provided her with instrumental support while Grace engaged in her physical activities. For example, Rachel recommended different exercise routines for Grace and helped her create her own fitness program that was not strenuous on her eye condition. Being mindful of Grace’s vision, Rachel assisted Grace with using “strength machines so that [she] could adjust it to [her] size and strength.” Rachel also helped her “specify the settings on exercise equipment with dials” such as treadmill and stationary bikes. Overall, Graces’ trainer supervised her while she worked out on gym equipment to make sure that Grace was safe while operating those machines:

“The health club [at Richmond Hill] has machines and weights that the personal trainer knew how to run, and so that was where we worked. I had a personal trainer come twice a week... [Rachel], my personal trainer looked after the machines for me there, and she led me as far as what I should be exercising. So that was a really good thing for me to do.”

Grace noted that she has not yet hired anyone to be her new personal health trainer in Fox Hollow because her recent move coincided with COVID-19, and thus, she was self-quarantining and still getting used to her new home at the time of the study. Concerning managing medications, Grace talked about her urologist, with whom she shared a very positive relationship. Grace said that her urologist is communicative when recommending any medical procedures (i.e., hysterectomy and bladder repair surgeries)
and medications to help control the symptoms of urinary incontinence. Grace thus felt that he provides her with sufficient informational and instrumental support relating to her bladder leakage:

“I just had the appointment [with Grace’s urologist] a couple of days ago, and he was great. He has suggested different things that might help with the leakage, and he was great. I had a hysterectomy and a bladder repair when I was, well, close to 50, and I needed to get that done again recently.”

Grace also mentioned how her urologist has a “very personable personality.” He was conscious and understanding of Grace’s vision loss and recognized that looking at specific measures are more difficult for Grace. Therefore, instead of indicating the amount of leakage-controlling medication she is supposed to apply in the metric system or imperial units, he recommended a different method of measuring the amounts of medications (i.e., using finger knuckles as a measurement system):

“He understood that I would have trouble seeing... He advised that... Like, I have a cream that I would insert into the vagina, and it should help with leakage. And so he said, ‘just take a small amount up to the knuckle’ and told me to do it every day. He called it a knuckle amount rather than telling me to use the applicator. So, yes, he understood what I was talking about as far as the vision loss goes.”

In an effort to support her community mobility, Grace remarked on how CNIB provides her with affordable transit passes for municipal transit in London, such as busses and trains:

“I have a CNIB card and CNIB transit. So, it cost me ten dollars for a year. They can’t get any cheaper.”

Grace added that the CNIB card allows her to travel alone to complete her errands and appointments (i.e., grocery shopping and doctor’s appointment) when her family and friends are not available, without worrying about the financial accessibility of using the public transit system. As such, Grace feels that the CNIB card that gives
discounts on her travel helps her live a “more active and independent life” in London. Noticing how the instrumental support from the University of Waterloo and CNIB facilitated Grace’s engagement in several IADLs, I asked Grace whether she desired any other services or support from these vision rehabilitation organizations. To this question, Grace responded that she used to have more active communication with CNIB when she knew someone personally from there. Unfortunately, the person with whom she had a personal connection retired from CNIB. Since then, Grace has had less frequent communication with the organization:

“I haven’t accessed them [CNIB] for a long time now. I used to contact [Anna], who worked for them, and I could email her or call her. But of course, she is retired now, so I haven’t tried to get anybody else.”

Grace expressed that before Anna retired, she used to visit Grace’s home to place raised bump stickers on the buttons of her home appliances (i.e., oven, microwaves, etc.). Using such tactile information, Grace could turn on and off the appliances more easily:

“I used to know a lady that worked for CNIB, but she has retired now, but she used to come and put little bumps on equipment. So that you would know where the on switch, and off switch were. And I think that I’m going to have to call the CNIB and they must have replaced her with somebody that would come and do that for me on my microwave and this new stove. I don’t know how to run the oven yet.”

Overall, Grace longed to be reconnected personally with another staff member from CNIB so that she could have her home environment adapted to be more vision-friendly and increase the overall safety of her home. Finally, Grace mentioned how Fox Hollow staff provided her with technological support (i.e., teaching her how to use Facebook and setting up Zoom meetings on her iPad) which assisted her in transitioning from physical to more online social interaction during COVID-19:

“[Fox Hollow] is trying to get things working again and getting people to interact with each other [during COVID-19]. And they are going to help with
**Zoom meetings and Facebook interaction. And they offer I think, help with iPad. Or they call them tablets, but I have an iPad, so they’re going to help with that.**”

Grace mentioned how this technological support was especially helpful for her as her vision has made it challenging for her to see mobile device screens for a prolonged time. As a result, she has had difficulties with learning to use new social media platforms on her own:

“*Well, with technology, it’s hard to see the screen because of my vision. So I don’t know how to use Facebook other than just looking at what other people do. So I’m looking forward to learning what other things can be done with Facebook.*”

**The Importance of Integrated Vision Care**

In talking about the vision care she experienced from various institutions (i.e., CNIB and the University of Waterloo) and her formal social networks (i.e., ophthalmologist and optometrists), Grace mentioned how it had been integrative in nature, with different vision care professionals using a collaborative approach to communicate information about her condition with one another. In particular, Grace mentioned the relationship between her optometrist, herself, and CNIB, describing how her optometrist relayed the documentation of her current vision status to CNIB so that CNIB could update her vision profile in their client records. Before Anna retired from CNIB, Grace communicated about her vision conditions with CNIB through Anna. However, after her retirement, Grace's optometrist took over Anna's role and conveyed the chronological account of Grace's disease progress and treatments received to CNIB at her request:

"*I have a new optometrist since I moved here to London, Dr. [Chris], and well, the CNIB contacted me when [Anna] retired, and they wanted an update on my vision. And so I called his office, and he said that he would do that, or his secretary would do that promptly.*"
Grace added that her optometrist is "a very friendly man" who is "also very informative." Her optometrist provided her with both instrumental and informational support by routinely conducting retinal imaging on her eyes and actively communicating to her about the progression of her vision loss:

"I like him [Grace’s optometrist] a lot because he's down to earth and helpful and explains it well. And he takes a picture of my retina when I go to him, and that's once a year. He's a very friendly man, but he's also very informative."

Grace noted that her optometrist had effective communication skills that made it easy for her to "understand his decisions" about a course of treatment for her macular degeneration. Moreover, Grace highlighted how important integrated vision care has been for her in terms of effectively coordinating the delivery of vision supports. For instance, she was "able to apply for a CNIB transit card and ADP assessment by CNIB because [her] optometrist had provided [her] health information to CNIB." As mentioned earlier in her narrative, these vision supports are necessary to facilitate her community mobility and access vision aids. Thus, integrated vision care ultimately supported Grace and her engagement in her desired occupations.

The Compounding Influence of COVID-19 on Occupational Engagement

At the time of the study, Grace was severely limited in the range of occupations she could engage in because of the cumulative impact of COVID-19 in addition to the effects of her vision loss and other health conditions (i.e., bladder leakage). Grace expressed that when she was still living in Richmond Hill, all of their public facilities (i.e., knitting club, fitness center, coffee club, etc.) were closed down due to COVID-19, which limited Grace’s participation in her desired hobbies and social occupations:

“In [Richmond Hill], the coffee club that I used to go to at least four times a week was canceled, and the knitting club was canceled. And the exercise as well. So it really meant that there was nothing to do except stay in your apartment or go for a walk”
After she moved from Richmond Hill to Fox Hollow retirement home, Grace was placed under self-quarantine for two weeks due to the residential enforcement of COVID-19 regulations. Due to her quarantine, Grace couldn’t engage in religious activities, an important occupation for Grace, even though churches were open at the time of her moving in:

“Since I’ve moved into [Fox Hollow], I haven’t been able to go to church even though my church has opened up because well, I am under isolation.”

Grace expressed that she felt socially isolated and bored during her quarantine as she was no longer able to participate in any occupations that involved physical contact with another person:

“Well, I feel isolated because I’m not able to even go down to the dining room [in Fox Hollow].”

Even after her quarantine ended, COVID-19 delayed, or otherwise cancelled, Grace’s participation in many of the occupations she needed or wanted to engage in. For instance, Grace mentioned how her healthcare appointments with her urologist for her bladder leakage has been “delayed multiple times and have changed twice, maybe three times” over several months. This delay was especially troubling for Grace as the leakage in her bladder compromised her community mobility by forcing her to stay close to washrooms and thereby limiting her traveling distances:

“Well, I have to stay close to a bathroom [because of the bladder leakage], and I wear a padding that helps to prevent leakage.”

In talking about her impaired mobility, Grace also talked about how COVID-19 caused Fox Hollow’s shuttle bus service to close down and how this made it challenging for Grace to shop for her groceries. Grace explained that she had always used the CNIB card to go to the grocery stores when she lived in Richmond Hill, but Grace was planning on using the shuttle bus from Fox Hollow once she moved into her new home. Unfortunately, Fox Hollow was not offering their bus service because of COVID-19, and she became more dependent on her daughter and son-in-law (in London) to drive her
around the community to complete her errands (i.e., bringing Grace’s groceries to her place):

“I have a CNIB card that says that I can ride any of the city buses, and I used them when I lived at [Richmond Hill]. But the [Fox Hollow], I understand, has a bus that takes people shopping. But not now; they’ve shut it down because of COVID. So my daughter and son in law had done my shopping ever since I moved in here other than milk and bread because I still have eggs that my daughter bought for me before I moved in.”

Overall, Grace noted that the cancellation of her healthcare appointments for her bladder issues and the ceased operation of the Fox Hollow bus, due to COVID-19, compromised her community mobility further and made her more dependent on her informal social network for rides. Grace emphasized that she experienced this impairment in community mobility “on top of the restrictions [she] already felt because of vision loss” and the consequent inability to drive.
Chapter 5: Results

In Chapter 5, the overarching themes constructed through the thematic and structural analysis of participants’ narrative data are presented. This chapter also provides an overview of the participants’ demographic information. In order to promote anonymity, the names of the participants, the people in their social networks, as well as the geographic locations presented in the quotes, have been replaced with the same pseudonyms presented in Chapter 4.

As shown in Table 1, the age range of the five participants in this study was between 67 and 91 years old. The length of time that the participants had been diagnosed with an ARVL condition ranged between 10 to 25 years. Three of the participants were diagnosed with age-related macular degeneration, and two participants had glaucoma. All participants were Caucasian females and identified as having partial sight. In particular, two participants self-disclosed as having mild vision loss, one participant self-reported an intermediate degree of vision loss, and two participants had severe self-reported vision loss. All study participants had children, but most of them lived alone, and were either widowed or divorced. Only one participant was currently married and living with her husband. All participants had more than a high school education, with most completing a university education. Most participants earned an annual household income of more than $50,000, with the exception of one participant who earned below $25,000.

Table 1: Participants’ Demographic Information

<table>
<thead>
<tr>
<th>Participant’s Pseudonym</th>
<th>Linda</th>
<th>Brendell</th>
<th>Jenny</th>
<th>Joanna</th>
<th>Grace</th>
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<td>Completed university</td>
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<tr>
<td>Annual Household Income</td>
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<td>$50,000 - $100,000</td>
<td>$50,000 - $100,000</td>
<td>&lt; $25,000</td>
</tr>
<tr>
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<td>Age-related macular degeneration</td>
<td>Glaucoma</td>
<td>Age-related macular degeneration</td>
<td>Age-related macular degeneration</td>
</tr>
<tr>
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<td>Mild (Partially sighted)</td>
<td>Intermediate (Partially sighted)</td>
<td>Severe (Partially sighted)</td>
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The five overarching themes relating to the shared aspects of social networks that emerged in participants’ descriptions of engagement in desired occupations while adapting to ARVL are as follows: (1) Maintaining Engagement in Social Occupations to Foster a Sense of Belonging; (2) Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs; (3) Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships; (4) Community Mobility as Essential for Preserving Social Relationships; and (5) Technology as a Support to Social Connectedness: Connecting via Technology versus in Person.
5.1. Maintaining Engagement in Social Occupations to Foster a Sense of Belonging

Throughout the interviews, participants consistently expressed their strong desire to maintain their involvement in meaningful social occupations despite the limitations of their age-related vision loss:

“I couldn’t see in the theater, the movies. I could barely see the stage because my sight is pretty narrow. But we [participant and her friends] still get together and do things together. In fact, another thing I really like doing is camping, which we’re doing right now. And a lot of times, we go with their husbands, my husband, and my dad, I mean camping. Now we do things like wine tours and all that kind of stuff too […] I enjoy travelling with people and my husband does all the driving when we travel because of my vision. For example, like when we’re visiting my daughter’s family in [Montérégie], so I just read and sleep on the way, and we play with our grandchild. He’s three years old, so he’s a lot of fun and never sits still, he is really cute, and we love him.” (Jenny)

Participants stated that engaging in occupations with their social networks helped them feel less isolated and enhanced a sense of belonging and connectedness with their community. For example, Linda described the importance she placed on maintaining social connections through occupation by stating:

“Having those close friends, it makes a difference, that support group. They’re not there, but they are part of your life. It’s what enriches your life. Being able to go and do things, learn things and see new places with them, you know […] It’s important for me to go out and do something with people every day. So, there is a rare day when I would be at home by myself and just sort of reading and doing nothing for a while. Most of the time, I have something scheduled; either a Scrabble club or something else. And I travel a lot, so at least one weekend a month, I’d be visiting friends, visiting my friends in Toronto or visiting my daughter, visiting my son, going here and there.” (Linda)
Unfortunately, at the time of the study, COVID-19 (an infectious pandemic disease first reported in 2019, caused by SARS-COV-2 coronavirus) acted as a barrier to interacting with one’s social networks, thereby limiting participants’ engagement in various social occupations, including social outings with friends such as going to the theaters or dinners and visiting each other’s homes:

“And our friends, we used to do theater every month. But we can’t anymore, so that’s down. And we used to go to each other’s houses, but now we don’t want to go into each other’s houses. And I don’t want to invite people here because of my dad, so we’ve gone out to a restaurant one time. And we did all go to one of my girlfriends’ house, and we ate outside, wearing masks when we had to go through the house. So I haven’t seen my friends as often as I used to do.” (Jenny)

Other social occupations, including physical activities (i.e., going to the gym, Aquafit, etc.) and cultural activities (volunteering in the community, participating in social clubs, attending peer-run courses, etc.) were also negatively impacted by COVID-19. These restrictions to occupational engagement were often associated with feelings of boredom and loneliness, further highlighting the connection between social occupation and belonging through describing the implications arising from decreased social occupation:

“There’s no going out to meetings. There’s no going out to courses, no Aqua-Fit, no gym, there are no social events. You know, we used to have social events. I used to do volunteer teaching with the Thames Valley School Board. None of that’s happening [...] And there are moments when I still feel somewhat isolated, even though we are getting together maybe once a week with a friend. And, you know, we did some takeout food last week. And then, when the restaurant patios opened, we went out for lunch on one patio. But, you know, you go once a week somewhere. That’s not what I’m used to. And so, yeah, there are moments when you sit here, and you go, ‘Okay, what am I going to do?’” (Linda)

“Well, in [Richmond Hill], the coffee club that I used to go to at least four times a week was canceled, and the knitting club was also canceled, and the exercise
as well. So it really meant that there was nothing to do except stay in your apartment or go for a walk [...] So, I feel isolated because I’m not able to even go down to the common dining room [closed down due to COVID-19].” (Grace)

In addition, participants who were not living with their families were particularly affected by COVID-19 as they had to either cancel or delay their visits with family, which typically brought them a great sense of belonging:

“‘My daughter, the one in [Montreal] facetimes me every day, and I talk to the grandson Alister every day. He’s always wanting to come to our place, of course, but because of the COVID-19, she’s afraid of giving us COVID-19, so we haven’t seen her since January.’ (Jenny)

“I have been going every Christmas to [Vancouver], but I’m not going this year because of the COVID-19. I don’t think the planes are going to be ready to, you know, to feel safe. So I’m not going this year.” (Brendell)

Participants also generally perceived that they were at greater risk of contracting COVID-19 due to their age and, as a result, were strict in self-imposing social distancing restrictions on themselves. Their vigilant attitude towards abiding regulations naturally impeded their ability to engage with their social networks, and participants generally shared a heightened sentiment of longing for social connectedness during COVID-19:

“I miss my people, but again, it’s not because of my eyesight, it’s because of this virus... I’ve been very, very strict about self-isolating [...] I don’t go anywhere, except for my walks, but I’m always on my own when I walk [...] So, it’s hard because people are not really connecting right now. Especially a lot of the older people are not as connected with this thing and everything else. Where I am and where a lot of my friends and people of my age and older are, even if you have the grandkids close by, during this [COVID-19], you’re not able to interact with them [...] So some of my friends felt isolated from their grandkids, even if they live around the block because they can’t be with them, for fear of getting the virus.” (Brendell)
On the other hand, for some participants, fostering a sense of social connectedness was not as important as the act of engaging in desired occupations, which often did not include others, but rather were solitary activities. This was partly as a result of social distancing requirements of COVID-19, but also due to a personal preference for some participants. For instance, Brendell remarked that she has always enjoyed solitude but felt that society considers spending time alone as synonymous with being socially disconnected:

“I have two ladies who work with me. I talk to them when we’re together, but I don’t socialize with them. I’m starting to sound rather snobby, aren’t I? But I’m not. I just, you know, it’s just something I’ve never done. See, I’m very independent... I’ve never been a person who interacts with a lot of people in my home [...] It doesn’t bother me. I like alone time. I don’t have to be with people all the time. It sounds terribly callous, doesn’t it? But it’s not. It’s just, you know, I just never had a lot of people in my home.” (Brendell)

For those participants who enjoyed being alone, COVID-19 provided them with the space necessary to enjoy solitary leisure activities (e.g., watching TV, doing puzzles, walking) and focus on their personal needs. This had not always been possible before COVID-19 due to feelings the participants had that they needed to be productive and contributing members of the community:

“Yeah. I never watched TV before, hardly at all, except in the evening and I treat myself to a baseball or a hockey game [...] Well, actually, it’s been quite fun because I’m a big sports fan. I think I told you. And on the sports programs, they'd been playing all the old baseball games, old tennis and curling and hockey. So I’ve been able to watch decent games. So that really makes me feel good.” (Brendell)

In practicing self-care during COVID-19, the participants desired to stay physically and psychologically occupied in an effort to provide themselves with purpose and structure to their daily lives:
“Well, if I didn’t do them [daily routines], I don’t know, I think it would be a terrible day. You know, I can’t imagine just sitting doing nothing. I never do that. I’m always sort of watching, reading or, you know, like walking. I love my walks. I really love that. In the winter, I walk up and down the corridor, but now I can walk outside. So it’s really nice [...] Well, I also do more puzzles. I love puzzles and things because it keeps my brain going. You know, this is a sort of peculiar time because normally, I wouldn’t be home. I’d be in the office doing stuff. So if you’re home all day, you have to find things to do.” (Brendell)

Some participants described comfort in living alone, however, they acknowledged that this was because they had friends or family members living nearby who could come to their assistance if needed. Therefore, participants described the importance of positively perceived social support in fostering social connectedness. One participant, in particular, expressed that despite living alone, she felt supported, knowing that her friends and brother were in the immediate vicinity of her neighbourhood:

“I live alone. I live in a senior’s apartment complex. So, there are people around me here all the time, and so it’s not like I’m isolated. And I don’t need to get out that much so I’m quite happy being by myself. And my brother lives in the city and he lives close. So that’s a bit of a comfort. I know if I’m in trouble, I got him to contact.” (Joanna)

While participants generally enjoyed engaging in social occupations with their immediate informal networks (i.e., friends and family members), they stepped back from larger group social occupations, such as exercise classes and club activities. Such occupational disengagement partly stemmed from a fear of slowing the group down, or otherwise being a burden, as they generally felt overwhelmed by the fast pace of the group:

“Well, if I had gone to a [exercise] class, I would have had trouble seeing what the leader was doing.” (Grace)
“Well, I used to help with the Coffee Club, but I gave it up because there was so much deterioration in my eyes that there were different things that I could not do that I used to be able to do, and so I gave it up. I used to be able to, we used to sell cards so that people didn’t have to bring money each time they came to Coffee Club. And I used to be able to fill in the forms that told what day that was and how much money we took in. And once I couldn’t fill in that form, then I gave it up.” (Grace)

Participants also frequently disengaged from competitive occupations, such as Bridge, as their vision loss interfered with their ability to play cards without needing accommodations, such as large-print cards:

“Well, my favorite pastime was playing bridge. It’s competitive, and I really enjoyed it. But it got to the point where my vision was not good enough to play in the good games [...] I need larger cards, and they don’t have those at the competitive bridge games.” (Joanna)

Based on the participants’ narratives, it seemed that a sense of belonging was an important driving force behind their engagement in social occupations. While feelings of social exclusion and negative perceptions of the self (i.e., viewing oneself as a burden or as not having the ability to keep up with certain occupations or groups), acted as barriers to older adults’ engagement with social occupations, the close informal social networks of participants helped them to substitute their discontinued social occupations with other activities. For instance, Joanna described that she now plays Bridge socially with her neighbours, as opposed to competitively, where there is less emphasis placed on speed:

“People will tell me... if the cards aren’t right in my hands, and I need to see. Like, I can ask, ‘what’s that’? And they’ll tell me, they’re very good. They realize [that I have vision impairment] because usually, they are people that live in the same complex as I do.” (Joanna)
5.2. Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs

This theme is broken down into three subsections. The first sub-theme demonstrates the varying needs of participants across different severities of vision loss and focuses on how formal networks support participants’ pursuit of fulfilling their needs. The second sub-theme explores the barriers in accessing vision care support from these formal networks. The last sub-theme describes the wide ranges of social support provided by informal networks and how participants use them to engage in diverse occupations.

5.2.1. Formal Network Usage across Different Severities of Vision Loss as Sources of Informational and Instrumental Support.

All participants described experiencing changing occupational and psychosocial needs as the severity of their vision loss progressed. For instance, several participants noted the increasing range of occupational adaptations needed as they transitioned from vision loss in a single eye to both eyes:

“I’ve had glaucoma now for well over 15 years, and vision loss has been very slow. I’ve lost about half the field of vision in my left eye but having two eyes, you don’t notice it unless you close the one and then the other one isn’t working […] Though as soon as my good eye got impacted, I couldn’t function with just the one that’s lost half its vision. So, I needed someone to drive me, even to help me walk.” (Linda)

Participants accessed various supports from different social network members in order to fulfill these changing occupational needs. Additionally, the ways that they interacted with their social networks varied depending on the severity of their vision loss symptoms. For instance, participants with milder vision loss were less reliant on their social networks for help adapting to the changes in their occupational engagement, which mostly comprised of difficulties with driving, reading, or prolonged use of monitors:

“My eyes just get blurry, and then I start seeing double, and I can’t... So I have to be careful not to just read. Like in my younger days, I would just read a book
for hours. You know, like when you’re studying at university, studying for hours,
I can’t do that […] And I have a great sensitivity to light, so I have trouble going
outside […] Driving long distances gets harder. It’s the concentrating on
watching the road that gets hard.” (Linda)

“On the London Scrabble Club, we’re all playing online instead of going to the
meeting where we usually would play each other in person. So we’re using
online capabilities to do that. And that again, it’s a little bit harder when you
can’t see that well, to play for two hours or three hours like on the screen. I find
that difficult.” (Linda)

Participants with milder symptoms of vision loss generally used compensatory
strategies, not involving social networks, to manage pragmatic challenges. For example,
they avoided driving at night or took more frequent breaks while engaging in desired
occupations (i.e., reading or working on computers):

“I drive, but I don’t drive at night… I find the new cars with the white headlights,
like they blind me. I just don’t see well. You know, there’s some new cars, and
their headlights are very, very white, and I don’t want to have an accident.”
(Brendell)

“I do quite a lot of work on the computer. So some of that is challenging for me,
because like I said, I can’t work at the pace that I used to work. So I have to do
things more slowly. I have to be careful not to overdo it.” (Linda)

Rather than relying on social networks for practical supports, participants with
milder symptoms of vision loss exchanged emotional support with their informal social
networks in an effort to cope with the psychological impact of their vision loss diagnosis.
As an example, Linda mentioned how her friends would check in on her to ensure her
personal wellbeing after a major eye surgery:

“But my friends who know my vision problems, they’ve become very solicitous.
You know, they’ll ask, How is your eye? How are your glasses? How is it
doing?” (Linda)
Although participants with milder self-reported symptoms of vision loss focused primarily on their psychosocial adaptation while discussing changes to their occupational engagement, they also talked about the vision care support they received from their formal social networks. In particular, they described how their optometrists and ophthalmologists provided them with access to healthcare referrals, diagnostic tests (i.e., for measuring intraocular pressure and visual field), medications (i.e., eye-drops), laser treatment, surgery, and information regarding their vision loss progression:

“My ophthalmologist explained to me that glaucoma is like a plumbing problem. So you have blockages in the pipeline. So that prevents the normal sort of self-cleaning process inside the eye. So it gets blocked up, and then the pressure builds up, and that can damage the retina, and that’s what causes the blindness, the build-up and pressure.” (Linda)

“Nowadays the optometrists, they always check the pressure in your eye. As soon as they detect an increase in your intraocular pressure, they monitor that, and if it reaches a certain critical point, they send you to see the ophthalmologist. When you reach a point that the high pressure doesn’t respond anymore to the medications, the next step is usually some lasers, what they call laser surgery or laser treatment. What they’re trying to do is to, with the laser through the eye, they try to open the drainage valves so that the fluid from inside the eye would flow more quickly.” (Linda)

Compared to participants with mild vision loss, those participants with self-reported severity of the vision loss at the intermediate or advanced stage tended to involve their social networks more heavily to maintain their engagement in desired occupations. In relation to vision care, those participants with a greater severity of self-reported vision loss not only described the instrumental and informational support provided by their optometrists and ophthalmologists, but also from low-vision rehabilitation organizations. For instance, participants expressed how low vision rehabilitation providers, such as the CNIB and the University of Waterloo Centre for Sight Enhancement, supplied them with various assistive devices (i.e., digital hand-held
video magnifier, CCTV), subsidized transit passes, phone operator services, and home visits:

“The phone service, it’s just a zero and then zero again, and then you tell the operator the number you want, and they connect you without you having to look it up.” (Jenny)

“I have a CCTV that I got through the University of Waterloo, and that was five years ago, but it’s still working, and so I’m using it as well... And with CNIB, I have a CNIB card and CNIB transit. So it cost me ten dollars for a year. They can’t get any cheaper [...] I used to know a lady that worked for CNIB, but she has retired now, but she used to come and put little bumps on equipment so that you would know where the on and off switches were. And I think that I’m going to have to call the CNIB and they must have replaced her with somebody that would come and do that for me on my microwave and this new stove. I don’t know how to run the oven yet.” (Grace)

By accessing instrumental and informational support provided by their formal networks, participants were able to maintain engagement in various IADLs (i.e., financial management, preparing meals, grocery shopping, and attending medical appointments) as well as leisure occupations (i.e., doing puzzles and watching television):

“I like doing puzzles too, and that’s also trickier when I can’t see what’s on it. So sometimes, I use the magnifier, and it allows me to finish faster.” (Jenny)

“For things that you do need to read, like labels and instructions and if I want to know the programs on TV, for example, that kind of stuff, I use this magnifying glass, and I use it a lot every day. I take it to grocery shopping. I remember too, if I want to read a label on a can, for example, or price of something on it, I have to use this [...] I use that for doing bank racks or visa too, checking the visa, stuff like that.” (Joanna)

Participants with more severe self-reported vision loss also described their interactions with formal support networks who were not providing medical care, such as
personal health trainers, store clerks, and retirement home staff. For instance, Grace explained how her personal trainer helped her create a custom fitness program and ensured her safety while she was operating gym equipment by assisting her with adjusting machine settings to her size and strengths:

“**The health club has machines and weights that the personal trainer knew how to run, and so that was where we worked. I had a personal trainer come twice a week [...] My personal trainer looked after the machines for me there, and she led me as far as what I should be exercising. So that was a really good thing for me to do.**” (Grace)

Another participant described how the staff from her retirement home taught her how to use online social network platforms, such as Facebook and Zoom, to assist her transition from physical to online social interactions during COVID-19:

“**[Fox Hollow] is trying to get things working again and getting people to interact with each other [during COVID-19]. And they are going to help with Zoom meetings and Facebook interaction. And they offer, I think, help with iPad. Or they call them tablets, but I have an iPad, so they’re going to help with that.**” (Grace)

Unfortunately, because of COVID-19, participants experienced delays in their medical appointments, which they felt had negative influences on their vision care. Participants discussed how this lack of access to vision care consequently impeded their occupational engagement, such as their ability to drive:

“I was losing my vision. I felt like I wasn’t able to see as well as I could. And I’ve changed glasses three times this year. And so, I wanted an appointment. But he [optometrist] said because I’m older, that they were making special appointments for older people, because of COVID-19, and I wanted it in June, but I couldn’t get it till August. And oh my God, I can’t see very well. I can hardly drive now. I don’t want to wait until August.” (Jenny)

### 5.2.2. Barriers to Current Vision Care Support.
Even before COVID-19, however, all participants who self-reported as having intermediate or severe vision loss symptoms noted the following barriers in accessing low-vision rehabilitation supports. Firstly, participants spoke of how they lacked information on the services offered by rehabilitation organizations due to limited or discontinued communication with the staff after initial contact:

“Well, I guess it would be nice to know when new things come out. I don’t have any communication with them. I have a little catalogue of theirs. I haven’t looked at it lately, but I’m sure it’s still there. But honestly, I’m not sure what they can do. I really don’t know.” (Joanna)

“I haven’t accessed them [CNIB] for a long time now. I used to contact [Anna; previous CNIB staff], who worked for them, and I could email her or call her. But of course, she is retired now; so I haven’t tried to get anybody else.” (Grace)

Even when older adults were aware of the available resources, for those with severe vision loss, their inability to drive posed a physical barrier to accessing low-vision rehabilitation services, as they had to rely on others to drive them:

“But I have a friend who was there for her own reasons this week. And they told her about the shop on Queens or Oxford. I’m not sure, but anyways, there is a shop that they can get different magnifying glasses and things. So I’m going to go there with her next week. But I’ve had very, very limited access to them.” (Joanna)

Furthermore, participants expressed a desire for integrated vision care services. They felt that increased communication amongst healthcare professionals (i.e., optometrist, ophthalmologist, low-vision rehabilitation specialists, and family physicians) could enable a more coordinated delivery of customized vision care:

“She [optometrist] said, ‘well, I’ll contact your own doctor [family physician] and then your specialist [ophthalmologist] at the Ivey clinic.’ And so she wrote to them right away. And my own doctor, what did she do... Oh, she helped me
change something about my diet, and everything was just more efficient.”

(Jenny)

Participants also discussed the need for more effective communication between healthcare professionals and patients, expressing their preference for those healthcare providers who convey information on relevant treatments in accessible ways. For instance, healthcare providers who were less authoritative and more receptive to patient’s concerns about their vision loss were perceived much more positively by participants:

“He [previous optometrist] wasn’t communicative at all... I don't think he recommended any support. He just told me that I had it [glaucoma]. And he said he referred me to Dr. [Macky] at IVEY, so I should visit him, and that was it. And I just thought we’ve been with him so long and decided I didn't like him [...] So I called another optometrist, and she could take me the next week. So I went to her, and I like her. I really like her. She gave me much more information than I had ever had. I told her my eyes were always hurting and dry, and she gave me a Bruder Mask, which is supposed to help with the eye drops and things like that. And she gave me a lot of really good ideas, and I thought, ‘Wow, I’m gonna stick with her.’” (Jenny)

5.2.3. Informal Networks Provide a Comprehensive Range of Instrumental and Emotional Supports.

Overall, participants mainly discussed their usage of instrumental and informational support while describing how their formal social networks facilitated their engagement in desired occupations. On the other hand, with regards to their interactions with informal social networks, participants described a wider variety of social support types that they provided compared to their formal social networks. These included not only the informational and instrumental types but additionally, the emotional, positive social interaction, and peer support. For instance, participants described how their friends and family were their primary sources of emotional support as they offered them a sense of stability, comfort, and positivity and demonstrated reciprocated appreciation of each other’s company:
“We talk about everything, I tell him [husband] everything, and he tells me mostly everything. He’s my basic and most go-to emotional support person [...] We always confide in each other. We don’t always see eye to eye, but we understand each other’s point of view. That’s very important. Sometimes he gets his way, and sometimes I get my way.” (Jenny)

“So, we talk, like I mean, she [daughter] talks and I talk, and we just chat, chat, chat. And sometimes half an hour at a time, which is good. You know, and that’s an important part of my days, that phone call. So I think it’s an important part of her day because she’s always there [...] Oh, and she always says, ‘mama, I don’t know what I’d do without you.’ And that makes me feel good.” (Brendell)

In particular, participants expressed feeling emotionally connected to those peers who shared a common experience of ARVL or were the same age and gender. Participants described their peers with a shared disability experience (often, also their similarly aged peers, but not always) as having a more tacit understanding of the needs of the participants based on some of their own health challenges, and they could better relate and empathize with each other’s struggles:

“And so I find that being in that organization, that is all senior people, that there is a lot of understanding and a lot of patience with people needing that extra time or the extra help or not being able to see something on the board.” (Linda)

“My father also can’t see. So I can understand it [her father’s actions and thought process] better like he doesn’t want to watch TV at all anymore. I can understand why he wouldn’t now.” (Jenny)

Here, participants explained that sharing a disability experience with others was not restricted to just vision loss. In fact a majority of the study participants described how they were dealing with health conditions, in addition to the vision loss, and explained how these impairments, together, negatively influenced community mobility, engagement in sports (i.e., playing tennis, walking), and hobbies (i.e., knitting, crocheting):
“I used to do a lot of knitting and sewing, but my hands have got arthritis, and I can’t do that anymore.” (Brendell)

“But I personally, my hands are so funny. I can’t hit a tennis racket anymore. It’s just too painful, and now my big left knee is starting to... I can hardly walk far at all. I’ve had to cut the walks out just the last couple of days. But it’s really, really painful [...] I don’t know if I’ll ever do the walks again. This is upsetting me a bit, you know, that I can’t do it [...] I’m wondering now, the big thing is shopping. I’m going shopping tomorrow morning, and I’m just wondering if I’ll be alright doing that.” (Brendell)

Participants’ peers with a shared disability experience helped the participants engage in desired occupations while dealing with health comorbidities as they provided informational support relating to the progression of their shared diagnoses (i.e., ARVL or other age-related health conditions) and shared strategies participants could use to cope with their health challenges:

“Having both my daughters have glaucoma... and my daughter that works at CBC, she knows everything. You can’t tell her something she doesn’t know already. And so, you know, if I say something about glaucoma, she’ll correct me. She gives me more information than anybody does about it [...] I’ll do things, and she goes like, ‘Oh, you shouldn’t do that, it’s not good for glaucoma.’ I can’t remember what they are now, but I’ve done a few things, and she’s like, ‘No, no, that’s not good for it.’” (Jenny)

“Sometimes there’s some suggestions from my friends that come about how to deal with it [arthritis], if there’s a specific thing you’re having a problem with.” (Joanna)

Several participants also discussed how reciprocal exchanges of emotional support with their female friends were integral to their sense of wellbeing. For instance, Jenny described how her friends helped her to manage her stress by providing a female perspective:
“My girlfriends and I, for twelve years, we’ve been sticking together doing social things and to talk about our problems, and the reasons for why certain things are happening in life. So, it’s a stress relief, and it is a different point of view that they provide me.” (Jenny)

In addition, participants discussed how their family members and friends advocated for them in various social settings, for instance, while they were engaging in social club activities, to protect them from being taken advantage of as a result of their vision loss:

“I had a lot of help up until I quit. And they [participant’s friends] would help me fill out the forms, and the only negative thing that I can think of was one lady put her cup on the top of her head. And, of course, I couldn’t see that. So she was saying that she wanted another cup of coffee. And I didn’t see it. And there were a lot of people that understood that I couldn’t see the cup on top of her head. They told her that she should not do that anymore when I was on job.” (Grace)

Another participant discussed how her daughter acted as her spokesperson in medical appointments to explain to the doctor about the challenges she might face with using prescribed medication due to low vision:

“[Betty; participant’s daughter] was there [hospital] with me, and she explained to him that, you know, I wouldn’t be able to see a measure.” (Grace)

Furthermore, family and friends were described as important sources of joy and entertainment as they provided participants with positive social interactions (i.e., watching TV shows, camping, going out for dinner, concerts), and physical activities (i.e., riding bikes and walking):

“I have a group of friends, and we go to different theater shows, and we go out for dinner at night. So, they provide me with entertainment. We go and do entertainment together, like we get to go to different places that my husband and I never go to, like new restaurants and things like that. We always go to more
different places than we do with men. Or sometimes, we get together with their husbands and do things together.” (Jenny)

“We [participant and her husband] just went for a walk in our camping. We do a lot of walking together. And so we try and walk every day, and we bike ride together and when we’re camping like this week, most of the time we just sit at the front of the motor home, and just look over at the lake and look at the kids swimming and everything.” (Jenny)

Here, participants also described the times they needed support from their informal social networks during these social outings (in unfamiliar environments). For instance, participants often asked their friends to read small prints, such as on restaurant menus:

“Sometimes, I go and forget my magnifying glass to the restaurant, and they’ll read the menu to me.” (Joanna)

In another participant’s case, Jenny relied on her husband when she rode her bike so that he could take the lead in terms of finding the safest route, reading street signs, and ensuring that she avoided any obstacles:

“I don’t go too fast. I slow down, and we try... I follow my husband, like he goes ahead of me, and I follow him [...] I just can’t read them [street signs]. My husband has to read them for me.” (Jenny)

Finally, participants’ informal networks provided them with technological assistance (i.e., setting up Zoom, navigating accessibility features on mobile devices, iPads, or computers), financial support (i.e., for internet, cab services, gym membership, low-vision assistive devices), and other instrumental support for participants’ desired and required IADLs such as house chores, grocery shopping, driving (i.e., to medical appointments, low-vision rehab centers, stores), and cooking:

“My son in the State is going to pay for my Internet connection... And [Betty; daughter] and [Carter; son-in-law], who live here in London, also helped me with grocery shopping [...] Well, if I wanted to go to Costco, they would take me,
or they would pick up things for me there. And well, they usually don’t charge me for the full amount of groceries they buy for me [...] I am also dependent on my daughters to get to doctor’s appointments. And my youngest daughter, she was the one that put the Libby, which is the program for the libraries, and she put it on my iPad for me.” (Grace)

“My husband helps me a lot. He helps with the meals and laundry, and what else? Oh, everything outside and inside [...] For places that are farther away, my husband drives me. Well, both of them, my husband drives, and my girlfriends do too.” (Jenny)

5.3. Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships

Throughout the interviews, all five participants described a desire to maintain independence following vision loss, however, there were differences in terms of how much independence was desired. For some participants, a sense of independence was so vital to their wellbeing, that losing independence was equated to a life not worth living:

“Well, I think if I start giving up on things, my main reason for living is going. As long as I can go shopping and do things, then I don’t think about dying. I think if I couldn’t do it, I’d think, ‘Why am I alive, it’s not worth it?’” (Brendell)

For many participants, being dependent on others was seen as a burden, and participants were reluctant to ask for help unless they perceived an imminent risk. For example, a participant reluctantly called on her social network following an eye surgery as she considered it to be a necessary support for enabling her function:

“Well, I always hesitate [to ask for help], but before, during, and after surgeries, I’ve needed my good friends near me [...] Because right after the surgery, you know, when they first do it, you can’t see with that eye for a day or so. With the bad eye, I wouldn’t be able to function.” (Linda)
“Well, while shopping for groceries, I often ask where this is, or that is because I can’t find some things. But banking, I just go to the bank, though I don’t do that very often anymore. And I don’t need help crossing the street or that kind of stuff. I try not to be a nuisance to people unless I really need it. I try not to bug people and complain. No, I don’t want to be a nuisance.” (Joanna)

Participants also discussed how their desire to maintain autonomy stemmed from their life-long experience of being independent and self-sufficient. For example, as a single mother raising two children, Jenny spoke of her identity being tied to feelings of strength, resilience, and dealing with adversity:

“But I’m really proud of all of them [participant’s children]. They’re doing really well. I was pregnant at 17, married at 18, and we stayed married for 18 years and then divorced. So I raised them pretty young, and the youngest one, I raised her pretty much on my own. So they did pretty well for an 18-year-old mom […] It [Raising two children at a young age] wasn’t easy, but you know, we never regretted it, but it was hard work. And now, I wonder ‘how did I ever go to university and have a baby? And I worked part-time.’” (Jenny)

Participants also expressed that disclosing their ARVL condition was important to receive necessary support, but there was a general reluctance to do so with individuals outside of their close social network:

“Well, I don’t always talk about it [vision loss diagnosis] to everybody, so not everybody is aware.” (Linda)

On the other hand, some participants were more open to disclosing their vision loss, and accepting help from others, as they prioritized their occupational engagement over feelings of independence and privacy. This attitude was partly fostered by the support they received from family and friends. For instance, Grace’s family recommended that she use an indicator of her vision loss, such as the white cane, to ensure help is provided from informal support network members when participants were out in the community:
“Well, they [participant’s sons] both think that I should carry my cane more often, and I did take it with me yesterday when I went out for a walk… And so I guess with my cane, people then know that I might need help, and that’s what my children have said all along.” (Grace)

When talking about accepting help, all participants discussed the importance of reciprocity in social relationships to retain their sense of independence. Mutual exchanges of support enabled participants to feel equal to their social networks, and in turn, made it easier for them to ask for help as they did not feel like a burden, but rather, useful:

“When they [participant’s friends] need something, then I’m going to, you know, I help them. It’s that kind of a reciprocal thing, it’s not so much that I need, and they don’t. You know, everybody has something they need.” (Linda)

“If they needed support, you just do it. But one thing it does do is, it makes you feel a little freer to ask for help from them if you needed it because it’s reciprocal.” (Joanna)

Participants expressed that they achieved reciprocity by giving back the support they received through materialistic goods or financial means, acting as a caregiver (i.e., to their parents), playing a role of a confidant, and exchanging emotional support with their informal networks:

“I think it’s therapeutic for her [participant’s neighbour] as well because when she comes, I hear everything she’s done all day. You know, like a full resume of what she’s done all day. So I’m sure it’s helpful for her as well as me […] And I give my daughter 350 dollars a month because she has very little income. She’s on a disability, and that lets her stay in the apartment she’s in.” (Brendell)

“Well, since my father’s 96, what I do for him is, I get up and make his meal, and then he lies down, and he goes to bed […] He’s very easy to care for as a caregiver. He sleeps a lot of the time and everything. So, all I really do is make his bed and cook and give his meal. Oh, and I bring a White Board for him
because he also can’t see. So, I write down stuff on the White Board for him.”

(Jenny)

Overall, participants associated being a helper with an enriched quality of life as it provided them with purpose and a sense of independence:

“Definitely it [playing a role of a helper] gives me a purpose. You know, like if you’ve got nothing to do what would you do with yourself? “That’s [helping others] where I get a lot of joy from. With family, too, right? Kids and grandkids and all that.” (Brendell)

5.4. Community Mobility as Essential for Preserving Social Relationships

Throughout the interviews, one of the most prominently discussed occupations amongst participants, as being influenced by their vision loss, was driving. For many older adults, their ability to drive was important for preserving a sense of autonomy and supporting their community mobility, as it enabled them to make necessary trips into the neighbourhood and travel to and from work and volunteer positions:

“If I lose my vision more, and let’s say I can no longer drive at all. That changes how you function, right? Because we’re used to jumping in the car to go to the store, to go anywhere, right? So that would be the first sort of biggest thing. Like not being able to be autonomous in the sense of, like I said, pick up and go wherever I want to, when I want to. That sort of thing, you know?” (Linda)

“I hope that when things settle down [after the pandemic is over], I can start going back and doing my [volunteer] work at SLR, and it won’t be a problem. If I couldn’t drive there, I’d have to resign. And that would be a problem.”

(Brendell)

Community mobility provided older adults with the ability to stay connected to their social networks, reduced feelings of social isolation, and facilitated participation in meaningful social occupations (i.e., visiting music concerts, pharmacy, medical appointments, shopping malls, and community sports centers):
'You jump in the car, and you go somewhere, even if it’s just to drive around. You need that change of scenery. You need to feel like you’re not housebound. You need to feel like you can go and do something. So even if it’s just to go to the pharmacy and pick up a prescription, you feel like you’ve done something fun.’” (Linda)

Accessing community mobility, whether it was through a car or an alternative method of transportation, such as public transportation, was also how participants visited their family who lived outside of London:

‘My thing with the driving is that my son lives in New York State and his family. And my daughter and her family live in Quebec. So until now, I’ve been able to see them quite often because I drive […] Well, I mean, there would be options of flying or taking the train, but they are a lot less simple and a lot more expensive.” (Linda)

Although older adults desired to maintain driving independently to preserve their participation in occupations with their social networks, those with severe vision loss considered it unsafe as they might get into an accident. To avoid these perceived risks with driving, participants employed alternative strategies to support their community mobility, such as using public and private commercial transportation in order to avoid needing to rely on members of their social network for rides:

‘I can take a taxi, and I do. For medical things, that’s when I really have to go out. I use a taxi for things like medical and lab works or stuff like that.” (Joanna)

Traveling using public transportation services was considered, by many participants, as a more independent way of accessing the community rather than asking for rides. For instance, participants expressed how relying on others for rides eliminated the ability for spontaneous travel and further restricted them in terms of when, where, and for how long they could spend at a store while following the schedules of their family or friends:
“When my husband died in 2011, it meant that I was dependent on family and friends for getting around because he was my driver [...] I have to follow other people’s plans, and there’s increased wait-times to go to the places I want to go.” (Grace)

One participant even went so far as to move from a smaller town to London so that she could use public transportation and not have to rely on members of her social network to get around her community:

“I moved to London in 2013 because there are buses here. I lived in a village in [Southampton] with a thousand people, and they didn’t even have a taxi. And of course, no buses. So that’s when I moved to London, and I’ve enjoyed it ever since.” (Grace)

Another participant did something similar whereby she moved to a new neighbourhood, where her home is close to a commercial area, so that she can access her community by walking instead of having to rely on others for rides.

“I moved here because I was going to lose my driver’s license, and it’s handy to turn to Maisonville mall and Loblaws, and it’s a handy place to be. And that was because of my vision, that I wouldn’t be able to drive. So yes, I could walk to those places.” (Joanna)

Overall, participants assigned great importance to their community mobility and strongly associated it with maintaining their social relationships. They sought ways to maintain community mobility as autonomously as possible while managing their vision loss.

5.5. Technology as a Support to Social Connectedness: Connecting via Technology versus in Person

With the growing presence of COVID-19, participants began to substitute in-person social interaction with online social platforms (i.e., Zoom, Facebook Messenger,
Facetime, emails, etc.) in an effort to remain engaged and connected with their informal social networks:

“We all have been relying on technology, so whether it’s the simple phone call or this kind of a zoom thing. All of my friends that I know are zooming or facetime in with their friends and their family.” (Linda)

“During the COVID-19, we’ve [SLR] had to shut down. So since March, we haven’t been able to do any of that [executive meetings, peer-based courses, and programs, etc.]. But we’ve started having zoom meetings, and we’re preparing to launch all of our forces in the fall via zoom.” (Linda)

Some participants also used technology to maintain contact with their formal healthcare providers:

“I don’t know if it has changed for my vision, but yes, I don’t see my doctor. It’s mostly by phone if there’s anything wrong. It’s quite different. Well, I’d much rather be there in person. But he’s very good on the phone. I can get him anytime I want, and I don’t have a real problem that way.” (Joanna)

Still, other participants turned to technology to support their ongoing participation in leisure occupations. For example, Joanna discussed using her computer or iPad to play cards during the pandemic, as she did not feel comfortable playing in a social group:

“I can play better with larger cards, or I can play on the computer as well, or on the iPad. Well, it [computer and iPad] just provides an avenue for me to do it, that’s all, because now because of COVID-19, we can’t... I don’t play it socially, only because I think it’s too dangerous.” (Joanna)

Although participants saw technology as providing a way to connect with their family and friends, which was better than nothing, it was less satisfactory than the kind of social connectedness they felt when engaging with their social networks in-person.
Participants, therefore, described the importance of physical contact for facilitating a deeper level of social connection:

“It makes a huge difference even just to be in the same room with each other, even if you’re not within arm’s reach. It’s a very different kind of communication when you’re actually in-person than when you’re looking at, you know, at a screen like this. And a lot of my friends have mentioned that too. You notice it, it’s better than nothing, but after a while, you still miss that person, like you want to touch that person [...] You have to get past the screen to really have contact with someone, and so it just makes your heart ache, because you can’t touch them and you can’t be with them, but there they are talking to you.” (Linda)

Some participants also discussed how their vision loss complicated their ability to use online technologies, thereby heightening their perceived risk of social isolation during COVID-19, when they were forced to transition from in-person to online social interactions:

“So there is the vision thing that comes into play, if you don’t have the visual capacity, then you’re kind of locked out of even that technology. I’m not there yet, but I can see where it’s possible that in the future, I could be really in trouble even with that.” (Linda)

Here, participants discussed how they received training from their social networks (i.e., retirement home staff, friends, family, etc.) or independently taught themselves how to use platforms such as Zoom, Facebook, and speech-to-text programs:

“I was teaching myself all the different audio and using the microphone to dictate things, to write emails, and trying to teach myself what to do if I didn’t see anyone.” (Linda)

“Well, with technology, it’s hard to see the screen because of my vision... So I don’t know how to use Facebook other than just looking at what other people do. So I’m looking forward to learning what other things can be done with Facebook.” (Grace)
On the other hand, using technology to support social interaction during COVID-19 was made easier for some participants whose family members lived far away, as they were relying on social media platforms for social interactions even before COVID-19:

“No, I like it [using online platforms to interact]. We [participant and her daughters] talk on the phone and social media. And again, messenger, or whatever. We talk every day pretty well.” (Jenny)

5.6. Conclusion

The themes presented above demonstrate the complex ways that informal and formal networks support and constrain participants’ occupational adaptation throughout gradual vision loss. The following chapter will conclude the present study and outline my interpretations of findings with respect to a social capital theory, as well as existing and future research.
Chapter 6: Discussions

In this chapter, I first discuss the present study’s findings in relation to the existing literature, focused on older adults’ use of social networks to help manage their engagement in occupation following vision loss. These dominant themes are also explored and interpreted against the framework of social networks theory. Lastly, I present the strengths, limitations, and future directions of this research, focusing on implications for delivery of vision care services and programs.

6.1. Situating Research Findings within the Existing Literature

6.1.1. Maintaining Engagement in Social Occupations to Foster a Sense of Belonging.

Older adults with ARVL, who participated in this study expressed how engaging in social occupations, whether it be visiting their close social networks, volunteering, or attending group recreation, religious, and physical activities, reinforced their sense of attachment and purpose in their community as they could take part in various social roles such as familial, friendship, and community roles during these social engagements. Participants also described experiencing feelings of isolation, loneliness, and boredom when their social participation became restricted during COVID-19 (a pandemic that started in 2019 caused by severe acute respiratory syndrome coronavirus 2, or in short, SARS-CoV-2) as well as when they encountered challenges with social occupations due to their visual impairment. These findings provide further support of the existing literature that engaging in occupations with one’s social networks is important for fostering a sense of belonging and connectedness. For instance, in alignment with the present study, Stafford et al. (2018) noted that visually impaired older adults perceived greater benefits, and more positive meaning, with occupations their social networks are involved in than occupations only involving strangers, and were motivated to engage in similar occupations as the ones that their social networks are engaging in.

On the other hand, the present study also demonstrated that not all social occupations fostered a sense of belonging. In fact, some participants described stepping back from occupations that heightened their feelings of social exclusion or that made
them feel like a burden to others. For example, participants avoided social occupations that involved members that were insensitive to their needs as an older adult with vision loss, as well as those that were too fast-paced, such as competitive group card games, as one example. This is in line with previous findings whereby older adults with visual impairments commonly withdrew from occupational engagement, and avoided seeking help from others, because they feared that they would be misunderstood or ridiculed for their visual needs (Kaldenberg, 2019; Matti et al., 2011; Pollard et al., 2003; Spafford et al., 2010). The present study builds on previous research by demonstrating that informal social network members helped older adults with vision loss find alternative social occupations as a substitution following their disengagement from previously enjoyed social activities. Such occupational substitutions enabled a prolonged and continued sense of belonging and connection amongst the study participants. The existing literature has, thus far, mainly focused on the involvement of informal social networks at the stage of initiating social engagement, not following disengagement from social participation (Kaldenberg, 2019; Latham, 2013; Silverman et al., 2017). The ways in which informal networks can facilitate meaningful social connection after occupational disengagement requires further examination.

In addition, although study participants generally desired to maintain involvement in social occupations, some older adults preferred to spend time alone. They welcomed the increased time they spent in solitude during COVID-19 and saw it as quality self-care time where they could indulge in solitary leisure activities they previously desired, but did not have time for. Contrary to this study finding, there was a paucity, within the literature, of information regarding older adults’ preference towards introversion. In fact, an abundance of evidence supports the beneficial influences of participation in social occupations on the psychosocial wellbeing of visually impaired older adults (Giles et al., 2005; Jin et al., 2019; Li et al., 2020). This research bias may be due, at least partially, to the researchers’ and/or participants’ preference towards sharing narratives that parallel external constructs of successful aging (such as being extroverted, socially active, independent, and productive), resulting in the omission of narratives focused on positive experiences of introversion (Calasanti, 2016; Feng & Straughan, 2017).
6.1.2. Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs.

In line with previous works, the study participants faced various occupational and psychosocial challenges throughout the progression of their vision loss and utilized social support from diverse network members to cope with their needs. According to a number of existing studies (Alma et al., 2012; Desrosiers et al., 2009; Swanson & McGwin, 2004), a consistent argument has been that there is no direct correlation between the severity of vision loss and levels of occupational engagement. While the present study does not correlate degree of vision loss with severity of occupational restriction, it demonstrates how older adults experience these variables together in their overall adaptation to ARVL, and may help make sense of the findings from these previous studies. Older adults from this study who self-reported having severe vision loss, appeared to face more significant difficulties with certain occupations, such as community mobility and group interaction, which, at times, led to their disengagement from occupation. At the same time, participants with greater self-reported vision loss also relied more heavily on their social networks to overcome these occupational challenges, such that, in the end, they were able to maintain a similar level of engagement in desired occupations as older adults with milder self-reported vision loss.

Participants with greater self-reported vision loss appeared to interact with a larger formal social network, consisting of more diverse members than those with milder self-reported vision loss. For participants with milder self-reported vision loss, their formal social support networks largely consisted of healthcare professionals only (i.e., optometrists, ophthalmologists, and family physicians), however, in the case of participants with greater self-reported vision loss, they were additionally reliant on low-vision rehabilitation services (LVRS), such as the Canadian National Institute for the Blind (CNIB), who provided access to low-vision assistive technologies and affordable transit passes, as well as formal networks who were not otherwise involved in healthcare (i.e., store clerks, retirement home staff, etc.). Despite the clear benefits of low-vision rehabilitation services on participants’ occupational engagement, many participants did not use rehabilitation services to their full potential. Here, in line with previous research findings (Boyce et al., 2014; Chiang et al., 2011; Kaldenberg, 2019; Southall and Wittich,
2012; Wittich et al., 2013), the present study identified barriers to accessing LVRS as stemming from a lack of awareness of available resources due to limited communication between service providers and service users, a lack of coordination between professionals from different vision care agencies and the resultant delays in referrals, and geographical barriers, such as the need to travel long distances to acquire services.

While formal social networks predominantly provided the study participants with instrumental and informational support, informal social networks, such as family and friends, were involved in a more comprehensive range of support types, including emotional, informational, instrumental, positive social interaction, and peer support. For instance, family and friends were the study participants’ primary source of positive social interaction support, as they accompanied them on a variety of leisure (i.e., camping, going out for dinners, concerts, movies, etc.) and physical occupations (i.e., biking, walking). In addition, informal networks, and in particular peers, provided various instrumental and informational support for the study participants’ IADLs, such as household chores and orienting oneself in unfamiliar environments, which is consistent with the findings of Horowitz et al. (2005). Furthermore, study participants perceived that sharing the same gender, age, or disability as their peers meant that they could better understand and empathize with the experiences of the study participants. Similarly, Silverman et al. (2017), who conducted a study with visually impaired older adults, suggested that sharing a similar disability status or age group provided a unique insider perspective that created a deeper connection between network members. This tacit understanding was important for participants of this study and previous related works (Cohen, 2004; Jensen et al., 2013) because older adults with low vision did not need to explain themselves while requesting assistance and could more easily receive support without asking for it directly. As a result, participants were more reliant on their informal networks rather than formal networks for their daily occupational engagement and emotional support. Similar findings from Kaldenberg’s (2019) study reported that older adults with chronic disabilities, such as ARVL, tended to interact more with informal networks, especially peers, as oppose to more formal social support networks.
6.1.3. Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships.

Maintaining reciprocity in relationships, through mutually exchanging social support with one’s social networks, was important for participants to retain their sense of autonomy after losing vision, as it made them feel less dependent on others, even when asking for their help. Similar to findings from past research with older adults with ARVL, the study participants spoke of maintaining independence as a crucial factor in living a fulfilling life as it helped to improve their sense of purpose, self-esteem, and well-being in their older age (Dahlin-Ivanoff et al., 2000; Funk, 2016; Mitchell et al., 2008; Teitelman & Copolillo, 2005; Wilkie, 2007). This desire for independence is consistent with the Western cultural emphasis on autonomy; a recurrent theme in a number of previous works involving not only older adults with ARVL (Berger & Porell, 2008; Girdler et al., 2008; McGrath et al., 2017; Wang et al., 2008), but also younger cohorts (McElhaney & Allen, 2012) and broader disability groups (Falter et al., 2003; Strnadová, 2019). In the present study, participants reported that their life-long experiences, rather than vision loss alone, shaped them to value independence and resilience to adversity, meaning that they had always desired autonomy even prior to losing vision. In order to maintain their sense of autonomy, participants avoided asking for help from others except in a situation where they perceived the imminent risk of bodily harm or when engagement in the occupation was perceived to be more valuable than maintaining autonomy. In both circumstances, participants disclosed their vision loss as a way of requesting support from others, however, there remained a general preference to only reveal one’s vision loss to intimate social support networks.

With close social networks, older adults could maintain reciprocity in relationships more easily because they could mutually exchange social support without replicating the support type they received. For instance, the study participants often assumed the role of confidant, to their family and friends, providing them with emotional support. In turn, the older adults were offered instrumental (particularly with IADLs) and/or informational support. The reverse situation also occurred where older adults provided financial support to their close social support networks and, in return, received
emotional support for their psychosocial needs. Similar to this finding, Reinhardt (2001) conducted a hierarchical, multiple regression analysis in their cross-sectional study involving 570 older adults with ARVL and found that there was more reciprocity in increasingly intimate relationships, because such close relationships allowed for more substitutability in exchangeable support types. Overall, the present study emphasized the importance of mutual exchanges of social support and demonstrated how such reciprocity is more feasible to achieve in relationships with informal social networks.

6.1.4. Community Mobility as Essential for Preserving Social Relationships.

The study participants, as a result of their vision loss, experienced difficulties with driving. Further, they perceived community mobility as essential for participating in community-based social occupations (i.e., going out for dinner, concerts, and volunteer positions) and staying connected with family and friends living in different cities. To maintain community mobility, participants either relied on their close friends and family members for transportation or used public transportation. Regarding relying on informal networks for drives, participants in this study found it preferable to rely on their spouse, over their friends, children, or siblings. They expressed feeling a greater sense of guilt when asking their friends for drives over their spouses. If reliance on a friend for rides was necessary, the study participants worked hard to schedule their trips to match their friends’ schedules. Similar findings have been found by Sengupta et al. (2014), where the researchers found that visually impaired older adults who are female and married were more likely to rely on other drivers than those of any other marital status (i.e., widowed, separated, divorced, single, etc.). Through this finding, researchers suggested that female visually impaired older adults may prefer to rely on their spouses over their friends for drives, as greater availability of spousal support increased the frequency of times older adults asked others for drives.

Relating to the use of public transportations, Schryer (2019) identified some of the barriers that older adults with visual impairment may face while using public transit systems including a lack of public transportation availability in rural regions, inconvenient stops, difficulties getting on and off public transit, and long travel times. In
the present study, similar barriers were reported by study participants. To address these barriers, some participants chose to move to new cities or neighbourhoods to gain easier access to public transportation or commercial areas within walking distances. Participants took such actions, despite having informal social support networks to rely on for drives. The extent participants went through to have access to reliable public transit indicates how vital public transportation is to support older adults’ independence with community mobility.

In addition, similar to other studies involving older adults with ARVL (Schryer, 2019; Sengupta et al., 2014), driving cessation in this study was more pronounced amongst participants with more advanced self-reported vision loss. Those with milder vision loss had not completely given up driving, but instead had modified when and how they were driving such that they only drove for short distances or during the day to ensure they were minimizing their exposure to driving-related risks. This tendency to avoid driving at night, longer distances, and in unfamiliar environments has been similarly documented in Sengupta et al.’s (2014) research.

6.1.5. Technology as a Support to Social Connectedness: Connecting via Technology versus in Person.

The use of assistive technology (such as CCTV, iPad, text-to-speech software, magnifiers, etc.) has been shown, in the existing literature, and the present study, to support various occupational needs of visually impaired older adults such as reading, writing, sending emails, shopping, and cooking, to name a few (Copolillo, 2009; Fok et al., 2011; McGrath & Astell, 2016). While technology use by older adults with ARVL has been well documented in the context of supporting daily occupation, there had been less information regarding its use to facilitate social connection, with a few exceptions. For example, Fok et al. (2011), found that assistive technologies can enable older adults’ community mobility, thereby promoting their social engagement. Unlike previous works, however, the participants in the present study were forced to change their social interaction patterns because of COVID-19. Therefore, present research uniquely revealed the role of technology in maintaining social connections in an otherwise physically
disconnected state. For instance, this study examined how older adults with ARVL adopted technologies such as Zoom, Facebook, email, and phone calls to virtually connect with their informal and formal networks to substitute many of their previously in-person social occupations. For example, technology was used to attend virtual healthcare appointments, engage in leisure activities, such as online games (i.e., Bridge cards, Scrabble, etc.), and to interact with family and friends. That is not to say, however, that the use of assistive technologies was not met with some difficulty. For example, some participants found it strenuous on their eyes to play online games because of prolonged time using a monitor. Others, found the technologies themselves to be non-intuitive and needed assistance from their social networks for set up and training, such as with Zoom, Facebook, or audiobook applications (‘apps’). Similarly, in a study by Smallfield et al. (2017), providing training to use technology enhanced visually impaired older adults’ long-term usage of online technologies. In the present study, such training was provided in both formally structured group sessions (i.e., from retirement home staff) and one-on-one training provided by informal support networks. As such, this study demonstrates the importance of social networks in facilitating technology use amongst visually impaired older adults.

6.2. Relating the Study Findings to Social Capital Theory

The study findings demonstrate a clear interplay between older adults’ social networks and the obtainment of their goals – to engage in various occupations while adapting to vision loss. This was in line with Burt’s (2001) and Lin’s (2001) social network analysis of social capital theory, which outlined that individuals use the social capital created by their social networks to decide and take action on their downstream goals such as seeking employment, civic engagement, social inclusion, continuing education, and improvement of health. In line with Burt and Lin’s social networks approach to social capital theory, this study’s participants described how they accessed instrumental, informational, emotional, and positive social interaction support from their social network. Participants then used these resources to support their physical and emotional capabilities to engage in desired IADLs, leisure, social, and volunteer activities. For example, members of participants’ informal networks, such as family and
friends, accompanied them in many leisure and social occupations such as volunteering, going to the theater or out for dinner, and playing cards, thereby providing positive social support. During these social interactions, participants also exchanged emotional support with their informal networks, and therefore, these social occupations helped foster a sense of belonging amongst participants. Social occupations also served as an outlet where participants could exchange informational support with their informal networks regarding where to access low-vision supports, how to set-up or use technology, and strategies to modify certain occupations. Some informal networks also provided informational support in the form of advocacy, conveying participants’ vision-related concerns about medical treatments to healthcare professionals, and preventing others from exploiting participants’ visual impairment (i.e., by ensuring that participants are being paid the right amount for the products they are selling in a marketplace interaction).

Informal networks provided instrumental support in various ways; sometimes in the form of financial aid (i.e., paying for participants’ groceries, taxi app, gym membership, internet services, assistive devices, etc.), and other times, by directly doing certain occupations for participants, such as household chores, cooking, or driving. In particular, receiving rides provided participants with the opportunity to access their communities, whether it be entertainment venues, the doctor’s office, or shopping thereby supporting their community mobility. The facilitation of community mobility enabled participants’ engagement in community-based occupation such as grocery shopping, visiting LVRS or healthcare appointments, or picking up a prescription at the pharmacy.

In the case of instrumental and informational support, participants’ formal support networks were another major provider of these supports. For example, vision care professionals provided participants with information relating to their ARVL diagnosis, provided treatment and medication, as well as offered appropriate referrals. Similarly, low-vision rehabilitation services provided assistive devices and subsidized public transit passes, thereby facilitating community mobility. While formal support networks were essential sources of instrumental and informational supports, they did not assume the role of providing emotional support, for example. In addition, participants perceived that reciprocal relationships were more achievable in informal networks, and there were
greater informational and physical barriers to accessing formal support. Here, the use of social capital theory guided the direction of my literature review as I inquired about the value of social networks in gaining social capital. In turn, these articles I read relating to social capital helped me recognize the diversity of social networks and social support being described in participants’ stories and informed how I was classifying various examples of networks and supports throughout the analysis of participant data.

In the present study, formal networks consisted of more diverse and heterogeneous members compared to informal networks whose members shared greater similarities with the participants (peers in terms of age, disability, gender, educational backgrounds, etc.). Therefore, there were generally weaker ties between participants and formal network members than informal networks whose relationships with participants were characterized by stronger ties and thick trust. Relating similar findings to social capital theory, Burt (2001) and Lin (2001) saw the resources provided within homogenous intra-group members as bonding types of social capital and classified resources exchanged between inter-group members through heterogeneous ties as a bridging type of social capital. In line with findings of the present study, past research utilizing social capital theory in disability and rehabilitation studies, sociology, and other related fields (Bassey et al., 2019; Geys & Murdoch, 2010; Kim, 2018) has demonstrated that bridging social capital is predominantly associated with promoting access to external resources and dissemination of information from individuals of dissimilar socio-demographic backgrounds. On the other hand, the promotion of social cohesion, based on shared social identity and mutual trust, was more strongly associated with the bonding type of social capital. However, while bonding and bridging forms of social capital provided access to different social support types, there was also an overlap between these typologies of social capital, such that one network member was never identical or distinct from another member in all social categories. For example, in the present study, one participant had adult children who shared similarities with them in terms of gender (female) and disability status (same diagnosis of ARVL) despite being in a different age group. Other participants had friends and spouses of the same age group but not a shared disability status (not having visual impairment). Nonetheless, together, they shared emotional and informational support to cope with participants’ struggles with vision loss,
and this amalgamation of bonding and bridging social capital were not mutually exclusive (Geys & Murdoch, 2010).

Finally, the present study suggests that expanding and explicitly adding the concept of occupational engagement to Burt's (2001) social network approach to social capital theory may augment its integration with other existing models of social network analysis. In Burt's (2001) delineation of social capital theory, he suggested that a person A can achieve one's goals faster by gaining bridging social capital or having ties with network members who can act as a broker between dissimilar groups (someone who is a member of both group B and C) than gaining bonding social capital by being connected with within-group members. Burt (2001) explained his research results by stating that being connected to diverse networks can provide information that is additive rather than overlapping, which allows one to access a broader range of resources and opportunities than having redundant information. On the other hand, other social network theorists such as Fukuyama (1997) viewed that individuals can better serve their interests by obtaining more bonding social capital because in-group members have strong ties with one another and can work in concert with one another to protect each other from exploitation and ensure that resources flowing within the group are reliable. However, the findings from the present study suggest that one form of social capital may not be universally advantageous or useful for all situations, and in fact, the desirability of a particular social capital may depend on the type of interest one pursues. The types of interests discussed in Burt's (2001) model were limited to competitive occupations focused on attaining skills valued in the marketplace. These included earning a higher income, becoming a prominent figure or obtaining a higher social status/position faster than others, and leading important projects. It did not include people's mundane routines, ADLs, IADLS, and occupations relating to leisure, self-care, and volunteering. However, for older adults with ARVL who participated in this study, engaging in such mundane occupations and not the ones competitive in nature was at the center of their needs and interests. In addition, participants in the present study demonstrated that they sought after different types of social capital from various social network members for different kinds of occupations they are engaging in. For instance, for occupations that needed expert knowledge, such as receiving medical treatments, accessing vision aid technologies, or
other rehabilitation services, participants sought after bridging social capital from their out-group contacts (formal networks). On the other hand, participants reached out to their in-group contacts (informal networks, especially peers) when they were engaging in leisure and other social occupations as they were looking for a sense of belonging, and these network members provided unique understanding and empathy for participants' struggles with ARVL. This suggests that depending on one's occupational goal, having solid bonding capital based on trusted relationships can be just as important as being connected to a social network member who can bridge oneself with an out-group member.

6.3. Study Strengths and Limitations

One of the strengths of this study is its methodological coherence with my paradigmatic position and research question at hand; “How do social networks of older adults with ARVL facilitate and constrain their engagement in desired occupations?”. Situating myself within a constructivist paradigm, I believe that individuals construct their social realities by reflecting on their life events, which they subjectively experience through the interactions with their surrounding socio-cultural and physical environments. I conducted recurring semi-structured narrative interviews with participants to co-construct their subjective realities, which aligned with my ontological and epistemological beliefs. The approach I took to interviewing, provided the participants with adequate time and emotional space to take the lead in story-telling, and enabled them to actively involve themselves in an in-depth meaning-making process of their embodied experiences with ARVL, occupational engagement, and interactions with their social networks. In addition, I practiced member reflection with the participants by requesting their feedback on my interpretation of their respective stories after having reconstructed their narrative accounts. This process promoted the participants’ authority and privilege over the knowledge claims made throughout the research process and helped mitigate the power imbalance between myself (as the researcher) and the participants.

Another strength of my research was the heterogeneity in the demographic backgrounds of my participants. I recruited participants from two distinct organizations
and was able to achieve maximum variation among my participant pool. Participants had varying diagnoses of ARVL, self-reported severities of vision loss (ranging from mild to severe loss symptoms), duration of living with ARVL, ages, marital status, number of children, socio-economic status, and educational levels. Since my research findings were heavily context-driven (participants’ experiences varied and were shaped by the surrounding environments and people that they interacted with, as well as their personal demographic attributes), the heterogeneity in my participants’ demographic backgrounds enabled a more holistic and broadened understanding of older adults’ unique experiences with ARVL. For instance, I was able to gain insight into how the demographic qualities of older adults with ARVL may have served to influence: (i) the types of occupations they engaged in; (ii) the kinds of adaptations they experienced with their occupational engagement; (iii) the subsequent strategies they developed to manage these transitions; (iv) who comprised their informal and formal social networks; (v) what types of social support they had access to; (vi) and how dependent they were on their social networks.

On the other hand, one limitation of the present research was that, due to the social distancing and travel restrictions imposed during the COVID-19 pandemic, I had to collect data from my participants via virtual interviews only. As mentioned in Chapter 3, using Zoom and the telephone to complete data collection posed certain communications challenges. For instance, unstable Wi-Fi and phone connections occasionally caused interruptions to the conversations' flow, and sometimes, I could not reach the participants at an initial attempt. In these situations, I had to either re-schedule the interview session to a different date and time, or call the participants through another phone number. It was also hard to gauge the participants' emotions during pauses or silences in a conversation, as I could not see the participants' facial expressions and could only rely on information relayed through their vocal tones and word choices. Nonetheless, even with the above-stated communication barriers, all participants touched upon an expansive range of topics and elaborated thoroughly on their experiences, yielding rich data regarding older adults' use of social support to manage vision loss and the subsequent changes to their occupational engagement. However, it is possible that an in-person interview, where one does not need to worry about technological challenges,
would have encouraged better rapport building and overall communication with participants would have been more organic and spontaneous.

6.4. Future Directions and Implications

6.4.1. Future Research.

The present research expanded on the existing narratives of older adults’ adaptation to ARVL, in particular, pertaining to their use of formal and informal social support in adjusting to various occupational changes, as well as raised awareness of the multitude of emotional and physical barriers faced by visually impaired older adults. Although this study explored older adults’ perspectives from varying demographic backgrounds, its findings are yet confined to female Caucasian older adults with ARVL. Given these parameters, future research should consider the occupational experiences and social support use of older adult males, as well as members of varying ethnoracial groups.

Previous research has documented gender differences in patterns of help and health-seeking behaviours and social network use among older adults with chronic illnesses (Creighton, 2010; Gyasi et al., 2019; Kupers, 2005). For example, both Creighton (2010) and Kupers (2005) found that men with disabilities were less likely to utilize formal healthcare services and request help from others, as compared to women with disabilities. However, while women used more social support than men, in general, and accepted assistance from more diverse social networks, men were more reliant on their close friends than women (Creighton, 2010; Kupers, 2005). Both studies posited that prevailing social narratives of gender roles, which promote dominance and independence as qualities of idealized masculinity, may pressure men with disabilities to tolerate compromised health or hide emotions when faced with hardships. These gendered norms may, in turn, partially explain men’s avoidant attitudes towards help and health-seeking behaviours. On the other hand, Gyasi et al. (2019) noted no significant difference in the use of health care services among men and women, especially for older age groups. They explained that advancing age is strongly correlated with chronic comorbidities regardless of gender, thereby increasing the need for healthcare services across all genders (Gyasi et al., 2019). Considering these inconsistencies in gendered
patterns of accessing social support and using healthcare services among older adults, larger-scale future research including older adult men with ARVL would be beneficial in identifying the influences of gender on visually impaired older adults’ utilization of social networks for facilitating their occupational and psychosocial adaptation to ARVL.

Findings from existing literature also suggests that cultural values play an essential role in shaping the communities’ healthcare practices and service structures for vision care, as well as collective social attitudes towards blindness and individual’s awareness of one’s vision loss condition (Huang et al., 2013; Lee et al., 2017; Mogk, 2008). For example, a recent study by Lee et al. (2017) determined the rate of awareness (recognizing the diagnosis and understanding its functional implications) for age-related macular degeneration (ARMD) and cataracts among Korean older adults to be lower than 2% and 20%, respectively. Another population-based study by Huang et al. (2013) revealed that the awareness rates of Malay Singaporean older adults (between ages of 40 to 80) of their vision loss conditions were less than 1% for ARMD, 8% for glaucoma, 15% for diabetic retinopathy and 22% for cataracts. Both studies attributed these low awareness rates to false representations and negative widespread stereotypes against ARVL in mainstream literature and pop-culture (Huang et al., 2013; Lee et al., 2017). In Korea, the term vision loss was often misrepresented as a complete lack of sight and commonly associated with severe functional challenges or difficulties in maintaining autonomy and completing desired occupations (Lee et al., 2017; Mogk, 2008). Therefore, Korean older adults more easily recognized diagnoses of vision loss that were more abrupt and symptomatic, like cataracts, as blindness than ARVL conditions such as macular degeneration that posed a more gradual hindrance to their functionality (Lee et al., 2017). They also sought eye examination and treatments less actively for macular degeneration than cataracts because of the slower onset of ARMD, which further contributed to its lower awareness rate (Lee et al., 2017).

In addition to shaping social attitudes toward ARVL, cultural differences might impede older adults' access to vision care by posing various other challenges. For instance, Hon et al. (2011) and Hynie et al. (2011) noted that recent immigrants with physical and mental disabilities commonly experience social exclusion resulting from
language barriers, differences in religion, and immigration status while rebuilding their social networks. Therefore, newcomers to Canada often face additional difficulties while obtaining various social supports and community resources needed to treat their disabilities (Hynie et al., 2011). In addition, persons with disabilities, with ethnic minority status, were found to have lower socioeconomic status than their White counterparts (Emerson et al., 2003; Park et al., 2002). Such higher poverty rates among ethnic minorities were also correlated with increased marital conflicts, less access to social programs, and lower compliance rates to medical services (Emerson et al., 2003; Park et al., 2002). In the context of older adults with ARVL, these additional challenges may pertain directly to the quality of vision care they receive. Therefore, it is crucial to further evaluate how immigrant status and/or ethnoracial older adult groups interact with their formal and informal social networks to navigate their vision loss and occupational experiences.

Further, the present study observed that older adults’ occupational engagement is not only influenced by the severity of their vision loss but also their relationship with social networks. For instance, more significant self-reported vision loss symptoms appeared to contribute towards greater levels of occupational disengagement, but the presence of social networks helped to ensure that this disengagement was time-limited, by helping the older adults with ARVL re-engage in similarly meaningful occupations. Other studies, such as Wong (2007), stated that older adults’ occupational engagement was mediated by the length of time older adults lived with ARVL, as time played a significant role in older adults’ ability to access LVRS. Conducting longitudinal studies (following older adults with ARVL from an initial diagnosis through the progression of ARVL) may help strengthen the present study’s findings by revealing the dynamic ways that older adults with ARVL interact with their social networks at various stages of their vision loss journey.

Finally, this study was conducted during the COVID-19 pandemic, and it elucidated how the physical distancing requirements imposed restrictions on how older adults with ARVL connected with their social networks to support occupational engagement. Future studies should investigate the impact of the COVID-19 pandemic on
the occupational and social engagement of older adults aging with vision loss, including the use of strategies, such as technology, to support ongoing participation. Here, the present study outlined how social networks could help visually impaired older adults overcome the barriers in learning new technology. This finding is especially relevant to present society as digital transformation of occupations are rapidly increasing and becoming embedded within daily practices including the digitalization of healthcare, cooking, shopping, banking, leisure activities, and social interactions (i.e., via online messaging or video platforms) (Hughes & Vafeas, 2019). Therefore, future research should aim to better understand the role of social networks in facilitating older adults’ technology use.

6.4.2. Recommendations for Vision Care Services, Programs, and Policies.

This study demonstrated that as older adults with ARVL gradually adapt to their vision loss, their needs for vision care services also evolves. However, visually impaired older adults were often unaware of the LVRS available to them and could not access or employ them immediately when they experienced changes to their vision. Therefore, older adults with ARVL saw a benefit in maintaining contact with low-vision rehabilitation organizations as it enabled them to be more aware of the services available to support their occupational needs. Older adults with ARVL also indicated the need for better collaboration and communication between different vision care systems as well as between the professional and patient/client. Implementing the following initiatives may facilitate continued support of older adults' adaptation to vision loss, occupational engagement, quality of life, and utilization of social support from various networks groups throughout their lifetime.

1. The present study demonstrated that the informal networks of visually impaired older adults (i.e., family members and friends) reduce both physical and informational barriers to accessing vision care services. For instance, informal social support networks provide older adults with transportation to desired destinations, share vision-care related information, and advocate for their needs in healthcare settings. Considering these facts, low vision rehabilitation services (i.e., CNIB) may consider sending newsletters and/or emails about their upcoming events, programs, and new assistive devices to both older adults with ARVL and
their informal networks (Duggan, 2011). Connecting with a clients’ social network may help low-vision organizations, such as the CNIB, increase their communication with visually impaired older adults (assuming that social networks would inform the older adults about the services). Utilizing visually impaired older adults’ own informal networks to mediate continued contact with the clients is an alternative approach to sending staff to client homes for personal visits. Home-visits are one of CNIB's current methods of keeping in touch with visually impaired older adults and raising their awareness of the organization's available programs. However, home visits are difficult to sustain when there are a growing number of older adults with ARVL seeking this service. Although CNIB can increase the number and duration of home visits by employing and assigning more staff to this task, this method is financially costly and time-consuming.

2. Low vision organizations may also consider implementing a hobby club for sight loss groups to support the autonomy of the person with ARVL. In the hobby club, participants can share and engage in their hobbies (i.e., Bridge cards, board games, camping, choir/music group, and audiobook club) with their peers who also have vision loss. Each hobby activity can be modified to accommodate the needs of visually impaired individuals. For instance, for Bridge card and board games, the hobby club can offer braille adapted versions of the games or cards in large print. The members of this hobby club can teach one another the hobbies they enjoy themselves and can learn new sustainable skills (i.e., knitting and crocheting) without the fear of being judged for their visual impairment as they are being taught by their own peers. In addition, the pace of the activities in this hobby club will be tailored for those with visual impairment, therefore, the hobby club can enable older adults with ARVL to re-engage in group activities (i.e., group fitness class) that they previously enjoyed but have currently disengaged because of being unable to follow the pace of the group. Overall, the hobby club can act as an avenue where older adults with ARVL can meet new people, build their peer support networks, and maintain independence.

3. Vision care professionals should actively engage in post-diagnosis communication with visually impaired older adults. The present study indicates
that older adults with ARVL desire adequate explanations from vision care professionals about their vision loss diagnosis and available resources (i.e., medical practices, assistive technologies, and other rehabilitation services). Participants also demonstrated a preference toward vision care supports that incorporated their input, as compared to authoritatively conveyed information. Considering these facts, vision care professionals should facilitate an environment where visually impaired older adults can openly ask and share opinions about their vision. In doing so, vision care service providers may find it beneficial to collaborate with older adults' informal networks, as they play important roles in advocacy (Wong, 2007). For instance, informal social networks may help older adults express their concerns with ARVL conditions, personal goals in daily living, things they found helpful in maintaining their functional ability and occupational engagement. By involving informal social networks in the delivery of formal vision care and subsequently enabling advocacy for visually impaired older adults in healthcare settings, vision care professionals may be able to better understand older adults as a whole person (about their lifestyle, attitudes, and circumstances surrounding them), not just their health needs, and thereby connect with their patients on a deeper level. In turn, older adults with ARVL may feel improved satisfaction with the vision care they receive (Wong, 2007).

4. Study findings highlighted the importance of emotional and positive social interaction supports for enhancing visually impaired older adults’ occupational engagement and demonstrated how these two support types are primarily provided by older adults’ informal social networks rather than formal networks. For instance, visually impaired older adults in this study preferred to engage in social occupations with their close friends rather than with strangers, as these close friends already knew about their ARVL condition, understood their struggles with vision loss, and could accommodate for their needs without much explanation needed. In contrast, participants avoided large group activities not involving their close informal networks because these activities were generally fast-paced, and participants did not want to be seen as a burden to the group nor want to explain their ARVL conditions to strangers. Therefore, having close
informal networks to do activities with was an important factor that enhanced visually impaired older adults’ participation in social occupations. Considering these findings, informal networks of visually impaired older adults should aim to increase the emotional and positive social interaction supports they exchange with older adults with ARVL regardless of the availability of other support types. In fact, visually impaired older adults were generally less reliant on their formal networks than informal networks and less likely to exchange positively perceived social support with their formal networks even though both formal and informal social networks provided a wide variety of instrumental and informational supports. In providing emotional and positive social interaction supports, informal networks may consider encouraging older adults to take on a helper role by recognizing and expressing appreciation for older adults’ contributions in their interactions. This recommendation relates to the present study’s findings that visually impaired older adults associate taking on a helper identity with preserving their sense of independence and achieving greater reciprocity in their relationships. In contrast, informal networks should avoid taking the following actions, which led to some of the negative experiences that participants identified within their interactions with social networks: (1) rushing a person with ARVL and not allowing them to engage in occupations at their own pace; (2) misunderstanding or overlooking the underlying reason for why a person with ARVL would want to disengage from certain occupations and being insensitive to their struggles with vision loss; (3) undermining their autonomy and making them feel like a burden; and (4) taking advantage of their visual impairment.

5. In addition to the above suggestions, it is also necessary to consider the broader environmental context, such as societal structures, policies, products, and architectural designs that can shape, and frame, how individuals engage in occupation. Many occupations that we engage in are designed in such a way that is non-inclusive of those with disabilities, such as ARVL. For instance, an occupation, such as biking, requires the cyclist to use their vision to identify obstacles in their surroundings. Incorporating universal design principles into consumer products and promoting inclusive architecture, however, may enhance
the flexibility of how occupation is engaged in among populations of diverse ages and disabilities and help mitigate the structural inequities between the occupational engagement of those with and without ARVL (Miesenberger & Kouroupetroglou, 2018). For example, in the context of biking, a universally designed bike may have an ultrasound sensor attached that can detect and notify the cyclist of the surrounding obstacles (Miesenberger & Kouroupetroglou, 2018). Therefore, vision becomes no longer necessary in this occupation, and one can engage in it without changing the capabilities of the person performing the occupation. Other examples of universal design that addresses the needs of individuals with ARVL include the incorporation of tactile cues, changes in heat, sounds, and illumination (Anderson & Mellon, 2018). These design elements can be used for different environments such as floors, sidewalks, elevators, and entryways, which can help with transiting and navigating between indoor-outdoor environments as well as for products such as television or DVD remote controls, microwave, stovetops, camera, and online game software (i.e., sound effects for navigation, identifying enemies, etc.) (Anderson & Mellon, 2018; Chakraborty et al., 2017; Miesenberger & Kouroupetroglou, 2018).

6.4. Return to Reflexivity

Through my thesis process, my understanding of aging and ARVL changed from something that people have little control over to a much more dynamic and complex experience of confronting and overcoming challenges. My previous work experiences in long term care homes may have influenced my preunderstandings because the conversations I had with the residents largely revolved around how they miss their family and friends, how there are not many people in the long-term care home who would listen and empathize with their pains, and how many of their complaints often get dismissed or go unheard. While engaging in the literature review for this thesis, I noticed the many challenges described for an older adult living with ARVL and was naturally drawn to social supports that were negatively perceived by older adults. However, participants in my study often spoke of their ARVL-related challenges as something they could overcome, and they never phrased their narratives as being in a constant state of
challenges or difficulties. In fact, participants mainly discussed the positive aspects of their interactions with social networks when explaining how their lives were linked to others'. They also portrayed their agency even while describing the supports they received from others; such as how they decided to use those social supports, for what purpose, and what they did in return to give back the supports they received. Overall, participants' main messages about their experiences of aging and living with ARVL did not revolve around resigning occupational engagement, but rather, it acknowledged their challenges, highlighted how they found other means of occupying themselves, and discovered new values, meanings, and joy through those processes.

6.5. Conclusion

This research explored the links between informal and formal social networks and the occupational experiences of five older adults with ARVL. Five central themes, namely (1) Maintaining Engagement in Social Occupations to Foster a Sense of Belonging; (2) Diverse Social Networks Fulfill Different Occupational and Psychosocial Needs; (3) Retaining a Sense of Independence through Seeking Reciprocity in Social Relationships; (4) Community Mobility as Essential for Preserving Social Relationships; and (5) Technology as a Support to Social Connectedness: Connecting via Technology versus in Person, emerged from this narrative study. The research findings address gaps in the existing literature by highlighting the complexity of how older adults access and utilize various types of social support from distinct social network groups, while psychosocially adapting to their visual impairment and subsequent transitions in occupational engagement. By highlighting the benefits of functional and structural support in maintaining visually impaired older adults' occupational goals, the present study may help to inform future research in gerontology and occupational science and help reconfigure vision care service provision for older adults aging with vision loss.
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Appendices

APPENDIX I: Recruitment Email Information

PARTICIPANTS NEEDED FOR A RESEARCH STUDY

Who: Older adults 60 years and older with age-related vision loss (includes: macular degeneration, glaucoma and diabetic retinopathy).

What: We are looking for volunteers to participate in a study to understand how the social networks of older adults influence their engagement with meaningful activities after being diagnosed with age-related vision loss.

When: You will be asked to participate in three sessions (approximately 1-2 hours each) over a period of 4 months. The three sessions will take place on a date and time that is convenient for you.

Where: Interviews will be conducted in person at a location that is convenient for you, including but not limited to your home, your local community, or the university where the researcher works.

If you are interested in participating in this study or if you would like more information, please contact:

Principle Investigator
Colleen McGrath, PhD

Ji Won Kang, Co-investigator
APPENDIX II: Telephone Script

Research Project Title: Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influence of Social Networks

This script will only be used when interested participants contact the research team to learn more information about the study. They will have heard about the study from the CNIB, CCB, SLR, BGCL, and/or KSCC through a recruitment flyer or email.

This telephone script will be used by co-investigator, Ji Won Kang, or the principle investigator, Dr. Colleen McGrath, when a participant calls the researcher to inquire about participating in the study.

Hello, this is Dr. Colleen McGrath’s research lab. This is [name of the Research Assistant/Primary Investigator] speaking, how may I help you?

*If participant expresses interest in participating in the study

Thank you for your interest in this study. Before we move on to discussing details regarding the study, I would like to ask you a few questions to confirm your eligibility to participate. You can answer with a yes/no response.

1. Are you 60 years of age or older?
2. Do you self-identify as having age-related vision loss (which includes macular degeneration, glaucoma, and/or diabetic retinopathy)?
3. Have you lived with ARVL for a minimum of 6 months?
4. Are you comfortable participating in sessions in English?
5. Are you willing to share your stories about the changes you have experienced in terms of the activities you take part in and the people you interact with since you developed vision loss?

*If participant answers yes to all questions, will continue with sharing details regarding the study

*If not, I am sorry, you do not meet the eligibility criteria to participate in this study, thank you for your time and good-bye

The study is being conducted by Ji Won Kang, who is a Master’s student in Health & Rehabilitation Sciences (Health & Aging) program at Western University. This study will examine how social networks of older adults influence their engagement with meaningful activities after being diagnosed with age-related vision loss. The study will involve three interviews that will each be 1-2 hours long, depending on how much you want to share. These interviews will be conducted in person [the researcher will substitute ‘in person’ for ‘via Zoom’ if social distancing requirements, as a result of COVID 19, are
The first meeting, which is a narrative interview will address topics related to how you take part in activities since your vision loss, and how this relates to the people in your life. The second session will be a semi-structured interview, and the questions during this session will aim to build and expand upon the ideas and responses you shared during the first interview. Before the third meeting, the researcher will send you a draft-rendering of your story either via email or a physical copy mailed to you (depending on your preference). In the third and final interview, you will have an opportunity to reflect and share your perceptions about the draft-narrative account, as well as clarify and elaborate on information that you shared with the researcher during the first two sessions. Would you be interested in hearing more about this study?

If no, thank you for your time, good-bye.

If yes,

I am now going to read to you the letter of information over the phone [letter of information will be read clearly to the participant over the phone and participants will receive a copy via e/mail for their reference]

Do you have any questions? [Any questions they may have will be answered at this time]

Do you agree to participate in this study?

*If no, thank you for your time and good-bye.

*If yes, will continue with the study

For further inquiries related to this project, you may reach out to us via the following contact information:

**Principle Investigator**
Colleen McGrath, PhD
519.661.2111 Ext: 81174
cmcgrat2@uwo.ca

**Ji Won Kang, Co-investigator**
MSc student in Health & Rehabilitation Science
Western University, London Ontario
519.495.0504
jkang256@uwo.ca
APPENDIX III: Email Script

Research Project Title: Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influence of Social Networks

This script will only be used when interested participants contact the research team to learn more information about the study. They will have heard about the study from the CNIB, CCB, SLR, BGCL, and/or KSCC through a recruitment flyer or email.

This email script will be used by the co-investigator, Ji Won Kang, or the principle investigator, Dr. Colleen McGrath, when a participant emails to inquire about participating in the research study.

Hello,

My name is Ji Won Kang. I am a Master’s student in the Health & Rehabilitation Sciences (Health & Aging) program at Western University. Thank you for your interest in the research study that I am conducting, along with my supervisor, Dr. Colleen McGrath, and my two advisory committee members, Dr. Carri Hand and Dr. Debbie Laliberte-Rudman.

In order to participate in this study you must be: 1) 60 years of age or older; 2) self-identify as having age-related vision loss (which includes macular degeneration, glaucoma, and/or diabetic retinopathy); 3) have lived with ARVL for a minimum of 6 months; 4) be comfortable participating in sessions in English and; 5) be willing to share your stories about the changes you have experienced in terms of the activities you take part in and the people you interact with since you developed vision loss.

This study will examine how social networks of older adults influences their engagement with meaningful activities after being diagnosed with age-related vision loss. The study will involve three interviews that will each be 1-2 hours long, depending on how much you want to share. These interviews will be conducted in person [the researcher will substitute ‘in person’ for ‘via Zoom’ if social distancing requirements, as a result of COVID 19, are still in effect at the time of data collection] at a location, date, and time of your choosing. The first meeting, which is a narrative interview will address topics related to how you take part in activities since your vision loss, and how this relates to the people in your life. The second session will be a semi-structured interview, and the questions during this session will aim to build and expand upon the ideas and responses you shared during the first interview. Before the third meeting, the researcher will send you a draft-rendering of your story either via email or a physical copy mailed to you (depending on your preference). In the third and final interview, you will have an opportunity to reflect and share your perceptions about the draft-narrative account, as well as clarify and elaborate on information that you shared with the researcher during the first two sessions.

A letter of information about this study has been attached to this email. If you are willing to participate in this study, or have more questions, please contact the researcher at the contact information provided below.
Principle Investigator
Colleen McGrath, PhD

Ji Won Kang, Co-investigator

Thank you,
Ji Won Kang
APPENDIX IV: Letter of Information

Project Title: Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influences of Social Networks

Principle Investigator
Colleen McGrath, PhD

Co-investigator
Ji Won Kang

1. Invitation to Participate

You are being invited to voluntarily participate in a project aiming to study how social networks of older adults influence their engagement with meaningful occupations after being diagnosed with age-related vision loss (ARVL). To participate in this study, you need to: (1) be 60 years of age or older; (2) have a diagnosis of ARVL (including macular degeneration, glaucoma, and/or diabetic retinopathy); (3) have lived with ARVL for a minimum of 6 months; (4) be able to communicate in English; and (5) be willing to share your stories about the changes you have experienced in terms of the activities you take part in and the people you interact with since you developed vision loss. A maximum of 5 older adults will be invited to participate in this study.

It is important for you to understand what participation in this study will involve. Please take the time to read the following information carefully and if there is anything that is not clear or if you would like more information, please contact the researcher using the details provided. Thank you for reading this letter.

2. Why is this study being done?

In Canada, the population is aging and the number of older adults with low vision loss is expected to increase significantly over the coming years. Previous research has identified an association between the presence of an ARVL condition among older adults and decreased engagement in their occupations. Engagement in meaningful occupations can play an essential role in (re)establishing values, self-identities, and goals for older adults, and can subsequently elevate their sense of satisfaction and self-rated health. Existing studies suggest that an older adult’s perceptions and experiences of their ARVL condition are likely to be shaped by interactions with their social network, however, there is limited
research focusing on how these social networks inform their occupational engagement. Therefore, the goal of this project is to better understand how older adults with ARVL story and make meaning of the roles that their social networks play in both facilitating and constraining their engagement in desired occupations.

3. How long will you be in this study?

If you choose to take part in this study, you will be asked to participate in three sessions of interviews (approximately 1-2 hours each) over a period of 4 months. Each of these meetings will be conducted in person [the researcher will substitute ‘in person’ for ‘via Zoom’ if social distancing requirements, as a result of COVID 19, are still in effect at the time of data collection] at a date, time, and location that is convenient for you.

4. What are the study procedures?

You will meet with the researcher three separate times.

During the first session, you will participate in a narrative interview. During this session, you will be asked a single major question by the researcher, related to how you take part in activities since your vision loss, and how this relates to the people in your life. After you have finished telling your story, the researcher will prompt you to provide further detail or information on specific topics raised by you. This session will be audio-recorded.

During the second session, you will participate in a semi-structured interview. In this interview, you will be asked a set of pre-determined, semi-structured, and in-depth questions that are based on the ideas and responses you generated from the first interview. This session will be audio recorded.

Before the third meeting, participants will be given a copy of the narrative that the researcher has written based on the experiences you have shared during the first two interviews. In the third and final interview, the researcher will ask you to reflect and share your perceptions of the narrative. You will be invited to provide feedback and make any changes you would like to see. The final rendering of your narrative account might not be an exact replication of your experienced story, but you are welcome to provide feedback in this final interview session to confirm the plot points, alter your responses to previous interview questions, and give overall feedback on the researcher’s interpretations.

All sessions will take place on a date and time that is convenient for you.

5. What are the risks and harms of participating in this study?

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 sessions will be scheduled based on participants’ convenience, and you can request to stop a session if you experience any discomfort or fatigue.

6. What are the benefits of participating in this study?

You may not directly benefit from participating in this study, however, your views may help influence the services, programs, and policies that are put in place for older adults with ARVL as it demonstrates how older adults use their interactions and relationships they share with people to manage ARVL-related changes and support their participation in meaningful activities.

7. Can participants choose to leave the study?

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. If you wish to have your information removed, please let the researcher know. We may give you new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

8. How will participants’ information be kept confidential?

Representatives of the University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records for monitory purposes.

All three sessions of interview will be audio-recorded. In addition, the researcher will take observation notes during each interview. All identifying information will be removed from these notes. What you say will be typed out by the researcher. The only people who will listen to the recording will be members of the research team. The only people who will read the interview transcripts will be the research team.

To protect your identity, only an identification number will be used to identify recordings, notes, transcripts, and interviews. You are free to request that parts of the recording be erased, either during or after the sessions. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file. 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 7 years.

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report.
9. Are participants compensated to be in this study?

To thank you for your contributions to the study, you will receive a $25 honorarium which will be provided in the form of a gift card of your choosing.

10. Whom do participants contact for questions?

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 Ji Won Kang at jkang256@uwo.ca or by telephone at 519-495-0504.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics, email: ethics@uwo.ca.

This letter is yours to keep for future reference.
APPENDIX V: Verbal Consent

**Project Title:** Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influences of Social Networks

**Principal Investigator**
Colleen McGrath, PhD

**Co-investigator**
Ji Won Kang

Verbal consent will be documented by the researcher, by checking the appropriate boxes on behalf of the participant.

Do you confirm that the Letter of Information has been read to you and have had all questions answered to your satisfaction?

☐ YES ☐ NO

Do you agree to participate in this research?

☐ YES ☐ NO

Do you agree to be audio-recorded?

☐ YES ☐ NO

Do you consent to the use of unidentified quotes obtained during the study in the dissemination of this research?

☐ YES ☐ NO

Do you agree to be contacted for future research studies?

☐ YES ☐ NO

Do you wish to involve a family member or close friend to act in the witness's role during this consent process to confirm that you have been adequately informed of the study prior to providing consent?

☐ YES ☐ NO
The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to the participant, and has had any questions answered.

☐ YES ☐ NO

_________________________________________          ______________________
Print Name of Researcher                      Signature

Obtaining Consent

_______________________________
Date (DD-MM-YYYY)

_________________________________________          ______________________
Print Name of Informal Witness                      Signature

_______________________________
Indicate the Relationship of the
Informal Witness to the Participant

_________________________________________          ______________________
Date (DD-MM-YYYY)
APPENDIX VI: Written Consent

**Project Title:** Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influences of Social Networks

**Principal Investigator**
Colleen McGrath, PhD

**Co-investigator**
Ji Won Kang

I confirm that I have read the Letter of Information and have had all questions answered to my satisfaction
☐ YES ☐ NO

I agree to participate in this research
☐ YES ☐ NO

I agree to be audio-recorded in this research
☐ YES ☐ NO

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research
☐ YES ☐ NO

I agree to be contacted for future research studies
☐ YES ☐ NO

__________________  ____________________
Print Name of Participant                  Signature

__________________
Date (DD-MMM-YYYY)

The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to the participant, and has had any questions answered.
☐ YES ☐ NO

________________________  __________________________
Print Name of Researcher  Signature

Obtaining Consent

________________________

Date (DD-MMM-YYYY)
APPENDIX VII: Interview Guideline

First Interview

Thank you for participating in this research, which will be looking at how social networks both support and limit the activity engagement of older adults with age-related vision loss (ARVL). In this interview, can you tell me about the types of activities you participate in since being diagnosed with vision loss, and how has your participation in those activities changed since experiencing vision loss? Also can you tell me about a time when someone either helped or hindered your participation in those activities? You can tell me your story in any way you like, and in any order, there are no correct or wrong answers. Once you are done telling your story, I will ask you some follow-up questions, to learn more about certain topics. Before we start this interview, are there any questions you would like to ask me? [Respond to all participant questions].

[At the end of the session, the researcher will ask the participants to answer the Demographic Questionnaire outlined in Appendix VIII.]

Follow-up questions

1. “Can you further explain about [insert participants’ response that needs elaboration or stands out to the researcher]?”

2. “Can you provide an example of [insert participant’s experience]?”
Second Interview

Participant1

1. In our previous interview, we discussed about your involvement in SLR and you mentioned that within SLR, there are networks of people that all have common challenges whether it be vision or hearing loss and there is a lot of patience among the members.
   - Relating to this, can you think of a particular time when you felt supported as a person with vision loss in SLR?
   - Also, have there ever been any experiences that made you feel particularly unsupported as a member of SLR?

2. You mentioned that young people are not always as patient with someone who “can’t see as well”. Can you think of any specific experiences or situations when you felt that?

3. You’ve mentioned that your vision loss has been a gradual process. Can you talk more about how that gradual process has impacted your activities and your level of reliance on your social networks? Do you think your experience is different from someone that experienced a more sudden loss of vision?

4. It seems like you are very socially involved and are actively participating in community events. For something like Aquafit, how do you manage that with vision loss? Did you have to do the activity any differently?

5. When you have challenges out in the community, at the grocery store for example, do you tend to ask for help from others? If so, how do you find people when you ask for help?

6. It seems like driving and travelling are important activities for you. Can you talk more about why they are so important? Also, have you changed anything about how you drive since your vision loss? (i.e., bring someone with you, rely on rides more, take public transit, etc.)

7. Are you accessing any other vision rehabilitation supports like the CNIB, for example? If so, what do they help you with and if not, why?

8. In our last interview, you talked about getting new glasses from your optometrist. How do you find your relationship with your optometrist? Is it a generally positive relationship? Are there supports you wish they provided but currently don’t?

9. It sounds like you have some great friends who are very caring. Can you talk about the specific types of support you have received from your friends?
   - When you need support are you pretty open to asking for it? Do you ever hesitate to ask for help?
10. You’ve mentioned a few times that you worry for the future and are concerned about living alone. What is it about the future that you worry about?

11. You said that worrying doesn’t solve problems. Can you talk to me a bit about how you manage emotionally with vision loss as you appear to have established some really positive coping strategies?

12. You mentioned that you really miss your people because of COVID-19 and I can certainly appreciate that. I’m wondering, do you feel that older people with vision loss have been particularly affected by social distancing requirements due to COVID? Can you talk to me a bit more about how your engagement in activities has changed as a result of COVID?
Participant 2

1. You talked about your grandchildren in our last interview. Can you describe what your relationship or interactions are like with each of your grandchildren?
   - Can you think of a particular time when your grandchildren supported you?
   - How do you support them in their lives?
2. Can you expand on your relationship with your optometrist?
   - What does your interaction with him normally look like during your doctor visits?
   - Has your doctor ever recommended anything to you that has been particularly helpful (changing something in the home layout, assistive technology, etc)?
   - Do you access any other types of low vision supports, such as CNIB?
     i. If so, what have they helped you with in the past? If not, why don’t you access those supports?
     ii. Could you ever envision yourself using them in the future? If yes, for what? If not, why?
3. When you had flesh-eating disease on your hip, you said that your neighbor, Henny came to help immediately after your discharge from hospital. Could you explain a bit more about who she is and what were the particular ways she supported you during that time?
   - You mentioned that she still comes to visit you daily. What role does she play in your life?
   - What does she currently do to help you? Is that different from how she helped after you got out of hospital?
   - Are there ways that you help Henny? How so?
4. How do you manage your travel when you go out to visit your daughter or grandchildren who live out of province?
   - You also mentioned that you continue to drive. Have you changed anything about your driving (such as not driving at night, going with someone, etc.)?
5. It seems like you are a very independent person. Is that a fair assessment? Why is being independent so important to you?
   - Are there any circumstances where you will ask for help? If so, can you tell me about a time when you asked for help and who provided the help for you?
6. You apologized a few times in our last interview for not always craving the company of other people. Do you ever feel pressured to hang out with people socially, or feel as if it is something you are supposed to do?
7. It sounds like throughout your life, you have often taken on the role of being a helper to other people. For instance, you’re an executive member of SLR, you’ve helped Marianne deal with her mother, and you also support your daughter financially.

- Why is helping so important to you? Do you feel that being a helper enriches the quality of your life? If so, how?

8. You’ve mentioned several times that vision loss is just a part of you. Do you think that your vision has shaped how you think about your identity in any way? If so, how? Do you think your vision has influenced how others act around you?

9. You’ve mentioned that you really enjoy going out for walks, but you don’t go outside in the winter. Are there any particular reasons why you prefer not to go outside in the winter? Does it have anything to do with concerns for safety?
Participant 3

1. During our first interview, you mentioned that your vision loss makes it harder to eat. Can you expand on what difficulties you now have with eating?
   - Do you go out to restaurants with your family or friends?
   - How do you find tasks such as grocery shopping? Were there any times when you needed help from people at the store? Can you tell me about those?

2. You mentioned that it’s a little trickier to see where you’re walking now. Can you tell me about a time when you experienced challenges while walking? (What are some strategies you use to overcome those barriers)

3. You talked about how you enjoy watching television and biking with your husband.
   - How do you manage watching TV? Are there certain strategies you use to help with watching television?
   - How do you maneuver your bike with impairments in your peripheral vision? What are some strategies you use to manage any difficulties you may experience while riding your bike (i.e., overviewing traffic situation, finding routes, avoiding obstacles, evaluating distances between others etc.)?
     - Can you tell me about a time when you had to use one of those strategies while out riding your bike?

4. During our first interview, you said that you hardly ever drive now. Why is that?
   - Are there any situations where you will still drive? If so, are there strategies you have to use to make sure you are safe while driving?
   - Do your family or friends tend to drive you places now? How do you feel about that?

5. You talked about using a magnifier to help you do puzzles. What other assistive devices do you use and what tasks do they help you with? Can you tell me about a time when you used an assistive devices to support your daily activities?

6. During our last interview, you said that your glaucoma got a lot worse over the years and it sounded like you were preparing for a future where your vision might worsen. Can you tell me what you are doing to prepare for that?

7. What do you know about the Canadian National Institute for the Blind (CNIB)? Do you use their services? If so, which ones?
   - Have the services you’ve used at the CNIB been helpful?
   - Is there something more that CNIB could provide that would be useful for you?
   - Do you use other vision supports apart from CNIB?
8. Last time, you mentioned that your husband and your girlfriends play different roles in your life.

- You said that your husband is strong enough to help you with a lot of things and plays a number of social roles. Can you expand on what kinds of social roles he plays? Is he someone you talk to about your vision loss?
- You said that talking with your female friends provides you with new perspectives and helps you de-stress. Are there certain things you are more comfortable talking to your girlfriends about rather than with the two men in your life? Do you talk about the struggles you have with your vision loss with your friends?
- What do the women in your life provide for you in terms of social supports? (i.e., Do they help you with certain things? Bring you places? Etc.)

9. It seems that you are very involved in providing care for your father. How do you manage those caregiving responsibilities with your vision loss?

10. You talked about how you and both of your daughters have glaucoma. Given that you are all experiencing the same diagnosis, what type of social support do they provide to you? What type of support do you provide to them?

11. Given that we’re doing our interviews during COVID crisis, can you tell me about a time when you experienced disruptions to the activities you want to do? How has COVID impacted your interactions with your social networks like your family, friends, ophthalmologists, etc.?

12. You talked about three optometrists last time. How did the first optometrist (the one who had glaucoma himself) communicate your diagnosis to you? Were there any supports he recommended to you at the time?

- When you think back on your previous encounters with your optometrists, can you recall a time when you had a particularly positive interaction? What about a time when you had a really negative interaction? Can you tell me about those?
Participant 4

1. During our first interview, you said that you don’t play bridge cards competitively because they don’t allow the use of larger cards.
   - Were there any other times when you felt that there was lack of accommodation for visually impaired individuals for the activities you wanted to do, or used to do?
   - Can you talk more about how you modified how you engaged in other activities to maintain your engagement?

2. You mentioned that you don’t read anymore, but instead you use audio books and watch TV to get informed about the news.
   - How do you manage watching TV? Are there certain strategies you use to help with watching television?

3. You said that you take the train to visit your daughter and that you use the walker to go to the lounge and there’s a wheelchair waiting for you there.
   - Is the use of wheelchair and walker needed from a mobility standpoint or do you pre-arrange this because of the vision?
   - Do you travel alone, or do you go with someone?
   - Were there any times when you needed help from people at the train station? Can you tell me about those?

4. You also said that you don’t travel or go to music concerts, theaters, and ballet much now. Is this aversion caused by your vision loss, or COVID, or age, or all of them?
   - Can you expand on what challenges you now have with travelling related to your vision?
   - Are there any occasions where you would travel or has it completely stopped?
   - How does vision loss interfere with you enjoying music concerts, theaters, and ballet to the fullest?

5. You mentioned that you’re playing cards on iPad now because of COVID. Can you tell me about other times when you experienced disruptions to the activities you want to do because of COVID? How has COVID impacted your interactions with your social networks like your family, friends, ophthalmologists, GP, etc.?

6. You said that because you’re not driving anymore, it restricts your mobility and makes you more dependent on others. How does that make you feel?

7. From our last interview, it seemed that you and your friends enjoy pastimes together, like going to dinners, music concerts, and walking.
   - What do your friends provide for you in terms of social supports? Do they help you with certain things when you go out for meals or walks? Do they bring you to
places when you need to get around the town? What type of support do you provide to them?

- Are they someone you talk to about your vision loss?

8. You also said that although you live alone in a senior’s apartment complex, you don’t feel isolated because your brother lives close by, and you keep in touch with your daughter frequently via phone calls.

- It seems that they both have your back but support you in different ways. Can you expand on how they differ in terms of the social support they provide to you? How do you support them?

- Do you ever get together with your brothers and do things? Can you talk more about those occasions?

- Do you talk about the struggles you have with your vision loss with your brother and daughter?

9. It seems like you enjoy having some alone time and want to maintain your independence. Is that a fair assessment? Why is being independent so important to you?

10. You said that you don’t want to be a nuisance to others but you also won’t hesitant to ask for help when you need it, like you mentioned how you asked someone at grocery store when you didn’t bring your magnifying glass.

- Were there any other times when you asked for help (i.e., when you’re out on the streets, shopping, or banking), can you tell me about those? Who provided the help for you?

- How do you manage balancing between accepting help from others and maintaining your autonomy?

11. You said that because of your arthritis, you aren’t able to knit as much as you want, and you feel bored and frustrated at times.

- Are there times when you feel frustrated because of your vision?

- Can you talk to me a bit about how you manage emotionally during these times as you appear to have established some really positive coping strategies?

- Is knitting something you do alone, or are you a part of social knitting group?

12. You said that you have a “Bosch thing” but you don’t use it much. Can you explain more about what Bosch is, what it’s for, and why you feel that you don’t need it yet?

13. From last time, you seemed satisfied with your interactions with your ophthalmologist, both with the second last one (one that’s your brother’s friend) and the new one. What kinds of services or treatments do they provide to you (do they prescribe medicine, do you get surgery)?

- When you think back on your previous encounters with your ophthalmologists,
can you recall a time when you had a particularly positive interaction? What about a time when you had a really negative interaction? Can you tell me about those?

- You said that your ophthalmologists are very communicative to you, and answer your questions well. Do you think they are communicative with other healthcare professionals as well, like the optometrist, your general practitioner, or other specialists? Is it easy to get referrals from them?

14. You talked about your general practitioner briefly. What do you usually visit your GP for? Were there any supports he recommended to you related to your vision?

15. What do you know about the Canadian National Institute for the Blind (CNIB)? Do you use their services? If so, which ones?

- Have the services you’ve used at the CNIB been helpful?
- Is there something more that CNIB could provide that would be useful for you?
- Do you use other vision supports apart from CNIB?
Participant 5

1. You talked about how your daughters have helped you with accessing low vision aids, moving to new home, driving to destinations, and providing you with financial support. Are there ways that you support them? Can you talk more about those occasions?

2. You mentioned how you feel more dependent on your family and friends after losing your husband and your ability to self-drive. Can you expand on why you feel this way?
   - Can you tell me about a particular time when you asked for other’s help to engage in an activity you wanted?
   - How do you feel about being more dependent on others? Do you ever feel hesitant to ask for other’s help?

3. You also talked about how you have two sons. Do you ever get together with your sons? Can you talk more about those occasions and how you interact with them?
   - Do you talk about the struggles you have with your vision loss with your sons?
   - Can you expand on how your sons provide support to you? What kinds of support do you provide them?

4. You mentioned how you are planning on having an appointment with your doctor about a leakage in the bladder. Can you expand on the relationship you share with your doctor?
   - Other than the problems with leakage, what else do you visit your doctor for?
   - Do you talk about your vision loss with him?
   - Can you expand on how he supports you? What kinds of services has he provided to you?

5. You mentioned how you were part of the coffee club and knitting club in Cherry Hill, but you decided to quit when you couldn’t fully engage in club activities because of your vision loss.
   - Can you recall a time when your club members either helped or hindered your participation in club activities when you had difficulties with club activities because of vision loss? Can you talk more about those occasions?

6. You talked about how you were part of a fitness club and had a personal health trainer who helped you exercise.
   - How do you manage exercising with vision loss? Were there any times when you experienced difficulties with exercising because of your vision loss?
   - Are there certain strategies you use to help with exercising?
- Were there any times when your health trainer helped you overcome the barriers in exercising caused by vision loss?

7. You mentioned how University of Waterloo supplied you with CCTV five years ago. Do you still use vision supports from University of Waterloo?
- Have the services you’ve used at the University of Waterloo been helpful?
- Is there something more that University of Waterloo could provide that would be useful for you?

8. You mentioned how CNIB provides you with affordable transit system that allows you to be mobile within the community.
- Have the services you’ve used at the CNIB been helpful?
- Is there something more that CNIB could provide that would be useful for you?

9. You mentioned how you received laser treatment for your macular degeneration from your optometrist. Can you describe what your relationship or interactions are like with your optometrist?
- When you think back on your previous encounters with your optometrist, can you recall a time when you had a particularly positive interaction? What about a time when you had a really negative interaction? Can you tell me about those?
- What other services has he recommended to you relating to your vision loss?
Third Interview

1. Does my rendering of your story reflect what you wanted to convey? Does my storyline capture the important aspects of your experience with ARVL, social networks, and participation in activities?

2. Is there anything you would like to omit, add, or change from my interpretations?

3. Do you have any further feedback on your participation in this research?
APPENDIX VIII: Demographic Questionnaire

1. Please identify your gender ___________________
2. What is your age? ___________________
3. Which racial and/or ethnic group do you identify as (multiple responses allowed)?
   ____ Arab/West Asian (e.g. Moroccan, Egyptian, Armenian, Lebanese, Iranian)
   ____ Aboriginal (e.g. Inuit, North American Indian, Métis)
   ____ African (e.g. Jamaican, Haitian, Somali)
   ____ East Asian (e.g. Chinese, Korean, Japanese)
   ____ South Asian (e.g. Pakistani, East Indian, Si Lankan)
   ____ South East Asian (e.g. Cambodian, Malaysian, Vietnamese, Laotian)
   ____ Caucasian
   ____ Caribbean
   ____ Latin American/Hispanic
   ____ Filipino
   ____ Other (please specify) ___________________
4. What is your highest completed degree of education?
   ____ Some high school
   ____ Completed high school
   ____ Some university
   ____ Completed university
   ____ Some college
   ____ Completed college
   ____ Post-university degree
5. Please specify your marital status
   ____ Married
   ____ Single
6. Do you have children (Y or N)? If yes, how many children do you have?

7. What is your annual household income?
- < $25,000
- $25,000 - $50,000
- $50,000 - $100,000
- > $100,000

8. What is your ARVL diagnosis?
- Age-related macular degeneration
- Glaucoma
- Diabetic retinopathy
- Other (please specify) ____________________

9. How much can you see with your ARVL condition?
- Partially sighted
- Completely blind
- Can partially perceive light
- Other (please specify) ____________________

10. How long have you been diagnosed with your ARVL condition?

___________________
APPENDIX IX: Research Ethics Approval

Date: 13 May 2020
To: Dr. Colleen McGrath

Project ID: 115681

Study Title: Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influence of Social Networks
Short Title: Occupational Engagement of Older Adults with Age-Related Vision Loss: Understanding the Influence of Social Networks
Application Type: NMRB Initial Application
Review Type: Delegated
Full Board Reporting Date: June 5 2020
Date Approval Issued: 13/May/2020
REB Approval Expiry Date: 13/May/2021

Dear Dr. Colleen McGrath

The Western University Non-Medical Research Ethics Board (NMRB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMRB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMRB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

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<th>Document Name</th>
<th>Document Type</th>
<th>Document Date</th>
<th>Document Version</th>
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<td>Demographic Questionnaire</td>
<td>Paper Survey</td>
<td>01/Apr/2020</td>
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<td>Email Script</td>
<td>Recruitment Materials</td>
<td>17/Apr/2020</td>
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<td>Interview Guideline</td>
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<td>01/Apr/2020</td>
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<td>Verbal Consent/Assent</td>
<td>03/May/2020</td>
<td>3</td>
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<td>Letter of Information and Written Consent</td>
<td>Written Consent/Assent</td>
<td>03/May/2020</td>
<td>3</td>
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<td>Recruitment Materials</td>
<td>17/Apr/2020</td>
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<td>Telephone Script</td>
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Documents Acknowledged:

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<td>Community Resources</td>
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<tr>
<td>Screening Questionnaire</td>
<td>Screening Form/Questionnaire</td>
<td>05/May/2020</td>
<td>2</td>
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No deviations from, or changes to the protocol should be initiated without prior written approval from the NMRB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMRB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMRB who are named as investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMRB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 0000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

[Signature]
Research Ethics Officer on behalf of NMRB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Curriculum Vitae
Ji Won Kang

EDUCATION

Master of Science in Health & Rehabilitation Sciences, Health and Aging Field
Expected graduation 2019 – June 2021 (London, ON)
WESTERN UNIVERSITY

Honours Bachelor of Science with Distinction in Human Biology, Health and Disease Specialist Program
2014 – 2018 (Toronto, ON)
UNIVERSITY OF TORONTO

AWARDS AND RECOGNITIONS

Ontario Graduate Scholarship $15,000
2020 - 2021

New College In-Course Scholarship $750
2016

Faculty of Arts and Science, Life Sciences Dean's List Scholar
2015 - 2016

CERTIFICATION AND TRAINING

SafeTALK Certified
2020 (London, ON)
CMHA MIDDLESEX
  ● Completed training in suicide alertness

Dementia Friendliness Certified
2020 (London, ON)
ST. JOSEPH’S HEALTH CARE LONDON
  ● Completed workshop from Alzheimer Society London and Middlesex
ACADEMIC CONFERENCE

Oral Presentation

Poster Presentation


WORK EXPERIENCE

Teaching Assistantship, Department of Health Sciences
WESTERN UNIVERSITY
● HEALTSCI 2711B – Health Issues in Aging
● HEALTSCI 1110A – Personal and Social Determinants of Resilience and Wellbeing

Graduate Student Assistantship, Department of Health Sciences
Aug. 2020 – Nov. 2020
WESTERN UNIVERSITY
● HEALTSCI 9007 – Motivational Interviewing

Research Assistantship, Department of Laboratory Medicine and Pathobiology, and Department of Human Biology
2016 – 2018
UNIVERSITY OF TORONTO
● Genetically mutate certain domains of a protein called Patched-1 (Ptch1). Determine the specific functions of each domain of Ptch1 protein and identify novel biological molecules that interact with Ptch1, specifically at the luminal domains
Lab techniques used: (1) Yeast-Two-Hybrid Assay, (2) DNA cloning and PCR amplification, (3) immunofluorescence (to trace the localization of mutant Ptch1 within cells), (4) western blots, (5) cell culture, (6) Luciferase Assay

**VOLUNTEER EXPERIENCE**

**24/7 Crisis Support Line volunteer**

2020 – Present
CANADIAN MENTAL HEALTH ASSOCIATION (CMHA)
- Provide confidential supportive listening and information as necessary to individuals calling the Support Line. Assess and triage crisis calls when needed and link callers to the Crisis Response Line when necessary. Utilize a database and other resources to provide community referral information to callers.

**Functional Electrical Stimulation (FES) Therapy volunteer**

2020 – Present
PARKWOOD FITNESS CENTER
- Assist participants with using ergometers and FES rehabilitation technique to enable muscles to work and perform activities even when they are paralyzed through neurological disease or injury.

**Geriatric Ward Visitor**

2019 - 2020
PARKWOOD INSTITUTE MENTAL HEALTH CARE
- Provide specialized care and support to older-adult patients who live with late onset mental illnesses or severe behavioural responses. Work collaboratively with patients, their families and our external partners, whether in hospital, in their own residence or in long-term care homes, to provide holistic care that focuses on assessment, treatment, rehabilitation, prevention, family/community support and education.

**Executive Member**

2018 – 2019
STRENGTHIN
- Organize and deliver a series of workshops that aim to reduce suicide and substance use in local high school communities by raising awareness of the importance of mental health. Collaborate with other school boards, student leaders, educators, and parent groups, and promote positive interaction between/within social groups. Review other mental health relevant programs and services delivered by the board of health.

**Long Term Care and Adult Day Service Volunteer**

2015 – 2019
ST. JOSEPH’S HEALTH CARE LONDON