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The Coping Strategies of Older Adults with Age Related Vision Loss (ARVL) – A Narrative Account

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

The goal of this study was to share the stories of older adults with age-related vision loss (ARVL) and how they have coped to maintain meaningful occupational engagement. Grounded in a constructivist paradigm, data collection and analysis were guided by the narrative inquiry methodology. The participants consisted of six older adults aged 60 or older, diagnosed with one of the following ARVL conditions: macular degeneration, diabetic retinopathy, and/or glaucoma. Participants were recruited from vision loss non-profit organizations such as the Canadian National Institute for the Blind (CNIB) and the Alliance for Equity of Blind Canadians (AEBC). One older adult was recruited through snowball sampling, and two were participants in previous research conducted in the Vision Loss in Later Life Research Lab (VITAL). Data collection occurred across three narrative interviews. Each of these interviews were audio recorded, and semi-structured. These interviews took place both over the phone or in person, as per the older adult's request. Fraser's (2004) line-by-line method was employed to produce a thorough thematic analysis based on the stories shared by each of the older adults. Three main themes were identified, and coping mechanisms were grouped by family including: (1) *Psychological coping mechanisms*, (2) *Social coping mechanisms* and, (3) *Behavioural coping mechanisms*. This research expands knowledge on how older adults cope with ARVL and the importance of maintaining meaningful occupation for older adults with vision loss. The future directions and implications of the research are discussed and unpacked as well.

Keywords: Age-related vision loss, older adults, coping, occupational engagement, narrative inquiry, gerontology, psychological coping, social coping, behavioural coping.

Lay Summary

This study aimed to share the stories of older adults as they explain how they have coped with age-related vision loss (ARVL), a term that includes three diagnoses including macular degeneration, diabetic retinopathy, and glaucoma to maintain participation in their favourite activities. Six older adults (aged 60 or older) participated in three narrative interviews and shared their stories about the various ways in which they cope and navigate barriers related to low vision. Analysis of the participants shared stories elicited three main themes: *(1) Psychological coping mechanisms, (2) Social coping mechanisms and, (3) Behavioural coping mechanisms.* Findings from this study could help to inform improved low-vision rehabilitation services for older adults with ARVL, as well as bring research awareness to the importance of coping and maintaining occupational engagement for other older adults with ARVL.

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Chapter 1: Introduction

For much of your life, you can choose what occupations you engage in. These occupations are how you meet friends, build social connections, and feel connected to your community. These occupations give you a sense of purpose and you often feel a sense of joy when you participate in occupations that are meaningful to you. You might never imagine that there will be a day when you may not be able to continue engaging in those occupations that you love. However, into older adulthood, you may be diagnosed with macular degeneration, glaucoma, or diabetic retinopathy, one of the three age-related vision loss (ARVL) conditions. Following this diagnosis, you notice it is more difficult to maintain your engagement in meaningful occupation. What once brought you joy, now brings about feelings of frustration and anger. You start to withdraw from these occupations in the hopes of saving yourself from these feelings of frustration, but eventually you begin to refrain entirely from certain occupations, and this leads to a loss of independence, feelings of depression, and social isolation. Another option, instead of withdrawing entirely from occupation following an ARVL diagnosis, is to adapt in order to continue pursuing these meaningful occupations. The coping process begins with an appraisal of the threatening situation arising from the stressful event caused by a disruption to the older adults' environment, which becomes the focus of the coping. This is followed by a series of reactions or coping skills which aim to mitigate these negative feelings (Brennan et al., 2000). There are many ways in which an older adult with ARVL may adapt or cope with ARVL in order to continue participating in the occupations they love and that give their life meaning.

1.1 Problem Statement, Significance, Rationale

Low vision is defined as “having a significant loss in visual acuity or visual field that is not correctable to normal vision with spectacles or contact lenses” (McGrath & Corrado, 2019, p.

378). Age-related vision loss (ARVL) is a category of low vision and includes three conditions including: macular degeneration, glaucoma, and diabetic retinopathy. Together, these are the three most common low vision conditions among older adults (McGrath & Corrado, 2019; Watson, 2001). In 2017, vision loss was one of the main contributors to the number of years lived with disability in the Canadian older adult population, aged 65 years and older (Mick et al., 2021). The most prevalent eye diseases in the population are related to ARVL and there is a correlative increase in ARVL cases as the Canadian older adult population ages (Canadian Counsel for the Blind [CCB], 2021). It is estimated that 35% of Canadians aged 60 and older are facing vision loss and this is important to note as vision loss issues in Canada cost the economy \$32.9 billion in 2019, and these numbers are projected to rise significantly with each year that passes (CCB, 2021).

ARVL is commonly associated with significant negative implications on the physical, cognitive, psychological, and social functioning of older adults including a loss of previous life roles which, in turn, creates negative implications for older adults' feelings of control and self-worth (Girdler et al., 2008; Swenor, 2020). In addition, losing vision in later life can lead to a decreased ability to perform normal daily occupations, including activities of daily living as well as decreased information processing speeds and errors in decision making (Boey et al., 2021). Such loss of meaningful occupation can result in a complete shift from how older adults engaged in life before their ARVL diagnosis. It is important to focus on the meaningful occupations of older adults because, when restricted, occupational deprivation can lead to negative effects, such as psychological distress; an increased risk of falls; greater likelihood of medication errors; social isolation, decreased life satisfaction and depression; compromised health-related quality of life; and premature admission to nursing homes (Berdeaux et al., 2017; Berger & Porell, 2008;

Brody et al., 2001; Harada et al., 2008; Hooper et al., 2008; Kleinschmidt, 1999; Laitinen et al., 2007; Laliberte Rudman & Durdle, 2008; Li et al., 2011; Mitchell et al., 2008; Rees et al., 2007). The research also demonstrates that when older adults seek help from different resources, such as community organisations or other peers who are similarly experiencing ARVL, they are able to continue engaging in meaningful occupation (Smith et al., 2009). As such, engagement in meaningful occupation is possible to maintain, so long as the appropriate resources and coping mechanisms are employed.

Lazarus and Folkman's theory of stress and coping frames how people deal with stress in their environments and explains the processes employed to cope with this (Biggs et al., 2017). People are consistently appraising stimuli in their environments and generating the appropriate emotional response based on how they are feeling. If a stimulus is appraised as stressful, the distress felt by the person will initiate "coping strategies to manage emotions or attempt to directly address the stressor itself" (Biggs et al., 2017, p. 352). This is the same process that an older adult with ARVL goes through when faced with the stressful event of not being able to complete tasks or engage in occupations the same way they did prior to losing their vision.

Given the known negative psychological implications associated with impaired vision, the mental health of older adults with any form of vision loss should be considered, as they are grieving the loss, not only of their vision, but of the loss of their favourite occupations and resulting sense of independence as well (Swenor, 2020). Mental health and coping factors should be discussed across all age groups, but especially among older adults experiencing ARVL as they are in the process, or have already experienced, losing one of their five integral human senses. Losing your sight to a visual impairment could have extreme negative effects on mental health, which are just as important to discuss as physical changes to the body that comes with

getting older (National Academies of Sciences, Engineering & Medicine, 2017). Poor mental health, and a lack of healthy coping strategies to deal with this could take a toll on the lives of older adults and start to negatively affect the meaningful occupations that they enjoyed prior to experiencing ARVL (National Academies of Sciences, Engineering & Medicine, 2017). The greater the level of functional loss due to ARVL, the greater the level of depression in the older adult (O'Donnell, 2005). Despite the importance of mental health research, the current low vision literature lacks a dedicated focus on the psychological coping strategies used by older adults with ARVL, especially concerning its effect on the older adults' ability to participate in meaningful occupation (McGrath & Corrado, 2015). Coping mechanisms are important to understand as it allows for the creation of more tailored care approaches intended to improve the psychological wellbeing of older adults with ARVL (Swenor, 2020). It is, in turn, these improved care initiatives that will lead to improved low vision rehabilitation services (LVRS) for those aging with vision loss (Swenor, 2020).

1.2 Research Purpose and Questions

The primary goal of this study was to better understand how older adults with ARVL cope with barriers to meaningful occupation. Within the existing literature, there is a call for more research concerning vision loss in older adults, with a specific focus on exploring their use of coping strategies (Boerner & Wang, 2012; Dreer et al., 2008; Fenwick et al., 2019; Glen, 2008; McGrath & Corrado, 2019; Robertson et al., 2006; Rovner et al., 2011; Schilling et al., 2011; Sturrock et al., 2018.) To address this gap in the literature, this study will seek to answer the question: *How do older adults with ARVL narrate their experiences with coping in ways that support engagement in meaningful occupation?*

1.3 Defining the Language Used in this Study

In academic literature, terms are often used interchangeably, however, they may have different meanings. As such, it is important to have a comprehensive understanding of the language used throughout this thesis. To help ensure a consistent understanding amongst all readers, the following terms have been defined: age related vision loss, coping strategies, occupation, and occupational engagement.

1.3.1 Age related vision loss (ARVL)

Low vision is defined as “having a significant loss in visual acuity or visual field that is not correctable to normal vision with spectacles or contact lenses” (World Health Organization [WHO], 2008). Age-related vision loss (ARVL) is a category of low vision and is characterized by three conditions including: macular degeneration, glaucoma, and diabetic retinopathy. Together, these are the three most common low vision conditions among older adults (McGrath & Corrado, 2019; Watson, 2001). Of the major vision loss diagnoses in Canada, 9% face diabetic retinopathy, 11% are diagnosed with glaucoma and 15% have macular degeneration (CCB, 2021). ARVL can be distinguished from other forms of vision loss due to the lived experience of the older adult. With ARVL, the older adults experience with vision has been “normal” up until the diagnosis, typically accompanied by well-established familial, employment, and social roles (Brennan et al., 2000). Vision loss in Canada is projected to become more prevalent with an estimated two million additional diagnoses by 2050, one of the causes of this being an increase in the Canadian older adult population and the subsequent increase in ARVL diagnoses (CCB, 2021).

Macular degeneration is characterized by reduced visual acuity, visual field, and contrast sensitivity due to scotomas affecting the central field of vision (Watson, 2001). A scotoma is a

blind spot in the visual field which affects acuity (Armenta, 2021; see Figure 1). There are two kinds of macular degeneration, the wet and the dry variety (CCB, 2021). Dry macular degeneration has no current approved treatment, while the wet variety, which can quickly lead to vision loss, does have an approved treatment (CCB, 2021). The CCB (2021) states that treatment for wet macular degeneration involves prescription of drugs that block angiogenic protein vascular endothelial growth factor (VEGF), which is produced in the retina of patients with macular degeneration. Macular degeneration does not always lead to complete blindness, and peripheral vision may be retained due to the acute degeneration of the macula, which serves sharp, central visual abilities (CCB, 2021). Activities such as reading, watching television, driving, and maintaining or developing personal relationships become difficult with macular degeneration (Boey, 2021; CCB, 2021). There are currently 2.5 million Canadians living with macular degeneration, which may have long lasting impacts on their independence and quality of life (CCB, 2021).

Diabetic retinopathy is characterized by elevated glucose levels in the blood which cause the retinal blood vessels to swell and leak, causing vision loss (CCB, 2021; see Figure 2). There were 116,198 Canadians who reported living with diabetic retinopathy in 2019 (CCB, 2021). Diabetic retinopathy presents itself clinically through reduced visual acuity, light scatter, glare and contrast sensitivity, colour and image distortion and finally possible nearsightedness (Watson, 2001). Essentially, anyone who is diagnosed with diabetes is at risk for developing diabetic retinopathy and will show some symptoms within 20 years of the diagnosis if blood sugar levels are not properly and consistently maintained (CCB, 2021). There are one million Canadians who have a diagnosis of diabetic retinopathy and can face challenges with reading small print, navigating social situations, and loss of familial roles (Boey, 2021; CCB, 2021;

Devenney et al., 2011). Early diagnosis, as well as treatment, can assist in minimizing vision loss (CCB, 2021). The CCB (2021) reports that anti-VEGF medication should be prescribed as treatment if metabolic control of blood sugars levels, pressure, and cholesterol is not an effective primary treatment.

In 2019, the CCB (2021) reported that there were 129,101 Canadians living with glaucoma. Older adults with glaucoma face degeneration of the optic nerve resulting in loss of peripheral visual fields (Watson, 2001; see Figure 3). The optic nerve is responsible for transmitting the impulse of sight to the brain, and when damaged, gradual vision loss occurs with the peripheral vision eventually narrowing to a central tunnel (CCB, 2021). Due to this gradual degeneration, and the fact that peripheral vision is affected first, the vision loss associated with glaucoma may go unnoticed by the affected person for some time, thus it is important to maintain regular eye doctor visits when there is a known familial risk (CCB, 2021). There is no cure for glaucoma, however, the main symptom is high pressure in the eye, which does have an approved treatment plan to reduce discomfort (CCB, 2021). Treatment may reduce progression of glaucoma and involves decreasing the ocular pressure through surgery, drugs, and laser therapy (CCB, 2021). People with glaucoma may find it difficult to engage in occupations such as community mobility and reading, due to the loss of peripheral visual field (Boey et al., 2021; Watson et al., 2001).

Figure 1

Normal vision is shown on the left, contrasted with the degeneration of the central field of vision caused by macular degeneration as shown on the right.



Note. Effects of macular degeneration vs normal visual field, from Mayo Clinic, 2022, <https://www.mayoclinic.org/diseases-conditions/dry-macular-degeneration/symptoms-causes/syc-20350375>

Figure 2

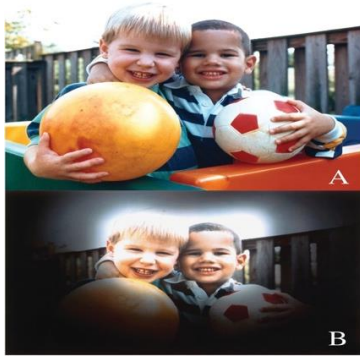
Normal vision is shown on the left, while the effects of retinal blood vessel damage caused by diabetic retinopathy is shown on the right.



Note. Effects of diabetic retinopathy vs normal visual field, from Central Florida Eye Specialists website, 2020, <https://www.theeyespecialists.com/uncategorized/diabetic-retinopathy-what-you-need-to-know/>

Figure 3

Normal vision is shown on the top. Loss of peripheral vision due to optic nerve damage caused by glaucoma is shown on the right.



Note: Effects of glaucoma vs normal visual field, from Oregon Health & Science University (OHSU) website, 2020, <https://www.ohsu.edu/casey-eye-institute/what-you-need-know-about-glaucoma>

1.3.2 Coping Strategies

Lazarus and Folkman’s theories on stress and coping define coping as “constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (Lazarus and Folkman, 1984, p. 141). It is important to note that coping is a dynamic process which includes “conscious, purposeful actions employed when an individual appraises a situation as stressful” (Biggs et al., 2017, p. 353). Lazarus and Folkman (1984) describe coping strategies as a tool aimed to directly manage the stressful stimulus or to regulate any emotions arising as a direct consequence of a stressful encounter. This alludes to two different forms of coping, problem focused coping (PFC) and emotion focused coping (EFC) (Biggs et al., 2017).

PFC identifies the problem itself as the main stressor and will be accompanied by coping strategies to mitigate the problem (Stanisławski, 2019). The goal of PFC is to resolve the

cognitively appraised, external problem (Lazarus & Folkman, 1984). As Lazarus reflected on his theory in later years, he determined that PFC and EFC are deeply intertwined with much overlap between the coping strategies employed, and that distinguishing the two can lead to the oversimplification of the very complex process of coping (Stanisławski, 2019). An example of PFC is problem focused crying where the goal is receiving support in resolving a problem (Band & Weisz, 1988). EFC focuses on managing the internal, emotional reaction to the stressor and in turn will employ emotional coping strategies (Stanisławski, 2019). Conversely to PFC, an example of EFC is emotion focused crying, where the goal is eliciting emotional support from others or releasing feelings (Band & Weisz, 1988). It is important to highlight that the goal of the mechanism employed is what determines if the coping will be problem focused or emotionally focused. Both examples use the same coping mechanism, crying, to help mitigate any identified stressors but with different goals or desired outcomes. During the cognitive appraisal, the person will decide whether the internally or externally appraised stressor is more stressful and the appropriate mechanism will be employed (Lazarus & Folkman, 1984).

Once coping strategies have begun to be used, the stressful situation is reappraised to determine the success or effectiveness of the coping efforts that have been employed (Biggs et al., 2017). This is done to determine if the nature of the stressful situation has changed to irrelevant or positive (Biggs et al., 2017). If adaptation to said stressful situation was successful, coping strategies are no longer employed. Conversely, if adaptation is unsuccessful, further coping strategies will be employed until the situation is resolved. Repeated instances of unsuccessful coping mechanisms will lead to psychological disturbances such as clinical depression, anxiety, chronic mental stress, excessive worrying or burn out (Cimarolli et al., 2012; Lazarus & Folkman, 1984, Sabel et al., 2018). Psychological disturbances are both a symptom

and an aggregate of ARVL, often leading to an aggressive cycle of further progression of vision loss and further psychological disturbances (Sabel et al., 2018). The retina and the eye are both affected by ARVL and directly connected to the brain, thus they both rely on the vascular system (Faiq et al., 2016; Sabel et al., 2018). With an overlap in neural circuits, and the known negative effects that prolonged exposure to stress hormones have on the human body, it is possible that experiencing stress could lead to progression of visual problems (Sabel et al., 2018).

It is important to remember that the stress and coping process is a continuous cycle. It is a transaction between the person and their environment. When there are disruptions to this equilibrium, the adaptive coping process is enacted to aim for maintaining the perfect balance (Biggs et al., 2017). The term ‘coping strategies’ will be used interchangeably with words such as psychological adaptation and coping mechanisms, which are all terms frequently used in the current vision loss literature (Smith et al., 2009).

Coping strategies are needed when people go through different experiences in their daily lives. These experiences are called affects and involve the different psychological states which require valuation and regulation (Gross, 2015). These different affective states include appraised stressors, lived emotions, and overall mood (Gross, 2015). Affective states can be adjusted in different situations to serve a purpose, and this feature is what allows them to be modified or regulated after appraisal of a stressful event (Gross, 2015; Lazarus & Folkman, 1984). The coping strategies used from person to person are unique and personalized to their own situation/context. This includes a variety of mechanisms, including alleviating stress responses and changes in emotion or mood based on situational context (Gross, 2015). Coping strategies are important to consider regarding older adults with ARVL because in analyzing these

individual emotional regulatory strategies, tailored rehabilitation processes can be developed which consider the psychological needs of that person (Swenor, 2020).

1.3.3 Occupation

There is little consensus among researchers regarding a single all-encompassing definition of occupation (Watters, 2013). Perhaps, occupation is best defined as “individually crafted, distinct and uniquely felt experiences that are purposefully chosen by individuals to achieve and shape identity” (Watters, 2013, p. 1). For the purposes of this study, occupation will be defined as any such activity that brings upon the feeling that their life has a purpose, and that they have a meaningful, personal goal to pursue (Ikiugu, 2015). Occupations are complex human processes which may allow for expression, restoration, and rejuvenation to take place, even after the participation in the activity has stopped (Watters, 2013). Occupations consist of “the day-to-day activities that enable people to sustain themselves, to contribute to the life of their family, and to participate in the broader society” (Brown et al., 2013, p. 1245). The Canadian Association of Occupational Therapists categorize such occupation into self-care, productivity, and leisure (Brown et al., 2013; Canadian Association of Occupational Therapists, 2016).

Ikiugu and colleagues (2019) define meaningful occupation as “all the things people do every day that are purposeful, meaningful and culturally relevant” (p. 2029). Meaningful occupations are only important due to the unique human experience of participating in an activity and the specific needs the person may have (Watters, 2013). It is important to maintain engagement in meaningful occupation, because without it, older adults struggle with having to sacrifice the integrity of their well-being (Watters, 2013). Occupations are fundamental to maintaining human health and wellbeing and have been shown to have therapeutic potential (Brown et al., 2013).

1.3.4 Occupational Engagement

Similar to occupation, occupational engagement is also privy to disagreement regarding a formal definition (Black et al., 2019). There is a general understanding that occupational engagement goes beyond simply performing activities, and that engagement must involve a multidimensional interaction of the mind, body, and spirit, thereby acknowledging the psychological and cognitive aspects at play (Black et al., 2019). Occupational engagement is seen as one of the basic premises for health and well-being in humans (Black et al., 2019). For the purposes of this research, occupational engagement will be defined as participation in an occupation that contributes to the make-up of that person's individual identity (Morris & Cox, 2017). This is important to distinguish, as when we are co-constructing the narratives with the older adults in this study, we are looking for them to share their life stories surrounding the occupations that hold meaning and value to them.

1.4 Researcher Positionality and Reflexivity

Reflexivity is a crucial part of the qualitative research process. It requires a continuous internal dialogue, involves a critical self-evaluation of the researchers' own positionality within the research, as well as an active sense of acknowledgement and recognition that the position taken may have a direct effect on the research process and outcome (Berger, 2015). Positionality is framed within the ontological, epistemological, and methodological stance of the researcher (Berger, 2015; Guba & Lincoln, 1994). Reflexivity is important because it allows the researcher to increase focus on self-knowledge, offering a deeper understanding of their role in the creation of knowledge while carefully self-monitoring the impact of personal biases and experiences on the research (Berger, 2015).

This study will be guided by a constructivist paradigmatic lens. As such, I aim to understand, as well as reconstruct, any previously held beliefs in order to stay open to new information and interpretations (Guba & Lincoln, 1994). In line with the paradigmatic values of constructivism, my research will aim to unpack, in a collaborative way, the coping strategies used by older adults with ARVL to support their engagement in meaningful occupation. A reflexive journal has been kept since the start of the research study process, detailing my thoughts, feelings, and experiences in an attempt to be as transparent as possible.

My research question was inspired by my grandmother, who started losing her vision during older adulthood. I am a second-generation Caribbean, whose family is very much immersed in the Caribbean culture, despite my parents having lived in Canada for most of their lives. That being said, seeking out and receiving a formal medical diagnosis is not a typical outcome in this community. There are many black communities in Canada who experience a lot of distrust in Western medicine, due to years of facing systematic racism which leads to subsequent generational trauma that is then passed down (Dryden & Nnorom, 2021). My grandmother was diagnosed with Parkinson's when I was 18 years old, but the effects of the disease had been present for many years prior. My grandmother never enjoyed going to the doctor, not even for a general checkup and was very vocal about this. These attitudes were present and similar on both my mother and my father's sides of the family, despite having both separately immigrated to Canada from various Caribbean islands in the sixties. Even to this day, my father still perpetuates the same distrust in Canadian doctors, mirroring the same behaviours and feelings that he learned from my grandmother. My grandmother and I did everything together, so I had the interesting perspective of watching her lose her vision slowly. Early on in her treatment, she had been misdiagnosed with cataracts. There was a possibility of my

grandmother having diabetic retinopathy, but as the Parkinson's quickly progressed, her doctors focus on an accurate vision loss diagnosis and treatment faded, in favor of other treatment plans. One of her meaningful occupations was doing crosswords and puzzles, and as her vision declined, she tried different adaptations for years until she could no longer engage meaningfully. My grandmother attempted using large print crosswords, magnifying glasses, she attempted switching to a digital format rather than paper, getting a stronger prescription for her reading glasses and using different hues of light amongst many other adaptations over the years.

One day, during a regular visit, I noticed she was using an extra-large print crossword puzzle book, and she was the happiest I had seen her in a while. At the time, this was an adaptation that worked for her as the vision loss was not so severe. This moment led me to think about how no one on her team of doctors cared to ask her about how she kept engaging in her meaningful occupations. While she received exercises to rehabilitate the rapidly declining left side of her body, she was never given the tools to adapt and maintain participation in the occupations she loved doing, both psychologically and physically. Despite the existing research stating the importance of maintaining meaningful occupation in cases of ARVL, there were no rehabilitation efforts spent in this area. This sparked my initial interest into the world of coping mechanisms related to ARVL.

Another important step when outlining your positionality is to articulate any presuppositions you have when entering the research field. The following statements demonstrate my preunderstandings as they relate to my research topic prior to meeting my participants:

- 1) ARVL has a direct impact on participation in meaningful occupation;

- 2) coping mechanisms are important to identify to ensure continued engagement in meaningful occupation;
- 3) psychological coping mechanisms are not properly addressed in the literature in relation to maintaining meaningful occupation among older adults with an ARVL; and
- 4) lack of engagement in meaningful occupation has negative psychological and physical consequences.

Based on my preunderstandings, the following assumptions were made for the duration of the study:

- 1) Each participant had a deep understanding of their ARVL diagnosis and coping mechanisms they used to support continued engagement in meaningful occupations;
- 2) Participants were sharing real and authentic stories about how they have coped with ARVL to support engagement in meaningful occupation, psychologically, physically, or both.

The questions chosen to ask participants were informed by my preunderstandings as well as by my assumptions made prior to meeting participants and commencing data collection.

1.5 Thesis Outline

This chapter provided the necessary background information required for a comprehensive understanding of my research question while also providing insight into the reasons why I chose to pursue this research study. Working definitions of the key terms related to this research study were provided, including: ARVL, coping strategies, occupation, and occupational engagement to promote a deeper understanding of the language used throughout this thesis. Chapter two will provide a thorough literature review detailing the previously published studies in this research area. Chapter three will describe the methodological approach

taken for this study, including paradigm, methodology, epistemology, ontology, and the guiding theoretical framework. Furthermore, participant recruitment, data collection, and data analysis will be unpacked in this chapter. Chapter 4 will include the individual narrative accounts for each of the study participants, while chapter five will explore the common themes garnered from data analysis across the six participants' narrative accounts. Finally, in chapter six, limitations, future directions, and implications of the research findings will be detailed and discussed as well as how this current research fits within existing ARVL and coping mechanism literature and the significance of this research within the context of research, policy, and vision rehabilitation practice.

Chapter 2: Literature Review

In this chapter, a review of the literature was conducted to gain an understanding of the existing literature concerning the coping strategies used by older adults with ARVL, particularly in relation to maintaining occupational engagement. First, I unpack the relationship between meaningful occupation and later life, followed by how occupational engagement is impacted for older adults with a chronic disability and finally I analyse how occupational engagement is affected by ARVL specifically. Next, the relationship between older adults and coping is unpacked. First, we explore literature surrounding coping with typical changes in later life, followed by how older adults cope with disability when they face a chronic disability. Finally, I discuss how older adults with ARVL cope with their vision loss. I reviewed the existing research about older adults with ARVL and coping strategies used to maintain occupational engagement, before positioning my own research within existing gaps. It was important to understand what has already been researched in relation to coping and older adults with ARVL, so that my own research can contribute to the existing literature.

2.1 Meaningful Occupation and Engagement

2.1.1 Maintaining occupational engagement in later life

When people think of older age, it is typically associated with a withdrawal from meaningful occupation due to the complications of aging. The dominant, albeit inherently ageist, popular view of old age in western society is that of a steady decline and a withdrawal from ordinary life altogether, or that older adults do not enjoy physical or social activity (Hugman, 1999; Kite et al., 2005). Participation in meaningful occupation does decrease as people get older, with men participating less than women (Law, 2002). While there are certainly older adults who choose to withdraw from certain activities in later life, older adults who choose to maintain their meaningful occupations are becoming the norm. When considering increased life expectancy due to societal advancements, many older adults now have more time on their hands once they reach older adulthood and have fewer firm commitments (Adams et al., 2011). With this new freedom to make more choices, older adults are redirecting their energy into the tasks and activities of their choosing. Older adults could choose which meaningful occupations they focus on and the time to optimize their performance (Yancura & Aldwin, 2008).

Recently, there has been more recognition of the reciprocal relationship between physical and psychological health and increased well-being and quality of life in older adults (Owen et al., 2021). There is no denying that maintaining physical activity in later life is important for the continued health, safety, and well-being of older adults (Hultqvist et al., 2017; Whitehead & Blaxton, 2016). Simply staying active in later life is linked with lower levels of perceived distress and depressive symptoms (McHugh & Lawlor, 2012). That being said, many older adults shy away from traditional forms of physical activity and prefer to get their daily physical activity from the daily tasks that bring them enjoyment (Crombie et al., 2004; DiPietro, 2001). Older

adults who continue to participate in meaningful occupations, which give them a sense of purpose, are often physically and psychologically healthier than older adults who do not partake (Irving et al., 2017; Kim et al., 2013; Owen et al., 2021). Meaningful occupations that engage physically, socially, and psychologically, while also challenging the older adult, are important for healthy aging (Nilsson et al., 2015).

Achieving a higher sense of purpose that accompanies engaging in meaningful occupation is important for older adults to experience. Irving and colleagues (2017) found that older adults who saw themselves as having goals to strive towards, and who felt like they had a purpose, may develop a deeper sense of resilience against adverse life stressors. Engaging in meaningful occupation in later life can provide older adults with the ability to effectively combat some of the natural complications of aging, and this may give some insight into how and why meaningful occupation is linked to healthy and successful aging (McKnight et al., 2009; Owen et al., 2021). Older adults' priorities and preferences may change as they reach later life, but they do not cease to exist. The same holds true for meaningful occupation. Although engagement in occupation may change as the body changes, older adults still seek the fulfilment that meaningful occupation brings, despite getting older.

2.1.2 Meaningful occupational engagement for older adults with a chronic disability

Aging is a heterogeneous process with a myriad of variation in the physical, social, and psychological domains of older adult functioning (Owen et al., 2021). That being said, as we naturally age, our bodies may deteriorate to different degrees. Some older adults continue engaging in meaningful occupation with little to no concern, and some older adults struggle, due to the presence of a chronic disability. Just because an older adult is disabled, it does not mean that they are not able to engage in meaningful occupation. Various environmental, physical,

cognitive, or sensory impairments can make participation in meaningful occupation difficult to maintain, thus the older adult will miss out on the important associated health benefits such as increased overall health, overall psychological wellbeing, and decreased feelings of depression (Bronk, 2014; Pinguart, 2002; Sarvimäki & Stenbock-Hult, 2000; Tam, 2020; Owen et al., 2021). Oh and colleagues (2021) found, in their American cross-sectional study of the National Health and Aging Trends Study (NHATS), that more than half of the older adults with a disability engaged in meaningful occupation, but rates were lower than for older adults who did not have a disability. These findings suggest that living with a chronic disability has a direct impact on the older adult's ability to maintain occupational engagement.

Ashe et al. (2009) did a cross sectional study, employing the use of the Canadian Community Health Survey Cycle 1.1 (2000/2001) to determine the proportion of older adults who achieved the recommended amount of time spent engaged in leisure and physical activity. They were able to identify that while 30% of older adults over the age of 65, with no history of chronic disability, achieved the recommended amount of time spent engaged in meaningful occupation, only 23% met government recommendations if they were living with a disability (Ashe et al., 2009). Although these older adults have disabilities, it does not mean they strive towards meaningful occupation any less (Oh et al., 2021). In fact, older adults with a disability report that they enjoy meaningful occupations such as walking, gardening, and home exercises, much like older adults without a chronic disability (Ashe et al., 2009; Owens et al., 2021). Oh and colleagues (2021) suggest that disability is the direct cause of cessation of meaningful occupation for those older adults. If these older adults could effectively cope with their disability, cessation wouldn't be the default and meaningful occupation may continue. Life satisfaction significantly correlates to involvement in meaningful occupation and social integration for

people who experience a chronic disability (Law, 2002). This is important because it highlights the similarities in attitudes toward occupational engagement across the different populations. Seeing as occupational deprivation is linked to poor health and well-being (Law, 2002), a lack thereof could further aggravate the negative symptoms or struggles associated with the disability of the older adult.

Williams & Murray (2012) investigated the lived experiences of three older adults, aged 68 to 78, and their struggles with occupational adaptation following a stroke and the subsequent long-term disability. Employing the use of in-depth interviews, this study gave a snapshot into how occupation is affected for older adults living with a chronic disability (Williams & Murray, 2012). One participant faced severe physical challenges, including the use of a wheelchair following the stroke. This participant reported an extreme restriction of her meaningful occupations, due to reduced mobility. Without the adequate coping skills needed to maintain her engagement, she ended up giving up many of her meaningful occupations (Williams & Murray, 2012). Another participant in the study, described the transition to home life and maintenance of meaningful occupations as “murder” due to the physical disabilities they faced after their stroke (Williams & Murray, 2012, p.43). This is a very serious statement to make and the comparison to death is telling as to how important maintaining meaningful occupation is to older adults.

2.1.3 Engagement in meaningful occupation with ARVL

Older adults with ARVL face a specific set of challenges when attempting to maintain their engagement in meaningful occupation following their vision loss diagnosis. Smith et al., (2009) conducted a qualitative grounded theory study with seven older adults with ARVL to examine, and understand, how engagement in occupation affects the adaptation process for older adult women who are visually impaired. The authors presented nine categories discussed by the

participants concerning adaptation to ARVL and maintaining meaningful occupation including: visual impairment, concurrent issues, threats to performance, losses, getting help, methods of doing, abilities, integration of losses and abilities, and adaptation. They were able to identify that different ARVL diagnoses are associated with different effects on meaningful occupation depending on what area of the eye was affected and its relative importance to the specific occupation (Smith et al., 2009). For example, the participants with macular degeneration struggled more with maintaining meaningful occupations that required attention to fine detail because of the affected central vision (Smith et al., 2009). On the other hand, participants with glaucoma struggled to maintain meaningful occupation, such as community mobility, due to challenges with their peripheral vision. (Smith et al., 2009). Smith et al. (2009) also found that their participants with various health challenges, on top of ARVL, had a more difficult time coping and maintaining meaningful occupation due to the presence of further barriers. Smith and colleagues (2009) state that the level of visual impairment and concurrent health issues negatively influence participation in meaningful occupation for older adults with ARVL. Maintaining meaningful occupation is a unique and personalized process for each older adult and different occupations will be more difficult to maintain than others.

Meaningful occupation is just as important to older adults with ARVL as it is to older adults without a chronic disability. Girdler et al., (2008) conducted a qualitative study exploring the impact of ARVL on the lives of older adults, specifically detailing the relationship between ARVL and meaningful occupation. When discussing vision loss, the participants tended to group their occupations as existing either before or after their ARVL diagnosis, reinforcing the fact that vision loss had a negative impact on their ability to continue doing the things they either need to, want to, or are expected to do (Girdler et al., 2008). Girdler et al., (2008) found that participants

experienced a “discontinuity” to meaningful occupation and that post ARVL diagnosis, there was a total life transition which posed a serious threat to their previously established lifetime meaningful occupations. Bouchard and colleagues (2003) sought to assess the impact of vision loss on a specific meaningful occupation, reading, as well as other integral daily tasks. Reading is a popular occupation for many older adults, regardless of the presence of a disability (Bouchard et al., 2003). Bouchard et al. (2003) found that the older adults in their study, were reading significantly less due to their vision loss diagnosis. These older adults still read for the same reasons they did prior to their diagnosis, for enjoyment, learning and current events (Bouchard et al., 2003), but the existing visual barriers made it difficult to maintain this meaningful occupation, especially without supports or accommodations.

Regardless of the underlying ARVL diagnosis, participants in the Smith et al., (2009) study felt they had experienced a severe loss of independence resulting in disappointment of not being able to participate in personally meaningful occupation. Occupations are meaningful because they give the older adult a sense of purpose and positivity. These beneficial feelings can be quickly taken away from an older adult with ARVL who requires various supports from others to maintain meaningful occupation. Girdler et al., (2008) found that participants who had to ask for help or rely on others to continue meaningful occupation experience psychological distress and feel embarrassed to continuously ask for help coping (Brennan et al., 2001; Girdler et al., 2008). These occupations will no longer be as meaningful or beneficial if participation is a constant reminder of your physical disability and the independent activities that once brought you joy in the past.

2.2 Older Adults and Coping

2.2.1 How do older adults cope with typical changes due to aging?

Aging and the subsequent coping that is associated with it, is such a diverse process that each older adult will have a different experience. Compared to younger adults, older adults are more vulnerable to stress due to age related changes in physiological systems, thereby increasing their vulnerability to everyday stressors (Yancura & Aldwin, 2008). On the other hand, older adults also report less perceived stress and overall stressors as compared to younger adults (Jeon & Dunkle, 2009). With less perceived stress overall, but more physiological stressors, older adults' coping strategies will change to reflect these new appraisals. Older adults may use fewer coping strategies in later life, but this falls in line with lifespan developmental theories which suggest that as older adults age, they conserve their energy by using more efficient coping mechanisms (Baltes et al., 2005; Yancura & Aldwin, 2008).

Seeing as older adults have navigated the use of different coping mechanisms in their day to day lives, they are able to differentiate between those that were successful and those that were not. Older adults tend to use emotion focused coping when uncontrollable stressors are appraised or when they feel that the problem is more than they can handle, falling back on problem focused coping when faced with stressors perceived as manageable (Aldwin, 2007; Yancura & Aldwin, 2008). When compared to other stressful events that older adults may have to deal with later in life, health related events are more likely to lead to emotion focused coping strategies (Moos et al., 2006).

Older adults battle the assumption that they should withdraw from typical social interactions in later life as well as many other negative stereotypes (Hugman, 1999) from younger age groups, which can take a toll on the older adult. Because of this struggle to cope with negative social interactions, Moos et al. (2006) suggest implementation of intervention programs to teach older adults appropriate coping skills to resolve specific stressors. Even

healthy older adults who age in the most optimal ways will face some health challenges (Yancura & Aldwin, 2008), so it's best to provide older adults with healthy coping mechanisms and tools to overcome any appraised stressors (Moos et al., 2006).

2.2.2 How do older adults cope with a chronic disability?

Chronic disability is very present in the Canadian older adult population, with prevalence increasing with age and over time (Tam, 2020). While certain conditions are more prevalent than others, the 2017-2018 Canadian Community Health Survey identified 37% of older adults reported having at least two of the ten most common chronic disabilities included in the report (Public Health Agency of Canada, 2021). With these statistics in mind, it is important to consider how this segment of the population copes with chronic disability. Older adults with a chronic disability are reported to face challenges with their mental health, tied to a fear of losing independence and subsequent decreased quality of life (Gignac et al., 2000). These are well known fears that older adults are already known to face in later life, now further exacerbated by a co-morbidity of health problems. Gignac et al. (2000) investigated the behaviours of 286 older adults with osteoporosis or osteoarthritis and how they coped to continue living life to its fullest despite chronic disability. They found that 21% of older adults' behavioural efforts to manage their disability relied on giving up their meaningful occupations altogether or restricting participation (Gignac et al., 2000). On the other hand, 40% of the behavioural efforts reported were compensatory, which involved substituting one activity for another (Gignac et al., 2000). It is unfortunate, in specific cases where the older adults felt they were forced to give up certain activities because they saw no other choice as they did not have access to healthy coping mechanisms. When older adults fail to adopt healthy coping mechanisms, they may become

increasingly dependent on family or friends to support their daily activities. Unfortunately, this can lead to increased psychological distress (Bunn et al., 2017; Nyman et al., 2017).

An older adult will cope with chronic disability differently than an older adult will cope with the typical aging process, but the two are more similar than they seem at first glance. Logan and colleagues (2006), in their descriptive correlational study with 50 older adults aged 65 years or older, examined age differences in coping strategies used by inpatients recovering from hemodialysis-related disorders. The study found that older participants use fewer coping strategies as compared to their younger counterparts. This highlights the similarities in coping between older adults with a chronic disability and those without, both cohorts are more conservative and employ fewer coping mechanisms than younger demographics (Baltes et al., 2005; Yancura & Aldwin, 2008). While they can be similar, there are also stark differences when considering the coping mechanisms of older adults with a chronic disability. Successful coping does not always come easily to older adults, especially when they are dealing with the negative effects of a chronic disability. The previously mentioned study by Williams and Murray (2012) found that after dealing with the initial stroke, older adults struggled to accept a potentially long-term disability as well as the impact that the stroke would have on their meaningful occupations (Williams & Murray, 2012). Loss and change are difficult to deal with in any circumstance, especially if you have not been shown, or have no experience with, healthy coping.

Different chronic disabilities will yield different emotional challenges, resulting in the use of different coping strategies as well. Yancura and Aldwin's (2008) literature review on coping and health in older adults examined various studies; one reporting that non-cancer patients experiencing chronic pain, preferred using problem focused coping strategies, though they found the effects to be modest (Barry et al., 2004). It must be noted that the participants in

this study were experiencing persistent, chronic pain which wouldn't be mitigated easily by traditional coping mechanisms (Yancura & Aldwin, 2008). This could factor into why the problem focused coping strategies employed were not seen as successful, when in reality, the pain was not likely to subside, regardless of coping. These small details are critical when examining the effectiveness of coping behaviours, and for older adults with a disability, it could be incredibly discouraging, and physically taxing, to continue searching for their preferred coping mechanisms while trying to adapt to life with a disability. Taking these factors into consideration, we need to educate older adults with a chronic disability about coping mechanisms and support this population through tailored rehabilitation programs that value the importance of coping and subsequently, mental health and well-being.

2.2.3 How do older adults cope with ARVL?

Coping can be challenging for older adults with a chronic disability, but there are specific challenges for older adults coping with ARVL, particularly the psychological struggle that older adults with ARVL face while attempting to adapt to their diagnosis (Brennan et al., 2001). For example, coping with an ARVL diagnosis requires the older adult to appraise and then subsequently cope with negative emotions such as shock, fear, panic, or distress (Nyman et al., 2012). This time of diagnosis is full of life changes, and it can be overwhelming to navigate with little to no support or guidance. This has been described as a grieving period for some older adults with ARVL (Senra et al., 2015), as they mourn the loss of their vision and life as they knew it before.

Older adults with ARVL frequently struggle with the mental toll their vision loss diagnosis has on them, including such mental health issues as the onset of depression or low self-worth following a vision loss diagnosis; feelings that can persist for up to two years post-

diagnosis (Nyman et al., 2012). This period, when the older adult receives their ARVL diagnosis, is critical in determining how effective coping with ARVL will go overtime and when further challenges present themselves. Senra et al. (2017) completed a systematic review to summarize current research regarding the psychological adjustment to irreversible vision loss in adults. They identified that the most significant psychological issues arose in the early stages of learning to cope with vision loss and suggest that anyone at risk of ARVL seek mental health services early in the vision loss process (Senra et al., 2015). It is important that the feelings concerning diagnosis are explored early on and appraised so that they do not continue to have a negative effect on the older adult and influence the adoption of healthy coping strategies. Acceptance of the diagnosis is key as it helps to facilitate better psychological well-being (Nyman et al., 2012).

Older adults' benefit from their years of life experience when it comes to the adoption of healthy coping strategies. Though receiving an ARVL diagnosis is a new event, most older adults are familiar with previous coping mechanisms they have employed to overcome other adverse situations. Older adults with ARVL tend to use coping strategies from multiple life domains, including the behavioral, psychological, and social domains (Brennan et al., 2000). The experimentation part here is important, because it highlights the use of various previous appraisals combined with these new experiences to inform subsequent coping with ARVL. A different study states that the most effective ways to cope with vision loss were found to be the activation of new coping strategies (Senra et al., 2015), which could be difficult for an older adult to access due to lack of resources or support. If older adults can marry past experiences with their new reality and diagnosis to inform new coping mechanisms, they may find greater success in coping with ARVL.

Coping with ARVL is heavily reliant on the supports received from family, friends, and the community. For an older adult with ARVL, receiving social supports is often the difference between being able to retain a sense of independence or becoming increasingly dependent on others (Brennan et al., 2001). Independence is a key factor in the lives of most Canadian older adults, especially for those with ARVL. Typically, older adults rely on family for emotional support, but in the case where the perceived burden was too great, or family was unavailable, older adults rely on friends (Brennan et al., 2001). Research shows that emotional support from family, friends, and peers is a key coping strategy that helps support the psychological wellbeing of older adults with ARVL (Brennan et al., 2001; Nyman et al., 2012). Older adults truly value their social support networks, as they assist the older adult in coping with ARVL and adapting to these many new life changes (Brennan et al., 2001). While some older adults do enjoy familial and social supports to cope with ARVL (Brennan et al., 2001; Nyman et al., 2012), Senra et al. (2015) demonstrates the negative feelings that come from losing independence and having to rely on others for support. Poor adjustment to ARVL was characterized by having an overprotective social support system, and experiencing feelings of loneliness, shame, trust issues, isolation, and helplessness (Senra et al., 2015).

Coping is a complex process, with different categories and types that are differentiated by their goals when being employed by the person. Different types of coping have proven to be better suited for older adults adjusting to a vision loss diagnosis. Senra et al. (2015) identified that older adults who engaged in problem-focused coping mechanisms had a better chance of adjusting to their ARVL diagnosis. Problem focused coping aims to mitigate the problem at hand causing the stress rather than emotion focused coping which aims to mitigate the emotions of the person. By directly attacking the appraised barrier, these older adults may be more successful in

coping with ARVL. McGrath et al. (2019) conducted a meta-synthesis of the existing qualitative literature with the goal of identifying the psychological adaptation strategies used by older adults with ARVL. They identified that older adults with ARVL commonly compare their own situation to those who were perceived as being in worse circumstances, which acts as a form of cognitive refocusing to better manage their lives with ARVL (McGrath et al., 2019). Reframing how they see their own situation and comparing to people who are perceived as “worse off” is a common coping mechanism for older adults with ARVL (Bitner et al., 2010).

Many studies have found that when older adults are confident and optimistic about their futures, they were more successful at coping (Brennan et al., 2000; McGrath et al., 2019; Senra et al., 2015; Weber & Wong, 2012). On the other hand, there are older adults with ARVL who do not have the same positive disposition, and feel things such as regret, frustration, and fear which is linked to less successful coping (Weber & Wong, 2010). It may seem obvious, that staying positive would be associated with better coping, but this is a task easier said than done when an older adult with ARVL is struggling with a loss of independence, poor self-image, and fear of progressing vision loss (Bitner et al., 2010; McGrath et al., 2019, Weber & Wong, 2010). Bitner et al. (2010) held focus groups with eight older adults who were legally blind from retinitis pigmentosa, a progressive vision loss condition. They uncovered a theme which they labelled “kicking and screaming” which described older adults who would “fight to maintain their independence in the face of worsening vision” (Bitner et al., 2010, p. 464). These older adults used terms like panic and devastation when describing the emotions they felt while living with their vision loss condition (Bitner et al., 2010). These older adults were having a hard time coping with vision loss, which shines light on the importance of providing older adults with ARVL with the proper supports to navigate these feelings. Sabel et al. (2018) ran a literature

review study to frame the relationship between stress and ophthalmological diseases, and they found that stress can act as aggregate, and a symptom of most vision loss conditions. This highlights the importance of healthy coping and finding ways to mitigate any appraised stressors to promote mental and physical health.

2.2.4 Older Adults and Coping with ARVL to Maintain Meaningful Occupation

The benefits of coping for individuals with ARVL have been well established in the literature (Ashe et al., 2009; Bitner et al., 2010; Brennan et al., 2000; McGrath et al., 2019; Senra et al., 2015; Smith et al., 2009). Additionally, the difficulties that older adults experience with respect to coping with ARVL and the psychological distress that accompanies this difficulty have been detailed in past studies (Bouchard et al., 2003; Brennan et al., 2001; Girdler et al., 2008; Nyman et al., 2012; Sera et al., 2015; Weber & Wong, 2010). Engagement in meaningful occupation has been found to support the psychological wellbeing of older adults as it diverts attention away from the more emotionally challenging aspects of ARVL (Girdler et al., 2008). Given the paucity of research in this area, further exploration of the occupational challenges faced by older adults with ARVL and the ways in which they use healthy coping strategies to support continued occupational engagement is warranted to ensure older adults receive needed services to maintain meaningful occupation and gain the associated health benefits.

2.3 Conclusion

Older adults with ARVL cope with their vision loss in many ways. It has been previously established that meaningful occupation is difficult to maintain with ARVL but there is not sufficient literature detailing how older adults cope to maintain engagement in occupation. This is concerning, considering the benefits of maintaining meaningful occupation are well documented in the literature. Multiple studies agree with this stance and even go so far as to state

this missing link as a limitation within their studies (McGrath et al., 2019; Nyman et al., 2012; Senra et al., 2015). This study will address these limitations and gaps in the literature by providing firsthand narrative accounts from older adults with ARVL and detailing the coping mechanisms they use to maintain meaningful occupation.

Chapter 3: Research Methodology and Methods

3.1 Paradigmatic and Theoretical Approach

3.1.1 Paradigm

According to Guba & Lincoln (1994), a paradigm is a set of convictions about one's world view stemming from their ontological, epistemological, and methodological beliefs. Paradigm informs the lens through which the researcher conducts their research. This study adopted a constructivist paradigm. Constructivism aims to understand, as well as reconstruct, any previously held beliefs to stay open to new information and interpretations (Guba & Lincoln, 1994). Constructivists value the voices of all and strongly believe in the co-construction of knowledge (Guba & Lincoln, 1994). Co-construction of knowledge involves both the researcher and the subject of investigation being connected in such a way that the findings, or the data, are created together as the investigation proceeds (Guba & Lincoln, 1994). In line with the paradigmatic values of constructivism, my research unpacked, in a collaborative way, the coping strategies used by older adults with ARVL to support their engagement in meaningful occupation.

3.1.2 Ontology

Ontology seeks to understand the nature of reality (Guba & Lincoln, 1994) and is often depicted on a spectrum from relativism to realism. In this study I adopted an ontology of relativism, to acknowledge the existence of “multiple, local and specific constructed realities”

(Guba & Lincoln, 1994, p.109). On the other end of the spectrum, realism acknowledges the existence of one, true, objective reality (Guba & Lincoln, 1994). Constructivists hold a relativist point of view, and as such, they believe in the existence of multiple realities, which are context specific (Guba & Lincoln, 1994). This ontological positioning has been reflected in this research as I understood the realities of each of the story tellers, without attempting to prove the accuracy of said events. The life experiences they were sharing are their reality and I accepted that as their truth in the same way that I value my own and the other story tellers' realities.

3.1.3 Epistemology

Epistemology chronicles an investigation between “the knower (or would-be knower) and what can be known” (Guba & Lincoln, 1994, p. 108). Constructivism sees this relationship as transactional and subjectivist, which means that the knower and the investigator are connected, and the findings are co-constructed together (Guba & Lincoln, 1994). The knower can take many forms, but within this research, the knower is referred to as the storyteller. The knower bares the knowledge needed, and as researchers, we seek to cultivate and transform their knowledge for all to have access to. This was achieved in this research by building a trustful relationship with the storytellers and involving them in each step of the research process. In building a strong relationship with good foundations, the researcher and the storyteller can properly embark on their investigation of the storyteller's experiences. The researcher focused on cultivating positive, trusting relationships with each of the possible participants during the recruitment phase by thoroughly explaining the study, the researchers own background with older adults facing ARVL, and by inviting the possible participants to call or email at any time if they had any questions or concerns. To ensure that this relationship is transactional, in return for them sharing their stories with the researcher, the findings, in the form of an individual narrative,

were given back to the participants in hopes that they could use the information to promote further reflection into their own experiences of coping with ARVL and maintaining meaningful occupation in their daily lives. The relationship maintained the subjectivist aspect of epistemology as the researcher acknowledged that the stories being shared by the participants are a part of their own truth, and it is not up to the researcher to question or prove anything.

3.1.4 Research Methodology

Methodology concerns how the researcher will go about obtaining knowledge or finding out what can be known (Guba & Lincoln, 1994). This research adopted a narrative methodology to gain knowledge about the life stories of the study participants, or storytellers, as they are commonly referred to in narrative studies. Narrative inquiry allows for the reconstruction of the human experience in relation to others as well as societal structures (Pinnegar & Daynes, 2007). The term narrative analysis encompasses a family of different types of analytical tools used in interpreting texts in the story (Riesman, 2008).

The hallmark of narrative methodology is the narrative interview, which values biographical knowledge as narrated by the person with lived experience (Chase, 2005). At the heart of the narrative inquiry is sharing stories with others. This is a concept that has been enjoyed by humans for centuries, thus, narrative inquiry has deep historical roots (Pinnegar & Daynes, 2007). Due to the 20th century critique suffered to qualitative research about its credibility as a “real” science, narrative methodology was not again considered a valid method of inquiry until thirty years ago (Pinnegar & Daynes, 2007). The resurgence of the narrative methodology can be attributed to the unravelling of some of the key ideas upholding the popular positivist belief system at the time (Pinnegar & Daynes, 2007). The current form of narrative

inquiry was conceptualized as a methodology for use in the field of higher education by Dr. Cononley and Dr. Clandinin (Lindsay & Schwind, 2016).

Stories are seen as valuable because they are a basic tool that people use to communicate and create understanding with other people and for themselves (Feldman et al., 2004). When people share their stories, they are reflecting on a particular understanding of the social and political relations at play in their lives (Feldman et al., 2004). Through the stories shared by the older adults in this study, we were able to directly investigate the social and political structures at play when considering those coping skills that supported the engagement in meaningful occupational engagement for older adults with ARVL. While the story itself is the heart of the narrative methodology, the sequencing of the story is important to note as well (Feldman et al., 2004). The structure of the story shows what is important to the person sharing it in terms of practices, ideas, places, and symbols (Feldman et al., 2004). It is up to the researcher to interpret the stories of others and ask why they chose to tell the story the way that they did and interpret the deeper meanings that lie within the story details (Feldman et al., 2004). I was able to achieve this during interviews by asking carefully curated follow up questions, allowing me to clearly interpret the older adults story. It is within these details that I was able to capture meaningful experiences of the older adults and be able to share these experiences with other older adults who have ARVL and who may struggle with coping.

This study undertook a performative method of narrative inquiry, where dialogue produces narratives to be analysed as data (Hollingsworth & Dybdhal, 2007). Constructivists take a hermeneutical approach, which supports the idea that all meaning is hidden, only to be discovered through deep reflection stimulated through conversation between researcher and participant (Ponterotto, 2005). Taking a constructivist approach to the narrative methodology

means that there is little separation between researcher and participant, which allows for the co-construction of data, valued by this paradigm (Hollingsworth & Dybdhal, 2007). The narrative methodology acknowledges that even where co-construction of knowledge is key to rich data production, the researcher inevitably holds more power over the conversation (Hollingsworth & Dybdhal, 2007). This aspect of the narrative methodology was addressed in the proposed research, as constructivism encourages constant reflection and acknowledgment of biases. This research also adopted the hermeneutical approach reflected in both narrative and constructivist methods and aims to uncover the hidden knowledge concerning coping mechanisms of older adults with ARVL through discussions between the researcher and the older adults participating in this study.

My rationale for choosing a performative narrative inquiry was because I wanted to be able to highlight the lived experiences of older adults with ARVL. To my knowledge, anchored in comprehensive literature review, there are no previous studies that have captured the lived experience of older adults, detailing how they cope with ARVL to maintain participation in occupation. Listening to the stories, thoughts, and feelings of older adults is the best way to identify their lived experience with current coping strategies. It also allows us, as researchers, to identify coping strategies that have a positive impact of the lives of older adults. Narrative methodology values a collaborative effort when generating new information. Being able to work hand in hand with each older adult that participated in this study ensured that as researchers, we captured genuine experiences that could possibly resonate with other older adults who come across this work and provide new ideas for coping with ARVL to maintain their meaningful occupations. If older adults, outside of this study, can relate to the participants' stories, it may

inspire them to try different coping mechanisms and possibly help mitigate the feeling of being alone while facing ARVL.

3.1.5 Theoretical Framework

Grounding this study in a guiding theoretical framework helped to convey not only the researchers' deepest values but also provided a roadmap as to how the study would process any newly generated knowledge (Collins et al., 2018). Lazarus and Folkman's transactional theory of stress and coping was used as the guiding theoretical framework for this study.

Lazarus and Folkman define stress as "exposure to stimuli appraised as harmful, threatening or challenging that exceeds the individual's capacity to cope" (Biggs et al., 2017, p. 352). Stress exists in multiple forms, including as an external stimulus, as a response, as an individual and environmental interaction, or as an individual and environmental transaction (Biggs et al., 2017). There exists a bidirectional nature when considering the interactions held between a person and their environment. Lazarus and Folkman focus their transactional theory of stress and coping within these environmental life stressors (Biggs et al., 2017). Lazarus and Folkman emphasize the importance of evaluating how well the coping behaviours work in the environment based on the final outcomes experienced by the person of interest (Radnitz & Tiersky, 2007). Adaptive behaviour can only be considered 'successful' if the full consequences of the outcome are examined, thus Lazarus and Folkman also place great importance on the role of appraisal within the coping process. It is important to remember that the stress process is a continuous cycle of transactions between the individual and their environment, and Lazarus and Folkman's entire theory is built on this concept (Biggs et al., 2017). The theory of transactional stress and coping focuses on two primary features: cognitive appraisal and coping effectiveness (Biggs et al. 2017).

Cognitive Appraisal. Cognitive appraisal involves an evaluative judgment based on the personal significance of an experienced event which is based on knowledge of the event while representing any attempt made at determining personal meaning (Radnitz & Tiersky, 2007). Transactional theory explains that the intensity of a stress response is mediated by the appraisal process (Biggs et al., 2017). This response is not truly mediated until the situation is resolved in the persons eyes, as these encounters will remain fluid and are subject to change (Radnitz & Tiersky, 2007). As different emotional and behavioural responses are made, there may be an effect on the relationship between the person and the situation and in this case, reappraisal of the situation may occur along with a change in emotion and behaviour (Radnitz & Tiersky, 2007). Cognitive appraisals are important because they allow for decisions to be made about the required response to a situation at hand by creating a personal estimation of the stressors a person may encounter, as well as by affecting the type and strength of emotion experienced (Radnitz & Tiersky, 2007). People are constantly subconsciously appraising stimuli in their environment, but when it comes to the stress-coping response, the primary appraisal generates emotions, and if any stressful stimuli are identified, the distress initiates different coping strategies to manage emotions or directly address the stressor (Biggs et al., 2017). Lazarus explains that these appraisals pull together two sets of forces, the individual's personal agenda and environmental factors (Biggs et al., 2017). There are two forms of appraisal which Lazarus and Folkman consider in their theory, primary and secondary appraisal (Biggs et al., 2017).

Primary appraisal focuses on the specific transaction between the person and the environment while determining the significance of that transaction to the person's well-being (Biggs et al., 2017). Transactions may be deemed as positive, irrelevant, or stressful, where stressful transactions are further appraised (Biggs et al., 2017). Secondary appraisals come into

play in response to the primary appraisal and this is where a person is taking inventory of their resources, the coping options available to them, and the environments' probable reaction to these coping mechanisms, if used (Radnitz & Tiersky, 2007). Based on the relationship between these two appraisal processes, a coping mechanism is chosen, which may prompt a new emotional response which will interact with the appraisal process once again (Radnitz & Tiersky, 2007). This is a dynamic process, and it is continuous as we absorb new stimulus and situations through our daily life (Radnitz & Tiersky, 2007). It is important to note that both primary and secondary appraisal are independent processes which work together; one is no more important than the other despite how they were named (Biggs et al., 2017).

Lazarus and Folkman place extreme importance on the appraisal process within their transactional theory of stress and coping, and they emphasize that it is the perception of the event, which is stressful for the person, not the event itself that will determine whether coping strategies will be initiated and if the stressor has been resolved (Biggs et al., 2017). There is extreme variation within every human's personal agenda, and it is because of the ambiguous complexities that come along with each external environmental context that we see such great differences in the appraisals made by individuals in the same or similar environmental contexts (Biggs et al., 2017).

Coping effectiveness. Lazarus and Folkman define coping as “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Biggs et al., 2017, p. 353). Coping is a dynamic process, which takes place after primary and secondary appraisals have been done and allows for a constant flux between appraisal and emotional response (Biggs et al., 2017). Lazarus and

Folkman identified the two types of coping styles that people use, including problem focused and emotion focused coping (Biggs et al., 2017). Coping efforts are either aimed at managing the stressor, which is problem focused, or emotional regulation due to the stressful encounter, which is emotion focused (Biggs et al., 2017). The environment is constantly being reappraised by the person experiencing it, and this is how the situation is analysed to determine if the coping mechanisms chosen were effective (Biggs et al., 2017). Coping processes set out to produce an outcome which is later appraised as favourable, unfavourable, or unresolved, with the latter provoking the person to consider different coping mechanisms as an attempt to resolve the issue (Biggs et al., 2017). If unsuccessful adaptation to the situation has been identified during the cognitive reappraisal, then different coping mechanisms are employed instead, but if the situation continues to be negative, this may lead to psychological disturbances (Biggs et al., 2017).

This study unpacked the different coping mechanisms, including psychological, social, and behavioural coping, used by older adults with ARVL. Lazarus and Folkman's theory of stress and coping was used to frame this study because it is still seen as the cornerstone theory for research concerning psychological stress and coping (Biggs et al., 2017). Although Lazarus and Folkman's theory of stress and coping was used to guide the data collection and analysis process, the researcher remained open to new ways of 'seeing' the data that did not directly align with the central tenets of the theory. The transactional relationship between cognitive appraisals and the corresponding coping mechanism explains how an older adult with ARVL identifies the stressful stimuli preventing them from participating in meaningful occupation and subsequently employs a coping mechanism to mitigate the issue. The coping mechanism must then be appraised as successful for it to support meaningful occupational engagement. The transactional

nature of this theory frames how the older adults are reacting to the stressful stimuli in their environments due to their ARVL and demonstrates how they cope with this.

3.2 Research Methods

3.2.1 Study Context

This study was carried out in London, Ontario; a Canadian city. In 2016, London boasted a population of 494,069 people, with 23.3% (115,365) of the population being 60 years of age and over (Statistics Canada, 2019a). For the duration of the research project, I lived, worked, and attended school in London. As the COVID-19 global pandemic became more of a risk to the older adult population with new, dangerous variants of the virus beginning their circulation, restrictions were constantly changing. All the recruitment organizations who had circulated the study flyer to their members ended up doing so virtually, which led to the enrollment of participants from across southwestern Ontario, including Toronto and Ottawa as well as London. In 2016, Toronto boasted a population of 5,928,040 with 3.2% (191,320) of the population being 60 years old or older (Statistics Canada, 2019c). Finally, Ottawa had a population of 934,243 with 21.3% (199,130) of their population being represented by older adults aged 60 and older. Of the Ontario population aged 65 and over, 2.3% (54,900) have diabetic retinopathy, 8.6% (207,000) reported that they have been diagnosed with age-related macular degeneration and 7% (179,300) reported having glaucoma (Statistics Canada, 2019b).

During data collection, London was in phase three of re-opening due to the on-going COVID-19 pandemic. In 2019, the novel coronavirus, SARS-CoV-2, began a world-wide pandemic. Older adults were one subset of the population who were most vulnerable to COVID-19. Phase three of re-opening began on July 16th, 2021, in Ontario and required 70-80% of adults aged 18 and older to have one dose of their vaccination, and 25% to have both doses for

at least two weeks (Office of the Premier, 2021). Because of this, there were various restrictions in place to promote social distancing, such as, limits of 100 people for outdoor public gatherings, indoor social gatherings with limits of 25 people, and indoor sports facilities with a maximum capacity of 50% (Office of the Premier, 2021). Due to these social distancing restrictions put in place, many older adults were socially isolated from the general population. My data collection began in September of 2021 and was completed in June of 2022. In turn, this changed the way in which data collection needed to proceed. For example, a popular request amongst many of the older adults in the study was to have interviews conducted in person, which was an accommodation that could, unfortunately, not be met due to Canadian COVID-19 pandemic restrictions and rapidly changing health advisories. Many of the facilities housing the meaningful occupations enjoyed by older adults with ARVL had been closed since the start of the pandemic and remain so into 2022. Even when open, some of these activities were extremely modified to adhere to provincial COVID-19 guidelines.

3.2.2 Inclusion Criteria

To participate in the study, research participants had to: 1) be 60 years of age or older; 2) have a diagnosis of ARVL (including macular degeneration, glaucoma, or diabetic retinopathy); 3) have a diagnosis of ARVL for at least one year at the time of recruitment; and 4) be able to communicate in English or French. The reason why I chose to recruit older adults who had their vision condition for at least one year was because I wanted to ensure that the older adults were past the initial stages of coping with their ARVL diagnosis, and that they would have lived with their ARVL for long enough to be able to share stories of coping to maintain meaningful occupation.

3.2.3 Participant Recruitment

In qualitative research, the necessary sample size is not pre-determined and depends on the many contextual factors of the researcher's study (Butina, 2015). It is suggested to determine a minimum sample size and then to increase if necessary (Butina, 2015). This method maintains the flexibility needed in qualitative research and thus, a minimum sample size was determined for this study based on previous qualitative studies of a similar nature. Following Butina's (2015) guidelines and considering past narrative studies (Brennan, 2008; DeMedeiros, 2016), it was decided that at least five older adults with ARVL were needed for this study. Once recruitment efforts began with the final recruitment organization, the AEBC, I decided to increase the sample size to include six older adults. This decision was made to ensure any participants that reached out once the recruitment flyer was circulated at the AEBC would have a chance to participate in the study and to ensure maximum variation across my sample of older adults by diversifying my sample further. The final participants recruited from the AEBC ensured that we gathered stories from at least one older adult from each of the three diagnoses under the ARVL umbrella (macular degeneration, diabetic retinopathy, glaucoma).

I recruited study participants through organizations such as: the Canadian National Institute for the Blind (CNIB), the Canadian Council of the Blind (CCB), the Alliance for Equality of Blind Canadians (AEBC) and the Occupational Therapy and Vision Rehabilitation Network (OTVRN) through the Canadian Association of Occupational Therapists (CAOT). We also connected with senior's day programs in London, such as the Victorian Order of Nurses and Dearness Home. Senior centers such as Kiwanis Senior Center, Horton Street Senior Center, and Hamilton Road Senior Center were contacted for recruitment as well as Central Optometry, a

London based optometrist. The study adopted convenience as well as snowball sampling for data collection.

Convenience sampling is a type of non-probability sampling which involves “researching subjects of the population that are easily accessible to the researcher” (Etikan et al., 2016, p.2). Convenience sampling allows the researcher to access easily accessible participants who suit the study’s recruitment needs (Etikan et al., 2016). Rather than taking a sample from the general population, recruitment organizations who cater to members that would fit our study sample were chosen as recruitment locations. Canadian low vision groups, such as the AEBC, CNIB, and the CCB recruited one participant each. It is important to acknowledge that the sample would have looked different if a different recruitment method was selected (Etikan et al., 2016). Because we recruited largely from organisations for older adults with vision loss, we have excluded a subset of the population who may not have access to these services.

Snowball sampling involves recruiting additional possible participants through the participants already recruited (Ghaljaie et al., 2017). Snowball sampling was useful as it expanded the reach of the study’s recruitment strategy. Asking the eligible participants to spread the word was an easy way to find other older adults who belonged to the ARVL community. I was able to secure one participant through snowball sampling, as a participant provided my contact information to a friend of theirs who reached out to me to participate in the study. The remaining three participants were recruited by contacting participants from my supervisor, Colleen McGrath’s Vision Loss in Later Life Research Lab (VITAL), who had previously consented to being contacted again for future participation in research. The VITAL lab is housed within Western University, and I have been a member since 2020 when I began my Masters’ with Dr. McGrath. Across all recruitment strategies, we enrolled seven participants in the study,

however, one participant decided to leave the study resulting in six participants for whom there was a complete data set.

The study was approved by Western University's Non-Medical Research Ethics Board (NMREB), as well as reviewed in accordance with processes at each recruitment site. A gatekeeper was identified within each of the recruitment organizations, who emailed the flyer to their respective networks and members. Interested participants contacted the research team directly for more information about the study and a screening questionnaire was completed (see Appendix IX). The flyer and recruitment email provided the participants with the study objective as well as any risk or benefits associated with participation in this study. It also provided the contact information of myself and my supervisor so that those who were interested in participating could reach out directly to the researcher. After sending the initial recruitment email (see Appendix III) or informing possible participants, each of the recruitment agencies 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) in this study.

3.2.4 Study Design

Informed Consent Procedures. Potential participants contacted the research team by email or phone. An email and telephone script was used, depending on the method of initial contact (refer to Appendix III and Appendix IV for the email script and telephone script). Eligibility of possible participants for the study was confirmed using a screening questionnaire (refer to Appendix IX or the screening form). If the interested participant answered yes to all screening questions, then the letter of information was read aloud to the potential participant and was sent to them via email for their reference. If this interaction took place via email, the letter of

information was emailed to the participant for review. Potential participants were also given the option to receive the letter of information via posted mail if they requested to do so. Any questions the participants had regarding the research were answered.

Participants had two choices to complete their informed consent forms: (1) verbal consent with a witness (see Appendix VI) or (2) written informed consent (see Appendix V). Participants were given these options to respect autonomous decision making. When offered, all but one of the older adults opted to proceed with the verbal consent process rather than proceed with the written consent. I acknowledged that the participants in my study have ARVL, which may have affected their ability to read and sign the written consent forms. Participants who chose to give verbal consent for study participation had the letter of information read aloud to them to confirm they had a proper understanding of the study. Once verbal consent was obtained, I then noted this on their verbal consent form with the date and their written name on the consent form as well as my own signature and date as the witness. In addition to consenting at the onset of the study, all participants provided process consent at the beginning of each interview.

Data Collection. Data collection took place over the course of three separate interview sessions with each participant, informed by Wengraf's (2001) biographic-narrative interpretive method (BNIM). Please refer to Appendix VII for a detailed protocol and example questions for each participant interview session.

One participant completed the narrative interview but did not complete the subsequent semi-structured interview nor did they complete the final interview. Despite repeated attempts to reach this participant for follow up interviews, the participant did not get in contact with me again. This data was not used in this study, nor did it contribute to the subsequent data analysis. The remaining six participants attended the narrative interview, the semi structured interview and

the final interview all of which were audio-recorded. These six participants all received a \$10 Tim Horton's gift card as an honorarium for participating in this study.

Narrative Interview. To begin the initial narrative interview session, the letter of information was reviewed and any questions the participants had were answered. A list of mental health resources available in the community or virtually was given to each of the participants at the beginning of the first session. Furthermore, I had asked participants if they preferred a specific pseudonym or not, to which the choice was noted on the master list of the older adults' pseudonyms and identifying information. Following the BNIM process, one single question was posed to the participants, which guided the subsequent discussion (Wengraf, 2001). This was done to empower the story tellers to "begin, construct and end their narrative on their own terms" (Corbally & N'Neil, 2014, p. 7). The participants were asked: "*Can you tell me the story of how you have coped with your age-related vision loss since your diagnosis?*". In line with the narrative methodology, I attempted to avoid any interruptions to the participants storytelling so as not to influence or place any of my own biases into the narrative. I wanted the participants to feel comfortable and safe sharing their stories with me as a researcher, thus my goal was to gain the trust of the participants from the start.

Five narrative interviews took place over the phone, and one interview took place over Zoom with the camera off. Interview sessions ranged from 40 minutes to two and a half hours in length. Throughout the interview, I kept reflexive notes, detailing any thoughts and feelings I was having about the story being shared as well as any areas I thought would need further questioning. I detailed any emotions that were evoked by participants for later analysis once I began transcription. I completed typed transcription into a Word document in order to promote full immersion into the stories shared by the older adults.

Semi-Structured Interview. The second, semi-structured interview session followed Wengraf's (2001) BNIM approach and allowed me to clarify and gain more information about the stories shared in the first interview session. The second session took place at least two weeks after the first interview. During this interview, participants were asked pre-established questions which prompted each of the older adults to share more of their story (detailed in Appendix VIII). Specifically, there was a focus on how the coping strategies identified in the first session have a direct impact on the older adult's participation in meaningful occupation. The need for flexibility was key here, as each question asked to the storytellers reflected the specific narrative they shared during the first interview. For example, if a storyteller mentioned that they use meditation as a psychological coping mechanism, but they did not mention how this relates to a specific meaningful occupation, the questions asked in the second interview attempted to prompt the participant for more 'story' related to their use of meditation to support occupational engagement.

Four of the semi-structured interviews took place over the phone and two interviews occurred in person at the home of the older adult (which, at the time, was permitted based on easing COVID-19 restrictions). Similar to the narrative interviews, the semi structured interviews ranged in time from 35 minutes to two and a half hours. Transcription for each of the semi-structured interviews was done using NVivo, a qualitative data analysis and transcription program, however, the researcher was still required to listen to the audio recordings in order to fill in gaps in the transcripts.

Final Interview. Prior to the third and final interview session, a draft narrative account was produced by the researcher, based on the contents of the previous two sessions. This narrative account included the stories shared from the transcript containing rich information about coping

with ARVL to maintain meaningful occupation, layered over my objective voice as a researcher. These narratives were created after analysis of the first two transcripts, with a goal of conveying the older adults' story of coping to maintain meaningful occupation. There was at least a one-month break in between the second and third session during which time the draft narrative account was produced. Once written, the researcher shared the narrative (via email, mail, or home delivery) in advance of the third session, to allow the participant time to read the narrative. Additionally, I offered to read the narratives over the phone or over Zoom to each older adult once they received them, prior to the final interview session. All six of the participants took this offer. During the third interview session, the researcher and participant reviewed the narrative together to determine if it was a plausible rendering of the older adult's story. The researcher made any changes/edits to the narrative, mainly correction of names of people or places as requested by the participant.

3.3 Data Analysis

Fraser's (2004) line by line narrative analysis approach was used in this study. This approach to data analysis is said to be intensive and is suggested for use in studies with less than fifty participants (Fraser, 2004). The transcripts of the audio-recorded interviews, reflexive journals, and the re-constructed narratives were analysed. Data analysis began after the first interview had taken place to inform subsequent data collection. There are seven phases to Fraser's narrative analysis that were applied to this data.

3.3.1 Line-by-Line Narrative Analysis

The first phase of line-by-line narrative analysis includes hearing the stories and experiencing each other's emotions (Fraser, 2004). This phase occurs both during the interviews and after they have finished (Fraser, 2004). Following Fraser's (2004) guidelines, I asked myself

questions such as: What ‘sense’ did I get from each interview? How did each interview tend to start, how did it progress and how did it end? Did I have adequate support to engage in work of this nature? Was I open to developing further insights about myself, “including insights that are derived from raking over past experiences that are painful?” (Fraser, 2004, p. 187). It is important to complete this phase to ensure we are not over intellectualizing the stories of the older adults and really valuing the emotional aspects they have shared with the interviewer (Fraser, 2004). To capture the emotional experience of the participants adequately, reflexive journal notes were taken by the researcher to describe any feelings that emerged during the interview. The audio recordings of each of the participants interviews were also listened to multiple times to promote immersion in the data.

Phase two of narrative analysis includes transcribing the data (Fraser, 2004). Transcriptions are deemed useful as they offer a more accurate rendition of the interview for analysis rather than just memory (Fraser, 2004). This phase of data analysis allows the researcher to get closer to the stories of the participants for a deeper and more thorough analysis (Fraser, 2004). The questions I reflexively considered during this stage were: Did I have adequate time to transcribe the material on my own? Have I omitted or misheard any segments of the shared story? How detailed will my transcription be for the purposes of my research goals? (Fraser, 2004). The transcription of the first interviews of each participant was typed by hand in a Word document, by the lead researcher, to promote immersion into the data. The following interviews were transcribed using NVivo, a qualitative data analysis software. The transcripts were then cleaned, whereby personal identifiers were removed, pseudonyms were applied, and any silences and pauses were indicated at the points in which they occurred. One of the study participants’

requested that parts of the shared story be removed prior to data analysis; which was done by the researcher.

Phase three of data analysis refers to interpreting the individual transcripts of each participant (Fraser, 2004). Tone of voice was noted during each of the interviews for later analysis in this step. Furthermore, body language was noted for the two in person interviews. Questions I considered during this phase of analysis were: What are the common themes across each older adult's respective story? What words are the older adults choosing and how are they used? What are the meanings behind the words used by the older adults? Are there any notable silences or pauses and what might they signify? (Fraser, 2004).

Phase four of data analysis involves scanning across different domains of experience, including the various intrapersonal, interpersonal, cultural, and structural aspects shared within the participants stories. These domains were identified and examined for their effect on each the participant's individual narratives. This is done to avoid problems of social determinism and to get to the root of how people interact with different dimensions of the environment (Fraser, 2004). Intrapersonal aspects involve intra body-mind experiences shown through self-talk and confession to hidden thoughts and feelings (Fraser, 2004). Interpersonal aspects are those that involve other people while cultural aspects refer to a larger group of people displaying similar group behaviours and traditions called cultural conventions (Fraser, 2004). Finally, structural aspects are seen in reference to modes of social organization such as class, gender, or age (Fraser, 2004). For example, some participants discussed their socio-economic status, and this was analysed to determine its influence on coping with ARVL and maintaining meaningful occupation. Fraser suggests that researchers consider the following questions during this phase: Which parts of the story have interpersonal interactions and how do they connect to other parts

of the story? Are there any cultural conventions present and how do they affect the story? What social structures are present and what is being said about them? Is there any evidence of popular culture coming out in the stories? (Fraser, 2004). Each aspect discussed was coded based on its influence on the participants ability to cope with ARVL and engage in meaningful occupation.

Phase five of the narrative analysis includes linking the personal with the political (Fraser, 2004). Dominant discussions, and their social conventions, are analysed in relation to being the interpretive frameworks of the stories (Fraser, 2004). Commonly referenced as one of the most prominent theories used to frame stress in research (Dillard et al., 2019; Herman et al., 2020; Knapp & Sweeny, 2022; Lowenstein et al., 2019), Lazarus and Folkman's transactional theory of stress and coping was thoroughly examined and its ideas about stress and coping acted as the guiding theoretical framework for this study. Questions considered during this phase included: What relationship do the stories have to the transactional theory of stress? What might other researchers say about my interpretations? Do the shared stories support or negate any claims made by Lazarus and Folkman? Am I clearly distinguishing myself from the older adult's stories or are they becoming overshadowed by my analyses? What responses might the participants make about the analysis (Fraser, 2004). Anywhere the participants exhibited the stages of coping with stressful stimulation in an environment or cognitive appraisals were coded for during this stage. Conversely, anywhere participants exhibited behaviour that did not align with the transactional theory of stress was coded for as well.

Phase six involves looking for commonalities and differences among participants (Fraser, 2004). Content, style, and tone of the participants were compared. Any patterns that emerged between the stories were documented. Fraser (2004) suggests asking yourself the following questions during analysis: What are the emergent themes shared across each story? How are

common stories unveiled? Are provocative stories avoided and what are the implications of this? How are the older adults' lived experiences affected by their material living conditions? How am I selecting the stories that represent my research question? The stories attended to the most must have reflected on a coping mechanism and how it related to maintaining a meaningful occupation in that person's life. The discussed occupation should have been impacted or made more difficult due to ARVL. This criterion also ensured that the stories selected reflect my research question. Looking at how the stories shared by the older adults aligned with any initial assumptions I may have had prior to interviews and what aspects I found surprising were detailed reflexively. Furthermore, any ideas that are seen as unpopular or commonly disputed were unpacked here, to ensure that every aspect of the story has been analysed thoroughly, despite any personal biases that may exist.

The seventh, and final phase, is writing the narratives of the personal stories (Fraser, 2004). It is important to remember here that by pulling together the stories of the older adults, I am also telling a story of my own (Fraser, 2004). Questions considered during this phase of analysis were: Are my analyses relevant to my research question? Are my interpretations fair? Have I developed any blind spots? Have I been respectful towards participants when I wrote their narrative? Does my writing style acknowledge my subjectivity? How did my research supervisor respond to reading drafts of the created narratives? (Fraser, 2004). Multiple drafts were produced to achieve the best possible rendition of the stories shared by the participants. During this step, it is imperative that the analyst is checking to see if the written analysis being produced corresponds with the stories shared by the participants as well as the objectives of the proposed research (Fraser, 2004).

Coding and data analysis of each of the three interviews were done in one Word document per participant. All reflexive notes taken were documented on paper in the lead researcher's reflexive journal.

3.3.2 Reconstruction of the Narratives

Narrative reconstruction began following completion of the first and second interview as well as the subsequent data analysis. The narratives were written from a third person lens to ensure anonymity of the participants. The major plot points of the stories shared, and coping mechanisms employed by the older adults were the basis of the narratives. These narratives were then layered with my interpretive voice, informed by my previous history in academia, world view, personal motivations, sense of morality, lived experience, paradigmatic positioning, and the guiding theoretical framework of Lazarus & Folkman's (1984) theory of stress and coping (Rice & Ezzy, 1999). These narratives, now reconstructed, were then included in the research data set, and were analysed using Fraser's line-by-line coding method. The narratives were compared to elicit the commonly discussed stories across participants, namely common coping mechanisms to support continued meaningful occupational engagement.

My supervisor reviewed, and provided feedback, for each narrative. With her insight, she helped me to tease out the stories from the transcripts, specifically related to coping with ARVL and maintaining meaningful occupation. She also helped me to reorganize content to create a cohesive story about the older adults employed coping mechanisms.

When the narrative was finalized from the researcher's point of view, each one was read to the participant in full during the third and final interview session. If changes were suggested, they were made and applied to the narratives. Each of the older adults agreed that the co-created

narratives were a fair representation of how they coped with ARVL to maintain meaningful occupation and at that point, the narratives were finalized.

3.3.3 Generation of Overarching Themes

After developing the individual re-constructed narratives, I compared the coping mechanisms being used by each participant in an effort to draw out patterns or similarities. Fraser (2004) highlights the importance of searching for recurring themes, but also the outliers between the shared stories. In doing so, I began to generate a deeper understanding of commonly employed coping mechanisms. I emailed this data analysis summary to my supervisor, and we had a meeting to discuss the overarching themes we had both generated after review of the document. During this meeting, I was able to practice some reflexivity and garner a deeper understanding of the data through discussion and challenging any pre-conceived notions I may have held. This led me to a deeper understanding of the data and shined light on the connections between the stories shared by each participant. The three overarching themes, and their subcategories (see Chapter 5), were finalized at the end of the meeting with my supervisor.

3.4 Data Management

Pseudonyms were given to each participant to help ensure anonymity. To make sure that all storytellers were protected, any identifiable information, such as names of people and places, were removed or changed to the corresponding pseudonyms.

A master list, to track participant identities, was created and was only accessible by the research team. This master list included the names of participants, the names of anyone discussed in the participants stories, specific locations mentioned, demographic information, and contact information (including phone numbers, email addresses, or home address). The master list, and all hardcopies of data with identifying information (i.e. descriptive data, written notes, consent

forms, and any non-cleaned audio files and transcripts) were stored on campus, in a locked cabinet in a locked office. All electronic versions of identifiable data were downloaded to an OWL project site (Western University's online learning management system, which requires a unique Western user ID and password). Any 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 and destroyed after seven years.

3.5 Ethical Considerations

Due to the sensitivity of the topic and the chosen population, precautions needed to be put in place to protect the mental health of the storytellers. Visual impairment classifies my sample of older adults as a vulnerable population under ethical guidelines. We are discussing how they adapt but there are both positive and negative coping mechanisms that exist. When asking people to share intimate details of their psyche, it may bring up negative or unwanted feelings and I needed to have systems in place to support the participants in those situations.

3.5.1 Risk to the Participant

During the interviews, if it became evident that the older adults was emotionally distressed, I would stop and ask if they wished to stop recording, take a break, and re-collect their thoughts, postpone the interview, or discontinue participation in the study altogether. Storytellers were reminded of the resources that were made available to them in the first session and another copy of those resources was offered to them if needed. Process consent was obtained by the researcher at the beginning of each interview to ensure participants' ongoing consent to participation. Further, any supportive measures I could have taken, such as words of encouragement, were practiced throughout the sessions. There was an instance during the first interview where a participant started to appear overwhelmed when I asked a question that they

could not remember the answer to. To comfort the participant and ensure that they were supported, the researcher assured the older adult that it was okay not to have the answer in the moment and suggested coming back to the question later in the interview or in the subsequent interview session.

3.5.2 Maintaining Confidentiality

Maintaining the confidentiality of participants is seen as the primary obligation of researchers (Sabar & Sabar, 2017). To make sure that all storytellers are protected, any identifiable information, such as names of people and places, were removed or changed to pseudonyms. Participants were reminded that they did not have to share anything they were uncomfortable sharing and were able to withdraw any information or their participation altogether if they wished. All confidentiality concerns were detailed in the letter of information and was discussed with the participant prior to joining the study.

3.5.3 Addressing Power Imbalance

Although effort was made to attend to power imbalances, it is undeniable that power does play a role in the research process. During the first stages of research, up until the data analysis phase, the power fell to the participant, as the researcher needed their story to produce any work (Sabar & Sabar, 2017). Following the data collection phase, the power then shifted to the interviewer to analyse and make sense of the data (Sabar & Sabar, 2017). I respected the participants agency to share their story however they wanted, without checking for accuracy. I was transparent about all aspects of the research and encouraged the participants to ask any questions they may have had. I attempted to form a meaningful researcher-participant relationship with each older adult to foster a safe environment where the participants felt comfortable sharing their stories and that they could trust me to recreate a plausible,

representative narrative. Co-construction of the narrative is highly valued during this process as the researcher and the participants work together to construct a final narrative that encapsulates the lived experience of the older adult with ARVL.

3.5.4 Who Owns the Narrative?

One of the ethical implications of a narrative study surrounds the question of who “owns” the narrative. Ownership of the story is synonymous with having the rights to tell the story (Welch, 2009). When the participants sign the consent form, there was a section detailing that in participating in this study, they are giving me the rights to share their story as well as publish the work upon completion. Most people who are not familiar with the academic research process assume that their contributions end once the interview is over, when that is not the case (Sabar & Sabar, 2017). To minimize any confusion, the publishing process was explained to participants at the beginning of the first interview and at the end of the final interview. The participants were also given the opportunity to share their thoughts and give input on the created narrative where any required changes to the narratives were explored with the researcher. Ownership of the story does not fall solely on the participant at this point, it is co-owned by the researcher and the participant. I also provided the final copy of participant's narrative accounts either as a physical copy or via email.

3.5.5 Accessibility Concerns

To make the study accessible for the older adults with ARVL, the researcher made every attempt to honour any request for accommodation. The participants were asked what is needed from the research team to make participation seamless and accessible for them. For example, documents were made available in large print. During the recruitment phase, I dropped off consent forms to the home of a possible participant to accommodate an accessibility request. The

researcher was also able to send documents electronically to each participant so that the older adults could use screen reading software on their computers to read the documents. Every older adult was given the opportunity to choose the location they were most comfortable in and the means (Zoom versus telephone versus in person) that best suited their needs. Training to use Zoom was provided by the researcher, if requested by the participants. Some participants explicitly expressed a preference for phone interviews rather than using Zoom due to accessibility concerns and the reliability of their personal electronic devices. Participants were encouraged to use whatever assistive technology needed during the research process.

3.5.6 Relational Ethics

Relational ethics considers the presence of an ethical self-consciousness, where researchers are mindful of themselves, their actions and the consequences said actions may have on others (Tracy, 2010). To maintain relational ethics, a reflexive journal was maintained throughout the research process. This was done to ensure that I was holding myself accountable for my decisions and that I stayed focused on the proposed research question. I began each of my interviews with older adults ready to learn from their rich lived experience, rather than imposing my own thoughts, values, or beliefs onto their stories. One of my pillars was treating each of my participants with the respect they deserve, and this is something I came back to and explored reflexively after each interview. During interviews, there were times when the older adult would express points of views or beliefs that directly contradicted those of my own, and to maintain relational ethics, I would write my thoughts and feelings in my reflexive journal and ensured I remained neutral and positive. Despite the fact that I was made upset by multiple remarks made during the story telling process, I valued the established researcher-storyteller relationship and

explored these feelings reflexively to ensure it would not overshadow any subsequent interviews or the data analysis process.

3.5.7 Procedural Ethics

Procedural ethics are important to maintain as they relate to accuracy of the data, encouraging the researcher to avoid fraudulent activity or any omissions of data (Tracy, 2010). Procedural ethics require that each storyteller is treated with respect and that they are engaged in the research process in a collaborative manner. Appropriate language regarding their ARVL condition and their age was always used. For example, the older adults were always ‘affected by their diagnoses’ during discussions rather than having the diagnosis frame who they are as a person. Furthermore, all recommendations and guidelines put in place by the Research Ethics board of Western University were followed. Research participants have a right to know what the research is about, possible consequences that exist with participation, and that they have the right to refuse participation (Tracy, 2010). Each participant was fully informed about research goals and any possible risks, and they were reminded of their right to withdraw at multiple points during the interview process. All personal information regarding the participants was kept safe through password protected encrypted digital files, or in a locked cabinet or fireproof safe for any physical materials. Privacy was maintained in the transcripts by changing all identifiers and using pseudonyms for any names mentioned. These strategies reduced the risk of deductive disclosure, in which the identity of participants may be determined by people who may recognize specific pieces of information about their lives (Tracy, 2010). When the narratives were presented to the participants for authenticity, any other identifying pieces of information they wanted excluded or changed was addressed at this time.

3.6 Quality Criteria

Tracy's (2010) Eight Big Tent Criteria for qualitative research were used as a guide to ensure that this study was done in a way that maintained quality. The eight quality criteria include: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence (Tracy, 2010). Tracy (2010) provides these eight markers of quality in a qualitative study for researchers to use to ensure their study has the components necessary to be scholarly and reliable. This is a very flexible model which allows for different qualitative studies to adopt the quality criterion in ways that best represent their work (Tracy, 2010). In the following paragraphs, I discuss how each criterion have been addressed within this study.

3.6.1 Worthy Topic

Tracy (2010) places importance on the topic of interest being relevant, timely, significant, and interesting. The literature review completed indicated a gap in the literature concerning the psychological coping mechanisms of older adults and their effects on engagement in meaningful occupation. Exploring a relatively untouched area of research concerning older adults with ARVL is interesting. Furthermore, this research is significant as it recommends rehabilitation strategies that consider the psychological impact of ARVL on the lives of older adults. It also provides suggestions for improving community resources and garnering greater community awareness about ARVL.

3.6.2 Rich Rigor

Rich rigor involves the study using appropriate theoretical constructs, data, and time in the field, sample, methods of data collection and analysis (Tracy, 2010). As a researcher, I committed to immersing myself in the stories shared by the older adults by setting three-hour time slots for interviews. The typical BNIM interview is completed in 90 to 120 minutes, and at

least two hours should be scheduled per session (Wengraf, 2001). I felt that after three qualitative interviews, this was sufficient time spent with each older adult to gather rich, rigorous data from the stories they shared. My sample of six older adults provided me with much demographic variation, thus I felt that the stories were varied enough for the purposes of this study. My goal was to allow for a natural flow of conversation without time pressures, and I valued any and all stories that my participants wished to share with me. There were instances where interviews would run for longer than the 2-hour allotted time slot, but that did not immediately mean the end of the meeting. I would always wait until the older adult was done telling their story, and the final question asked was always: “Did you have anything else you wanted to share about how you cope with ARVL to maintain meaningful occupation?” to ensure that the story was shared in full. Data collection is referencing Wengraf’s (2001) biographic-narrative interpretive method (BNIB) to qualitative interviewing and analysis references Fraser’s (2004) line by line technique. The theories and work used to guide this research are well known, reputable sources in the qualitative research world.

3.6.3 Sincerity

Sincerity is judged by the presence and quality of self-reflexivity about subjective values, biases, and transparency regarding methods and challenges faced during research (Tracy, 2010). I engaged in self-reflexivity throughout the study by maintaining a reflexive journal. Reflexivity was key in navigating any negative emotions that came on throughout the study. As a young, black, female researcher, I am aware that I hold strong subjective values and various biases due to facing racism and sexism throughout my life and academic career. Unfortunately, there were multiple occasions while sharing their story when a participant would make a comment that I found sexist, racist, or generally offensive. I had no choice but to face these biases head-on and

unpack them reflexively to ensure that I was not letting them influence my relationship with the storyteller. Another emotional challenge faced was the death of my grandmother, who inspired my research and this study. To address any challenges I faced, I engaged in regular dialogue with my research supervisor regarding the research process and how to appropriately address my biases or negative emotions that came up. By unpacking and addressing these moments in the research process, this ensured that the reader was aware of the researchers' positionality and its influence on the study process.

3.6.4 Credibility

Tracy's (2010) requirements for credibility involves including thick descriptions with concrete detail; explanation of all non-textual knowledge and proper demonstration; crystallization; multivocality; and member reflections. The findings of the research were explained using rich data, including quotes and excerpts from the transcribed interviews. Furthermore, I strove to collect and record rich and meaningful data throughout the study. Rich and meaningful data were the stories that contained ample detail about the coping mechanisms used by older adults to support meaningful engagement in occupation followed by careful analysis (Barrett & Twycross, 2018). Crystallization leads to more rigorous research by offering trustworthiness and credibility to the data (Stewart et al., 2017). Crystallization was focused on as the participants and I took breaks between each interview session to fully immerse ourselves in the data and to reflect on the analysis experience to identify any emerging patterns or themes. Crystallization was also a focus during the reflexive process when detailing the thoughts and feelings experienced by the participant and myself during the process of this study. Furthermore, crystallization took place as we examined the links between the different interviews for each participant. Multivocality was integrated as the voices of the storytellers were represented

throughout the study findings. The storyteller's point of view is at the center of narrative research and, as such, was emphasized through member reflections.

3.6.5 Resonance

Resonance refers to a presence in a study, when the research can move audiences through representation, naturalistic generalizations, and transferable findings (Tracy, 2010). My research shared the direct experiences of older adults with ARVL and their coping strategies. As such, the results may be applicable to other groups of older adults facing chronic disability who are trying to manage the challenges of having a disability while maintaining participation in meaningful occupation. As the readers of this thesis reflect on the details and descriptions provided by my storytellers, they will (hopefully) be moved and feel the personal aspect provided by the narrative methodology. I strove to collect rich data and ask questions which drew these stories out of my storytellers.

3.6.6 Significant Contribution

To maintain quality, a study must provide significant contributions theoretically, practically, morally, methodologically, and heuristically (Tracy, 2010). Theoretical significance relates to how the study provides theoretical contribution while looking into existing theories or concepts and analysing how they make sense in a different context (Tracy, 2010). Lazarus and Folkman's stress and coping theory provided a framework for understanding the coping mechanisms of the older adults who participated in this study as well as their responses to the stressors they associated with their meaningful occupations. The different coping styles included in this theory are extremely helpful, as they serve to distinguish the coping mechanisms used by the participants. For example, emotion focused coping has been shown to be maladaptive whereas problem focused coping has been associated with more positive outcomes (Biggs et al.,

2017). In identifying the coping styles being used, we can give that back to our participants in the hopes that the information may lead to adjustments or improvements in ineffective coping mechanisms. Furthermore, Lazarus and Folkman place importance on the extreme variation in coping responses which exists from person to person. This resonates well with the study as we, as researchers, strived to capture the individual experiences of older adults without assuming that there is one blanket coping experience for those with ARVL. Since it is only the perception of the event which is stressful for the participant rather than the event itself, each person will have a different coping mechanism determined by their own personal cognitive appraisals. Even the cognitive appraisals are mediated by their personal factors as well, reiterating that the coping process is specific to each person. In adopting Lazarus and Folkman's theory of stress and coping, this study maintains theoretical quality.

Practically significant research aims to be useful or to solve an on-going problem (Tracy, 2010). This study is practically significant as it shines a light on the lack of research focused on coping strategies of older adults with ARVL. More specifically, this study aims to be phronetic, where the analysis will enable practical knowledge and ample space for transformation (Tracy, 2010). The analysis in this study aims to unearth the coping mechanisms used by older adults with ARVL to support occupational engagement, and that is practical knowledge. This study leaves space for transformation within the health and rehabilitation field so that health care professionals and academics can further consider the psychological side of low vision rehabilitation services.

Moral significance is described as being able to capture how researchers "cope with situated problems and provides implications that may help participants develop normative

principles about how to act” (Tracy, 2010, p. 846). As researchers, we identified the situated problem, being a lack of consideration of the coping mechanisms used by older adults with ARVL to support engagement in meaningful occupation. To cope with this, we built and executed a research project which aimed to solve this problem and provide more research in this area which will fill the existing gap in the literature.

Methodologically significant research involves engaging with the methodology in an insightful way (Tracy, 2010). Methodologically, this study is significant because it utilises the narrative methodology to share the stories of older adults with ARVL and their coping mechanisms in relation to maintaining meaningful occupation. This concept has not been previously explored from a narrative approach; thus, the research will make a significant methodological contribution to the field.

Heuristically significant research will propel people to pursue further research and generates curiosity in readers that can lead to new academic discoveries (Tracy, 2010). Heuristically, this study strived to promote further research that consider the psychological aspect of low vision rehabilitation services, which is an important area for continued research development.

3.6.7 Meaningful Coherence

Meaningfully coherent studies achieve their stated purpose, accomplish what they aim to, use methods and representation practices that complement the theories and paradigms used, and effectively integrate reviewed literature (Tracy, 2010). Meaningful coherence was achieved in this study by following the planned procedure set out in the ethics protocol. Furthermore, any adaptations to the protocol were made to achieve the goal of capturing the experiences of our

storytellers. For example, a change was made to the recruitment materials to better suit the members of the Alliance for Equity of Blind Canadians as per the request of the chapter president. The wording of the flyer was updated to include a time frame for their members response, and further clarification of what will be asked of each older adult during each interview was added as well to the recruitment materials. This request was made during a meeting held with the lead researcher to discuss the logistics of having this organization circulate the study flyer. Constructivist narrative methodology was cohesive throughout the study by following the writings of both Guba & Lincoln (1994) as well as Tracy's (2010) work on the constructivist paradigm and qualitative research quality, respectively. All aspects of the study were interconnected and linked back to the main research question.

3.7 Conclusion

Chapter three provided an outline of the study's context, described the philosophical and theoretical frameworks that guide the study as well as the methodology, methods, and ethical consideration.

Chapter 4: Reconstructing Participants Narratives

4.1. Kim's Story

Kim and I connected in December of 2021. Kim is an 87-year-old woman, born in Ottawa, Ontario. Kim is widowed and lives by herself in a retirement community located in London, Ontario. Kim has faced vision problems since she was young as she was born blind in one eye. In 2011, Kim was additionally diagnosed with macular degeneration. The onset of the vision loss accompanied by macular degeneration was gradual and went unnoticed by Kim, until a routine eye exam in 2011, and Kim now self-identifies as being legally blind. Kim has two children, one of whom is a daughter who lives in their hometown of Ottawa and a son who lives

in British Columbia. Kim's daughter visits often and helps her out in whatever ways Kim needs, mostly keeping Kim busy with her company or going to get groceries. Kim has a brother who she is close with who lives in London as well. He and Kim speak on the phone monthly and see each other for holidays and family events. Kim enjoys watching sports, knitting, listening to audiobooks, spending time with her loved ones, and playing cribbage or bridge. Kim and I held our interviews over the phone, as this was Kim's preferred method of communication. During the conversations between Kim and I leading up to the first interview, Kim presented herself as a very headstrong and independent lady. Kim continued to demonstrate this in the stories she shared with me during our interviews.

Kim's Gradual Progression of Vision Loss. Kim has been dealing with the effects of vision loss since birth. Kim has been blind in her right eye since she was old enough to remember. Being blind her whole life, Kim was accustomed to coping with the trials and tribulations of vision loss as she had no choice but to deal with it. Not knowing anything different, Kim never spent a lot of time being worried about her lack of vision and did her best to fit in despite only being able to see out of one eye. When talking about her macular degeneration, Kim was nonchalant and didn't have much to say about it. It gave me the sense that the ARVL diagnosis was not something shocking or new for Kim to deal with. Kim explains her nonchalant attitude given that she had managed vision loss all her life:

"Well, I've been blind in one eye, well, almost totally blind since I was born. But I don't, as a young person, I don't recall, you know you're so used to it that you don't feel that it's depriving you. You get along anyways, as best you can..."

By the time Kim was diagnosed with macular degeneration in 2011, it didn't change much for her at all, as the onset had been very slow and gradual. Combined with her original

visual problems, by the time Kim was diagnosed, she hardly noticed the problem herself. When I asked Kim if being diagnosed with macular degeneration had any effect on her due to her previous vision condition she said:

“I guess it [my vision] was gradually getting worse, but very gradually. I haven’t been angry about it or anything like that.”

Having already dealt with vision loss, this influenced the way that Kim coped with the macular degeneration as her condition progressed. When I asked Kim if the previous experience with being blind made it easier for her to adjust to her diagnosis of macular degeneration, she said: *“Oh, I’m sure it did.”* The progression of the macular degeneration was so gradual that when I asked if receiving a new diagnosis changed anything for her, Kim said, *“No, no, it’s very, very gradual. So, you know, you hardly know you have it.”* Kim had already appraised the stressful situation of receiving a vision loss diagnosis, and had previously put, successful coping mechanisms in place. Kim could barely remember the circumstances surrounding her diagnosis with ARVL as the change had such little effect on her visual abilities at the time and the possible stress from this event was already mitigated. Having dealt with vision loss for many decades prior reinforced Kim’s original coping mechanisms of acceptance and resilience, as this is how she’d been psychologically coping with vision loss since early childhood:

“And, psychologically, I don’t think it’s bothered me that much because I’ve had vision problems all my life, and you know, this was another one. I don’t think it’s been an issue that way.”

Coping With the Loss of her Driver’s License. Being aware of her own visual abilities, Kim made the decision to give up her license and her car on her own when she noticed her macular degeneration progressing, despite driving being the main means of accessing her

meaningful occupations. Losing her license was one of the biggest losses that came with ARVL for Kim:

“Well, my vision was going, and you know, and I was planning for it cause I moved where I am today because of that. I knew I wasn’t going to have a car and I wouldn’t be downtown without a car. I guess it was kind of hard to see where the curb was and stuff like that. ...I remember driving down [the] street, [not] being able to see the curb properly and thinking that I shouldn’t be doing this. Then I was of course worried about hitting somebody.”

Kim was very matter of fact and knew what she is and what she is not capable of. Having dealt with different forms of vision loss for her whole life, Kim has her own way that she likes to do things and she does not like to waver from that. When I asked her how she felt giving up her car, knowing that this was an important piece of her life and knowing that it would accompany the loss of access to some of her meaningful occupations, Kim said:

“Well, it was surprisingly... I was relieved more than anything because I was nervous and tense about driving, and it was just a bit of a release. It didn’t feel sad or anything like that.”

The loss of her car came along with a newfound difficulty in accessing and participating in her meaningful occupations, such as: grocery shopping, visiting friends, visiting the town where she grew up, going to restaurants, or running basic errands. Kim’s cognitive appraisal identified the event of losing her car as stressful and she employed two different psychological coping mechanisms to mitigate the stressor. Kim highlighted the importance of keeping a positive attitude and moving forward with acceptance, which are the two coping mechanisms she employed when facing the stress of the voluntary loss of her licence. When I asked her about a

time when she had to remind herself to stay positive and be accepting in the face of vision loss, the situation with her car is what came to mind, she explained her appraisal and coping mechanism employed for the situation:

“Well, I think that one of the big things is the loss of my car. I don’t remember specifically my thinking at the time, but I mean, what can you do. I gave it up voluntarily and, you know, I don’t know, you just accept it. It’s all you can do. ... Well, I accepted it because you can’t really do much about it. I mean, what can you do? You can’t just sit and mope about it.”

Kim recognized that she still needs to navigate her community and has employed behavioural coping mechanisms to support her in doing so. To cope with the loss of meaningful activity through this newfound loss of transportation, in the past, Kim would use the city bus or taxis to continue running errands and going grocery shopping. Though these actions help to mitigate the loss of meaningful occupation tied to the loss of her licence, Kim began to experience struggles with these coping mechanisms as her visual abilities gradually worsened, due to macular degeneration. Though taking a taxi used to be visually accessible for Kim, she rarely does now. Kim also has access to the city bus but doesn’t use it because it’s *“not handy enough anymore”*, and she struggles to visually navigate using public transportation on her own. When asked about taking the city bus, Kim said: *“It’s a bit of a walk from here, no, it’s too much. It’s hard getting on and off, up the steps, you know?”*

Kim was more open to, and would prefer, taking the local shuttle bus to continue navigating the community but faces new struggles with this due to COVID-19 related restrictions of her local shuttle. To keep the residents safe and eliminate possibility of transmission, the shuttle has not been running:

“Well, where I live, we have our own little bus and it goes to grocery stores and does different things, you know, during the week, but since COVID’s been going, it hasn’t been running. I pretty much count on friends to do that, to take me, or my daughter when she comes.”

Kim also employs a social coping mechanism to help her continue with her meaningful occupations by relying on her friend who lives in the same retirement community as her or by relying on her daughter to drive her places when she needs to go out. Due to the convenience, Kim prefers to wait to participate in meaningful occupation until her friend or her daughter is available to drive her:

“I mostly rely on friends to either bring me something or take me with them. I have a neighbour next door who’ll take me. She took me yesterday and I went out grocery shopping. She knows that I can’t drive.”

Kim’s Independence and its Relationship to Meaningful Occupation. Kim is widowed, has few family members close to her, has children who live out of town and has very few people who she can rely on for help. Kim lives on her own, but this does not bother her, as she prefers to remain as independent as possible. Kim values being an independent woman, and this is one of her pillars in life. When I asked Kim what a typical day in her life looked like, all her daily occupations were independent, solitary activities:

“Well, I sit in my chair, and I knit, and I don’t watch TV in the morning at all and right now I’m not watching it till news time at 5:30, 6 o’clock. I watch the news...and I play bridge on my iPad, and I do crossword puzzles. And I try and go for a walk every day.”

Participating in meaningful occupations by herself is how Kim prefers to live and she does her best to enjoy the solitude. Maintaining that independence is a coping mechanism for

Kim and it allowed her to comfortably participate in her meaningful occupations without having to worry about relying on others. Kim values her independence and when I asked her about how independence acts as a coping mechanism for maintaining meaningful occupation in the face of macular degeneration, she said:

“I don’t like being told what to do and I like being able to make my own decisions. My daughter, she tries to help a fair bit and we get along really well but other than that, I don’t have anybody really much interfering.” and *“Well nobody knows what I want or how I feel the same way that I do. I can’t give up my independence because of that. I know what I want and what I can do and what I can’t do.”*

Kim understood that relying on someone other than herself to participate in meaningful occupation is sometimes necessary. Kim often receives rides from her neighbour to go grocery shopping or allows her daughter to assist her in completing her daily errands. Kim seemed uncomfortable while talking about relying on others, as this is something she avoids doing at all costs. Kim would rather be independent and figure things out on her own rather than ask for help, and this is a coping mechanism she falls back on often. Asking for help is difficult for Kim and makes her uncomfortable, so she will wait for her friend to approach her rather than reaching out, unless it is an emergency. Even then, Kim would prefer not to have to ask for help:

“And I just have one friend who does drive. And I don’t ask her, I guess if it were something urgent, I might. Like, I had to mail a parcel to my son for Christmas and to get to the post office, so I asked her if she would help me with that. But other than that, I just wouldn’t, I would just wait till she asked.” and *“I don’t push it; I don’t push her to do things. She knows that I like to do things and I have a lot of time on my hands. I wait,*

usually, for her to contact me, we'll either go out in the car for groceries or to play cribbage."

Kim would rather wait until help was offered to her and avoids reaching out for assistance at all costs. When I asked Kim why she is hesitant to ask for help, she explained:

"I don't think people particularly want to do it, otherwise they'll offer. You know, I'm perfectly able to get a taxi. I'm independent for one thing, and I don't think people want to do it, otherwise they would offer." and *"I just avoid do[ing] it [asking for help] because I'm not comfortable doing it. People know my situation, and if they want to help me, I figure they will offer. And often they don't and that does upset me a bit, but I don't think too much about it. There's nothing you can do about it."*

Kim modeled her meaningful occupations and coping mechanisms around doing things on her own so that she can remain independent despite her progressive macular degeneration. Rather than depending on others and being upset, Kim moves forward with resilience and copes behaviourally with ARVL by relying on only herself to maintain meaningful occupation. When I asked Kim how she feels about contacting others to participate in those meaningful occupations that require the support of others, she said:

"You know, you can't initiate anything because you're always kind of begging for a ride if you do. So, you know, I couldn't do like going out for lunch or something."

Kim does not want to be perceived as someone who needs assistance or relies on others too much. This has been cognitively appraised as a stressful situation in the eyes of Kim, who continuously falls back on remaining independent and doing things on her own to cope with maintaining her meaningful occupations where possible.

Kim's Social Interactions and Relationships. While Kim values her independence, she does still have social relationships and interactions which helps her cope with ARVL and maintain some of her meaningful occupations. Having dealt with vision loss all her life, when Kim was initially diagnosed with macular degeneration, her social interactions remained the same. Kim has always struggled with recognizing people and putting faces to names, and this did not change with ARVL. Kim thinks she does just fine socially, and said:

“It didn't affect my interactions with other people” and “Social coping isn't an issue I don't think. I don't recognize people very well sometimes, but they all realize that, and I just ask: ‘Who are you’, and ‘Are you so and so?’”

Kim maintains casual relationships with her peers living in the same retirement community as herself and will explain her ARVL to people as she meets them and as she sees fit. Seeing as social interactions are not Kim's favourite activity, she appraises this as a stressful situation. The self-disclosure of her macular degeneration and the issues Kim experiences identifying faces helped her to behaviourally cope with navigation of these social interactions with her peers. Kim is aware that sighted people typically expect you to remember faces, names, and interactions easily after you've met multiple times – but Kim lives with vision loss and struggles to do so. Self-disclosure of her macular degeneration diagnosis is something Kim is used to doing, and it comes naturally to her to inform the people who she interacts with:

“I always have to tell people when I first become acquainted with them because I don't recognize them, you see, unless they're right up very close. So, they have to know that I'm gunna ask them who they are when I see them again. They recognize that and they understand, no problem, I don't think.” and “...I'm in a senior's apartment complex and my friends are mostly here. They understand. It's not an issue.”

Being that her social interactions are so limited, Kim assumes that the people in her retirement community will be understanding of her ARVL and won't expect her to recognize them as quickly as someone with no vision concerns could. Kim isn't ashamed by her vision loss and feels comfortable sharing her ARVL diagnosis with strangers. In the case that Kim must explain her ARVL to someone outside of this community or to somebody who may not have an immediate understanding of ARVL, Kim expects there to be a mutual understanding regardless of that persons' background:

"...I tell new people that you know, if I don't recognize them, I don't see faces very well at all and I just try to explain to them that if I don't speak to them or call them by name, it's because I can't see who it is." "I can't imagine doing that the first time I meet a person unless they're living here. Maybe I do, I guess? I haven't met anybody new in a while. I don't think I do. I'm pretty sure I don't get into detail. Unless I'm sure I'm going to be seeing a lot of them. I don't see a point in that." and "...I just expect them to understand!"

Kim's social circle is small, but this is how Kim prefers to live at this point in her life. She relies solely on interactions with her daughter and her one close friend in her retirement community. When I asked Kim if she had anyone else whom she would consider part of her social circle, she simply replied with: *"No, I don't think so."* This isn't a problem for Kim, and when I asked her if she wanted more people in her social circle who could help her cope with ARVL, she explained:

"No, really, I'm not – no. I could have them I think, there's lots of people here that I could talk to, but no, I have enough. You know, in my life, when I was young, I was more

active, I had more friends, more close people that I'm dealing with, but I don't need that now because I don't have the energy."

Kim focuses on her one friendship and spending time with her daughter when she comes into town. Supported by this friend, Kim can cope with vision loss and get drives to complete her various meaningful occupations like running errands and going grocery shopping. With her friend's companionship, Kim can continue playing her favourite game, cribbage, despite the difficulties caused by her ARVL. Kim values the time spent with her daughter, who helps Kim cope with ARVL by providing Kim with transportation and helping with banking or helping to read mail. Kim is aware of how important these relationships are to her and how they help her cope with ARVL to continue meaningful occupations. When I asked if these relationships help her cope, she explained:

"They for sure do because I get very bored, in my head, doing nothing, watching boring TV and I'm stimulated by other people and I enjoy doing that and it just makes life more acceptable and enjoyable and you know, it's not boring."

Kim does have other meaningful social interactions that she values when coping with ARVL, but they are few and far between. She has friends who she enjoys seeing from her hometown, but Kim rarely connects with them because only one of them still drives and she has no access to transportation herself. Her brother lives in town, but they don't interact often. Kim keeps to herself and receives fulfilment and help coping with ARVL from the few relationships she does maintain.

Kim's Minimal Use of Assistive Devices. Kim has been coping with vision loss her whole life; thus, she may have a different outlook on the use of assistive devices to help cope with her recent macular degeneration diagnosis in relation to meaningful occupation compared to

someone who lost their vision later in life. Kim has been avoiding the use of assistive devices since long before her macular degeneration diagnosis. When I asked her about coping with vision challenges all her life, she said:

“You get along anyways, as best you can, and I didn’t like to have to wear glasses. But you know, I could always get along without them except for reading and stuff like that. I can remember going on a date without glasses or going to a dance with no glasses. You look different, and people, I don’t think like it, but I did it anyways.”

With her new ARVL diagnosis, Kim had adopted the use of some assistive devices to help her behaviourally cope with ARVL and maintain her meaningful occupations. One of Kim’s meaningful occupations is reading, and this has become difficult for Kim to continue without the help of assistive devices. When I asked Kim which meaningful occupations were most affected by her ARVL, she said: *“I think it was the driving and bridge and reading of course.”* To continue enjoying books, Kim has shifted to using audiobooks rather than using assistive devices to continue reading. Audiobooks have been an important behavioural coping mechanism for Kim, and she explained how she’s enjoyed using them:

“I have, I don’t do it nearly as much as I did but I do enjoy them for sure. And thank goodness I have them because if there’s nothing on TV, which there isn’t right now, I like sports, and if that’s not on TV then what am I gunna do? So, I have audiobooks.”

Macular degeneration has produced a new challenge for Kim when grocery shopping, which is reading the labels on food items. Prior to the ARVL diagnosis, she was able to grocery shop without the help of assistive devices but now, Kim opts to use a magnifying glass to help her read hard to see labels both in the store and at home:

“Well, I can’t read the can labels so I use a magnifying glass all the time at home, and if I can’t read the label on a can, I’ll use my magnifying glass to do that.” and “What’s difficult now, it wasn’t originally, but now in the grocery store I can’t pick stuff out very well. I have to take a magnifying glass and even then, it’s difficult.”

Kim’s other meaningful occupation is playing games, specifically, bridge and cribbage. To continue playing her favourite games, Kim has employed the use of some assistive devices. Kim will use enlarged cribbage cards when playing with her daughter or with her friend. To continue playing bridge, Kim has given up on playing with others and instead opts to play virtually on her iPad, which she uses as an assistive device to cope with ARVL:

“Oh, I used to love bridge. Very, very, very much. And I can still do it on my iPad, but I can’t play with other people.”

Kim also uses a CCTV, when necessary, but not often, as she says it’s *“not comfortable”* to use for reading purposes. While Kim was sharing her story, I noticed that she did not mention the use of many different assistive devices and that Kim opted to prioritize the activities that were most important to her and only puts her energy into select meaningful occupations. Kim is used to coping with vision loss without the use of assistive devices, thus she proceeds this way when coping with her macular degeneration diagnosis. When she was born and initially faced vision loss a lot of the technology and advancements did not exist yet and so she had to learn to cope in other ways. When I asked Kim about her minimal use of assistive devices and if she would use more assistive devices if she had access to them, she said:

“Well, it’s an ignorance. I didn’t know about them and I’m really not too...I’m not aggressive about finding new stuff but once I find it or I’ve been told about it, I’m interested if it helps.” and “Yes, I would [use more assistive devices]. I have a friend

who's in a similar situation and she's experimenting with different kinds of glasses and I'm going to try them out too. But I don't mind my magnifying glass, it's kind of... I couldn't get along without it – I don't mind it.”

4.2. Randy's Story

Randy is a 68 year old male who lives in Toronto, Ontario. Randy was diagnosed with glaucoma 15 years ago, but he had lived with some visual challenges since he was a child. Randy grew up in Kingston, Ontario, the youngest of four siblings, three of whom also had visual problems. Randy is widowed and has no children. He spends his free time with friends, enjoying his favourite hobbies such as studying genealogy or listening to his favourite operas, working, and being devoted to his church. Randy sells commercial radio airtime to various clients and takes great pride in his work. Randy loves to laugh, and as he shared his story with me, he made sure to include as many jokes as he could. Randy is very outspoken and intelligent and loves to share his ideas and opinions with others. Randy tries his best not to let his ARVL hold him back from enjoying life to its fullest and strives to find solutions to his problems so he can move forward and stay positive.

Coping with the Initial Diagnosis. Randy was very familiar with the difficulties that accompany visual problems. Not only has he struggled with vision loss himself since he was young, but he also watched three of his older siblings and his late wife cope with vision loss as well. By the time Randy was diagnosed with glaucoma at the age of 53, it wasn't his first experience with receiving a diagnosis, as he had gone through something similar with his wife many years ago. Randy's wife passed away after battling retinoblastoma, a cancer that started in the retina but eventually spread. Randy was scared to receive his diagnosis and initially cognitively appraised this situation as stressful, like how he initially appraised the situation

surrounding his wife's diagnosis. Randy went as far as to say "it was kind of an instinctual reaction" due to his past:

"Well, when he said glaucoma, the "oma" part – the suffix at the end of the word – made me feel almost like its carcinoma, some sort of a cancer that's going to kill. ...spread to the optic nerve, then to the brain, then whatever. My wife had had a condition called retinoblastoma, there's that "oma" at the end of the word, so this is why it caused a fear reaction. She had to have one eye removed at age two to two and a half, and then the other eye was removed afterwards as well. So, this "oma"; O – M – A at the end of the word, rang in my head as a thing that's like – oh cancer, oh no, what am I going to do now."

To mitigate this new stressor, Randy coped by staying calm, and withheld an emotional reaction. Instead, Randy waited to receive more information from his doctor before more fear settled in and the situation became any more stressful. Some of Randy's fear stemmed from not knowing what his diagnosis meant and said: *"I didn't really know what glaucoma was"*. Randy had originally stood by his wife in a similar scenario concerning her terminal vision loss diagnosis, except now he was on his own and this put Randy back into that place of fear. Withholding an emotional reaction and waiting for more information was a successful coping mechanism for Randy in those moments, and these are strategies he has carried forward and uses daily:

"First, I had a very fearful reaction when he told me I had glaucoma, I thought: oh no, is this eye cancer, am I going to go blind, is my life over and finished? And he explained to me, no, it's just a pressure thing, it can be treated with eye drops and so on. Then, I visibly relaxed and I realized, I guess, I can be more aware of my mortality"

Protecting my Eyes and Staying Safe. When I first asked Randy about the coping strategies employed to maintain meaningful occupation, protecting his eyes is the first thing that came to mind. Protecting his eyes was one of the first things Randy had to learn to do with his new ARVL diagnosis because treating glaucoma and slowing down its negative visual effects requires a lot of patient-involved care and attention to detail. Though Randy already faced vision loss, he had multiple meaningful occupations which relied on having some visual abilities. That being said, Randy became determined to properly care for his eyes and slowing the progression of further vision loss to continue living life to its fullest and engaging in his meaningful occupations:

“...I just need to be aware that I need to take my drops on time, every 12 hours in order to keep this pressure in line because if the pressure gets too high, it can affect the optic nerve and cause bleeding and eventually blindness...so I don't want those sorts of things to happen obviously. ...I'm very careful and protective of my eyes. If somebody is coming up too close, sometimes I'll lower my head or either put my hand up. I don't want somebody getting near my eye, especially with little children, I'll quickly tip my hand in a way to intercept that cause that one good eye, I don't need to get a sharp object coming at me or a stick in the eye.”

With this new awareness of his ARVL, Randy found himself remaining aware of his surroundings to support his meaningful occupations in the safest ways possible. Randy likes to learn from his mistakes and uses recall of past mistakes as a psychological coping mechanism to inform him of how to stay safe in the future. Randy was aware of the challenges accompanying vision loss and has past experience appraising stressful experiences in new environments. To behaviourally cope with this stress, Randy remained aware of his surroundings and prioritized

safety. Randy was aware that the world is not always suited to people with ARVL and acts accordingly to stay safe when looking at potential living situations, when running errands, and when enjoying other meaningful occupation. Randy told the story of protecting himself and remaining aware of his surroundings here:

“Okay, well when I was protecting my eyes in that sense, it’s actually more when I’m out around and moving. I’ve learned to be aware of my surroundings. I moved into a gentleman’s house about a year ago and when I first came here, I didn’t pay attention the those first 3 steps to the front door. I would come out the front door, go bounding along and go – oh, the three steps are there – and I would land on my face and say – okay, remember the steps are there. The one who owns the house, the lady has quite a garden, pots out there, this house is not really made for the visually impaired, at least totally blind people would have a terrible time with it, cause you’d be hitting stuff with a white cane – but for me – its why I became very conscious of the details in my surroundings, where I go.”

Randy does not drive, so to maintain meaningful occupation, he relies mainly on walking and public transportation. These methods of transportation require attention to detail, especially because of his ARVL. Randy ensured his safety in situations where he was navigating the roads on his own by recalling previous experiences in similar environments. As for social coping, Randy would rely on a crossing guard for assistance at intersections when there was one available. Randy explained how he copes with navigating traffic by staying safe:

“I do try to be cautious and careful. I don’t dart across intersections maybe as quickly as I once did when I was say 20 years old. ‘I can beat this light’ and get halfway across. A couple of times I misjudged it and got halfway across and got to the safety island and

there's cars whizzing by me left and right, like okay, alright. I'm lucky where I am, if I'm going out in the morning, there's a guy there at the crosswalk. I'll come up to it and he'll say, 'Oh no, wait, don't go!' Cause I'm not gunna run across there in the wintertime, you can slip on ice and end up on your backside or on your face in the middle of an intersection and who knows when those cars are gunna start up again! One has to use discretion and judgement, which I think one learns as they get older, anyways, but yeah."

Randy does not enjoy going to the eye doctor but is aware of the need to do so. Though Randy has appraised this situation as stressful, he psychologically copes by relying on the knowledge from past experiences and by prioritizing his safety above all. Randy was so passionate about staying safe regardless of the situation, that even when he is at the eye doctor, he would challenge suggestions made by his eye care team based on his past experiences:

"Then those yellow drops they want to put in your eyes, I said, 'What are you trying to do'...what it does is it sort of freezes the eye a little bit and it enlarges the pupil a little bit. I don't want them to enlarge it the whole amount, I did that one time in Windsor... I was coming back on the bus and oh man, the light was pouring into my eye, I could hardly see where I was going to come home and I was actually worried about getting hurt because things were distorted and my view around me because the pupil really stands out so they can see the retina and stuff in the back of the eye, they got their reasons for it. Now when they do it, they give me a little bit of it, it enlarges a bit...and I could still get around, but I don't go for the full dose anymore cause I'm not gunna get hurt going home. 'Well, whose gunna take you home?', well, nobody, I've got to take the bus and the subway so just go easy on that enlarging stuff you're using."

Another way that Randy behaviourally coped to stay safe in his environment despite ARVL is by memorizing the locations he frequents. Randy says, “*I do a certain amount of memorizing as one of my compensatory mechanisms...in dealing with vision loss*”. For example, when Randy goes to the grocery store, this would be appraised as a stressful event, because he would not know where anything is located, due to ARVL. Randy has coped with this stress by going to the same grocery store and using his memory of where things are located to stay safe and informed. When Randy worked in an office, he would often walk home, which was stressful due to the many obstacles that exist when walking on the sidewalk. To behaviourally cope with this, Randy says, “*...there’s a number of obstacles that I had to be constantly aware of and judge my circumstances accordingly*”. Randy explains how he memorizes locations to cope, psychologically and behaviourally, with ARVL and continue meaningful occupation:

“...first, I have to learn the layout of the place, kind of memorize certain things. I guess I go by, like, landmarks, I guess you could say, its over there and such and such is in the corner and whatever, whatever and get used to the way things are arranged, the spatial awareness of the building or office or whatever the spatial arrangement of the room or situation I’m in, and once you know it then you just go ahead and do it. Compare it to learning a foreign language, you’re hesitant at first and you’re trying new words and phrases and translating, once you’ve been doing it for a whole while, then you become fluent, it just rolls off your tongue.”

Being aware of his surroundings and staying safe has been such a successful coping mechanism for Randy, that once he feels comfortable in an environment, Randy is able to move freely and continue engaging in his meaningful occupation with little to no barriers. Randy explains how being extra cautious has helped him to cope with ARVL:

“Well, I guess in situations where I’m familiar with my surroundings, then I can just move around like a sighted person. I don’t have to hesitate and go slowly like if I’m going into a darker area or later at night if I’m going to a restaurant and I’m trying to find where my street starts and whatever, I’ve gotta go with the flow depending on the circumstances. As I said, if I’m very familiar with the surroundings I can move about at ease but whereas if I’m not familiar with the surroundings, I tend to act more like a partially sighted or legally blind person because I don’t want to make a misstep or end up falling or running into something or whatever.”

Work and Co-Worker Relationships. Randy doesn’t let ARVL hold him back, and he’s maintained a fulltime job for the past few decades with the same company. Randy sells commercial airtime to a set of pre-determined clients. Randy takes great pride in his work and celebrated being one of the top four salespeople in the company. Work is not only a meaningful occupation for Randy, but it serves as a coping mechanism as well by keeping Randy both cognitively stimulated and socially engaged through the relationships he’s created with his co-workers at the company. Randy says:

“...we’re like a family” and “I must say that I do love my bosses as good friends and as great colleagues and as great humans. Sometimes I think they’re better, kinder, nicer people than some people in my own church. And that again is a strong statement”

One of Randy’s most meaningful relationships at work is with his boss, Paul. Paul and Randy have a deep friendship after having worked together for many years, and when Randy had to switch to working from home back in 2011, Paul and him were able to develop a system which allows Randy to cope and to continue his job despite the roadblocks in place due to his ARVL. Randy speaks highly of Paul, saying, *“...I have complete and total respect from the*

people that own the company, from my boss whose vice president, who does all my transactions.” Paul reads Randy’s emails to him every morning over the phone and helps Randy by typing his replies and keeping his inbox organized. Randy struggled to operate his computer and read emails efficiently, so Paul’s support is necessary. Paul also helps Randy by processing transactions once Randy secures the sale on his end. The attention to detail required to process transactions properly is made difficult by Randy’s ARVL, so Paul helps him to cope here as well. Wherever Randy runs into an ARVL related issue with work, he has full freedom to call on Paul and Paul will assist him however he can over the phone or online which allows Randy to continue working. Randy explained his procedure for coping with ARVL with Paul’s help:

“Okay, we have a procedure, I’ll call my boss and remind him about 9 o’clock there in the morning. Sometimes he’ll call me earlier if he’s, you know, up and going and doing stuff. I’ll say good mornings, do the pleasantries but then he will check my email. He has my passcode to get into it... so he will read me my emails, as he’s reading them, I’ll tell him – okay, we’ll keep this, we’ll put it in keepers if we keep it, we’ll respond to something so, he’ll respond, reply to that. He’ll type up my reply, which I keep it short, and then send it off to whatever. If it’s something that I may want a copy of printed, he’ll print it and then the next time he sends me a package...he will make copies of those...off the computer program, send those to me then I will call them up again to renew them, to do another campaign...and we will clean out the spam folder, the trash folder from time to time.”

Outside of work, Randy and Paul are polar opposites with different tastes and a ten-year age difference. Despite this, they get along so well that Paul extends his help to Randy for personal reasons as well. For example, Paul set up Randy’s e-transfer through his bank and

assisted Randy in buying tickets for his favourite orchestra, Berlin Harmonic, so that Randy would be able to attend. Because Randy struggles to access the internet independently, Paul also helped Randy stay up to date with any online news by passing along any related articles on the internet as Paul finds them. Paul prints them off and sends them to Randy via posted mail so Randy can use his own assistive devices to read the physical copies. Paul assists Randy by making purchases on Randy's behalf, over the phone, using Randy's banking information. When Randy talks about his friendship with Paul, he said:

"...sometimes if we're googling something..., he'll send me the picture or the story. For example, when Mic Jagger got knighted, the queen wasn't in favour of it and so there's a story that he [Paul] found looking on the Google and he said that prince Charles had knighted him and it was a one-page story, so he printed it out....He's my eyes and ears on the internet and he tells me different things or finds different things, so I've been able to cope. Now, when he retires in 5 years, that'll be a different story. I'll need to develop a strategy between now and then. But anyways, I'll deal with that as it goes along."

Randy also gets support from Paul with psychological coping. Seeing as work is one of the most important things to Randy, when he is feeling down or stressed, it shows in his work. Randy and Paul's work are so tightly intertwined that Paul can identify when Randy isn't performing like normal and will check in with Randy to make sure that everything is okay. This opens the door for Randy to begin psychologically coping with the stressors present in his life or at work. Randy told a story about a similar situation here:

"...he [Paul] says, 'We need to get you selling, you seem a bit down'. He and I kind of discussed it a bit and I realized, yeah, I let myself slip a little bit. Not doing as much as I could or should have been doing and I'm glad he brought that to my attention. I guess I

pulled myself back up and got going and said, 'Okay, I gotta make a paycheque, I got stuff to pay' ..."

Randy was aware of the challenges that ARVL brings with maintaining a job in the comfort of his own home without sighted people around to help. The help he receives from Paul allows Randy to continue this meaningful occupation but there are still components that Randy struggles with and must resolve on his own. To continue his meaningful occupation in the face of the appraised stressors at work, Randy copes by prioritizing organization in his workspace:

"When you have vision loss, you have to make sure you know where everything is, there's a place for everything. You have a sighted person who can glance across the room and say okay here's this here, whatever. But sometimes I forget where something is, so I go through a couple of files till I find it, sometimes, your memory sometimes, seniors' moments or sometimes you're stressed out about something else – your memory doesn't work as well when you're stressed out so you've gotta try and stay calm most of the time when you're doing your work. I find, having it organized makes it easier for me just to get to the information I need, to get the work done that needs to get done, to call this or that customer, whatever"

Social Stigma and Lack of Acceptance. Over the course of his life, Randy has faced discrimination due to his vision loss and then again later in life due to ARVL. Unfortunately, Randy is no stranger to the social stigma that exists surrounding people with disabilities and this feeling of not being accepted by his sighted peers has influenced his current coping mechanisms with ARVL. Randy has nystagmus, a symptom of his glaucoma, which is involuntary continuous motions of the eye. Randy has been discriminated against many times due his nystagmus and he has cognitively appraised this as a stressful situation:

“Generally, because of...the nystagmus, I usually explain that fairly quickly, off the top. Especially if I’m getting into new situations and people that don’t know me, because of my past where I’ve had people think I was basically an idiot because of the way my eyes moved...so that kind of was a formative experience when I was 20, 21 years old. This guy was hiring people for jobs and when he said to me that ‘To look at you, you look kind of dozy’... ‘They just have to talk to you for 10 minutes and realize that you’re an intelligent person’, so I thought, okay, if I’m giving the wrong impression because of the way that my eyes move, then I’ll explain my situation. Especially if I need help with something. ‘Look, I don’t see too well, I’m legally blind. Could you tell me such and such?’ I’ve done this, like, in different stores or situations where I found it was necessary to let them know the reason why I’m asking for the help. I just think it clarifies the situation” and “So, I realized, sometimes, eyes say a lot about the person.”

When I asked Randy if providing people with an explanation for why his eyes may be involuntarily moving acted as a coping mechanism for him when he navigates different social situations, he said:

“I think so. It clears the air. People understand where I’m coming from, at least to some degree, and we can kind of cope with each other rather than kind of stumbling and fumbling through situations and being prideful and hoping no one will notice because people do notice and obviously people notice the way your eyes move. I can get people sometimes on the bus and they get up and give me a seat. Sometimes I’ll take it, other times no...so people notice the movement of other people’s eyes, obviously and I’ve become very aware of that in the last number of years. And like I said, sometimes people get the wrong impression based on the way the eyes move...and people unfortunately

judge by the sight of their eyes very quickly, it's like the old story of judging the book by its cover and there's still a lot of prejudice out there, still a lot of misunderstanding concerning the nature of blindness and eye problems."

Explaining his ARVL to people he interacts with but doesn't know personally has been functioning as a successful coping mechanism for Randy so far, and it allows him to continue with some of his meaningful occupation, like in church. Randy teaches courses for his church, and to cope with the stressful event of being in front of a group of unfamiliar people and possibly being judged, Randy will explain his condition right away:

"...and tomorrow I have to teach a class, at church, one Sunday a month and I'll be standing up there in front of the whole bunch of them. So maybe I am a little bit nervous for that. So, I'm going to explain to them that for those who don't know me, quite a few of them do as members of the congregation, I don't see too well so if you say something while I'm teaching, just call out to me – Randy or brother Randy – to get my attention because I am not ignoring you and being a social snob because I do not see you. Also, in addition to that, a lot of these people listen to second language, so, I got my work cut out for me!" and *"...now we've got a system set up with a guy going around with a microphone so people can have the microphone when they want to speak because some people are very soft spoken and it's a rather large chapel. So, we've found ways to cope with it. And these guys are pretty great at church, they understand that I have eyesight challenge, and no one's made a fuss about it so it's okay".*

Randy struggles with not being accepted by his sighted peers and chooses to cope with this by clarifying situations and giving an explanation. Randy explained a past scenario at a church event that he ran with peers who knew about his vision condition. Randy was proud of his

contributions and felt on top of the world, wanting to celebrate by dancing with a lady. Instead, Randy faced discrimination from each person he asked to dance and was refused multiple times, his perception being that this was due to his appearance as a man with ARVL:

“So I thought, even there when you’re running single adults conference, and even though it’s a church setting, you still can’t get total acceptance because people think you’re an idiot because you can’t see too well” and “...it being a hurtful incident, but that had bothered me at the time and I’m thinking, man, you rise to the top of the world and they still can’t accept you because you’re blind”.

In his youth, the glasses Randy wore for his vision loss caused him to be targeted in public, with people thinking he was impaired or had access to drugs due to the erratic movement of his eyes caused by the nystagmus. This was cognitively appraised as stressful in Randy’s mind, thus moving forward he psychologically coped by being hyper-aware of how he presents himself both physically and verbally while out in public:

“Well, somebody once said the eyes are the window to the soul, so I feel I have to express myself fairly fluently in verbal manner, so people don’t think I’m an idiot or stupid or whatever because I was stopped back in the 70’s when I used to wear glasses and I had like a coke bottle spectacles, I think they called them. People were always asking me for a dime bag and I’m thinking what the heck is a dime bag. And they must’ve thought I was on drugs and that I was stoned because of the way my eyes were moving. And people had told me...that after alcohol intake, my eyes tended to move a lot... So, I’m very self-conscious about how I’m presenting myself”.

To avoid further discrimination, Randy will go as far as to even be careful with the language he chooses to describe his condition as a psychological coping mechanism: “I

somewhat don't like the word visually impaired too much, it implies drunkenness or drugged up or some sort of inebriated condition, so I say legally blind”.

Randy's other coping mechanism when dealing with avoiding social stigma and not being accepted as a man with ARVL is simply not bringing attention to the matter where possible. Randy is aware that this is not possible in every scenario and is comfortable asking for help, but if he thinks he can get away without bringing ARVL into the conversation, he says, *“For the most part, I try not to bring too much attention to it [ARVL]”.*

Advocacy. Because of his life experiences, Randy is very passionate about equal opportunity and accessibility for not just older adults with ARVL, but for people with all kinds of disabilities. One of Randy's meaningful occupations and simultaneous coping mechanisms were his advocacy efforts for the blind community. Randy's most recent advocacy effort is focused on improving and updating the Ontario government's Assistive Devices Program (ADP). Randy started this journey with the CNIB to improve the ADP after discovering that E-Sight glasses, an assistive device for people with vision loss, which aids in magnification was not included on the approved devices list. Randy found this device to be incredibly effective and useful, which led him to submit an application through the ADP to get a subsidy for the expensive E-Sight. Randy told me about his experience:

“...when I walked in, my regular eyesight as tested by the ophthalmologist is 20 over 200. When I was using the E-Sight device cranked up...we were 20 over 16. This was thrilling! This was exciting. This was high-definition vision. Couldn't believe it. ...I finally was able to read the sign 250 feet away down the street. I was reading busses that were coming up.”

Randy's application was denied, as the device was not on ADP's list of approved devices and thus his advocacy efforts were born. Randy reached out to the Canadian Council of the Blind (CCB) who was able to spearhead this advocacy efforts. Randy reached out to various stakeholders and the CCB was able to organize a team of people who will play a part in updating the ADP's list of eligible devices for subsidy to help people with disabilities across Ontario. Randy talks about his goal with this advocacy effort here:

"...we want to government to know that as far as they know now, there's about 2% of clientele that use the assisted devices program. Why are other people not using it? Why are people that may have used it in the past still not using it now? What can be done to overhaul and uptake to program so that the program, as it currently stands, has items listed on it that are not only out of date but 20 years old. New technology has been invented in the last 20 years, such as, smart phones and other things, that aren't even listed on the assisted devices program website because they haven't bothered to update and change with the times."

When I asked Randy how taking on this role as a leader, or an advocate, functions as a psychological coping mechanism for him, he said: *"Feeling I am part of a larger cause makes me feel that I can play a role, have a voice in what's going on, how we can help other people."*

Randy is well aware of how his own psychological coping will help other people with disabilities cope as well. This group effort and sense of comradery not only helps Randy to cope psychologically and maintain meaningful occupation, but it also helps others with vision problems to cope as well:

"I guess it is a collective coping mechanism for all of us. Some of the people are totally blind, some people have some sight, like myself. We're also trying to help deaf blind as

well, they need certain devices that maybe I wouldn't need, or a totally blind person wouldn't need but the deaf blind could use a few things that are particular to their situation".

Using Humor to Cope. Randy has a great sense of humor and has a hard time getting through a conversation without cracking a joke. While Randy shared his story with me, I noticed how often he uses humor and jokes while talking about himself and his life. Randy is very lighthearted and believes in making people laugh when he can. Like everyone else, Randy gets nervous in social situations with new people, and this is magnified due to ARVL. Rather than letting this stop him from participating in meaningful occupation, Randy faces social situations head on using humour to break the ice and psychologically cope with his ARVL:

"I'm not saying you can laugh your way out of everything in life, but I tend to use humour to try to downplay my own weaknesses and things of that nature."

Randy shared many different times when he was nervous to participate in seminars or teach at his church due to his ARVL but coped by joking about his own condition or the situation. Randy told a story about how he was unloading a trunk of food to help support his church's food bank and ended up having the trunk close on his head because he could not see. There was a small commotion, but Randy diffused the situation and coped by telling a joke. Randy knows that sometimes, his actions seem strange or stand out to people who don't know about his condition, but chooses not to let it bother him and copes using humor instead:

"I try to work humour into my life, into my day to day coping and hey, sometimes I learn to laugh at myself, you know if I've done something stupid. ...So, I learned, hey, you gotta laugh at your own mistakes and things that you do. Being prideful and arrogant just gives you more stress and maybe a heart attack sooner in life, and you don't need that!" and

“I’m not saying you can laugh your way out of everything in life, but I tend to use humour to try to downplay my own weaknesses and things of that nature”.

Many of Randy’s meaningful occupations involve people who are sighted such as going to restaurants, going to the theater, or teaching at church. Considering Randy’s past negative experiences with sighted people, I asked him if using humor made him more comfortable to interact with sighted people and continue meaningful occupation:

“Quite definitely, yeah. We all need to use ice breakers when we’re in social situations, where we don’t know a bunch of people so I just, yeah, I roll with the punches and take what comes and throw a quick one liner out there if you have something and make a joke, just basically, be yourself. Some people put on ears, try to reinvent themselves, try to be this, try to be that or whatever. Just be who you really are. Shakespeare said, I know thyself to be true and I think there’s a real, a certain punch to it.”

Support From Local Low Vision Service Providers. Randy prides himself on having a job despite having ARVL and being able to support himself without government assistance, despite the challenges that most people with ARVL face with securing and maintaining employment. That being said, Randy knows there are times when he does need extra help to support his meaningful occupations and he will seek this assistance from different local organizations that support the blind. Organizations such as the Canadian Council of the Blind (CCB), the Canadian National Institute for the Blind (CNIB), BALANCE for Blind Adults and the Alliance for Equality of Blind Canadians (AEBC) are the main organization that Randy reaches out to for help coping with ARVL.

Public transportation is Randy’s main means of transportation, and a lack thereof would be appraised as a stressor for Randy. CNIB helps Randy to cope by providing Randy with a free

bus pass that needs to be updated annually. Because Randy has access to this service through the CNIB, he can commute to where he needs to be and maintain meaningful occupation without having to stress over additional costs or navigating paperwork to receive a subsidy. With the CNIB's assistance, Randy can better cope with his ARVL to navigate public transportation free of charge.

BALANCE For Blind Adults, a local low vision service provider, has been a huge source of support by helping Randy cope with ARVL to maintain meaningful occupation. With the new vaccine mandate, Randy knew he would need to get vaccinated to continue some of his meaningful occupations. Randy would have struggled with setting this up on his own, scheduling the appointment, planning out transportation, finding the building on his own and then navigating the facility and producing any required paperwork or identification. Randy appraised this as a stressful situation to navigate and reached out to BALANCE to help him cope with this:

“And, with the vaccine, I got help from Balance, yes. The two appointments I went to were in two different places and a lady, Anita, I met up with her, we arranged a meeting place, went to each of these appointments and we were able to get in there and get it done. We had to sit for 15 minutes after and make sure you're okay and whatever and then we got to the subway, and she got off at [redacted] since she lives near there and I took my bus and went home. So yeah, I did get some help from Balance, and I appreciate that because these buildings, or the one down in the community center was rather large...”

Assistive Devices. Despite a glaucoma diagnosis, Randy prides himself on being a very visual person. Most of Randy's meaningful occupations require eyesight, but Randy does not let ARVL hold him back. Randy will employ the use of various assistive devices to help him cope

with ARVL and maintain his meaningful occupations, such as enjoying art, collecting various historical symbols, and reading history books.

Randy is aware of his struggles with operating the computer and technology due to his ARVL. Each time Randy must read a screen or use a new software, this is stressful for Randy, and it gets in the way of his ability to participate in some of his virtual meaningful occupations like reading the news, participating in remote church seminars, or doing personal research. BALANCE has been a significant resource as they have taught him how to navigate new technology:

“I’m not really too good with the computer and I’m thankful for...other people that have helped me out with stuff. As a matter of fact, I’m going down to see the people from Balance. ...so, I gotta go down and meet him next Monday and he’s gunna take me to see a lady that’s gunna show me how to do something with this iOS, this iPhone that I’ve got.”

The Alliance for Equality of Blind Canadians (AEBBC) has been useful in helping Randy behaviourally cope with use of assistive devices and technology to maintain his meaningful occupations. They were able to provide Randy with an updated iPhone, which he did not have access to before. iPhones are known to be helpful tools for those with ARVL, so when Randy was offered the chance to receive one, free of charge, he was excited. Having access to an accessible device has helped Randy keep updated on his favourite topics and news stories and continue his meaningful occupations:

“As far as other devices go, I do have an apple IOS phone that was given to me by AABC, because the AABC had money given to them by the city in relation to COVID and COVID and blind people. They’ve got some sort of a grant or something. Anyways, John

Tory, nicely, forked out some cash, something went and got all of these iPhones for blind people which was nice. There was 1 left, the president of the club asked me if I wanted it, I said yeah okay, I'll take it."

4.3 Pearl's Story

Pearl shared her story with me in December of 2021. In 1937, Pearl was born in Gault, now known as Cambridge, Ontario. Pearl is an 84-year-old widow, who lives independently in her home located in London, Ontario. Pearl and her late husband had three children together including two sons and one daughter. Pearl is very close with her eldest son, who lives closest to her in London, and supports her with her daily tasks. Pearl has many hobbies, such as baking, reading to her family, writing letters to friends, staying active in her community, and journaling. Before retiring, Pearl was a dedicated nurse, who took great pride in her work. Pearl made many connections and developed lifelong friendships through her college courses and her subsequent work. Pearl was very involved in the Christian church and religion throughout her life and continues these practices in her own way now. In February of 2012, Pearl was diagnosed with macular degeneration. She described her vision loss onset as gradual, and she never let the ARVL slow her down. Pearl described herself as partially sighted. Being a nurse, Pearl was familiar with the process, took the diagnosis in stride, and aimed to keep living out her days with warmth and positivity. Pearl is a loving mother, grandmother, great grandmother, and friend, and she carries this dedication to her loved ones with her as she copes with her macular degeneration.

The loss of Pearl's driving licence. Despite facing macular degeneration in later life, Pearl prides herself on being an independent woman who can get by on her own. Pearl lost her husband in 1985, and since then, has raised her children and supported herself and her family. Part of that independence was solidified by having her driver's licence and owning her car,

which allowed Pearl to freely go where she pleased. Pearl enjoys travelling and many of her family and friends live across the world. Those who lived within driving distance of her, she would frequently visit, however, this changed since the loss of her licence due to ARVL:

“...I haven't been able to see my cousin in Gault...she's 14 years my senior but has been very much part of my life forever. ...I think even when I was born. We've traveled together. We've been across Canada by train, plane, and we've been to England together and so she's very much part of my life. Until she got to the point that she couldn't travel anymore, but we went on a cruise together because she wanted to go on a cruise to Alaska. ...I haven't been able to go and see her. ...So that's been a major loss cause I haven't seen her for a long time now, but I keep in touch by phone.”

Pearl appraised the loss of her licence as stressful because it put further barriers on spending time with her cousin and engaging in her other meaningful occupations. To cope with this loss, Pearl did her best to adapt the activity and make modifications where she could. Pearl will employ these coping mechanisms until they are no longer appraised as successful. Even when keeping in contact with friends or family, Pearl continues modifying the activity until a successful coping mechanism is appraised. Pearl continued this pattern until she physically could no longer make any more adaptations, because of how much she valued her relationship with her cousin as well as the various meaningful occupations they enjoyed together. Losing the driver's license was a huge blow to Pearl, because she lost access to one of her biggest coping mechanisms and this was something she could not replicate or modify:

“I lost the ability, a major loss I encountered with losing my ability to drive, was being able to, when the world got too heavy on my shoulders, I could take off and drive to the cottage and stay there to find peace again. Sometimes I could be there for two weeks and

for the first week not see or talk to another soul. That was my safe place. My place to recharge my batteries. I could go anytime I wanted but once I can remember the last time I drove there, thinking this is probably the last time I drive and it was, and then haven't been able to go.”

Pearl relied on those moments, driving up to the cottage, being alone, taking in the scenery and then enjoying peaceful moments in her safe space by the water. This cottage holds very special family memories for Pearl. Pearl has gone through some personal, powerful experiences at that cottage on her own, and being alone is still a pivotal coping mechanism for Pearl. When she could no longer drive and get there on her own, Pearl attempted to adapt by accepting drives from family when they were on their way up to the cottage. Unfortunately, this was a compromise and didn't leave Pearl feeling as secure and refreshed as she once did. Eventually, Pearl did not want to compromise any longer, and she began to cope by shifting her frame of mind and finding those same comforting feelings she once had at her cottage, at her home in London:

“Okay, if I get to the cottage... if I don't get to the cottage, I've got to change...so my house became my safe place because I didn't think at that point, I would ever get to the cottage again but I've been twice, during COVID and it's not as easy but I've come to this place that now I've had that cottage for over 50 years. I was up there, you know, sort of 50 years after we got it, to celebrate and if I don't get back again, it's okay with me. At least I think it is. I've convinced myself that, you know, it's okay if I don't. I still like to go but if push comes to shove and I can't well, okay, I enjoyed 50 years up there.”

Coping with the support of family and friends. Pearl is very social and thrives on the relationships she has curated with her family and friends. Pearl has worked very hard to cherish

the relationships she has with her children, though it hasn't always been easy. Pearl has one son who lives closest to her, and she relies on him to assist with most of her daily tasks. Pearl's youngest son does not live close by, nor is he as supportive to Pearl, which takes a toll on her mental health:

"I've got two sons as a matter of fact. One is very helpful, and one is most unhelpful but that is neither here, well it is here or there because that bothers me that I depend so much on one son."

Pearl relies on her eldest son to bring her to medical appointments, take her to get her groceries, and drive her to meet up with friends. She is happy to have her son close to her because his support allows her to maintain a level of independence that she desires, while living in her home for as long as possible. Pearl can cope with any appraised stressors by employing the help of her eldest son:

"As long as I've got [my son] over there. Like, he popped in last night on his way home. He just had his COVID shot, took my grocery list, went, and got my groceries, brought them back, because he says, 'If I don't feel well tomorrow, I can't get your groceries'. He just adapts! He roles with the punches."

As for Pearl's youngest son, she has difficulties with him and his lack of willingness to help her cope to maintain meaningful occupation. Pearl and her youngest son have a strained relationship, and though he does help her cope in some ways, it often leaves Pearl appraising situations as far more stressful than before he was involved. Pearl's youngest son works with technology and has expert knowledge about computers. That being said, because he lacks the patience, Pearl would rather not receive help from him when she's struggling with technology.

Pearl relies on her computer to maintain meaningful occupation, but when she struggles, she will go to her eldest son who knows less about computers because of the trust they have developed:

“I did as much as I could and then...when [son 2] came in to put the antivirus thing, got that going, he made some changes to the desktop computer and when I went to use it froze and on Christmas Day [son 1] and [his wife] came over at noon hour and [son 1] worked at it. He's not a computer expert but he sat down, and he figured out what [son 2] had done. He changed it and so undid most of what [son 2] had done to suppose...supposedly make it date better for me and now I can use it again. So now, you know, but I would never, I would never ask [son 2] to come back in again.”

Pearl also relies on her daughter for help maintaining her meaningful occupations. They too have a strained relationship, but Pearl has been working hard to repair broken bonds and they are in a much healthier place now. Pearl's daughter helps her to read and reply to her mail and will drive her around when they are together:

“So then [daughter] came for the weekend. Now she came Thursday night, but she worked from here all-day Friday. Saturday morning, she spent over an hour on a phone call with three friends...So that took a big chunk and then there was lunch and of course supper and, you know, visiting and what not. So...in the time we had together, I thought we made darn good use of it.”

Pearl's daughter does not live close by, so when she comes to visit Pearl, she will stay for a longer period, which Pearl enjoys and really values. With COVID-19 and growing concern over getting her closest son sick, Pearl has been hesitant to have her daughter around as often as she would like, because Pearl understands the risks that come with COVID and its transmission:

“Except when she volunteered to come back again this month. All I could think of... well really, I didn't really get much time with her...and I thought if she can't come for a while, that's OK. So that for me was a very interesting reaction and particularly with COVID going the way it is. ... I'm very hesitant because I know I can't get sick because [son 1], an essential worker, and he has to go into the office every day. So, I don't want him getting sick. You know. So, and I don't know whether she understands that. That why I'm reluctant to have her come.”

Pearl has also maintained contact with friends from childhood, both from high school and nursing school. Her nursing school class meets multiple times a year and they celebrate big milestones together. These close relationships have proved to be useful for Pearl in later life, as she often relies on them for help coping with her macular degeneration and maintaining meaningful occupation. Many of Pearl's old friends continue to check in and keep Pearl accountable to continuing meaningful occupation and assisting her where she struggles. These relationships act as a psychological coping mechanism for her:

“...I've got a friend who will do various things, she's...not quite as old as I am – but, still driving and what not. But she will offer to do things and boy, does that make a difference. She phoned me on Sunday night, and we were talking, she says, are you deliberately growing out your hair? And I say, well, no. And you know, she has taken before to get a haircut, cause one time I did grow it out for a friend that was dying of cancer. But she's not afraid to ask those types of questions when she can do it. And I've got another friend that has health issues to, but she phones just to say, how are you doing? You know?”

One of Pearl's most meaningful occupations is travelling, and Pearl is lucky to have friends who help her cope to maintain this activity. Pearl appraises various stressors with

traveling due to her macular degeneration, but luckily, her friends help to mitigate some of these stressors for her:

“So, I mean, the last time that I went to PEI for a Lucy Maud Montgomery conference, [my daughter] came with me. Mainly because so that you know she could make sure that if anything with my eyesight that I could still [participate]...”

Maintaining these deep connections with friends is both a coping mechanism as well as a meaningful occupation for Pearl, because being integrated in the lives of her loved ones gives her a sense of purpose. When I asked Pearl if these lifelong, close friendships act as a coping mechanism for her, she said:

“Very much because I still feel I'm part of other people's lives that have been in my life for a long time. Including I could go back to having contact with a friend that I met when I was three. I have other ones that I started kindergarten with and so yes, those contacts are very important. So as far as I don't know. It's just being able to talk, go back along time with somebody and discuss the same thing, you know, and even my cousin [redacted], I've decided I'm going to phone her more frequently because I need to keep her mind active other than just what's now because if I phone her before 2:00 o'clock in the afternoon, she's not out of bed and that concerns me. So, yeah and I know she'll be back in bed after supper because you know, so I think I need to keep her going as well.”.

Adapting & preserving Pearl's favourite occupations. Pearl has lived a very full life, and with that she has some very specific meaningful occupations that truly bring her joy. From maintaining pen-pal relationships with old friends, reading stories to her grandchildren, or curating personalized story books for her great-grandchildren, Pearl likes to keep herself busy. Unfortunately, due to macular degeneration, many of these activities are made difficult due to

vision loss. Losing out on some of these meaningful occupations was not an option for Pearl, thus she chose to cope by making modifications that preserved the integrity of the meaningful occupation while still allowing her to participate.

One of Pearl's most meaningful occupations is maintaining a relationship with her grandchildren and great grandchildren. Pearl loves to read and write, and she shares these passions with each of her family members, starting from a young age. When macular degeneration was not a factor, Pearl would create personalized photo story books for each of her grandchildren and she loved to read all kinds of stories to them. As her vision began to deteriorate, she began to have trouble with these occupations, and Pearl appraised this as a stressful situation:

“I think what’s my biggest challenge is I loved to read. I loved to read for myself, I love to read stories to kids, and in September, my great granddaughter brought me a book at the cottage, my one week at the cottage, she was 2, she brought me this book, ‘Great-grandma, read bedtime story’. I couldn’t read the book. I found out afterwards that people with good sight had trouble, but she didn’t get upset – she just found another book and sat under another chair, under another light. So, I think that’s gunna be a thing.”

Much like her granddaughter, Pearl copes with this by simply moving on and dealing with it. She doesn't let herself get upset in the moment and will simply change what material she is reading by grabbing a new book with bigger text or making up her own story so that she can spend that quality time with her grandchildren or great grandchildren. Because Pearl enjoys reading so much, she refuses to simply give it up!

Reading is very important to Pearl, and she enjoys reading her own mail, books, and magazines. She understands her limitations due to macular degeneration, and she can no longer

read everything independently. Rather than give up her meaningful occupation, she employs the help of her son by having him read non personal items or by simply reading what she can until she can no longer continue. Lately, her visual abilities have decreased, and reading is becoming more and more difficult to maintain. When I asked her how she copes with ARVL to support her love for reading, Pearl explained:

“Oh, by trying to do what I can before my eyes get too tired and say enough is enough. Sort of like when some mail comes in, I'll start to read it and I think, no I got to leave that for [son 1]. Where maybe a year or 18 months ago I wouldn't have left it for [son 1]. ...I would've read it myself and then talked about it with him. Now I'm getting more and more, that you need to read this and then talk to me about it. So, I would say the amount of time I spent reading is a lot less than what I did, and I don't cover as much ground. Like I haven't picked up a book for, oh, I don't know how long?”

Pearl loves to stay in touch with her friends and family across the world. Specifically, Pearl enjoys writing letters. When I asked Pearl how she stays in contact with her friends and family post diagnosis, she said:

“Phone and email and occasionally letters, but mainly phone and email, but letters.... there are still letters to people that don't have computers or phone calls. I would say they're probably now getting more phone calls than letters but yeah”

While Pearl would prefer to write to her loved ones, she appraises the idea of losing contact as extremely stressful. Without skipping a beat, Pearl will write when she can, but behaviorally copes by adapting the activity and using emails or phone calls to fill that gap and fulfill the same feelings of staying in touch. When Pearl decides to write, it can be appraised as a stressful activity due to the macular degeneration. To cope with this, while still enjoying her

meaningful occupation and maintaining the integrity of the activity, Pearl makes simple modifications:

“I write very large, and I wear my letters are sort of short and to what they would be with information. I write very large. There are some instances where I write, and I get interrupted, and I have to stop in the middle of a sentence, and I find it very difficult even with a lighted magnifying glass sometimes to go back and read what I have written. If I can keep going with my train of thought I'm okay, but if I have to go back and read it and I've taken to printing a lot of the times. Like when I make grocery lists for [son 1]. I sit and look at the flyer on my iPad and I used to write down what I thought I needed. Now I print so that I can read it again and it also makes it easier. He doesn't have to decipher my writing either...”

Making these small changes and behaviorally coping with macular degeneration makes it possible for Pearl to continue her meaningful occupation of writing. Seeing as Pearl used to journal daily, this is something she still strives to continue in later life despite the vision loss. When I asked Pearl if she uses journaling as a coping mechanism, she told me that it most certainly was for her, and she detailed the many points in her life when journaling was her safe space and allowed her to cope with daily stressors. Pearl has modified her meaningful occupation of daily journaling and in simplifying the task, she is still able to maintain a daily journal for the most part. Rather than writing neat journal entries in their entirety, Pearl will cope by jotting down quick notes throughout her day or small meaningful things for her to later reflect on. It isn't perfect, but Pearl feels satisfied with her coping mechanism:

“...and I have a book that I call my daybook where I keep track of everything. It's just a three coil... three ring coil book and each page is a week and I try to put down each day.

I don't always succeed I try to put down, you know, things I've done just so I've got a date of when I did certain things, but I don't always get that done and then when I go back, I think, 'Oh, did that happened on Tuesday, or did that happen on Wednesday?'. Yeah, anyway...the word I use, adapt; you know."

Changes to Pearl's home. Pearl has been an independent widow since the death of her husband when her children were younger. She has also been living in the same home for many of those years. Pearl has raised her family in this home, and it holds many memories for her. Pearl always intended on staying in her home for as long as possible. This is supported by her eldest son, who helps Pearl with maintaining her daily activities. Pearl is confident in her choice of wanting to stay in her home, though sadly, she does not feel supported by her entire family in that decision:

"...when [I start] feeling a bit down and saying, oh I've lost another bit of independence, [son 1] will say, 'Well you deserve! The longer we can keep you in that house the better it will be for you!'. So, that makes me feel good whereas the other two [son 2 and daughter], if I would have a problem, in the past they would say, 'Well you should move. You should get out of there and get into an apartment!', and that didn't make me feel very good, you know. There was no help coming forth...so."

Despite the lack of support from her two younger children, Pearl does everything in her power to stay in her home and cope with her macular degeneration. When I initially asked her about coping with ARVL, she said: *"How have I coped? Well, I made changes in my house, I have."* Her home is her safe space after losing easy access to the cottage, and Pearl does not want to lose yet another safe space due to macular degeneration. Pearl treasures her memories in her

home, but she knows that with vision loss, she would need to make major changes to her home to achieve her goal of independent living:

“Decluttered. There’s a lot less stuff on the main floor. I’ve even decluttered upstairs and in the basement. ...Sifting and sorting. I mean, I’ve still got boxes of my mom and dad’s stuff here. I’ve got boxes of stuff that belonged to [my late husband]. My stuff, I’ve been doing quite well at saying I don’t need this, or I don’t need that and finding a new home for it. ...But there’s other stuff that I feel I need someone to go through with me. I know there’s stuff here that my kids, when push comes to shove and the house is emptied, will want, but I’m not really sure specifically what. ...So, when push comes to really shove, but I’m losing my attachment to it really. ...You really don’t, quote, need much. But then I have a long memory and when I look at stuff, it triggers memories and I remember who gave it to me and when and yeah.”

Decluttering has been a simple way for Pearl to cope with ARVL and strive to stay in the home. Pearl knew that as her vision progressively got worse, she would need to have less items around and she wanted to be able to decide what was important and what was not with her own eyes and judgement. Pearl also strived to keep her home clean, and with the macular degeneration, keeping everything tidy is not as simple as it once was. This was appraised as stressful for Pearl. To behaviourally cope with her vision loss to be able to stay in the home, Pearl sacrificed some of her independence and sought the help of monthly cleaners:

“I know my house is clean, sort of, to a certain extent, but I have decided I now have a couple coming in once a month to clean the house for me. So that was another sort of loss of independence.”

This sacrifice of independence is appraised as stressful, while it also acts simultaneously as a coping mechanism for Pearl's macular degeneration. Pearl psychologically copes with this stress by focusing on the areas where she still maintains her independence, and she reminded me while sharing her story: *"I still walk to the mall and the dentist on nice days or the bank on nice days. I hope to go to the dentist tomorrow afternoon"*.

Pearl understands that she cannot solely rely on herself and her son to stay in her home, so she does employ the help of local low vision organizations as an additional coping mechanism to ensure she can continue living in her home independently and doing things on her own:

"When this all started, I was contacted by something through CNIB for low vision, they sent a gal over, before I went to England, who gave me an awful lot of tips and said I will come back and we'll hook you up to other services that they provide, but then COVID happened. So, I think now, I'm gunna have to see if I can find that contact again. Because her attitude was, she said, 'CCAC will come in here and they'll tell you, you should move. Her group comes in and they say: what's your problem and how can we solve it. And if they can solve it then you stay put. Our attitude is we want to keep you as long as possible.'"

Learning that there were local organizations that will support Pearl's wishes of staying in her home has been a great coping mechanism for her. Though the pandemic has put a pause on things, Pearl intends on seeking these services out again to further support her efforts of behaviorally and psychologically coping with ARVL to stay in the home. Pearl has employed the help of the CNIB to help her cope with maintaining her other meaningful occupations, such as accessing the library and renting books from the comfort of her iPad. She knows the CNIB will support her wishes and advocate for her to stay in her home for as long as possible.

Learned experience from other older adults with ARVL. By the time Pearl was diagnosed with macular degeneration, she was no stranger to living and coping with vision loss. In reality, Pearl had been subconsciously preparing for that moment through experiences supporting her close friends and assisting them to cope to maintain their meaningful occupations despite their own respective vision loss. One of Pearl's closest nursing friends wanted to attend their class reunion, but she had lost her vision and would not be able to navigate the reunion or a new city on her own. Pearl's friend asked her, "*Are you willing to be my eyes if I go?*" to which Pearl replied: "*By all means*". Pearl adopted this attitude with all her friends and family who were experiencing vision loss and in doing so, she had a plethora of coping mechanisms and helpful tips to support her own meaningful occupations when she was diagnosed with macular degeneration. I asked Pearl if these experiences have turned into her own coping mechanisms, and she explained her story with one of her closest friends:

"Oh yes. Huge coping mechanism for me. Huge! ...I've also got a young cousin; she's lost her sight too and had a seeing eye dog which she has retired right now. So, knowing those two, I think I got a lot of coping skills that have just been part and parcel of my life. ... one day, two of us went to [town] to take her out to lunch. We phoned before we left [home] and she said, 'Fine, I'll be ready'. So, we got there, pulled into her driveway, she was still in her house then, and she didn't come out. ...So, I went in, and she was...standing in the middle of the living room floor, still in her night gown and dressing gown and said, '[Pearl], I'm lost. I have no idea where I am'. And I thought oh, I thought I've got to be spatially aware. So, when I get up at night, I don't turn the light on. I feel my way to the bathroom and feel my way back. ...And I thought, I've got to use my hands more. So yeah, in a lot of ways, she's paved the way for me."

Now that Pearl is in the position to need new coping mechanisms and advice on how to maintain meaningful occupation in the face of macular degeneration, she will often call up her friends and ask for advice or discuss their struggles together. The comradery acts as a psychological coping mechanism for Pearl, as it gives her the motivation to continue and enjoy her occupations just as those around her have in the face of vision loss. Pearl wants to be as prepared as possible. She's grateful to these have close relationships with people in similar situations so that she can prepare herself for her own progressing vision loss and continue striving towards her goal of independence:

“Yeah, so, it's things like that that have really, I guess in many ways, it's just prepared me for...you know? And I know at some point, that her son had to disconnect the stove so she couldn't cook, well I can still do that. What finished her was that she fell down the basement stairs, so that's made me all the more cautious. I take my cane, I hang onto railings, but I'm not nearly – I've got far more sight than we're dealing with, with her, so.”

One of Pearl's most meaningful occupations is staying in touch with her friends and family, but now, she has subsequently turned it into a coping mechanism for her maintaining her other meaningful occupations. She makes use of the knowledge that the people closest to her hold, and in doing so, she can learn new and effective coping mechanisms from the people who know her best:

“I need to keep in close contact with my blind classmate in [her town] and my cousin who is totally blind in [her city] because they, in general conversation, they can open doors for me that I need to think about without even asking questions. And particularly with [my cousin], she went blind, and she ended up getting a seeing eye dog which just in

the last year she has retired the dog. It's about 10, Sandy, now because she [Pearl's cousin] says 'if anything happens to me and Sandy is still considered to be a working dog, she has to go back to the school in Ottawa', where [she] got her [Sandy the dog] but she [Pearl's cousin] says, 'if I retired her eyes and looked after her myself then,' she says, 'then I can decide where the dog goes, when I can no longer look after.' So, I mean that sort of comes up. Now I would never of thought to ask about, you know, what happens to seeing eye dogs."

4.4 Morgan's Story

Morgan and I connected in January of 2022. Morgan is a 67-year-old woman, born in Prince George, British Columbia. Morgan made the big move across the country, and now lives in downtown Ottawa, along with her husband, son, and daughter. Morgan's son lives close to her and is usually available to assist Morgan however she needs. Her daughter lives outside of the city, though she still makes the time to visit and spend time with Morgan. Morgan is an educated and intelligent lady, who completed her bachelors in sociology & criminology and enjoys keeping updated with global politics and world news. In 2014, Morgan was diagnosed with cataracts and had them removed, but over the years, her diagnoses gradually progressed, and she now has all three ARVL conditions. Morgan's second diagnosis was glaucoma in late 2014, followed by the third diagnosis of diabetic retinopathy in 2015, and finally, macular degeneration in 2016 as her vision condition worsened, and her eyes became weaker. Today, Morgan would describe herself as legally blind. Morgan loves to travel with friends or her children, she enjoys being an active voice in her community and enjoying the company of friends while navigating city life. Morgan is very determined and sure of herself; she does not let ARVL stop her from doing whatever it is that she chooses. Morgan's no-nonsense attitude and critical outlook on life

have served her well, and it was inspiring to me as she shared her story of coping with ARVL to maintain her diverse meaningful occupations.

Morgan's Family. Morgan is very close with both of her children, and she enjoys spending her time with her loving husband. Morgan is fortunate to have the family support system that she does, as each of her family members support Morgan in unique ways, ensuring she is maintaining meaningful occupation when barriers arise with her ARVL. Her biggest supporter, and source of many of her currently employed coping mechanisms, stem from her husband, who has been blind his whole life. Morgan was sighted when she met her husband and did not have any visual deficits, so her husband was one of her first experiences of living and coping with vision loss. When I asked Morgan how her family played into her coping mechanisms and helped her to maintain her engagement in meaningful occupation, she said:

“I use my family resources, i.e. my husband who is actually blind, for knowledge and understanding. My children for support doing practical things...”

Morgan's husband lost his vision when he was very young in an accident, and Morgan is aware that he has decades of knowledge regarding how to cope with life as a blind person. Morgan and her husband get along well, and have open communication, which has served as a helpful coping mechanism for Morgan while dealing with ARVL. Whenever a stressor is appraised, Morgan knows her husband will help her to overcome whatever barrier is in her way. Morgan makes good use of this resource, and finds comfort in going to her husband for advice when she needs assistance coping:

“He is a resource I can go to when I'm concerned about something. However vague or clear. It doesn't matter and just talk about things.”

Morgan and her husband had to renegotiate their household roles when Morgan was diagnosed with ARVL. Morgan had been the one to do the sighted tasks to help her husband cope with his own vision loss. Now, Morgan is the one who needs support, and luckily, she has access to a blind person who has successfully coped with their vision loss and shares similar occupations to herself. Morgan's husband has always filled in the blanks and takes ownership over the simple tasks like washing the dishes or cleaning the counters. This alleviates stressors from her life and allows her to focus her energy on her own meaningful occupations. Though he has no vision, and Morgan still has some visual acuity, he will still go the extra mile to ensure that Morgan is happy and comfortable as she navigates this new phase of her life:

“He has picked up the slack in some of the household activities so that I just don’t have to do as much. I naturally was someone who did a lot of things so now he makes the coffee every morning. He doesn’t pour it. I pour my own glass of coffee because I don’t want to get up at his schedule...and he peels my morning orange which just lightens the load in the morning. It’s just a small symbolic jester that is pleasant.”

Morgan told a story of one of her and her husband's adventures, when they were hiking together in an unfamiliar area. As it began getting darker and darker, Morgan started to feel less confident that she would be able to guide them back to their car safely. Morgan was at a loss, and after trying a few simple solutions, couldn't think of a way to get them home. Morgan felt defeated, until her husband was able to employ a new coping mechanism that she had never thought of. By using their ears, they could approach the sound of the road, and either find their car themselves or find a passerby who could direct them. Morgan was astounded that her husband was able to navigate a situation like this with ease, and it opened her eyes up to the world of possibilities and meaningful occupations that she still had access to despite ARVL:

“Yes, it [having a blind husband] helps put it in perspective that there is a lot of engaging human activities that can be done without vision. It isn’t a death sentence it is just vision loss. It doesn’t mean I don’t have to adapt; I don’t have to adjust, and I don’t have to have sadness about some things. Like I do wonder if I go snorkeling if I’m going to see any fish anymore or are they all going to be black and white? Like those are things that I think about, but it doesn’t matter because I still get to go to that place and walk down the beach to the restaurant and eat and feel the warm sand.”

Morgan’s son who lives in Ottawa is always there to support his mom and help her to maintain her meaningful occupations however he can. He will drive her places and accompany her, making the city a lot safer and easier to navigate for Morgan. Morgan is thankful that her son lives so close and that she has easy access to him being right downtown. Morgan explained to me how her son helps her to continue meaningful occupation:

“Well, my son helps all the time because he is stuck living in the city and my daughter does not and he comes by once or twice a week, and we go say grocery shopping. Unless he is determined that COVID is so extreme that he thinks he should do his grocery shopping and I should wait in the car and listen to the news while he does it, but I still go because it’s an activity. He has often come by and gone for a walk but less and less because I live as close as you can live from downtown. ...So, I live in a large urban city and there’s a large homeless and drug related community that has emerged especially since COVID, so it’s not always safe for me to be out on my own, but he comes and we either drive somewhere or we do whatever.”

Morgan’s daughter, on the other hand, lives outside of the city, making it difficult to see Morgan as frequently. That being said, Morgan’s daughter is always willing to lend a helping

hand, and where her son assists with the day-to-day activities, Morgan's daughter is there to support her more niche occupations, such as travelling and interior design. Morgan loves interior design, and she passed her passion and talent onto her daughter, who Morgan entrusted to decorate their new condo when they moved in. Morgan's daughter helped her cope with a difficult situation she had with an interior decorator she had hired, and she tells the story here:

“Okay, when I could see it in our family, I had a keen sense of aesthetics and fine art and what not. My son has inherited none of that. It's very discouraging but my daughter has and so when we moved here, she did the design plans based on what I could see and what I told her. Not based on what she wanted but what I wanted. And she was really good at paying attention to me and creating a design plan and it was very interesting because at the outset we hired a decorator to do this and the decorator could not listen to instructions, nor provide feedback to really clear instructions written and oral and I think I'm fairly clear when I put my mind to it... 'I can't do this. I can't do that'. So, understand that in measure we took her on a tour of our new place, and I asked her to provide just a generic thing like which way to put the bed? Could it fit this way or that? She never did that. This decorator got it in her mind to talk about all sorts of grandiose ideas.... So, she got fired and I paid a very minimal amount and my daughter got hired for free. And she did it and she can do it and she can do it quite well.”

Morgan is grateful for the relationship that she has with her daughter. Morgan explains the fun she has when shopping and maintaining her sense of style with her daughter, which is difficult to manage on her own with ARVL. Morgan can cope with these visual barriers because she has the help of her daughter:

“So, I'm very, very pleased...and she does come and visit and we go shopping and she will help buy me clothes that she knows I'm physically comfortable in and that I will probably like the look of based on our past tastes and design expectations. I'm not a super fashionista but I like to look neat and tidy and well put together and I like all my fat bits to be suitably hidden from general scrutiny and so she has a good sense of that and a keen eye. And so, she can put things together for me that make me happy. And still keep me comfortable. I still wear Birkenstocks; I am aging happiest in so many ways so that she understands.”

Cynic Humour. Morgan is very quick witted and loves to have a good laugh. Her self-proclaimed cynical sense of humour has been consistent throughout her life, with many of Morgan's friends and family members being familiar with her sarcasm or her challenging them for the simple pleasure of doing so. When I asked Morgan about her psychological coping mechanisms, Morgan explained: *“Oh a few. Sense of humor. I like humor of all sorts and I like cynicism as well and I find that to be humorous. So, I enjoy all of that and that helps me manage.”*

Morgan is very aware of her use of humor to help her cope with not only ARVL, but also with her other daily life stressors. If Morgan can laugh about a barrier to her participating in meaningful occupation, such as an illegal protest (2022 Canadian Convoy Protest against COVID-19 restrictions which took place in Ottawa, ON) making her city impossible to navigate, she can cope with those feelings, and it allows her the mental clarity to find a solution:

“Oh, there's so many times I've used humor. There isn't a time I don't. So, I mean literally even this morning talking with my son about the protesters and stuff like this and you

know, is definitely not a...I use it constantly. I don't not use it. It's part of my everyday activity.”

Morgan truly understands the effectiveness of employing humor as a coping mechanism to maintain meaningful occupation, as this was often a tactic she used with others while employed with the Children’s Aid Society in her 20’s. Working with the vulnerable population of teens who often had dangerous offenses on their record was difficult, but Morgan found that humor helped her to navigate some difficult situations. When I asked Morgan if she thought that employing humour was effective in getting her to maintain meaningful occupation, she reminded me of her most difficult cases and how even those children were willing to do the tasks at hand if Morgan could make them laugh:

“...I worked in very, very, extreme, difficult problem areas and success in those areas if you use humor means that you don't get hurt by those kids. They have the urge to help you in what limited way they can, and I didn't have high expectations. My goal was to have them help themselves, so we'd often have that conversation...success breeds those skills so if I felt success over going home and having a good night with the kids and having no one do anything crazy, it was it was achievement I want to replicate. So, it's become part of my style.”

Traveling. One of Morgan’s most meaningful occupations is traveling. Morgan loved to travel the world before she was diagnosed with ARVL, but even post-diagnosis, Morgan has made it very clear that her intentions are to see as much of the world as she can before that is no longer an option for her. Though the recent pandemic has made travel more difficult for Morgan as an older adult with ARVL, she works through these difficulties to gain access to one of her favourite activities:

“I’ve travelled a lot and I like that. And I’ve tried to engage in some travel with a view to not being able to appreciate some of the things I’m going to do in the future because I won’t be able to see them. So, I’ve taken the initiative to create my own bucket list and COVID of course is putting a big damper on the pleasure of that list, but it is still there. So, I have travelled a great deal and I’ve tried to see things that I want to see before I can’t and find alternatives to some of that experience within travel as well.”

When I asked Morgan for an example of a time when her ARVL created a barrier for her while travelling, the biggest thing that resonated with Morgan was her lack of control over the trips she has taken. Being someone who is visually impaired, Morgan must rely on others for her safety, guidance, and assistance in navigating new terrain. Morgan is proud to be independent and so having to rely on others has come as a stressor for Morgan:

“...I mean I can't say that vision loss was a huge contributor other than I wasn't in charge of the whole event. I had to share. Once I had a tour of Newfoundland with my daughter and I had to tolerate her music because we always had this rule when they were little, that the driver chooses the music...then I had to listen to her stupid music and I got quite sick of it and she quoted me repeatedly and you know, ‘even you have to share’...I do tours now, where I never used to do tours, it used to be always individual and one of the things my kids said is there's too much difficulty in certain countries with regard to sorting out your plans and coping with them. So, ‘let's just do a tour’, so that a lot of it is sorted out and that has worked reasonably well, but then of course you were on a tour, and you do certain things that you might not be bothered otherwise, but I mean I...it's up to you to choose the tour...”

Travel is simultaneously a meaningful occupation and coping mechanism for Morgan, as the act of traveling is an escape from the regular life stressors that accompany ARVL. Prior to Morgan's diagnoses, she was able to travel mostly carefree, and while exploring the world, Morgan did not appraise stressors. Now, post diagnosis, travelling is not as carefree and requires an increased degree of planning and worry. When I asked Morgan about her relationship with traveling as a coping mechanism and a meaningful occupation, she explained:

"I think...it's complicated and a bit of both. I think I have to find a way of doing it so that it can be effective and it's not the same as when I used to just go somewhere, and roam endlessly and just managed that I can't do that anymore. You know, my last trip where I was able to just walk and wander. I could get lost and find my way out of it and figure out where a taxi was. I couldn't do that now. I mean I know the difference between the sidewalk and the street, but I don't know if I'm.... where I am exactly, and I don't feel confident that I can navigate that just alone. ... I do tours now and I'm very careful the tours I take. Or I go with my daughter in a place that she's confident just wandering around in like Newfoundland. We drove and walked, and we were OK because we understood enough of the language and what not. ...We didn't have a month to roam because I used to be quite comfortable really poking about a place. You know, we would go to a lot of cities where we just spend a week in the city going out every day, trying to see the sights. But it's different now and I do have to have some description. I like an informed guide with the knowledge of history and some issues related to that country. I don't require the guide of all guides. I just require someone who knows something and is sharing it reasonably well so I can learn something, and I like the feel of place. We were there [Uzbekistan] in October with hot and dry and a lot of the place is desert like, and I

enjoyed the feeling of that, and I did ruins... I have a very bad knee so I was the kind of person who shouldn't really be doing stairs, but I did it a few times 'cause I couldn't resist. You know, it was just fun."

Morgan told a story of traveling with her daughter, who she employed as her travel buddy. Morgan copes with the various barriers faced while traveling with the help of her daughter, who acts as her eyes. If Morgan's daughter is not available, Morgan will travel with a trusted friend or someone she believes has the wits to keep them safe while traveling in foreign countries. Morgan is picky with who she chooses to trust while travelling, especially when considering traveling with friends. Morgan has had some negative experiences traveling with friends prior to her ARVL diagnoses, and she is aware of how vulnerable she is with low vision, so she now plans accordingly.

Morgan also mentioned how she has adapted her typical travelling routine to be more accommodating of her ARVL. For example, prior to her ARVL diagnoses, Morgan enjoyed roaming a new city by foot with her husband and getting to know the local culture and important monuments while remaining self-guided. Morgan realized the impracticality of doing so with ARVL and the barriers that are now in place, thus she copes by hiring knowledgeable tour companies to guide her in these new places or by booking her trips through online services specifically designed for blind people who want to travel together with trusted guides and curated experiences. Specifically, Morgan hopes to use the UK based travel agency, Travel Eyes, who she is planning to travel with when she goes on her next international trip. Travel Eyes connects you with a sighted traveler, giving them a discount to have the sighted person guide Morgan through their adventures together. Morgan wants to see as much of the world as possible

before her vision loss progresses any further, and she will continue to employ coping mechanisms to circumvent any barrier to her participating in this meaningful occupation.

Morgan’s battle to cope at work. Morgan has had a successful career for most of her life, and at her final place of work, Morgan was there for 20 years before retiring. Morgan was still employed when she was diagnosed with ARVL. As her vision condition began progressing in its early stages, Morgan decided to keep working as this acted as a coping mechanism for her in the face of ARVL. Being in a familiar environment, doing something she knew how to do, and being somewhere where she felt comfortable, helped Morgan to maintain a sense of stability and function:

“I used my work experience just keeping functional for a while because it reinforced my intellectual and emotional capacity to function.”

Morgan enjoyed her work but having no license and no guarantee of transportation from her family or friends, presented a new barrier to her maintaining her engagement in paid work. To help her cope with the barrier of transportation into the office, Morgan would often use her local Paratranspo service, but it was unreliable and didn’t always get her to work on time.

Despite these challenges, Morgan felt fulfilled by remaining employed:

“...the job itself was engaging. I worked in the [redacted] program. And I was a civil servant, and I would work with all sorts of members of public. I understand the software we worked with. I was reasonably fast and effective worker and I enjoyed working with the public. Especially hard to serve members of the public. We had many people, and you can imagine when you are working for any [redacted] offices client’s call and they’re swearing, and they are really rude. People don’t wanna speak to them, but I don’t mind because it doesn’t put me off. It puts me on a package tour of how can I get this person

engaged. I can't help myself and I just really enjoyed interaction with people who had extreme difficulty coping and getting them on the right side of the law...and feeling like they had done it. ...I enjoyed the work.”

The sense of comfort Morgan associated with her employment was short lived, as her employer turned out to be non-inclusive and delayed implementation of the assistive devices that Morgan would need to work effectively in the office. When I initially asked Morgan how her employer had helped her to cope with her ARVL to support her engagement in work, Morgan said quite frankly, “*Well, my employer did not.*” Morgan’s employer actively fought against her pleas to make the workplace more accessible to her, and Morgan experienced many antagonizing moments, with staff and management. To continue working, Morgan had to implement her own accommodations and assistive devices, much to the dismay of her management team who would remove anything Morgan put in place to help herself cope, while explaining to Morgan that it wasn’t up to company standards. Morgan struggled to get legitimate reasons from supervisors and managers as to why her work could not accommodate her ARVL, especially because, at the time, Morgan was eager to continue her job. Sadly, Morgan could no longer find ways to cope in this environment, she was no longer happy, and she had to give up her paid employment, taking an early retirement. Morgan explains her difficulties with her employer here:

“...I find them [the employer] entirely despicable, and...they actually attempted to force me to retire by not paying me even though they had allowed me to work and then they decided they weren't ready for me to work. Even though I had been in the office working every day. All they [the employer] had to do was purchase some accessible devices that allowed for voice and magnification, and they don't always work with all the software demands at work, but they would have worked for 90% of them and they play games and

they sent me home for six months without wages... I did miss it [working] but eventually I couldn't cope with the lighting and the lack of flexibility on the employers' part and all sorts of issues. So, it was a big hassle and that's that."

Political Action and Advocacy Efforts in the Community. When I spoke to Morgan, I got the impression that she is very outspoken, and she isn't afraid to speak her mind. This rang true as Morgan told her story and described her advocacy efforts in the community for herself and others with disabilities. Morgan describes the difficulty she faces with e-scooters being left on her sidewalk, and this is a physical barrier to Morgan's engagement in meaningful neighborhood occupations as she cannot leave her apartment without the risk of running into a scooter or trying to navigate them as they are parked or being driven by users. Advocacy is Morgan's coping mechanism here, as she strives to make political changes that would make participation in meaningful occupation more accessible to her:

"I try to advocate when I see services that are not being spoken to or are being addressed and require people to participate against. For instance, I am working against the e-scooters in the city because they are left all over the place and they're a real hazard for blind people. Amongst others. So, I am political in that sense and I'm specifically political in regard to my disability."

I asked Morgan how this level of political activism and advocacy was a coping mechanism for her, allowing her to participate in meaningful occupation more easily and she explained: *"Well, it helps. It helps me understand where things are good and where things are bad"*. One of Morgan's latest political advocacy ventures surrounded COVID-19 and the provinces consideration of disabled people when socially distancing or getting vaccines. Morgan

explained the difficulty of standing in long lines to get a vaccine, or the troubles of social distancing when you are blind:

“I was very interested in having a vaccine program, when the vaccines first were about to be released in January a year ago, really year ago today, thereabouts, and I thought we really need something in this city and in this province for blind people and other disabled people 'cause we don't stand and wait for long times well. We don't social distance well. As you can imagine I'm not good at that cause I don't know where you are until I hit you, and so I thought well why don't we do something?”

Morgan fought hard and eventually contacted the proper public health officer to hear her concerns. Even when she was able to contact the correct person, they did not answer her various attempts to reach out and get some answers about how the province planned to support their disabled population through these troubled times. Morgan seeks out transparency in all matters, and she was not finding any transparent answers, however, instead of being discouraged, its situations like this that are why Morgan chooses to continue her advocacy efforts to improve not only her situation, but the situations of persons with ARVL more broadly.

Morgan enjoys a good challenge, and when dealing with such political matters, it can be extremely challenging, though Morgan can easily stand her own. These advocacy efforts have, in turn, created a new meaningful occupation for herself, while it also acts as a coping mechanism in many ways for Morgan:

“I get pleasure out of being difficult sometimes. Like I'm digging my heels in and saying no, you know, because I will advocate for myself. I will test the logic of my reasoning with all sorts of people, friends, and family. And what not because I don't necessarily

assume I know everything, but I do, I push back. And I am difficult if I, you know, if I feel unjustly treated. We have had that problem here in the condo.”

Morgan goes on to explain a situation in her condominium during COVID when the exercise facility was closed for social distancing. It was challenging for Morgan to travel to a different facility to use the pool and gym equipment, especially when one was within an elevators ride from her front door. Being that Morgan is aware of her rights and a politically active disabled person, Morgan knew that by law, she should be allowed access to these facilities, regardless of if there were social distancing rules or not. The president of the building would not hear Morgan’s pleas and after getting the correct information from city bylaw officers, there was still no progress. At this point, Morgan continued to cope with the barriers to her meaningful occupation of exercise and upped the ante:

“So I simply called the lawyer in and did human rights complaint because I had said, from the very, very beginning, I carefully constructed my letters or emails to him, saying I as a visually impaired person have not got access to public streets and walking the same way sighted people do and it's increasingly unsafe for me to be outside because we have a lot of problems in the area now with homeless people or drug addicts and I need these facilities because they are essential and that they ...there is no provincial initiative to close them. Once I started the human rights case, two weeks, three weeks later, he decided he would allow me to go for a swim if I sent... a letter from my doctor, giving him private information about my medical condition so that he could allow me to swim as a disabled person because he was operating the same program the city was offering disabled people to use it to swim”

Seeing as Morgan pays her condo fees and owns her unit in the building, she is aware that she is essentially suing herself. But to Morgan, that was not what was important. She was advocating for herself and others because she enjoys her meaningful occupation of exercising, and she didn't feel the need to suffer any more than she must to maintain participation. Advocating for herself and others is how she chooses to cope with these barriers and attempt to make a meaningful impact in her community. The sense of empowerment and independence allows Morgan to continue in her other meaningful occupations because "*...it just lets me know that I can*". Advocacy and political activism make Morgan feel confident participating in her meaningful occupations in the face of barriers related to ARVL:

"And I will do it [pursue the human rights case and sue the building]. I will do it because you have now pissed me off. And if I don't stand up for my rights who else will?"

Morgan's relationship with vision loss organizations. Morgan is very active in her community, and she is knowledgeable of many local services within her community that serve people with low vision. Morgan relies on some of these local low vision services to assist her in coping with ARVL. One that she is very familiar with, and uses on a daily basis, was her local Paratranspo service. Morgan relied on Paratranspo to get her to and from work while she was still employed and currently, she uses it to support her community mobility, such as going to dentist appointments or meeting friends across the city:

"For instance, we have Paratranspo here in Ottawa, which is a drive service, because I was no longer allowed to drive because I couldn't see. And I use that to get back and forward to work for a couple of years. Until I retired and I still use it to get to appointments."

Morgan is familiar with her local chapter of the CNIB, and she employs their help to cope with the barriers ARVL creates to engaging in meaningful occupation. Typically, they offer in home services and assist with coping with the various barriers to meaningful occupations such as cooking, maintaining personal hygiene and appearance, or help mastering new assistive devices and technology. Morgan finds this useful and welcomes the additional knowledge to make her meaningful occupations more accessible and life a little bit easier. Unfortunately, these kinds of services are not currently available in the community due to COVID-19 and the current restrictions in place. Morgan is looking forward to a time when the CNIB can enter her home and show her new ways to cope, safely:

“I’ve had, the CNIB has people come by and do stuff. I’ve had them come by a couple of times to help figure out clothing and sort things. To be honest, I probably need them more, but they can’t come anymore because of COVID, and they can’t do much. I use an iPad to get email and stuff like that and they have a software support that’s super helpful because it keeps me engaged in using my machine” and “They labeled my stove, which I still use those markings, to let me know where the general bake button is and then the start button and then the off button. I can eat with special glasses and a magnifying glass combined, find my way around the other options on the panel, but it’s not easy and so they came in and they did organize a few things in the home.”

Relying on strangers in the community. Morgan has many meaningful occupations that take her out of her home by herself, and sometimes she needs help coping with barriers that come up due to her ARVL. In a situation where Morgan did not know anyone, she would feel comfortable asking a stranger or a bystander for help her to navigate whatever the appraised stressor is at the time. When I asked Morgan about this, she said:

“Blanche Dubois says, ‘I have to depend on the kindness of strangers.’ I quoted this long before I lost my sight. I think we all have some social responsibility to each other and that's just a normal thing.”

This social responsibility to care for others in the community is a coping mechanism that Morgan can rely on as she lives her life and participates in her various meaningful occupations across the city. However, during the pandemic, there has been a notable change in the community. The surrounding areas of her apartment building is where Morgan once enjoyed spending her time, employing her typical coping mechanisms to navigate crowds, and limiting interaction with any aggressive or unsafe members of the community. Now, with less pedestrians walking the streets, there are more un-homed people and people with substance abuse issues laying in the street, making it dangerous for Morgan to navigate. Typically, Morgan would employ the help of a friendly passer-by to assist her in navigating the sidewalks, but with social distancing and less people to ask, this is no longer a feasible reality. This environment is appraised as stressful to Morgan, and unfortunately, to cope with this, she finds herself in a position where she must exclude herself from her meaningful occupations that take place outdoors.

Though she tries to stay inside as much as possible these days, Morgan is in good hands in her condominium community. Morgan and her husband chose to move here because of its helpful amenities and the communal support. These are coping mechanisms for Morgan, as this feeling of being taken care of by the collective allows her to put her energy into other meaningful occupations and cope with her ARVL in ways that she feels comfortable:

“I actually believe we need to rely on someone else all over the place in the community at large. And we all collectively do and that's why we live generally in groups. I mean I've

chosen to live in a condo downtown for reason. I need to know that there are some things that are going to be handled by the collective whole here. And everybody in the building... I don't...we are the only two with vision loss. So, everyone here enjoys that the garbage is taken out by someone else. The recycles is dealt with by someone else and all of those things. The people who enter the building is dealt with by the doorman and we appreciate all of that. That's the benefit of the collective here in just a practical way and I think in the bigger sense of the word, we all philosophically depend on the kindness of strangers..."

4.5 Liz's Story

Liz and I connected in January of 2022, when she shared with me her story of how she has been able to cope with barriers to meaningful occupation in the face of ARVL. Liz is an 80-year-old woman, born in 1941 in Stratford, Ontario. Liz stayed close to home, and raised three children in London, Ontario with her husband. Liz is a proud mother, grandmother, and great-grandmother, and she takes great pride in these roles and the relationships she has with each of her family members. Only Liz's youngest son lives close to her home in London, but she remains tightly connected to all of her children and can rely on her eldest son and daughter when needed. In 2017, Liz was diagnosed with macular degeneration. She currently describes her visual acuity as legally blind. She was formally diagnosed as such when her macular degeneration progressed from having one eye with the wet variety of macular degeneration, to having her other eye develop the dry variety. The onset of her vision loss was described by Liz as gradual, as she only noticed her vision was deteriorating one day while driving with friends, because a passenger had asked her if she could see something in the distance, and she realized that she could not. For the past five years, Liz has continued pursuing her meaningful occupations while navigating life

with macular degeneration, and she takes it day by day. To treat her ARVL, Liz has been receiving medical injections in her eyes since 2014. Liz enjoys crocheting, attending fitness classes with her friends, creating personalized story books for her grandchildren and great grandchildren, playing cards, and traveling around town to shop and visit with friends. Liz's positive outlook and humorous nature was very touching, and these traits are evident in her coping mechanisms. Liz takes her macular degeneration diagnosis in stride, and focuses on what she can do, and how she can keep herself and her loved ones happy.

The initial diagnosis & Liz's optometrist. Liz could be considered lucky, as she was part of the small segment of the population who were aware of their diagnosis in the early stages. Due to Liz maintaining frequent optometrists' visits and with an extensive family history of ARVL behind her, Liz had the tools to know what she should be looking out for, as did her doctor. This forewarning and open dialogue with her optometrist would eventually serve as a coping mechanism for Liz in other ways, but especially so when considering coping with the initial diagnosis:

"My optometrist...I had a good relationship with him, and he had said to me before I retired, when I was in my early 60s, that I had the makings of macular degeneration. So, it didn't really come as a big shock to me when my eyesight started to do things."

When dealing with ARVL, speed is of the essence with diagnosis and subsequent treatment. Patient prognosis is oftentimes more successful the earlier the ARVL is identified, and treatment can begin. Liz's close relationship with her optometrist afforded her this speed and Liz was able to get treatment and medication far quicker than if she had gone through the traditional referral process required when garnering services from multiple health care professionals. This quick turnaround may have had a direct effect on Liz's ability to continue participation in

meaningful occupation. Because she had access to early treatment, her vision did not have a chance to deteriorate without medical intervention, and she may have saved some of her visual ability this way – putting off various visual barriers early on:

“But because I had such a good relationship with him, he had got me into the IB clinic and right away, well I had cataract surgery, to eliminate the fact that cataract might be interfering with it, but then the cataract surgeon, when she checked them, took me immediately...and I had shots started in my eye that night and that would have been in 2014.”

When I asked Liz if she thought the speed and attentiveness of her optometrist, when dealing with her initial diagnosis, impacted her coping mechanisms and allowing her to participate in meaningful occupation, Liz said “*Yes, I do. Yes.*” Liz was adamant that her optometrist provided her with successful coping mechanisms that helped her to continue her meaningful occupations. This optometrist is now retired and has been for many years. Liz was sad to see him go, and she doesn’t have the same access or relationship as she did with her old optometrist, with her current doctors. Liz describes a physical coping strategy suggested to her by her doctor to monitor her visual abilities, ensuring that her acuity is not getting worse. This makes Liz feel more comforted to continue her meaningful occupations, knowing that she can check on her visual ability from the comfort of her own home:

“Okay, he [Liz’s optometrist] gave me, years and years ago, a grid to put on my fridge door and he said you look at that every week and what you see, and you will know if it gets worse, better, whatever. So, I did look at that...and when I looked at the grid, oh well I guess back in January. It was after I had the booster shot or the vaccine and I thought oh geez I wonder if that vaccine is doing something for my eyes because when I

got...I'm probably about 2 inches from the thing, but I could see a far difference than I could before. So, when I asked him about it, he said 'No. It's the IVF drops that are doing it. It's not the vaccine.' The booster. So, I said okay, that is fine. I was hoping it was. I've got this wonderful breakthrough."

The close relationship between Liz and her optometrist had a positive influence on Liz and her ability to cope with ARVL. The coping mechanisms provided to her over the years by her optometrist have been helpful to Liz since her diagnosis, but she couldn't put her finger on something specific because of how long it's been. She did, however, mention that though her optometrist was a great source for coping strategies, he never advertised vision loss rehabilitation services, such as the CNIB, which many Canadians employ and rely on for support when coping with ARVL. Liz thinks that the additional resources should be made more easily accessible and provided to ARVL patients as they visit their own respective optometrists' offices across Canada.

Vision loss through the generations. When I initially asked Liz how she copes with ARVL to maintain meaningful occupation, she informed me straight away that ARVL runs in her family, and she watched her mother and grandmother cope with their own macular degeneration diagnoses as she grew up alongside them. Liz assumed that eventually, she would be in the same position as the women before her, so when she was initially diagnosed, this did not come as a surprise. This knowledge acted as a coping mechanism, as she had a good idea of what would come in the future, rather than facing the unknown, as many other older adults with ARVL must endure upon diagnosis:

"Oh my gosh. How I have coped? ...Okay, my grandmother had this and my mother had this, so I kind of expected it to come my way."

When I asked Liz what coping mechanisms she learned from her mother, she talked about independence and maintaining that as her macular degeneration progresses. Liz watched her mother raise her and nurture their family all on her own while facing ARVL. Liz truly values the experiences she watched her mother go through and uses this as a basis for her current coping mechanisms. Liz acknowledges that there are some occupations she can no longer do on her own, but she enjoys participating in as many independent occupations as possible. Liz will always try to participate in meaningful occupation on her own, without support, as this makes her feel confident and brings her joy:

“Independence. I just do not like relying on people. Okay. As long as I can do it, I’m doing it. So, this is.... I can still cook. There is things I can’t do. I can’t read. I can’t, like you know, there is things I definitely can’t do but I’ve got the cane. I can go out for a walk. What else? Like I, I really value my independence.”

The knowledge passed down to Liz from her grandmother to her mother and now to herself has been a coping mechanism for Liz in more ways than one. Because Liz is so familiar with ARVL and how people present themselves when they may be struggling, Liz tells a story of how she made a lifelong friend with a similar diagnosis, and how they now rely on each other:

“To begin with, we used to go to Florida for two months every winter. And we use to go have a condo and we had a snowbird’s club and one of the women that was in this club, the first time I saw her, I was sitting in a room full of people and I watched her, and I said to my husband, ‘That woman is having vision problems’. So, I went over to her and introduced myself and said, ‘Do you have a problem with your eyesight?’ And she said, ‘How do you know that?’ So, I was telling her that my mom, I had dealt with my mom for years with that, and anyway, her and I became fast friends. We still are. So that was 15

years ago. So, we keep in touch over the telephone and compare notes and laugh about things and figure out what she's doing and what I'm doing and all those kinds of stuff. So, if it hadn't been for my mum, I wouldn't have picked up on that but neither one of us, like I had my eyesight then and it was funny and we go out together and I'd take her out and we'd go shopping and we went to all kinds of places and I was able to explain to her what was what and everything else, eh? And I can remember being in a restaurant and she had to go to the washroom, so she grabbed.... it was really narrow aisles, she grabbed the back of my pants, and we went left, right, left, right. So, we had fun with it too, eh?"

Liz cherishes the time she spent helping her mom cope with ARVL and now uses these tools to help herself cope, by finding others in a similar situation. Having friends and family who understand what you are going through and who can sympathize with the challenges of ARVL is a psychological coping mechanism for Liz, as this reminds her that she is not alone and that she can still lead a full, happy life, like her family before her and those in her social circle.

Losing her license & her independence. Prior to her macular degeneration diagnosis, Liz had many friends and family that she would drive through town to visit and participate in some of her favorite activities. One of those meaningful occupations was driving to the cottage with friends to spend time out of the city. It was on one of these normal drives, getting groceries with her friends up at the cottage, that she realized her vision was becoming a barrier to this meaningful occupation:

"Okay. I was up at the lake, and I was with a friend, and I had driven into [town] to get some groceries and we're coming back home, and she says, 'Do you realize that truck in front of you is turning left?' And I thought, 'Okay? That's not good'. So, I really thought

about it okay, and I drove, then of course I had to bring my car home here to London. The day I drove home to London, I really paid close attention to what was going on. What I could see, and I couldn't see and anyway, then once I got home here, I go to get groceries and stuff like that and began to realize I wasn't sure if I was seeing stop signs properly and I got worried that if a dog ran out on the road I wouldn't see it or if a bicycle was beside me and I just thought, no I shouldn't be driving... ”

Liz gave up her license voluntarily, as she was no longer comfortable taking the risk of possibly hurting herself or someone else. This was an extremely difficult decision for Liz to make, who values her license and associated the freedom to drive where she wants with her sense of independence:

“Your independence really disappears once you can't drive anymore. So, you're relying on someone to take you everywhere you want to go and if they don't want to go that day, you're out of luck. So that's the thing I want more than anything is to keep my independence. Even if I can walk.”

Maintaining independence was taught to Liz by her mother. Valuing her independence above all and relying on this sense of independence as a main coping mechanism presented a barrier for Liz when faced with losing her license. To conceptualize this and make the loss of the license easier to cope with, Liz relied on pulling from past experiences with her mother, allowing her to psychologically cope and come to a sound decision about her driving:

“But I just... I couldn't see myself driving. I just couldn't and I know with my mother, she drove because she was all on her own. She was a widow and she had to drop the car to do anything, and I remember her going through stop sign and getting in an accident and that was the last time she drove. So, I just thought no. I don't want that to happen to me.”

Liz did not want to stop engaging in her meaningful occupations simply because she could no longer drive, and she knew she would have to come up with some coping mechanisms to help eliminate this new barrier. Liz would have her husband drive her where she needed to be, and this allowed her to bridge the gap, and continue her meaningful occupations. Though he is not always thrilled to drive her, he will come through to support his wife:

“And I have a husband who might complain but he'll take me. Like I had to go to the hospital for an appointment at the Ivey the other day. And he was like, ‘Oh no. Not another appointment! Oh, I got to get up at 6:00 o'clock just to drive you there?’ So basically, that's what I do.”

Liz also relied on a close friend who still had their license, and who would drive Liz to her fitness classes. This was a great coping mechanism for Liz, because of the convenience, the additional social aspect, and the fact that fitness class was one of Liz's most meaningful occupations. Liz was able to cope with ARVL, both behaviorally and psychologically, navigating the barrier of not being able to drive to her meaningful occupations by relying on her friends and family where she could:

“I had a friend... I used to go to fitness three times a week and as it turned out in 2014, her son died and she was having great difficulty and didn't want to get out of the house and all that kind of stuff, so I took her to fitness with me one day and she agreed to come. So, eventually she drove all the time. So that was... that basically is my social life.”

Liz and her husband had to give up some meaningful occupations when they were no longer able to drive long distances. As Liz's husband got older, and his own health problems arose, he could no longer drive Liz around as much as he once did. Liz enjoyed driving up to the lake, and spending time with friends and family with her husband on their property. This was no

longer feasible for Liz due to ARVL. When I asked Liz how she copes with the loss of this meaningful activity due to ARVL, she explained:

“I don't know. I think about all the time and wish we were there but it's something that I have to be thankful that I was able to do. And that is how I have to approach things. I have to be thankful that I was able to go to Florida as long as I did and thankful, I had the place up at the lake as long as I did and could made good friends up there. I still have friends up there, so.”

It takes a village – Liz and her family. Liz has a large family, and she values the time spent with each one of them. Liz and her husband are grateful to have such a large family, as their children, grandchildren, and great grandchildren all support Liz with her macular degeneration. When I asked Liz about her children and how they play into her coping mechanisms to maintain meaningful occupation, she said: *“...basically, my kids look after us fairly well.”*

Liz still lives at home independently with her husband, who has his own health problems. Despite this, Liz's husband is still able to help her cope with the visual barriers that come with living independently. Liz's husband does not let his health problems stop him from helping Liz to cope. Liz feels comfortable assigning tasks where necessary, or if she's having troubles cooking or cleaning, she knows she can tell her husband what to do, and he will assist her:

“Like I'll peel potatoes and say, 'You got to check these potatoes now.' Like I have to make him do things too. You have to check these potatoes and make sure I got them right and you have to.... When you go past the stove can you see what it's doing? Do you mind setting the table? And things like this. I have to get him doing so he does the laundry for what it's worth.”

Liz and her daughter have a close relationship, and she is a great factor in Liz's social, psychological, and behavioral coping mechanisms for mitigating barriers to participation in meaningful occupation. Liz goes on to explain here:

“Okay, my daughter...would come to London and every time she came to London, oh we'd go shopping, we'd go out for lunch. She was wonderful. She just kept me going the whole time she was home here and doing things that I wouldn't do normally”

Liz's daughter helps her to cope in many ways. Behaviorally, she helps Liz by driving her where she wants to go and physically aiding Liz to continue her meaningful occupations. Socially, these interactions help Liz to cope as she gets to further develop this relationship with her daughter and continue their favorite activities together, despite the barriers present due to ARVL. Psychologically, these interactions and time spent with her daughter help Liz to continue her other meaningful occupations, as she feels good about herself, and the positivity radiates in other areas of her life.

Liz feels very supported by her two sons as well. Liz refers to her youngest as the “go to” son because he lives in London, and he's close enough to her home that she can rely on him in a pinch if an issue arises. Both him and his partner help Liz by driving her to Kingston to visit with her extended family, which is another meaningful occupation that Liz holds dear. Liz can no longer make the drive, nor can her husband, and this is appraised as an extremely stressful situation for Liz. Her grandchildren and great grandchildren live in Kingston, so when they can't come and visit her, Liz likes to be able to visit them:

“My husband doesn't drive to Kingston that's way too far. About a five-hour drive, so [Liz's son]'s partner, is from London here. So, when she comes home to visit her parents, we go back with her and then she comes back here again to drive us home...”

Liz's eldest son is a great source of coping for Liz when she appraises stressors with maintaining finances and dealing with money. These are tasks related to her remaining independent in her home with her husband, and she relies on this son to assist her with finances. This way, their home, their independence, and their finances are secured. When I asked Liz if the division of coping related tasks amongst her different children and grandchildren helped her to cope with ARVL itself, she said: "*Yep, yes it does. Yes.*" and was very adamant that without this support system, she would not be able to cope with macular degeneration and maintain meaningful occupation:

"So, my kids, one is in London. He is the go-to. One is in Woodstock. He looks after all the financial stuff and the one in Kingston is my daughter and she's so far away but she's a nurse and she looks after all the medical stuff and medical appointments and all that kind of stuff."

Friends supporting friends and staying fit together. Before the pandemic, and restrictions to indoor gatherings were implemented, Liz loved going to her local fitness class to exercise with her friends. Liz would invite her current friends, meet other older adults, and stay healthy all at once. This was a very meaningful occupation to Liz, because the appraised barriers to participation were mitigated by relying on her friends and peers in the class to help her cope, stay on beat, and stay safe:

"Was going to fitness three times a week and everybody in my fitness class knew my circumstances and we would all have fun. Like they would be behind me and one of the guys would say, 'OK, coming up on your left' and I'd stick out my left elbow and you know we just roll around. We had lots of fun and I really miss that..."

To cope with her macular degeneration, Liz would cope behaviorally by employing the use of her peripheral vision to locate her friend and follow the choreography more easily. Being as her central vision is mainly affected by macular degeneration, Liz makes sure to maximize the visual abilities that she does have. Having a purposefully placed, trusted friend helped Liz feel more at ease, and more comfortable participating in this meaningful occupation. Liz also socially coped by informing the instructor and her peers of her macular degeneration and how this may present barriers for her during fitness classes:

“Okay, I had...a buddy, that went with me, so she just stayed with me. Okay, and I do have peripheral vision and she knew where I'd be able to see her, so that's where she would be and the instructor knew, everybody in the class knew. So, we made jokes about things. I belong to the center for activity in aging, so they were all old people all...we were there to have fun as well as keep fit.”

The sense of community and being around others who are helping her to cope with her ARVL while enjoying a fitness class, gave Liz the courage to continue participating. Unfortunately, due to COVID, classes are no longer running the same and Liz has not been able to go back to her fitness classes. I asked Liz if she thought that these fitness classes also acted as a coping mechanism for her, and she said: *“Yes, I do. I really missed that. Really miss it...”*. When I asked Liz for clarification, she explained further, *“Yes, definitely, and I find this COVID business, being cooped up in the house, I think your brain needs exercise, same as your body. I think it's gets stale.”*

Participating in this meaningful occupation and having fun in fitness classes with her friends is something that brought Liz happiness and was an integral psychological coping mechanism for Liz. Liz appraises many different stressors in her day-to-day life due to ARVL,

and these classes acted as a mini escape, providing Liz with the relief needed to continue her engagement in additional meaningful occupations:

“...they all know that I don't see very well, but everybody knows everybody, and we all joke around. Like...oh I will give you a funny...one day I had an immune problem and the doctor had put me on Prednisone? A really high dosage and it just made me hyper. Like I couldn't sleep. I didn't have time to eat. I didn't have time for anything. I was just on the go, and I went to fitness and one of the fitness ladies said whatever it is she's taken I want some. So, you know we had just a fun time. Like it was just fun. I mean we fitness and it would be like, 'Oh, look at you, galloping around and bugging people.' You know teasing. And we just had fun.”

Memorization. While sharing her story, I noticed that Liz employs memorization techniques and counting to navigate the barriers, namely in her physical environment. As it turns out, this is a coping mechanism that she has been using since before her diagnosis, but now it serves her particularly well given the ARVL: *“It just becomes an automatic. I don't know. It's just the way my mind works.”* This technique of memorization and counting makes it easier for Liz to navigate independently despite not being able to see well. If Liz can accurately count her steps and memorize landmarks in her surroundings, this makes her meaningful occupations more accessible and safer. Liz explains herself here:

“I just.... I don't know how I cope with it; I just do. I count. I've got 13 steps going downstairs. I have, when I reach the corner of my house, I have four steps and then I have another step up to the porch and then I have three steps up to my front door. This is how I maneuver things. I guess I have a good memory.”

One of Liz's meaningful occupations is going for a walk in her neighborhood by herself. This is an area she has become very familiar with due to her memorization techniques, and this allows her to continue going for walks on her own without worrying for her safety in a familiar area. Liz has had poor experiences when walking alone in areas she is not very familiar with, and not being safe is appraised as a stressor for Liz. Liz will count driveways, landmarks, mailboxes, or anything she knows will remain constant. Liz explains how she employs this coping mechanism to navigate her neighborhood:

“Okay, this is how it works for me. From the corner of my garage to my front door is eight steps. From my garage to the road is 10 steps. From my house to next door is 22 steps. Okay. That's how I do things. I have a good memory and I count, and I remember. If I go around the block, I go up to Louise boulevard and I know the first block has 5 driveways. Across the road, the second block has 6 driveways. Across the road and the third block has 3 driveways and then you turn. So that is how I figure things out.”

Liz also employs behavioral coping mechanisms by touching and feeling to memorize her surroundings. Liz was warned by the CNIB of the dangers that come with touching to guide herself and memorize her surroundings, but Liz finds this to be a successful coping strategy as it allows her to continue independent participation in her most meaningful occupations. Liz does her best to mitigate the spread of germs by using hand sanitizer, but she does not intend on giving up this coping mechanism any time soon:

“As say, I do a lot of counting on steps. I do a lot of feelings, touching and that was one thing. I did a lot of touching and I feel my way along places and the CNIB counselor that I went to, she said to me, ‘Will you quit touching places!’ and I'm like, ‘Well how do I know where I am, if I don't touch?’ and she says, ‘You have to learn. Quit touching

places. You don't know who's touched that and what's there and anything else.' So, but I still have to touch places. So, I touch places and I have hand sanitizer in my purse."

Liz's adaptation of her meaningful occupations. Liz is determined to continue participation in her meaningful occupations while remaining as independent as possible. Adaptation of her meaningful occupations is key here. Rather than giving up meaningful occupation, Liz will find ways to adapt and cope with the barriers. One of her meaningful occupations pre-diagnosis was playing cards. As her macular degeneration progressed, Liz could no longer see her playing cards. Liz coped by adapting the activity and using large print playing cards and buying different objects to make organization of her cards easier:

"The game I play, you don't have to know whether it hearts or diamonds or, you know, what shade it is. You just have to know what numbered is. So, I've got cards, that I can work with and we play this game with six decks of cards and I have a board that I can line my cards all up on, in order..."

To further cope with the visual barriers, Liz used a hands-free light on her head so that she can see even better. This coping mechanism is multi-faceted for Liz, as this was an item that her grandchildren bought her for Christmas. It's a humorous moment for Liz, and it makes her grandchildren laugh to see her playing cards with a light on her head:

"That's what I mean about me and my grandkids, okay. So anyway, I can use that, but I have two lights that run on batteries. Like you can charge them. So, I can put two, lights one on each side of me and manage to see what the cards are. Sometimes I screw up. I get fours and aces mixed up and I get six and nines mixed up and threes and eights mixed up but basically, we have fun."

Another one of Liz's adapted meaningful occupations is crocheting. Liz enjoys doing some crochet work, but there are many steps to the process, and she's had to make many modifications to continue doing this independently. The first of which is getting to the craft store to obtain materials. Liz would drive over to the craft store if she was running errands or walk over as she lives close. This is no longer possible without some modification, and Liz explains how she copes:

"So, I can go out and walk over to...I have to cross the road and I cross the road...I jay walk. I cross the road right in front of my condo. Which I shouldn't be doing but I find it easier than going to the traffic light. Okay, so I can go over to that mall, and I can walk around the mall there and I can go..."

Once Liz surpassed the first barrier of getting to the store, she had to navigate the store itself. Liz does what she can on her own and uses the eyesight that she does have to pick her colors as best she can independently. A new coping mechanism for Liz is requesting the help of those around her, even if she doesn't know them personally. Interacting with strangers is appraised as stressful for Liz, but she's doing her best to work through this as it is the best way to cope with the barriers in place when she is trying to navigate a store alone:

"...I know my way in Michaels because I go over there buy yarn. So, I can go in Michaels. I can find my way to the aisle, to walk down to the yarn. So, then I go, and I can feel. ...And touch all the yarn until I find what I want and then with colors I'll kind of...I kind of can see, like if it's red or yellow. Okay, so I could pick up a ball in yarn and I just hang around there until somebody comes along and then I'll say to them, 'Would this make decent slippers for a man?' And then they'd say, 'No, my husband wouldn't like that.' And I'm like, 'Well what would he like?'. I'm not afraid to speak up. I went to

Shoppers Drug Mart one time, and I got to the front of the store and there was no cashier there. I'm standing there and I just...there's no cashier so I just said, 'Excuse me. could somebody help me?' So, somebody does but I just find...what would I say...some things are really intimidating but I guess I'm getting past that. I don't know, I do things I would never have done before. Like I would never say anything like that before."

Liz takes pride in producing nice things for her family members, so she wants her projects to come out looking neat. Liz uses large patterns and thicker yarn so that she can feel more accurately for mistakes and check the quality of her work:

"Well, I go by feel. I can crochet. Crocheting if you make a mistake, it's not easy too or not hard to rip out and recover. Or if you knit something and you miss a stitch and you've done 20 rows, I'd have to rip out the 20 rows and begin again. So, I can crochet. As long as it's big enough that I can feel it. Just if my daughter in law, she says 'You need dish clothes'. She says, 'You're always complaining you want something to do'. She says 'Here's a big ball of yarn. I need dish clothes. That's what I'm doing right now. I'm making dish clothes. So, it's hard to sit and do nothing."

Crocheting is a simultaneous coping mechanism and meaningful occupation for Liz, as it allows her to escape the boredom she often feels due to COVID. Making items for her family gives her a sense of purpose and completion of a project is fulfilling for Liz. Liz takes this meaningful occupation a step further and sells her creations at a local craft shop. This brings Liz great joy and relief from the stressors of ARVL, and she uses the money she makes to put back into her craft and continue her meaningful occupation:

"Okay, anyway, the thing I have been doing...you can't just sit like a lump, so I have found if I get big yarn, I can crotchet. So, it ended up there's a place...that it's all crafts

they sell, on consignment. So, I make slippers, blanket and I'm making coasters and potholders and stuff like that and as long as it's big enough that I can feel it, I can crochet. So that's what I've been doing to amuse myself. So, I don't know, like you can only give away so much stuff. So, I found [the craft shop] and decided, you know, if you'll take this stuff, see if you can sell it. Because all I do is sell it and make enough money to buy more yarn."

Liz does it all with her computer! Many of Liz's meaningful occupations are made easier by being on the computer, and this has been a coping mechanism for her when facing macular degeneration. Liz has many programs downloaded onto her computer which make using it far more accessible. One that she uses often is Zoom Text, a software which magnifies the text, making it easier to read the computer screen. Before she had Zoom Text, Liz did not use the computer as she could not properly see the text, and this would be appraised as a stressful event:

"Well with the computer, I couldn't see the computer until I got Zoom Text. So, I just didn't use it." and "So, it magnifies... like I can control the magnification. Like I keep it at about 3 ½ or 4 but I can make it 8 if I want. So, I still have some peripheral vision that I can...as long as the font is dark enough, with enough contrast. Anyway, I find the Zoom Text...without that I wouldn't even use the computer. I wouldn't be able to use it."

Liz also relies on the use of her computer to write stories for her grandchildren, which is one of her meaningful occupations. When I asked Liz how she copes to continue her meaningful occupations of reading and writing stories, she simply said: *"Because I use the computer."* Liz must be able to produce stories in a pinch for her grandchildren when one is requested, and the computer allows her to do so quickly and easily while minimizing stressors due to ARVL:

“...before Christmas, my sister phoned me and she said, ‘I need a story within the next week.’ And I’m like, ‘I just sit here and crank out a story!’ she says, ‘No you put your thinking cap and I need a story about a wolf and a dinosaur.’ and she says her grandson every night, he wakes up with a wolf getting after him, so she says I bought him dinosaur pajamas and I want a story to go with it. So, I wrote her a story about a dinosaur and a wolf. You know, it’s fun stuff but as I say I can sit down on the computer play with it and do that.”

Liz uses her computer to cope with many of her meaningful occupations, such as crafts, making personalized birthday cards, quickly referring to old family recipes, keeping updated with local news, and writing poems. The programs that she has downloaded, such as ZoomText, have proven to be a successful coping strategy for Liz:

“Oh, what do I do on the computer? ... one of my jobs was graphic design. ...And I did all the pamphlets for Sunday school and anything that was going on. So, I have carried on with Word Perfect on my computer and I've got all my recipes in there so I can just print my recipes off. ...I used to make angels and then I make a poem to go with the angel that wished you happy birthday or happy anniversary or thank you or sympathy. ...That’s all on there. All my craft stuff, all my stories, all that stuff is all in there. Letters, like I can't handwrite cards and letters so.... and I have friends that are older that don't have computers so I will write letters on the computer and print them out and mail them. ...Occasionally I'd play Candy Crush. ... I read the paper. I go to CBC and read all that. Like news, I go in and read news and search around. I go in and search for recipes. ... I just find the computer really handy.”

4.6 Sam's Story

Sam shared his story with me in January 2022. In 1948, Sam was born in Nappanee, Ontario. Sam is currently 74 years old, and he lives independently in Toronto, Ontario. Sam is a single male, though he has three children from a previous marriage. His children do not live within the city, though Sam still does his best to keep in touch with them. Sam lives on his own and relies mostly on himself to cope with ARVL related barriers, but he welcomes the assistance from friends or the community from time to time. Sam is an educated male, who was able to achieve his general bachelor's degree. In 2012, Sam was diagnosed with macular degeneration, and he's been coping with the gradual loss of his vision for the past ten years. Sam would describe himself as legally blind. He shared with me the many stories of how he copes with his ARVL to maintain his diverse meaningful occupations despite the barriers he faces. Sam is a talented artist, who enjoys many creative forms such as photography, writing music, playing instruments, writing poems, and performing. Though these are very visual occupations, Sam does not let this slow him down. Employing a positive attitude, determination, and relying on his faith allows Sam the strength to eliminate barriers and continue creating beautiful art. Sam's craft and talent was inspiring to me, and his savvy coping mechanisms reflect his creative mind.

Making music, performing, and production behind the scenes. One of the first meaningful occupations that Sam shared with me was his love for all things music. Sam is an extremely creative individual, and loves expressing himself, and his emotions, through his work. There are many aspects of making music, and Sam embraces each one. From the writing of the songs to performing on stage, Sam has a coping mechanism in place, which he has developed over the years, to eliminate any barriers. The first coping mechanism Sam has put in place is labeling his CD's and keeping things organized. Sam cannot physically read the writing on the

label stickers, but he can feel for braille, and as such, will use this instead when he needs to do some labeling:

“I mean, okay, I also write braille, but I mean I hardly ever use it. I mostly use braille to label CDs but mostly I don't use braille much anymore, but I have the ability to write it and read it if I want to...”

Sam loves playing instruments, one of his favorites being the guitar. When you frequently play string instruments, you often develop callouses on your fingertips, caused by the repetitive strumming motions on the abrasive string. Sam developed these callouses, and it affected his ability to accurately interpret braille. Unfortunately, because of this, Sam's coping mechanism for labeling his work is starting to be appraised as less successful:

“The only reason that braille got to be harder for me is because of my guitar playing and that's because I mostly read with one hand and the hand, I use has got calluses on my fingers from playing guitar so much and so sometimes it's difficult to figure out what you're reading.” and *“So anyway, when I told you that I have difficulty with the reading because of my fingers is because you have to be able to read various letters in braille and sometimes, especially with numbers, but letters too. Sometimes I get the letters wrong because I can't feel all of the dots but that has nothing to do with eyesight.”*

Most of Sam's music files and composure happens using the computer. The computer has been an amazing strategy to assist Sam's coping, as he is able to continue his full production and writing of songs. Sam also employs his computer as a means of communication with others. Using the computer makes this much easier for him to achieve, and thus it serves as a successful behavioral coping mechanism for Sam:

“...but most of my writing is on computer. So, if I want to communicate with you, 9 times out of 10, we’ll either talk or if the Zoom decides to cooperate, or all email you. And that’s no problem. I mean that’s how I compose my songs; I use the computer to compose them and then when I compose them, I have a lyric file and then I also come up with the melody and rhythm and chords and stuff like that and when I get it back down and I memorize the song well enough, then I record it at home. So, the song I have for example has a written set up lyrics as well as the actual MP3. So writing is not an issue at all and I’m glad it isn’t because I do send a lot of emails to people about different topics or respond to emails or whatever.”

Much of Sam’s inspiration for writing music and songs was based on his visual interpretation of his environment. He wants his songs to convey something visually beautiful; painting a picture of the moment or beauty Sam was attempting to convey. Because his visual abilities have been affected by his macular degeneration, Sam can no longer “see” these references in his environment. This was appraised as stressful for Sam because he truly values the artistic form of his work. To psychologically cope with this and to continue writing songs as authentically as possible, Sam employs a visualization technique to be able to “see” these images. This technique allows him to replicate these visions into art, and the result is like when Sam himself was able to see his surroundings. Sam explains how he employs visualization to psychologically cope with this ARVL barrier and continue his meaningful occupation:

“I mean an example is, I wrote a song not too long ago. I recorded it on my last CD and it’s called ‘A Valentine’s Dream’ and it’s a song about a couple that are standing on a little footbridge over a little Thai river or canal or lake, whatever, ...it ...paints a picture, plus they have a back and forth conversation through the song and so the lady that I got

to sing the woman's part, after she did the recording in the studio she came over and she said, 'I want to ask you of something'. I said, 'Okay'. She said, 'Did you get this song from a picture?' And I said yeah, and I tapped my forehead. She said, 'You are kidding', and I said 'No, I could picture the whole thing in my head, and I wrote the song based on what I could visualize'. So yeah, that works for that. So, in other words it would work for even pictures I haven't taken but I'm thinking about how something would look. As well as other pictures but it takes the imagination and if somebody has been a picture, I've never seen that's not going to work because I won't be able to see it well enough. So, it has to be something I'm familiar with in some way.'"

Part of the process of making music that Sam enjoys is performing in front of a live audience. Sam gets a thrill from sharing his art with others and receiving feedback from a crowd. Sam will do performances wherever he can, and often sings for his church with their choir. Part of performing in front of others is personal appearance, and Sam prides himself on being a put together man. Because he cannot see well enough to differentiate between color and style of clothing, Sam has come up with a system to ensure that he is wearing outfits that match, with complementary colors. This system is a huge behavioral coping mechanism for Sam, as it ensures he can go up in front of audience without the worry of what he looks like. Sam explains how this system works for him:

"Okay, here's a cool one. Clothing. Especially organized clothing. I mean, I have a lot of clothes and I have always liked to dress in different colors...you got to wear things that look good together. So, one of the first things that you learn very quickly is always put the things that match, that go together on the same hangers, right? So, whenever I have a shirt that goes with a certain pair of pants, I'll always keep that shirt and pants on the

same hanger, no matter what...So that helps to make it easy. I can still see a little bit. So, I can make out a lot of the colors but some of them with patterns are harder to see. So that I have to make sure I put them in a certain place and keep them there. Like the top drawer I have pale blue and I roll my t-shirts up in a roll as opposed to flat. ...So, you know, on the left for example I have pale blue, in the middle I'd have beige or light cream. ...That kind of thing. So that helps. So as long as you don't screw up and put the wrong color in the wrong place.”

For Sam, the time spent song writing is a psychological coping mechanism that helps him to combat some of the negative feelings associated with ARVL. Song writing has a positive impact on Sam’s mental health as he can use that time to express his feelings and provide an outlet to deal with appraised stressors resulting from his macular degeneration:

“Anyway, writing songs gives you ideas for other things. Plus occasionally I've written something that I heard from an article I read or on the radio, whatever but I think mostly, I think the most, the best answer is, that writing a song and creating the music and doing that gives you a very strong sense of pride and it's a very rewarding exercise and I would say that the rewards that you get, help to keep you from, what a lot of people are suffering from, which is mental fatigue, mental illness, sadness, depression, anxiety, overdoing alcohol or drugs or whatever. All the things that are going on today that have increased dramatically in the last few years that you hear about all the time.”

Coping to continue photography. Aside from making music, Sam enjoys other artistic meaningful occupations, such as photography. Sam enjoys taking photos and doing the editing process on his own, as this is something that brings him great joy since before his macular degeneration diagnosis. Sam likes to intertwine his artwork, and there were often times when his

photography would help to inspire him when making music. Photography is a very visual activity and Sam is aware of all that goes into taking a good photo. Sam described the story of when he first noticed a barrier to this meaningful occupation due to ARVL:

“Okay, I think that the time that I started to notice a problem was probably around 2012 or 13 in there, and I had a camera, I still have it actually. It's not a digital camera. It's just a regular camera. ...Anyway, this camera, a little tiny view in it. This tiny little square. ...So, this little 'view finder' type thing, was a little tiny square and that was hard to see through cause it was really small. So that's what I notice first and then the second thing I notice of course is looking at pictures I couldn't see them very well anymore.”

The issue of the view finder and small, detailed markings for camera settings proved to be a barrier to Sam participating in this meaningful occupation, but he intends on trying some different strategies so that he can continue taking beautiful photographs. Employing the use of his cellphone as an assistive device, Sam has a plan for when it's time to get back out there and take more pictures:

“Now it just so happens that I have a phone that does have a camera, and I also notice that nowadays when you have a camera in a phone, the whole screen is your camera, instead of the little, tiny hole. So, I haven't tried it yet. I think I tried it once, but I haven't really gotten into it but I'm thinking I'm going to try to do a few shots someday and not now but when the winter goes. Outside I want to take a shot of something, anything at all just to see if.... how that works out because that might be a good way to go because the whole screen is a camera now. When you hold it up, you're looking at the entire view. So, I think it will be better. I just haven't... I think...I was at my brother's cottage a few years ago and I took a picture of the lake and that's the only thing I've done. I haven't really

played with it very much, but I think I'll get into that a bit because I find that I can sort of semi see it. That might be fun."

With COVID-19 restrictions in place, Sam hasn't been out in the community as much, and has less reason to be out taking photographs. Now that he has a new coping mechanism to try, and restrictions are becoming less severe, Sam will be able to get back to doing what he loves. Meanwhile, he can appraise if this new coping mechanism is successful or not for himself, informing more updated coping mechanisms so that Sam can maintain photography as one of his meaningful occupations.

Local supports and the community. Many of Sam's meaningful occupations can be supported and made easier by employing the assistance of local vision loss organizations in his city. Sam makes good use of many of these organizations as they can directly help him cope and provide him with new coping mechanisms that he can employ independently. For example, Sam enjoys reading but he no longer can do so conventionally using normal size print text. He copes with this barrier to his meaningful occupation by using audiobooks – sourced through either the local public library or the CNIB. The local public library has a system in place where they deliver the audiobooks to Sam's door once a month. The CNIB has a large online audiobook library and a system that works incredibly well for Sam. Sam explains his support from local organizations to help him continue listening to his audiobooks:

"...I love to listen to...books. I have two sources for talking books that's audiobooks, right? One of them is through the local...library system that delivers books once a month in a bag, and I give them the ones I've heard, and they give me new ones. And the other system is to the CNIB which has, there library is known as 'CELA'. CELA library. It's an online service and I can go on computer and go on their site and look up.... they'll have

book of the month or five top recommendations or whatever. ...I read I take notes on every book I.... read. I take notes and I keep them. ...I'll keep them as new titles and then alright, I'll go to CELA and try to get... them from there onto a virtual bookshelf, that I can then access with a little victor stream reader. ...It's a little digital reader. You can read the books there. You can also download podcasts. You can download and save radio stations and other stuff. So that's another hobby. I love to do that."

One of Sam's meaningful occupations involves walking to the pharmacy across the street from his home to do his shopping. As Sam's vision continues to deteriorate, spatial orientation and successfully navigating traffic has become increasingly difficult for him. Sam shared his brainstorming on how he can address these difficulties including relying on the CNIB to learn some new coping strategies that will allow him to continue participating in this shopping:

"Well, someone said, well I could get somebody from CNIB to come over and give me some instructions on how to do whatever but I'm still trying to figure out how that would even work because the issue is the issue, and I don't see that changing that issue. I don't know what they could show me that would make a difference but again maybe when the spring comes, I might fall back on that and see if they have anything...any advice to give me on that because you never know, they give me a pointer that I hadn't known, thought of. So, I will do that."

Another one of Sam's meaningful occupations is going for walks and exploring his local community. When his visual acuity allowed for it, Sam would go exploring by himself but sometimes, would go with a friend to fulfill his social needs. Recently, and as his visual acuity decreases, Sam has not been able to go for independent walks due to many safety-related barriers caused by ARVL. Being familiar with local low vision organizations and their services, Sam

requested assistance from a specific organization in finding a walking buddy or volunteer so that he could continue his meaningful occupation without worrying for his safety. Unfortunately, Sam has been waiting for over three years to be connected with a volunteer, and this was simply too long to wait. Sam expressed his frustration with the lack of effort on this matter and is still waiting to appraise a successful coping mechanism so he can continue this meaningful occupation:

“So, I was after [redacted non-profit] for a long time to get me a volunteer who would come and go for walks and I told you earlier, I think I told you that I used to love to walk exploring and now I don't do much of it because of safety issues. I mean you got to spend most of your time making sure you're on the right path. You don't get a whole lot of time to look around and then with poor vision, I don't see the detail I used to see. It doesn't mean I still wouldn't like to go for a walk. In fact, I went out for a walk a couple of weeks ago with someone from my church, but it wasn't a very nice walk because a lot of the sidewalks weren't shoveled properly and so on so it was a bit tricky. Nevertheless, [redacted non-profit] never did come up with a volunteer. After three, more than three years, so I gave up on that. I need to find a volunteer somewhere.”

Asking strangers for help to cope with ARVL. As Sam shared his story with me, he gave me the impression that he was very confident and sociable. These traits of his shine through when you consider some of his coping mechanisms. When I asked Sam if he felt comfortable asking strangers for help to support his continued engagement in a meaningful occupation, Sam quickly said: *‘No, I have no issues about asking help’*. Sam shared with me a story of a time when he faced an ARVL related barrier, and felt comfortable asking a stranger for help:

“One time I was at a cross walk. This is years ago and I’m standing there, and the guys says, ‘Would you like to have a hand to get across the street?’ I said, you know what I said, ‘it’s a fool that says...that refuses help. Of course, I’d like to have help.’ He thought that was funny but there are lots of people that I know of who have a really bad problem with this and it...what it relates to, and you might know this I’m sure, but what it relates to is insecurity inside themselves and not feeling comfortable with their own reality.”

Sam feels comfortable relying on others, even if he does not know them well. It wasn’t always this way, and Sam had to take the time to learn and grow into this degree of self-confidence. Sam told me about the difficulties he has with his other disabled peers, who may not have the same outlook on life:

“A friend of mine used to tell me that he went out to get the bus to go to work, and the guy lowers the platform at the front door for him and he refused to get on the bus. I said, ‘Why would you do that?’ ‘Oh, what does he think, I can’t walk?’ I said, ‘How do you know there isn’t somebody behind you who’s got a pair of crutches.’ ‘Oh, I never thought of that’. I said, ‘Well on top of that what’s the big deal?’ I would think that as a compliment and say thanks very much. So, there are a lots of people that have a lot...and some people get angry. They actually literally get angry if someone says you need some help, and they get mad. I’ve never been like that. I’ve always said, you know what, except the help if you need it and if you don’t, be gracious about it and say thanks I’m okay.”

Sam feels that when accepting help from others, he’s also doing them a service in return by educating them and spreading positivity, leaving the person feeling fulfilled that they were able to help a disabled stranger. Knowing this acts as a psychological coping mechanism,

allowing Sam to feel more comfortable asking for help and accepting help from strangers in public:

“She said to me, [Sam], when you’re out there and someone offers help, she said, ‘Even if you don’t need it, accept it anyways because sometimes you’re doing them more of a favor that they’re doing you’ and I said, ‘You know what, that’s one heck of a great point and I understand it totally’. People are often really happy when they have done something...you know I’ve had people that you could tell that they were really pleased that they help me get to the door to a place or the top of the stairs, whatever right? So, it is true.”

Sam is aware that he does not always present as visibly disabled, making it difficult or awkward to navigate asking for help in public. He does not use a cane every time he goes out and he could be mistaken as able bodied. Rather than letting this barrier stop him from asking for help when he may need it, he reframes his thought process and chooses to use moments like that to educate others about life with a disability. By educating sighted people in his environment, he is making participation in his own meaningful occupations more accessible, as well as for other blind or disabled people in the community. Sam gives further clarification as he shared this story:

“Here’s something else. People like us and it’s not just our disability its every disability but especially ones that people can conceive, can witness as being visual as opposed to someone with epilepsy you don’t know that they have epilepsy unless they have an attack. You don’t know. They don’t look any different than anybody else and then people with mental issues. They don’t, you don’t, you can’t tell by looking at them 90% of the time, so but a lot of blind people, you can tell and plus they’ve got the cane. Well not all of them but for years, I did not need one. Never used it but anyways, the thing is, we always

educating everybody. Every time we go anywhere, you actually, even when you don't mean to or even when you not thinking about it you are actually educating others because when they see you doing something, they learn something. So, it's a life's lesson in progress if you like. So, I'm fully aware."

From time to time, Sam will receive help from people in his building who know him and who are aware of his macular degeneration. Most of the people in the building do recognize Sam, and they are excited to help him out. That being said, Sam does not want to bother people, and finds that when it comes down to it, people are not as keen to help, or necessarily available to help, when needed. Sometimes his neighbors are busy, or schedules do not align with when Sam needs assistance. Sam does not want to bother people and so he finds this situation frustrating sometimes:

"I mean if I need help to go somewhere, do they have the time? Are they busy? Are they doing something else? Are they even home? I mean and you know when you get into this situation, it's always a, it's always a negotiation. So, I say to you, hey I wanted to go to Shoppers today, do you think you have some time just to walk me over there? And you go, well so today I got this I got these classes all day, I won't be done till late in the evening. Could we do it tomorrow? Oh, shit but tomorrow I've got bubba bubba blah. So, you know how it goes from there. It's like is you negotiating to get what you need and sometimes what you need is what you need now, not two days from now, and it can happen. So, this is more of what I'm talking about. I have a person that I sometimes get to help me with some scanning or something and it's always the same. I'll ask if she could help and she always says, you ask anytime. ...So anytime becomes a meaningless statement... Like there's been times when... I don't know what's going on the computer

because the voice quits and I can't read the screen, right, and I need someone to just look at it and tell me what it says... it might be an hour or two before she could even come down. So, I'm sitting here, and I go well, now I'm screwed. There's nothing I can do."

Sam is considering relying on strangers to help him cope with the challenges of shopping. He has a fear of crossing busy intersections because he can no longer see the crossing lines and is apprehensive about his safety when crossing the road on his own. Because the intersection is very busy, Sam cannot always guarantee that there will be a friendly pedestrian willing to help him when he gets to the intersection, so the ladies from the Shoppers on the other side of the intersection have offered him a solution:

"I have a Shopper's Drug Mart right across the street from where I live but I've had a bit of a problem in the last while because I've noticed that I don't see the zebra crossing lines as well as I used to... So, I thought well maybe it's me and because I'm at a weird intersection. It's like a T intersection and the cross bar of the T is not straight, it curves. So, it can be dangerous. If you get off the line. too far to the right for example, you can walk right in the middle of that intersection without even knowing until whatever, right? So, I've been afraid to go across the street. ...So, there's that I gotta worry about and I am anxious about it, but I haven't come up with a solution. The best solution I've had, but I haven't yet is a couple the women at Shoppers tell me, if you phone and I'm here then I will come and get you at the corner. And I said wow that would be really nice, and I know they would they are wonderful people and I love them dearly."

Coping with ARVL by following his faith. One of Sam's most frequently employed coping mechanisms is tapping into his faith, which has been an integral coping strategy for Sam, as he often feels that he is being led or guided to do things:

“Well one is prayers. I do believe that there's a higher power somewhere up there. ...I do say prayers every day. Not only for myself, in terms of thanking, being thankful for the blessings. I mean I've done a lot of stuff in my life that people are kind of amazed at. ...So, these are the blessing that I thank God for every single day and of course I pray for members of my family and other people that I know who are having trouble and so ask for help and so on and so I believe in all that. So that's one mechanism that...makes me feel good. ...it kind of grounds me in the sense that I am thankful for what I think I should be thankful for. I don't take it for granted. Like someone said to me. How do you write songs? How the hell do you do that? I said it's an invisible hand and they look at me and they go what? I go yeah. I think I'm getting sent stuff from time to time. That sort of accounts for waking up with a melody in your head. So, I grab my little recorder. I put it on and I'm half asleep but I'm humming the song so I can sit down the next day and figure it out and recorded it. So, whatever. So that's number one answer is that spirituality.”

Sam feels blessed to be able to maintain his artistic talents and that he's been able to live the life he has. Sam has been able to experience many things that people with ARVL may struggle with, such as writing and performing music, taking trips, and adventuring, or pursuing artistic endeavors, typically enjoyed by sighted individuals. Sam is certain these successes are due to his faith. His faith has helped him to cope with ARVL psychologically, because Sam feels he has the willpower to continue and keep living life to the fullest. He has appraised many stressors to continuing meaningful occupation, but he copes with this by reflecting on his religious teachings, staying positive, and remaining grateful for those occupations he remains able to participate in:

“I think that prayers help in this way. I'm always being thankful for all the things that I've had in my life. The blessings that I've had. The hobbies, the interests, the sports, the travel, the non-work-related skills I gained over the years. You know, the cooking, the music, support by other musicians that come to the studio to add to my CDs when I'm putting them on. The church congregation that I have become a family to me in ways as well. You know, other friends and relatives that kind of stuff. I find that recognizing what you have, helps you to move on from what you don't have...I think that being aware of what blessing you have had and things you've done in your life and experiences and memories and all that stuff, helps you to remember who you are. ...if I worry about that [ARVL and occupations he cannot maintain] it's going to bring me down, so I would say that's how that helps me to recognize well, look what you have still. I still have a good enough eyesight and I use it as best I can, and I guess that is my answer.”

Chapter 5: Results

In this chapter, demographic information for all six older adults will be detailed, along with a presentation of the overarching themes identified using Fraser's (2004) line-by-line process of data analysis. To protect participant anonymity, pseudonyms have been used, and all identifying information has been redacted (including the names of other people and places). Although the transactional theory of stress and coping was used to guide the data collection and analysis process, I remained open to ways of 'seeing' the data that did not directly align with Lazarus and Folkman's central tenets.

The older adults' pseudonyms and demographic information are detailed in *Table 1* below. In summary, the older adults in this study ranged in age from 67 to 88 years old. All six older adults could trace their family heritage back to England. Three participants resided in

London, two in Toronto, and one in Ottawa. With the exception of one participant, the older adults each had children, but only three of the participants had children who lived within 20km of their home. The highest level of education achieved by two older adults was high school, two completed college, and two completed their bachelors degree. Two older adults were married, three were widowed, and one was single. There were two males and four females in the study. One male had a diagnosis of macular degeneration, and the second male had a diagnosis of glaucoma. Three of the females had a diagnosis of macular degeneration, and the fifth female had all three ARVL diagnoses including macular degeneration, glaucoma, and diabetic retinopathy. Five of the older adults described the onset of their condition as gradual, while only one described their vision loss onset as sudden. The length of time since diagnosis varied between five years and fifteen years. All of the older adults self-identified as legally blind except for one, who identified themselves as partially sighted.

Table 1

Summary of Participant Demographic Information

Demographic Information	Randy	Pearl	Kim	Liz	Morgan	Sam
Sex	Male	Female	Female	Female	Female	Male
Age	68	84	88	80	67	74
Vision Condition	Glaucoma	MD ^a	MD	MD	MD, DR ^b , Glaucoma	MD
Years since diagnosis	15	9	10	5	8	10 years
Self-described visual acuity	Legally blind	Partially sighted	Legally blind	Legally blind	Legally blind	Legally blind

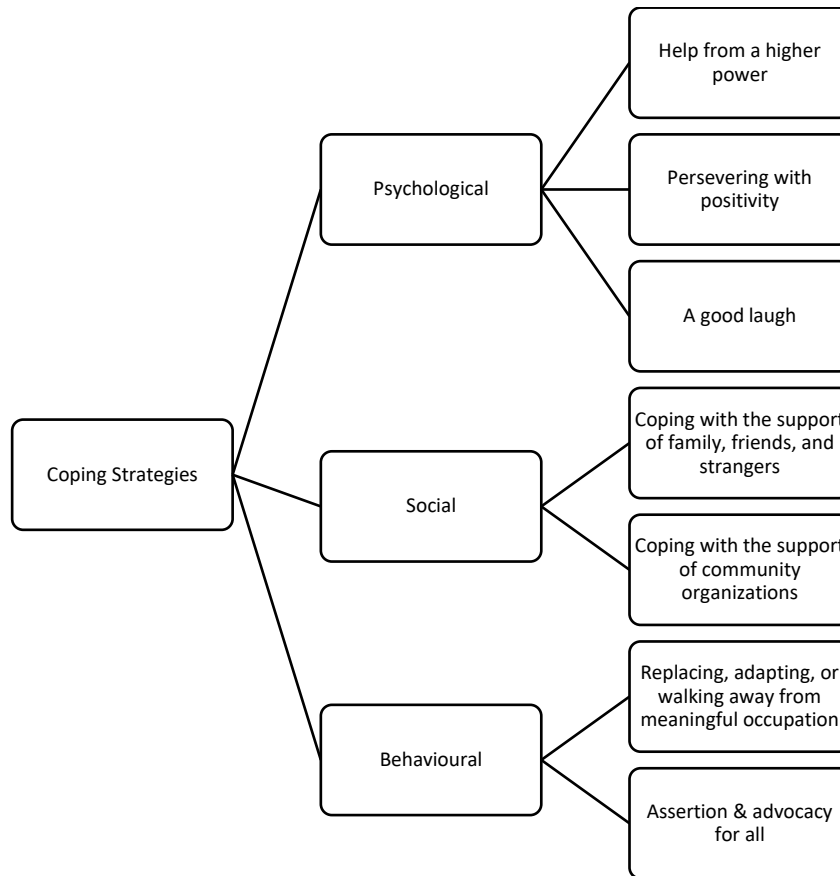
ARVL onset speed	Sudden	Gradual	Gradual	Gradual	Gradual	Gradual
Ethnicity	English	English	English	English	English	English
Residence	Toronto	London	London	London	Ottawa	Toronto
Highest degree of education	High School	College	College	High School	Bachelors	Bachelors
Marriage status	Widowed	Widowed	Widowed	Married	Married	Single
# of children	0	3	2	3	2	3
Children who live <20km from home	0	1	0	1	1	0
Birthplace	Kingston, Ontario	Gault, Ontario	Ottawa, Ontario	Stratford, Ontario	Prince George, BC	Napanee, Ontario

Note: a = Macular Degeneration, b = Diabetic Retinopathy

The three overarching themes relating to the coping strategies used by older adults with ARVL to support occupational engagement included: (1) Psychological coping strategies, (2) Behavioural coping strategies, and (3) Social coping strategies. The three overarching themes presented here are further broken down into subthemes, which will be unpacked and explored below (see Figure 4 below).

Figure 4

Themes identified through data analysis



5.1 Psychological Coping Strategies

The first overarching theme related to psychological coping strategies. As introduced in the previous chapters, Lazarus and Folkman’s (1984) definition of psychological coping entails the cognitive, internal efforts to manage stress and maintain mental health, however the individual sees fit. Because each cognitive appraisal begins as a mental, internal process before a coping strategy is deployed, psychological coping strategies were found to overlap with some of the social and behavioural coping strategies and were often used simultaneously. Psychological coping strategies involve navigating barriers to meaningful occupation by relying on internal and mental processes, giving the older adults the motivation to surpass any appraised barriers.

Various psychological coping strategies were discussed including travelling, pursuing employment, enjoying, or creating various forms of art, journaling, persevering through difficult times, following their religion of choice, humour, and remaining positive in dark times. Four psychological sub-themes were identified in the stories shared by the older adults including: (1) Help from a higher power (2) A good laugh, and, (3) Persevering with positivity.

5.1.1 Help from a higher power

A resounding theme across participants was their belief in a higher power and following the religious teachings of their respective Catholic, Christian, or Mormon churches. The participants described their reliance on faith as a psychological coping strategy that helped deal with the stressors of their ARVL.

Older adults in the study expressed strong convictions to their faith and many attributed their devotion to a higher power as one of the reasons why they were able to maintain engagement in meaningful occupation in the face of their visual challenges. This is best illustrated by Sam, who was able to psychologically cope with the challenges of his vision loss because of his steadfast faith and belief in a higher power:

“Well one [psychological coping strategy] is prayers. I do believe that there's a higher power somewhere up there...I do say prayers every day. Not only for myself, in terms of thanking, being thankful for the blessings. I mean I've done a lot of stuff in my life that people are kind of amazed at. ...Like I've done carpentry. I've done plumbing. I've done wiring. I used to help people with building. ...I've done lots of sports. I mean I've skied out in Alberta, and BC as well as in Quebec and different places...The music is a wonderful gift. ...So, these are the blessings that I thank God for every single day... So

that's one mechanism that...makes me feel good. ...it kind of grounds me in the sense that I am thankful for what I think I should be thankful for. I don't take it for granted."

The study participants did not always need to belong to a specific church, or follow specific religious teachings, to psychologically cope with their vision loss. For example, Pearl described her personal relationship with God, that existed outside the institution of church. She described how it uplifted her, particularly in times of hardship. When asked if her connection to religion helped her cope with vision loss, Pearl explained:

"I have that type of relationship but it's not with like one church and one church family. ...I mean, I've done things as a visitor that visitors don't normally do in churches...And not always in the same church. And there are other clergy that we've kept in contact...I guess being part of church and being part of the social fabric of church – the food banks and that sort of stuff."

There were various psychological stressors appraised when older adults would attempt to pursue meaningful occupation in the face of ARVL, such as a lack of confidence or being nervous to pursue an activity, leading to feelings of hopelessness and a loss of will to continue engaging in meaningful occupation. Religion provided psychological coping strategies for these older adults, and their faith propelled them to continue their participation in meaningful occupation. Randy, for example, explained how his faith helped him to cope with appraised ARVL stressors and continue meaningful occupation:

"...my faith, my religion has given me a foundation among which to build, to have a moral compass, to be able to see through and beyond situations that hey, this too shall pass, sort of thing, rather than getting bogged down in the negativity of the present moment..."

5.1.2 A good laugh

Throughout the data collection process, participants relied on their humour and making light of their situations, as they shared their stories of coping with ARVL. In fact, using humour was a commonly employed coping strategy for the older adults in this study. Being humorous and making light of their perceived shortcomings provided psychological relief, and many older adults appraised this as a healthy coping strategy. For example, Morgan shared how she used humour to cope with ARVL and how integral it was to her psychological wellbeing:

“Oh, there's so many times I've used humor. There isn't a time I don't. So, I mean literally even this morning talking with my son about the protesters [2022 Canadian Convoy Protest against COVID-19 restrictions] and stuff like this and you know...I use it constantly. [Actually] I don't not use it, it's part of my everyday activity.”

The study participants found that making lighthearted jokes about their personal situation allowed them the mental clarity needed to continue engaging in meaningful occupation that could otherwise be considered taxing to manage, given visual barriers at play. For example, when Randy shared his story, he explained how making jokes about his diagnosis allowed him to psychologically cope and make him feel more empowered:

“Somebody wrote a book, don't sweat the small stuff and in smaller letters, it's all small stuff. You know, if you look at it that way, it really is. ...I'm not saying you can laugh your way out of everything in life, but I tend to use humour to try to downplay my own weaknesses and things of that nature.”

Similarly, Morgan described how humour, and a certain level of cynicism, helped her feel more at ease with her ARVL: *“I like humor of all sorts and I like cynicism as well and I find that to be humorous. So, I enjoy all of that and that helps me manage.”*

The older adults described situations when they employed humour, particularly when out with sighted individuals almost as an “icebreaker” as Randy described it. From time to time, the study participants perceived confronting sighted strangers, and having to disclose their ARVL, as stressful. In those social situations, humour was appraised to be a healthy coping strategy, such that meaningful occupation such as going to work, visiting a museum, or going out for dinner could continue. For example, when confronted with the need to present in front of a group of sighted strangers in church, Randy used humour to manage his appraised stress:

“We all need to use ice breakers when we’re in social situations, where we don’t know a bunch of people so I just, yeah, I roll with the punches and take what comes and throw a quick one liner out there if you have something and make a joke, just basically, be yourself. Some people put on ears, try to reinvent themselves, try to be this, try to be that or whatever. Just be who you really are.”

5.1.3 Persevering with positivity

The study participants were often required to ask family, friends, and strangers for help coping with the barriers imposed on them as a result of their ARVL, which was often perceived as psychologically stressful. By persevering with steadfast positivity, however artificial it may be, the study participants were better able to cope with the stressors associated with asking for help. For example, Sam explained his philosophy of persevering with positivity as a strategy to cope with interacting with sighted people so that he could continue engaging in meaningful occupation:

“...it [persevering with positivity] makes a big difference and it’s a lesson that I’ve learned a long time ago. You know, if you are nice to people and you treat them with

respect, you get it back and if you don't you, you get that back too. It's a bit of that self-fulfilling prophecy deal when you get right down to it."

Some of the study participants described their perception of the blind community as being inherently negative, self-pitying, and complaining too much thereby acting as their own barrier to pursuing meaningful occupation. To counteract these negative perceptions of the blind community, some participants, such as Randy, opted to approach situations with steadfast positivity:

"I tend to agree with that in the sense that things are gonna happen to you in life, things that you don't expect, and one needs to be able to roll with the punches, adapt to situations. Too many blind people, I think, complain about situations, why me, why is this happening to me. A better attitude to have towards it is why not me, what can I learn from this situation, how can I improve the quality of my life... This life was not meant to be a piece of cake from the cradle to the grave and I accept that."

Despite employing the healthiest coping strategies to manage the challenges of ARVL, there were situations in which study participants were required to give up meaningful occupation altogether. To navigate this sense of loss, participants relied on remembering those experiences fondly, such as Liz, who shared the psychological hardship she faced when she could no longer make it to the cottage due to barriers related to her ARVL:

"I think about all the time and wish we were there but it's something that I have to be thankful that I was able to do. And that is how I have to approach things. I have to be thankful that I was able to go to Florida as long as I did and thankful, I had the place up at the lake as long as I did and could made good friends up there."

5.2 Social Coping Strategies

Social coping strategies, which include relying on family, friends, and community organizations were identified by the study participants as being used to help manage the stressors of ARVL and help them maintain engagement in meaningful occupation. Based on Lazarus and Folkman's (1984) definition of coping, social coping entails involving other people or organizations to manage appraised stressors in the environment. Informal networks, including local vision organizations were often called upon to help the older adults cope with barriers to meaningful occupation by assisting them to navigate more complex visual barriers. Furthermore, all six study participants shared multiple stories of relying on their informal social networks of friends and family, or the broader vision loss community, to cope with ARVL and maintain diverse participation in meaningful occupation.

Social coping mechanisms overlapped with both psychological and behavioural coping strategies, as many of the older adults in this study found coping, in any regard, to be easier in certain scenarios with the help or support from someone other than themselves. The older adults discussed many social coping strategies, such as: finding familiar faces for help, travelling with friends and family, getting advice and comfort from others with a disability, getting help from store employees or strangers, educating new people about ARVL, relying on vision loss services and community organizations and finally, relying on medical professionals. In this section, two subthemes under this overarching theme, are unpacked including: (1) Coping with the support of community organizations and (2) Coping with the support of family, friends, and strangers. These two themes are distinct, as members of each support group are clearly labelled and unique with little overlap between the two displayed when the older adults relied on social coping strategies.

5.2.1 Coping with the support of community organizations

Formal social networks are defined as the “material or spiritual assistance provided by formal organizations in accordance with relevant policies or laws and highlights the supportive relationship between the person and the organization” (Lu et al., 2020, p.2; Kang, 2021; Riendhart, 2001). The study participants described several formal social networks that they relied on for help coping with ARVL and maintaining meaningful occupation, including: CNIB, AEBC, BALANCE for Blind Adults, Paratranspo, CCB, and TravelEyes.

The study participants often relied on formal support networks to provide clear, simple solutions to navigating ARVL barriers. The formal networks providing these different services were experienced at managing the challenges of ARVL, thus the study participants relied on them to socially cope with important meaningful occupations such as: help reorganizing their living spaces, accessing reliable transportation, accessing volunteers to help navigate the community, and learning how to use assistive devices. For example, Liz described relying on her formal social networks, namely the CNIB, when she needed assistance reorganizing her kitchen so that she could continue her meaningful occupation of cooking:

“Oh, that was another thing CNIB did. [The volunteer] comes over to the house and she has put...little bubbles put on my stove for instance, on bake, and start, a timer, I’ve got it on the 1 and the 0 and then the same thing on my microwave...I have a little metal thing that measures a cup. So, it sits across a pound of butter, and it’s got a bubble on the one cup, and a bubble on a half a cup.”

BALANCE for Blind Adults was another low vision service provider, based out of Toronto, that some of the study participants relied on. During the time of data collection, COVID-19 was prevalent in Ontario. Due to the novel coronavirus, SARS-CoV-2, spreading

quickly in 2019, a world-wide pandemic was declared. Following safety protocols, that were largely dependent on visual cues and social distancing, was difficult to manage for older adults with ARVL, and this was appraised as stressful. Many study participants relied on their formal support networks to help them navigate these complex protocols. For example, Randy provided insight into his formal support network and how BALANCE was able to help him negotiate the challenges he faced during COVID:

“And, with the vaccine, I got help from BALANCE, yes. The two appointments I went to were in two different places and a lady...I met up with her, we arranged a meeting place, went to each of these appointments and we were able to get in there and get it done. ...So yeah, I did get some help from BALANCE, and I appreciate that because these buildings, or the one down in the community center was rather large and we had to stop at this desk and then stop at the next desk and then stop at the next desk and then how many times do they need to see your health card? It was a long and involved type of thing ...”

A unique social coping strategy employed by one of the older adults was to work with the organization Travel Eyes, to help support their occupation of travelling. Travel Eyes was a UK based company, focused on helping those with low vision to travel with the assistance of a sighted companion. This service was a great support for Morgan, who loved to travel but struggled with the detail that went into planning a trip, especially when travelling with ARVL. By leaning on this new player in her formal support network, Morgan was better able to cope with the stressors and continue her meaningful occupation of travelling:

“...there's a travel agency for vision loss people it's called...Travel Eyes, I think. ...they hook you up with a sighted person, just from the public, who pays for their trip, but they pay a little less than you by a third and you travel wherever you, they have quite a few

tours when there's no COVID. And I said to her if you can match the price for Travel Eyes, I'll go with you. If you, can't I'll go with Travel Eyes cause I'm putting a cap on my financial affections."

5.2.2 Coping with the support of family, friends, and strangers

Informal networks are defined as “help received from informal organizations or individuals” (Lu et al., 2020, p.3) and includes family, relatives, neighbors, friends, or strangers (Kang, 2021; Riendhart, 2001). There were many informal social networks employed by the older adults in the study, including: strangers (including store employees), family, friends, and other people who have vision loss, or a disability more broadly.

There were many times when the older adults shared stories of being alone, with no one familiar around, yet they needed help to engage in a particular occupation such as shopping at the store or crossing the street at a busy intersection. In these circumstances, the older adults would often ask a stranger, and although some older adults appraised asking for help as stressful, they understood that it was necessary in certain situations. Liz demonstrated this, when she employed her social coping skills and relied on her informal support network to continue meaningful occupation:

“...I will walk all the way down...and I wanted to cross the street.... I wanted to go to library. ...and I wanted to cross the road there...and I'd got as far as halfway across and then I didn't know what to do because cars were just going crazy past me and around me and everything. And I was stuck in the middle of the medium. In the road there, and a car stopped, and he said to me 'Okay, go, go, go.' And I went across then but then coming back I was scared to come back. So, I had walked back up the other side of [the street] and I thought oh I'm petrified to cross this corner and then I realized there were people

there and I said to somebody, 'Do you mind telling me when it's okay to cross the road here?' This is how I get away with things."

Self-disclosing their diagnosis to their informal networks proved to be a useful social coping strategy, as it made meaningful occupation easier to facilitate. Some of the study participants shared the sentiment that older adults with low vision can be rude and take their frustrations out on sighted people, creating a bad reputation among the sighted community. This was explained by Randy, who said: *"Many blind people, unfortunately, have a bad attitude towards the system and toward life..."*. Some of the older adults chose to self-disclose in an effort to not be perceived as rude, but rather a kind human who needs help from their informal network to support occupational engagement. For example, Kim explained her decision to self-disclose her ARVL to strangers to save herself the social embarrassment of not recognizing people, and possibly being perceived as rude in the public eye:

"Yes, and I tell new people that you know if I don't recognize them, I don't see faces very well at all and I just try to explain to them that if I don't speak to them or call them by name, it's because I can't see who it is."

The older adults spoke to how different people in their informal social networks supported different occupational needs. For example, the older adults relied on friends and family for help supporting personal occupations such as personal care, receiving rides to medical appointments or to run errands, and emotional support. This is demonstrated by Randy, whose close friend gave him the emotional support needed to continue pursuing his meaningful occupations despite ARVL barriers:

"We talk to each other on a regular basis on the phone like during the day or into the evening or whatever, I think she's helped me to, I guess, stay calm, believe in myself,

she's been supportive of the activities that I've been doing, and she told me that I had changed for the better since moving up here into this house. The people that I'm with seem to be more kind and caring and helping others."

Older adults also relied on strangers, such as store employees, to assist with community-based occupations, such as grocery shopping. Many of the older adults discussed how grocery shopping, or running similar errands, was a meaningful occupation for them which they enjoyed doing as independently as possible. In those scenarios where a store employee was available, the study participants commonly reached out for help with finding items or help navigating the store. For example, Randy shared a story about relying on employees to help him navigate the mall and public transit:

"Depending on where I am, okay, if I'm out in a mall and I don't know where I'm going someplace, I'll go to a security counter or someone in a uniform. I might go into a store and ask, oh, do you know where the such and such is, somebody can tell me. I'll ask a TTC person if say they have one of those deals [for discounted public transit fair], I didn't know about... So, I go to one of the people in their bright coloured uniform and I ask where I need to go if I don't know."

The older adults in this study also spoke about relying on other blind or disabled individuals within their informal networks to help support their participation in going to leisure classes, participating in activities of daily living, or successfully living independently. For those participants who had friends, family, or acquaintances who were blind, they relied on them greatly to overcome various ARVL barriers that they may have previously faced themselves, such as getting lost, asking others for help, or strategies to navigate life with sighted family and friends. In fact, watching members of their informal social network cope with similar situations

was an important social coping strategy for the older adults. This is demonstrated by Pearl, who was better able to cope with ARVL, by relying on her friends' experience with vision loss:

"[my friend] was taken somewhere on Christmas Day but was taken early and she said she was sat in a corner, and she says you know of course the women are in the kitchen preparing the kitchen meal. The son and somebody else are somewhere else. She says, 'I was just sitting there, with nothing to do, and I couldn't see a soul.' And I thought, 'Oh, well that's something to think about, isn't it?'. She says, 'I'll never go early somewhere again and be left like that,' because she said, 'it was awful!'. Nobody to talk to. No television. ...And she was in a strange environment, so she didn't dare get up from her chair, for fear she might fall and trip. So, I thought, oh, I got to tuck that piece of information away in my mind."

Relying on other disabled people, in their informal social network, left the older adults feeling empowered and supported to continue occupational engagement. This social coping strategy was used by every older adult who participated, as they all had at least one other individual with a disability in their informal networks that they could relate to and together, overcome various ARVL barriers. These were people who could understand the barriers faced by each other in a more complex way than others in their informal network, based on first-hand experience living with a disability. This was best described by Pearl, who had numerous people within her informal network, that experienced vision loss, who helped to support her social coping and maintain occupational engagement:

"I need to keep in close contact with my blind classmate in St. Thomas and my cousin who is totally blind...because they, in general conversation, they can open doors for me that I need to think about without even asking questions."

5.3 Behavioural Coping Strategies

The older adults employed various behavioural coping mechanisms to assist them in maintaining occupational engagement. Based on Lazarus and Folkman's (1984) definition, behavioural coping entails the self-driven, physical manipulation of the older adult's behaviour to manage any appraised environmental stressor. Behavioural coping was commonly employed by study participants, as maintaining their independence, and doing as much as their bodies would allow on their own, was the goal of many of the older adults as they faced ARVL. The older adults discussed many coping strategies, including not bringing attention to their ARVL, counting, memorization, using visualization techniques, minimizing risk, keeping busy, using assistive devices, setting up organizational systems, replacing, adapting, or giving up their meaningful occupation, and pursuing advocacy efforts. Two overarching subthemes were identified during the data analysis, including: (1) Replacing, adapting, or walking away from meaningful occupation, and (2) Assertion & advocacy for all.

5.3.1 Replacing, adapting, or walking away from meaningful occupation

When faced with a barrier to meaningful occupation, the older adults in this study took one of three routes to behaviourally cope. They would replace the meaningful occupation with something new, adapt the occupation to circumvent ARVL barriers, or they would give up the meaningful occupation altogether. Different occupations led to different outcomes, and each older adult engaged in a careful weighing of their options, as well as their previous life experiences, when deciding what to do. Various factors ultimately influenced the appraisal process including the cost associated with adopting the coping mechanism, difficulty employing the coping mechanism, the level of danger associated with continuing the meaningful occupation, as well as the importance or value placed on the meaningful occupation.

Many of the study participants employed the use of assistive technology and ‘apps’ as a behavioural coping strategy. Various devices and apps were discussed, such as: ZoomText, E-Readers, audio books, Be My Eyes, iPads, cellphones, and computers. Integrating new technologies to support participation in meaningful occupations often led to adapting or replacing the activity rather than giving it up altogether. The adoption and use of technology or ‘apps’ to support occupation, however, was heavily reliant on the older adult’s access to the technology, their remaining visual acuity, and the associated cost. For example, Liz discussed her use of assistive technology to adapt her meaningful occupation of graphic design on the computer:

“I got Zoom Text, there is a magnifier reader...So, it magnifies...like I can control the magnification. Like I keep it at about 3 ½ or 4 but I can make it 8 if I want. So, I still have some peripheral vision...as long as the font is dark enough, with enough contrast [I can see the screen]. Anyway, I find [that] the Zoom Text...without that I wouldn't even use the computer. I wouldn't be able to use it.”

Organizing the immediate physical environment was a behavioral coping mechanism employed by many of the older adults to adapt how their meaningful occupations were performed, rather than replacing them, or giving them up altogether. In the case of Sam, he loved being fashionable and prided himself on being color coordinated. To achieve this, Sam needed to adopt a high level of organization in his closet to compensate for his low visual acuity:

“I like all kinds of colors and I wear it all different colors but, you know, you got to wear things that look good together. So, one of the first things that you learn very quickly is always put the things that match, that go together on the same hangers, right? So, whenever I have a shirt that goes with a certain pair of pants, I'll always keep that shirt

and pants on the same hanger, no matter what. In the drawers... So, you know, on the left for example I have pale blue, in the middle I'd have beige or light cream...then on the right would be kind of oranges and the one down would have mid and dark blue on the left, greys on the middle and black on the right. And the next down.... we'd have white at one end, red on the other and let's say greens in the middle."

Each of the older adults participating in this study shared stories detailing the environmental adaptations they employed to support their continued engagement in occupation such as: modifying the home including using large print labels and color contrast, using strategies such as landmarks, counting, memorization, and visualization, being extra cautious and moving slower to avoid environmental hazards. Introduction of these environmental adaptations led to all three outcomes for the older adults including adapting, replacing, or ceasing the meaningful occupation.

Many participants explained the changes they made to their home to behaviorally cope with their ARVL and maintain living independently in their own homes. Morgan, whose partner was also blind, enlisted the CNIB to help them adapt their environment, replacing storage spaces with easily accessible cupboards and remove dangerous appliances to create a more ARVL friendly living space. Many of the older adults in this study felt that behavioral adaptation and modification of their living space was easier with support from someone sighted or from their formal network. For example, Morgan stated:

"Oh, they have a guy who comes with...He's a blind guy and he comes with a sighted person who works alongside him. They labeled clothing and we tried that. It didn't work so well but it was the start. They labeled my stove, which I still use those markings, to let me know where the general bake button is and then the start button and then the off

button. I can eat [independently] with special glasses and a magnifying glass combined, [or I can] find my way around the other options on the panel, but it's not easy and so they came in and they did organize a few things in the home.”

Rather than lose a meaningful occupation, many of the study participants decided to adapt their occupation by using markers in the physical environment to assist with neighbourhood navigation. For example, Liz used the strategies of counting and memorization to support her continued participation in taking neighborhood walks:

“Ok, this is how it works for me. From the corner of my garage to my front door is eight steps. From my garage to the road is 10 steps. From my house to next door is 22 steps. Okay. That's how I do things. I have a good memory and I count, and I remember. If I go around the block, I go up...and I know the first block has five driveways. Across the road, the second block has six driveways. Across the road and the third block has three driveways and then you turn. So that is how I figure things out.”

There were some older adults who found themselves in a position where cessation of the meaningful occupation was appraised as the best way to move forward and cope with their ARVL. For example, Morgan, Liz, Kim, and Pearl all had the same sentiment about giving up their driver's license voluntarily, earlier than medically required, due to the dangers they perceived with driving and their deteriorating vision. When they made this decision, they simply appraised the danger and risk to themselves or others as more important than maintaining this occupation. After weighing the decision, cessation was determined to be the best option as demonstrated by Kim here:

“I didn’t want to get in trouble with it [driving with ARVL] either. I remember driving down [the] street, [not] being able to see the curb properly and thinking that I shouldn’t be doing this. Then I was of course worried about hitting somebody.”

5.3.2 Assertion & advocacy for all

An interesting behavioural coping mechanism, employed by many of the older adults, centered around their advocacy efforts. There were two kinds of advocacy discussed including advocating for political and systems level change as well as educating people about ARVL.

For Pearl, her advocacy, on a federal and provincial level, was a behavioural coping mechanism that allowed her to continue consuming Canadian politics, as this was one of her meaningful occupations. As Pearl would come across injustices, she felt a moral obligation to help however she could. She was heavily invested in local politics and would write letters to different politicians when she believed something was not just. For example, Pearl has been an activist for the blind and disabled community during the pandemic, as she felt that they were not considered when rules and regulations changed, and their needs were not being met. Pearl appraised cuts to healthcare funding as stressful, knowing that she, and others with ARVL, rely heavily on these services. Writing letters to her government officials was an outlet for Pearl and left her feeling heard and empowered:

“...I must admit I have written at least five letters...during this COVID stuff, advocating on behalf of the marginalized and reminding him that he is the premier of all Ontario. You know, all the people in Ontario, not the people that are privileged enough to stay home and work but also the store people and the hospital and, you know, that sort of stuff. So, if that counts. Yeah, that’s been an outlet for me.”

Being politically active provided many of the study participants with the outlet needed to advocate for broader systems level change and inclusive policies that will better support the needs of older adults with vision loss. For example, Morgan appraised a dangerous barrier to her meaningful occupation, and possibly to other blind or disabled people in her community, namely the e-scooters which were being left across her city, with little to no organization. These scooters have no docking stations, and often they are left abandoned on sidewalks. They are often directly blocking walking paths. These barriers are random, and Morgan is unable to predict where an e-scooter may be left if she decides to go for a walk in her neighbourhood. Thus, to cope, Morgan will politically advocate for herself and other blind people as she cannot physically do anything about the scooters:

“I try to advocate when I see services that are not being spoken to or are being addressed and require people to participate against. For instance, I am working against the e-scooters in the city because they are left all over the place and they’re a real hazard for blind people. Amongst others. So, I am political in that sense and I’m specifically political in regard to my disability.”

The older adults in this study shared many stories of situations where they felt that existing policies did not protect them, or the services they needed were not made available by their government. This was always appraised as stressful, and to behaviourally cope with this, some older adults amplified their advocacy efforts and spearheaded initiatives to improve the well-being of not just older adults with ARVL, but people with disabilities in general. For example, Randy engaged in a provincial campaign to adapt the assistive devices program (ADP) such that sufficient adaptive supports will be available for Canadians living with a disability:

“Well, we were trying to improve the conditions for blind people in as many areas as possible. The climate, the education, standards of living, all these types of things. So, it’s sort of, I guess in a sense it’s a coping mechanism for all of us in the blind community, not just me personally. Feeling I am part of a larger cause makes me feel that I can play a role, have a voice in what’s going on, how we can help other people. ...I just didn’t like the way I was treated in the ADP, and I thought they kind of brushed me off cold and callously so I brought this back to our advocacy group and said something about it and it was suggested to me who I should reach out to...when the final thing is published, then that’s going to go to the Ontario government and several ministers in the government and I’m hoping that a positive change can be brought about through this advocacy effort.”

The older adults in this study also advocated for themselves and their needs by explaining their ARVL to people, to raise awareness and education about vision loss. This helped the older adults navigate social situations with sighted individuals without judgement, leaving the older adult feeling empowered to continue engagement in occupation. Some of the older adults, such as Randy, shared stories of negative experiences with people who were not educated about ARVL, which was appraised as stressful:

“What I mean is when I meet people and when I get to talking, I explain to them that I’m legally blind. The movement of my eyes, I think it’s a condition known as nystagmus...What it means is the muscles of the eyes are moving. I had a situation many years ago when I was a young man, 20 years old, 21 years old...and I talked to this guy from...an employment agency. And the guy said to me quite honestly, he said, ‘you know Randy, to look at you, you look a bit dozy but after talking to ya for 5 or 10 minutes, I

realized you were very intelligent'. So, I realized, sometimes, eyes say a lot about the person. ...90% of what we learn is through the eyes... ”

Often, participants were required to engage in occupations that involved navigating social situations with strangers or people who were not otherwise familiar with the older adults ARVL diagnosis. Coping with this appraised stress was often easily dealt with by offering a simple explanation where needed. For example, Sam explains here:

“So, I remember a kid came up to me one day, he's just staring. He says, ‘Wow what a cool eye you got.’ I said, ‘Yeah. It's a map of the world!’, and he thought I was serious. So, I don't have a problem. ...in fact, I realized many, many years ago that people like me or people with any kind of disability, are lifetime educators and it's true, we are educators. We have to be prepared to answer questions. We have to alleviate fear. We have to stand up for ourselves sometimes...”

Educating others about ARVL was important to most of the older adults and it left them feeling empowered and motivated. It was a behavioural coping mechanism in more ways than one, because it also spreads knowledge – hopefully leading to a more inclusive and accessible environment for older adults with ARVL. It is not always obvious that an older adult may have ARVL, and with lack of recognition, it can be hard to cope in social situations. This was demonstrated by Sam, who behaviourally copes by educating sighted people in his community so that he can more comfortably continue occupational engagement:

“People like us and it's not just our disability its every disability but especially ones that people can conceive, can witness as being visual as opposed to someone with epilepsy you don't know that they have epilepsy unless they have an attack. You don't know. They don't look any different than anybody else and then people with mental issues. ...you

can't tell by looking at them 90% of the time, so but a lot of blind people, you can tell and plus they've got the cane. Well not all of them but for years, I did not need one. Never use it but anyway, the thing is, we're always educating everybody. Every time we go anywhere...even when you don't mean to or even when you not thinking about it you are actually educating others because when they see you doing something, they learn something. So, it's a life's lesson in progress if you like"

5.4 Conclusion

The three themes presented and unpacked above, including psychological coping strategies, social coping strategies, and behavioural coping strategies, present the various ways in which the older adults, in this study, coped with ARVL to maintain meaningful occupational engagement. The following chapter will present a discussion of the results, concluding the present study.

Chapter 6: Discussion

In this sixth, and final, chapter, I will situate the study results in the existing literature surrounding older adults with ARVL and the coping strategies they utilize to maintain occupational engagement. This chapter has been organized around the three overarching themes of psychological, social, and behavioural coping strategies, however, not all sub-themes are addressed. Instead, I chose to highlight some sub-themes but also those underlying ideas and concepts I felt were most novel to this field of study. Next, I will relate these results to the guiding theoretical framework used in this study, Lazarus and Folkman's theory of stress and coping. Finally, the strengths, limitations, and future directions of this research will be unpacked, with a particular focus on how the results can inform improvements to current rehabilitation programs for older adults with ARVL.

6.1 Situating the research findings within the current literature

6.1.1 Psychological coping strategies

Psychological coping strategies used by older adults with ARVL, and how it supports engagement in meaningful occupation, are not well detailed in the literature. Those studies that address psychological coping strategies for older adults with ARVL focus on aspects such as relying on family, accepting the low vision diagnosis, cognitive re-structuring, avoiding negative thoughts, persisting with hope and positivity, and developing problem-solving skills (Brennan et al., 2001, Senra et al., 2015). Although these studies discuss psychological coping strategies, they fail to describe how such strategies help to maintain meaningful occupational engagement. This current research addressed this gap, by providing rich narrative accounts describing how older adults with ARVL are psychologically coping with ARVL to maintain occupational engagement.

Help from a higher power. Many of the older adults relied on their religious beliefs and faith to aid them in coping with the stressors of ARVL and continue their various meaningful occupations. Koenig et al. (1998) define religious coping as “the use of religious beliefs or behaviours to facilitate problem solving to prevent or alleviate the negative emotional consequences of stressful life circumstances” (p. 513) and is a conscious choice made by the individual (McDougle et al., 2016). The older adults in this study employed religious coping as a psychological coping strategy in the same ways described by Koenig et al. (1998), mainly to support their mental health and as a strategy to support their continued engagement in meaningful occupation.

Among those older adult participants who were religious, it was discussed, in detail, the deep connection they had with their ‘God’ prior to being diagnosed with ARVL. They found it

comforting to turn to this relationship to psychologically cope with ARVL stressors. Religious coping has previously been shown to improve the self-perceived mental and physical health of older adults (Koenig et al., 1998; McDougle et al., 2016) and for the older adults in this study, this certainly rang true.

This sense of peace and mental clarity brought on through religious coping was a common sentiment from the older adults who adopted this psychological coping strategy. The daily stressors of ARVL, and the burden felt by these older adults, often led to psychological distress, drawing them away from meaningful occupational engagement. Part of this psychological distress may stem from the fact that ARVL is progressive with little that can be done to manage or treat the underlying diagnoses. Seigel et al. (2001) discuss how religious coping is common in those scenarios where physical illness is only partly improved through medical or physical intervention. In these situations, people often turn to divine intervention to help them in ways that medicine cannot. Not only did religious coping provide the study participants with an outlet to alleviate mental stress, but they may also feel further supported in their recovery and encouraged to continue meaningful occupation with the strength of their faith propelling them forward.

Brennan et al. (2004) examined the effects of personal resources and social support in adapting to vision impairment for middle aged and older adults. The authors found that when older adults had sufficient social support, religious coping did not correlate to additional adaptation; findings which are further supported by the older adults in this study. As it turns out, the study participants who employed religious coping as a psychological coping strategy were minimally supported from either their informal or formal support networks. Religious coping

comes into play here, allowing these older adults to fill certain gaps perceived as missing from their lives, allowing them to feel similar levels of support through their faith relationship.

Independence and Self Sufficiency. Similar to the participants in Nastasi's (2018) qualitative study exploring the occupational lives of three visually impaired older adults, this study found that most of the older adults were motivated to engage in meaningful occupation and would adapt to ensure continued participation in the occupation. Specifically, the older adults in this study adapted by maintaining their independence where possible, leaving them feeling a sense of control. These older adults would refuse help from their informal networks to continue pursuing independent meaningful occupation such as going for walks, reading, and writing personal letters, or making home cooked meals for their families. This is similar to findings from Nyman et al's., (2012) systematic review, where they summarized perceived emotional well-being in older adults with low vision, as well as any appraised factors that could be inhibiting or promoting psychosocial adjustment post diagnosis. Maintaining independence was a commonly employed strategy to cope with the barriers ARVL posed to participation in meaningful occupation; findings which are supported by the results of the current study.

Nyman et al. (2012) identified that the loss of a driver's licence was a devastating loss for older adults with ARVL due to its symbolic, as well as actual, ties to independence and freedom. The current study supports these findings, as each of the older adults who had their licences and drove prior to ARVL had to employ psychological coping strategies to overcome the emotional distress they experienced when they gave up their licence. For the older adults in this study, driving was often appraised as the most secure means of transportation for them to independently pursue meaningful occupation, and without that, the older adults had to rely on their informal and formal support networks to facilitate occupational engagement. In their minds, this

correlated to a direct loss of independence. Walking, asking strangers for help navigating busy crosswalks, or taking public transit such as the bus, subway, or taxi were some of the ways in which the older adults fought to retain independence and psychologically cope with ARVL.

Many of the local low vision services, such as the CNIB, CCB, AEBC and BALANCE for Blind Adults, were key players in helping older adults psychologically cope with ARVL and maintain their independence. It also goes to show how social and psychological coping strategies are often interlinked, as the older adults often relied on both simultaneously to cope and maintain meaningful occupational engagement. The CNIB, for example, was one low vision rehabilitation provider that was used by many older adults to help them retain their independence. The CNIB offers various programs, such as orientation and mobility and independent living skills, both of which are focused on enabling occupational engagement while subsequently working to minimize environmental barriers in the home and community. Unlike players within their informal networks, such as friends, family, neighbours, or strangers, low vision rehabilitation services, which are a part of the older adult's formal support network, aim to teach the older adult how to cope, with the goal being eventual independence with the task. This, in itself, is appraised as a successful psychological coping strategy once they have been given the tools to maintain occupational engagement independently.

6.1.2 Social coping strategies

Social coping strategies were employed by each older adult who participated in this study. The thematic analysis identified two groups of social coping strategies employed by the older adults including, relying on their formal support networks, and relying on their informal support networks. Social coping strategies and the use of support networks employed by older adults with low vision are well detailed in the literature (Brennan et al., 2001; Cimaroli et al.,

2005; Elers et al., 2018; Marques et al., 2018; Ke et al., 2007) but few authors detail how older adults socially cope with ARVL to maintain meaningful occupation with a notable exception (Kang et al., 2022). In the current study, social coping strategies were frequently employed, such that they often overlapped with both behavioural and psychological coping mechanisms. Because the study participants had ARVL, facilitating the appraised coping strategy was much easier to achieve with support from either formal or informal players in their networks. Social coping strategies were often appraised for emotional support, help navigating unfamiliar environments, supports to maintain living independently, or assistance with transportation to meaningful occupations, as examples.

Coping with the support of family, friends, and strangers. Informal support networks typically consist of children, family, friends, siblings, spouses, or peers experiencing a similar situation, as detailed by Brennan et al. (2001) in their study which compiled three narrative data sets from different studies to develop a typology of coping strategies used by older adults with vision loss to support adaptation. In this current study, older adults heavily relied on others who had ARVL or a general disability, because they were able to share similar experiences and useful strategies for coping. Some of the study participants had family members who lived with ARVL and relied on their experiences for guidance and to navigate risky or dangerous situations. This sharing of information provided a form of psychological relief, allowing the older adults the mental clarity to continue other meaningful occupations such as cooking, navigating family dynamics post diagnosis, physical activity, or independent living.

The older adults in this study, with more advanced ARVL, generally required more informal support, compared to those who had less severe self-reported ARVL. This finding was supported by Ke et al. (2007), who found that greater visual problems led to more informal

support being required by the older adult. In Ke et al's. (2007) cross sectional, hospital-based study, they sampled 284 people aged 50 or older with late age-related macular degeneration and found that informal care may provide less specific assistance, but that this network was available for the older adults in times that were hard to predict. These unpredictable moments were more likely amongst the older adults who had more severe ARVL. Participants in the current study expressed their deep frustration with the unpredictability of formal networks, and thus chose to rely on friends and family for help coping to participate in specific meaningful occupations. For example, Randy had been waiting for well over a year to get in contact with a volunteer walking buddy from a vision loss rehabilitation organization but has heard no updates and still faces the same barriers to his meaningful occupation. Morgan had reached out to a vision loss organization looking for help regarding her local vaccine mandate procedure, and it took weeks of lack of communication and being passed on to different employees in different departments before she could get some answers. With experiences like so informing their appraisal process, relying on trusted loved ones in their informal networks was more likely in spontaneous situations when coping with an ARVL barrier to meaningful occupation.

Different people within the informal network were relied upon for coping with different meaningful occupations. Strangers and store employees were part of the study participants' informal support network, and the older adults in this study relied on these players in very specific instances, namely when they did not have a loved one to help them. This finding was supported by previous studies (Kang et al. 2022, Wang et al., 2008), but not fully unpacked for their influence on maintaining occupational engagement. In the current study, there was a staggering difference in the meaningful occupations supported by different players within the informal network. Family was typically called upon for help coping with personal activities, such

as receiving emotional support and encouragement to continue meaningful occupation, help with maintaining personal hygiene, financial assistance, or getting drives to medical appointments. The literature supports the fact that loved ones, and trusted friends, are usually the informal players to help support these types of occupations (Kang et al., 2022; Roe et al., 2001). For the older adults in this study who did not have a spouse, or who did not have a close relationship with their children or other loved ones, they mainly sought out, friends for assistance. Marques et al. (2018) conducted a study with 546 Portuguese older adults who had low vision to look at the association between informal care use and socio-demographic aspects. They found that those who were not married were 1.85 times more likely to rely on their informal networks, a finding that was supported qualitatively in this current study. Less personal players in the informal network were also called upon in situations when loved ones were not available or relied upon as a way to maintain community independence, such as when asking strangers for help when shopping.

Coping by relying on the support of one's informal social network was instrumental for many of the older adults in the current study as it enabled them to maintain their meaningful occupation of living independently in their homes. This is supported by Ke et al., (2007) who stated that older adults often found maintaining independence impossible without informal players in their social networks to provide assistance. If the older adult lived close to their children or had their spouse living with them, they relied on them heavily to cope socially, and these efforts were clearly recognized by the older adults as being mandatory for them to continue independent living. This contradicts findings from Elers et al's. (2018) study where they presented findings from 10 older adults (aged 74-92) and 31 members of their self-identified informal support networks. Elers et al., (2018) found that the older adults often overlooked, or

dismissed, the support received from their informal networks. This was in contrast to our study findings in which the older adults were openly grateful for the extensive support they received with social coping from their informal networks, especially from their loved ones and friends.

Coping with the support of community organizations. Formal support networks, specifically, low vision rehabilitation services, were a popular coping strategy for all but one of the older adults in this study. These formal organizations are often relied on for their ability to provide effective coping strategies for ARVL barriers and maintaining meaningful occupation. Ke et al. (2007) found that higher degrees of formal support were used by older adults who were older and had less visual acuity. This is supported by the current study, which found that older adults with greater degrees of self-reported vision loss tended to rely more heavily on their formal network to maintain meaningful occupation. Brennan et al. (2001) found that older adults relied on sighted guides to cope with ARVL and this was supported by the older adults in this study, who used local vision loss groups, such as the CCB or the AEBC, to source these sighted volunteers to support continued occupational engagement and cope with ARVL barriers.

Ke et al. (2007) found that their participants saw relying on formal support networks for help within the home as a sign of vulnerability and a threat to independence, which was a finding that was contradicted by the older adults in the present study. The older adults shared many ways in which they relied on their formal support networks for social coping and maintaining meaningful occupation, and they embraced the help. During COVID-19, to minimize transmission of the disease, many of these in home services were not available, and most of the older adults are awaiting their return to further support their ability to cope with ARVL and maintain independent living.

Kang et al. (2022) highlighted the importance of healthcare professionals and low-vision rehabilitation organizations within the formal network to support meaningful occupation in their narrative study examining the role of social networks and coping for five older adults with ARVL. The current study supports this, as without vision loss rehabilitation services like BALANCE for Blind Adults, Paratranspo, or the CNIB, the study participants would not have been able to access many meaningful occupations such as going to doctors' appointments, making it across town to get dinner with a friend, or getting to their place of work.

A problem identified by the older adults in this study was the lack of blind employees or volunteers, speed of receiving certain services, and the lack of marketing of low vision rehabilitation services to the ARVL community. Chiang et al. (2011) conducted a study detailing the global availability of low vision services using surveys and some secondary government sources. They found that low vision services were only available in 58% of countries globally and they were plagued with long wait times and a lack of standard program evaluation (Chiang et al., 2011). This leaves a large segment of the population unable to access these services and, for those who can, the experience is often negative (Chiang et al., 2011). This is supported by the older adults in this study, who had similar complaints about their formal networks. For example, most of the older adults, who were regular low vision service provider users, were on long waiting lists to receive in home supports or a sighted guide.

Chiang et al. (2011) stated that lack of awareness of low-vision programs, referral networks, and poor communication between clients and healthcare professionals were large contributors to the lack of access to low-vision services in developed countries. Even though many of the older adults in the present study were well connected with low vision organizations and reaped the benefits of including them in their formal social networks, they identified that

many of their peers with ARVL were experiencing struggles with their formal networks. For example, Morgan and Randy were well connected to their formal networks, but they were not aware of the challenges experienced by their peers with ARVL and chose to advocate for their support. In developed countries, ethnic minorities, refugees, and older adults are amongst those that are most likely to face barriers to accessing low vision services (Chiang et al., 2011). The older adults in this study were self-proclaimed advocates for disadvantaged populations, hence their strong desire for fair access to such services.

6.1.3 Behavioral coping strategies

Behavioral coping strategies were commonly employed by the older adults in this study to cope with ARVL and support continued meaningful occupation. Behavioral coping strategies of older adults with ARVL have been well detailed in the literature, and there were many overlaps identified between participants in the current study and past research studies.

Unfortunately, few studies tie behavioural coping skills to maintaining meaningful occupation. Skelton et al. (2013) performed a systematic review, assessing the effectiveness of environmental and behavioural strategies to reduce limited occupational engagement in older adults, and they found no research matching their search criteria at the time. Rather, they stated a need for a better understanding of the coping mechanisms employed by older adults to cope and maintain occupational engagement (Skelton et al., 2013). The older adults in this current study adopted several behavioural coping strategies to cope with ARVL and maintain meaningful occupation including replacing, adapting or cessation of meaningful occupation, employing the use of technology, organizational techniques, and various environmental adaptations.

Replacing, adapting, or giving up meaningful occupation. When the older adults in this study appraised a stressful barrier to meaningful occupation, and they decided that the best

course of coping was behavioural, there were three main routes they took: replacing the meaningful occupation, adapting how the occupation was performed, or giving up the meaningful occupation all together. The cognitive appraisal process, when deciding how to cope with a stressful situation, is a personalized process and as such, the strategies employed vary greatly from one older adult to another. Various factors were determined to influence the behavioural coping strategy chosen, including cost associated with pursuing the meaningful occupation, how important the meaningful occupation was to the older adult, and if there were any dangers associated with pursuing the occupation.

Receiving a diagnosis of ARVL is an important life transition for older adults with ARVL. Girdler et al. (2008) argued that meaningful occupation was a central factor when considering life transitions and moments of significant change in the life of an older adult. The life transition post-ARVL diagnosis was often jarring for the older adults and for some, meaningful occupation was difficult to conceptualize after losing their vision. Certain occupations, such as spending time with family, driving, travelling, and pursuing the arts were deemed as particularly meaningful for the older adults in this study. In cases like so, the older adults adapted how the occupation was performed to ensure they remained able to engage in it, while at the same time trying to retain the integrity of the occupation. Girdler et al. (2008) describe the psychological distress experienced by older adults who are forced to stop engaging in meaningful occupations, and the older adults in this study coped with this by adapting the occupation as much as possible.

There were situations when meaningful occupation could no longer be adapted, and in these cases, the older adults often had to replace the occupation with something new. Berger (2011) performed a study including 26 older adults with ARVL to gain an understanding of the

older adults lived experience with ARVL and how it relates to occupational engagement. Berger et al. (2011) explains that the older adults appraised the physical experience of participating in any occupational engagement as more important than pursuing a specific, pre-determined occupation. Their desire to engage in meaningful occupation was related to their motivation to participate in specific activities (Berger et al., 2011), and the older adults in this study supported this finding. Many of the older adults were realistic about their visual abilities and knew when they could no longer adapt an activity. Once the meaningful occupation started to lose its initial integrity, they would replace it with something new, that evoked similarly positive feelings. Brennan et al. (2000) states that the most employed behavioural coping strategies for the older adults in their study were novel, but the older adults in this study appeared to prefer adaptation of their current activities and coping strategies. This may be because many of the older adults in this study had previous experience coping with low vision and had the tools and knowledge available to adapt. Perhaps if this was their first time navigating ARVL barriers, the older adults would have replaced more of their meaningful occupations post-diagnosis.

If older adults could not replace or adapt the occupation, they would behaviourally cope by giving up the meaningful occupation altogether. For the older adults in this study, cessation of difficult, costly, dangerous, or no longer desired meaningful occupations provided the older adults the ability to pursue other occupations. Using semi-structured interviews, Glen & Crabb (2015) explored whether 16 patients with glaucoma used different coping strategies following diagnosis. They found that participants gave up activities and imposed self-restrictions on meaningful occupation, which led to compromised well-being and independence. These restrictions included only going places accompanied by a friend, limiting the amount of driving they did, or delegating important life tasks to family members. The older adults in this study

reflected similar behaviour which led to similar consequences. For example, many of the study participants expressed these sentiments when giving up the meaningful occupation of driving, which was a pivotal moment in many of the older adults' stories about coping with ARVL. Each of the older adults who drove gave up their licences on their own rather than waiting for them to be suspended, and this is because they appraised the dangers associated as too risky.

The use of technology to cope. In terms of behavioural coping, technology and assistive devices were used by each of the older adults in this study. They were central to the behavioural coping of the older adults and were often the reason for successful adaptation of meaningful occupations. One such important meaningful occupation of the older adults was maintaining connections with friends and family from across the world. Technology, such as iPads, cell phones and computers were the main assistive devices employed by the older adults to maintain these connections and behaviourally cope with the barriers preventing them from communicating in person. Many studies detail how older adults with ARVL employ technology, such as computers, telephones, and tablets, to connect with loved ones and maintain social connection (Elers et al., 2018, Kang et al., 2022; McGrath & Astell, 2016) and the older adults in this study behaviourally coped in similar ways.

Elers et al. (2018) reported that the technology employed by their participants was mainly to assist older adults in living independently in the home and providing communication pathways with healthcare providers, which contradicts the finding in this study which found that older adults relied on technology more so for pleasure and to maintain social connections. Community engagement was seen as much easier facilitated with the help of the older adult's social support network. The literature states that social networks are essential in terms of preserving people's community engagement, because of the social networks ability to support the older adults use of

technology (Elers et al., 2018; Fok et al., 2011; Kang et al., 2022; McGrath & Astell, 2016).

Older adults in this study share this finding, and many had struggles with using everyday devices due to ARVL but were aided by the support of their informal support networks.

Although the use of technology allowed the older adults in the present study to behaviourally cope with the stressors of their ARVL, it was not without its challenges. Cost, for example, associated with obtaining the technology was a barrier for many study participants. This is supported by research where study participants saw cost as one of the most significant barriers to technology acquisition (Elers et al., 2018; McGrath & Astell, 2016). The older adults in this study could relate to the high costs associated with some of the technology they saw as necessary to behaviourally cope with ARVL. Many of the assistive devices to support low vision are extremely costly, and the Assistive Devices Program (ADP) in Ontario currently only covers 75% of costs if the device is eligible for funding. The remaining costs fall to the older adult with ARVL, which can create barriers to technology acquisition and use.

Many of the older adults in this study struggled with using technology due to the visual challenges underpinning their ARVL diagnosis. In many instances, the study participants needed to rely on their informal support networks to learn how to use the technologies which led to feelings of dependence and psychological distress. Kang et al. (2022) found that older adults perceived many low vision technologies as non-intuitive for older, visually impaired users; a sentiment shared by the current study participants who complained of technologies that were so ill designed for the older adult user that it led to eye strain and fatigue.

6.2 Relating the study findings to Lazarus and Folkman's Theory of Stress and Coping

The study results demonstrate the cyclical and personalized nature of cognitive appraisals of stressors and employing various coping mechanisms to overcome those. Lazarus & Folkman's theory of stress and coping explains this process, which frames how cognitive appraisals are consistently happening to appraise stressors in the environment. A coping mechanism will be employed until the person deems the stressor as managed, and they feel content with the result. One of the three previously identified families of coping strategies; psychological, social, or behavioural may be employed to help mitigate the appraised stressor.

Many of the older adults with ARVL faced similar struggles and barriers to meaningful occupation, however, each person appraised different stressors and thereby coped differently. This highlights the individualistic properties of coping, which is one of the main points of Lazarus and Folkman's theory. There is much variation in personal agendas and the complex and ambiguous nature of external environmental contexts explain the many different outcomes of a single appraisal made in the same environment (Biggs et al., 2017; Lazarus, 1991). When you consider the variation between the older adults and their environments, this explains why there were such varied coping strategies employed in such different ways.

Cognitive appraisals only matter to the person themselves, and the stressor is only deemed successful if the person believes they have employed the proper coping mechanism and if they feel content with the outcome. The perception that the event is stressful is what determines if coping will be initiated or if the stressor is resolved, not the event itself (Biggs et al., 2017; Lazarus, 1991; 1999). This is based on life experience and personal feelings, so even when faced with similar ARVL barriers, we can see a variety of problem focused or emotion focused coping strategies being employed by different older adults. There are two types of

cognitive appraisals, namely primary appraisal, and secondary appraisal. The primary appraisal is suited to prescribe meaning to an interaction and determine the significance of said interaction to the individual (Lazarus & Folkman, 1984). We see many primary appraisals transpire with the older adult study participants as they initially appraised a situation to determine if there was an ARVL barrier. If there is an appraised barrier, and it is inhibiting occupational engagement, then the situation is appraised as stressful.

Secondary appraisals come into play after the primary appraisal has been made and meaning has been prescribed to an interaction. Secondary appraisals determine what must be done to manage the stressor and any resulting distressing emotions (Biggs et al., 2017). Various factors come into play here, for example: situational variables, evaluation of coping resources, and past coping styles employed in similar situations (Biggs et al., 2017). An interaction between these three mitigating factors is how the older adults in this study determined how they would cope and from which family (psychological, social, or behavioural) the coping mechanism would derive. Different older adults had different goals, and there were times when the emotions surrounding the barrier to occupational engagement was appraised as more stressful than the barrier itself, which lends to emotion focused coping. For example, this situation transpired when Pearl made the decision to give up her driver's licence, whereby she had to psychologically cope with this loss and deal with her internal emotions to navigate this perceived barrier to meaningful occupation. If the barrier itself is appraised as the problem, it will be directly managed by employing problem focused coping. For example, Liz appraised her eyesight as a barrier to playing cards, so she coped by getting bigger cards to play with. Emotion focused coping was mainly tied to psychological coping strategies, and problem focused coping typically was associated with behavioural coping strategies for the older adults in this study.

Coping involves “constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (Lazarus and Folkman, 1984, p. 141). The older adults in this study had different resources and different limits to what they found taxing. In each case, when a barrier was identified, a coping strategy was employed to reach cognitive resolution. This initial coping strategy was not always successful, and this was determined through cognitive reappraisals. Cognitive reappraisals weigh the outcome of the initially appraised coping effort and new information from the environment to determine if coping was successful or if the situation has changed from stressful to either positive or irrelevant (Biggs et al., 2017; Lazarus & Folkman, 1984). Coping is a continuous process, and reappraisals will continue to be made until the desired outcome is reached.

In the case of the older adults in this study, the first coping mechanism was not always appraised as a success, and they had to try using coping mechanisms from a different family to mitigate the stressor and maintain meaningful occupational engagement. Coping is seen as a dynamic and fluid process; a constant cycle of transactions happening between the older adult and the environment (Biggs et al., 2017). This is important to note because coping is rarely a success on the first attempt. Many older adults in this study shared the various ways they had to try to navigate barriers to meaningful occupation, and it was not always appraised as a success after the first, second, or even third coping mechanism employed. Older adults must remember that barriers are consistently being appraised, and it is a part of life to continue navigating them as new stressors and barriers may be appraised based on new information at any time. A scenario often seen with the older adult participants was with coping strategies previously appraised as successful in one situation, being cognitively re-appraised as unsuccessful in a latter situation

because of progressing ARVL. Rather than give up in these cases, the older adults had to cope with new barriers, or they would lose occupational engagement all together.

In all, Lazarus and Folkman's transactional theory of stress and coping provided a strong theoretical framework for this research. The study participants demonstrated their use of primary appraisals to assess their barriers to meaningful occupations, and secondary appraisals to deploy their coping mechanism of choice. The transactional, fluid nature of these appraisals was key to these older adults' success in coping as they navigated the differences between emotion focused and problem focused coping to maintain occupational engagement.

6.3 Study strengths and limitations

One of the strengths of this study was the strong researcher-participant relationship that developed over the course of data collection. There were three narrative interviews that took place with each participant, and this aided in developing a strong sense of rapport. This research used a narrative methodology and took a constructivist paradigmatic positioning and, in doing so, the co-creation of data and a trusting relationship was required between the knower and researcher in order to produce rich and meaningful data (Guba & Lincoln, 1984; Hollingsworth & Dybdhal, 2007). I wanted to ensure that each of the older adults who agreed to participate in this study felt comfortable with me as a researcher, as I was going to be asking personal questions about a topic that could be seen as sensitive. When we discussed sensitive topics, because the participants felt comfortable with me, they remained open to sharing their experiences, allowing me deeper insight into their utilization of psychological, behavioural, and social coping strategies. From the first time we made contact, up until the final debrief interview, I made every effort to ensure our interactions were comfortable, accessible, and left the older adults feeling as though it was a positive interaction. I respected the co-creation of data, and

always tried to minimize my ownership over the narrative, as it was truly a joint experience. In doing so, I was able to obtain rich rigor and credibility through the stories detailing various coping strategies employed by the older adults to maintain participation in their meaningful occupations. By the time data collection was completed, each of the older adults thanked me for the positive experience and told me how much they valued their time as participants in the study.

A second strength of this study was the diversity in type of ARVL diagnoses across the six older adults who shared their stories. While macular degeneration was the most frequent diagnosis, with four older adults self-identifying with this ARVL condition, I was fortunate to come across one older adult with glaucoma and one who self-identified as having all three ARVL diagnoses. Having perspectives of how an older adult copes with each of the three ARVL diagnoses provided a richer depiction of coping with ARVL.

Although the diversity of ARVL diagnoses was a strength, a limitation of the study was that two participants had previous visual problems diagnosed in childhood, prior to being diagnosed with ARVL later in life. It is plausible to hypothesize that the coping strategies of the two older adults with over 40 years' experience coping with low vision may have developed more comprehensive coping strategies than the older adults diagnosed with ARVL in later life. During data collection, once my supervisor and I realized that the first two participants recruited both had extensive experience coping with vision loss prior to ARVL, purposeful sampling was utilized to recruit older adults who were new to low vision and would have more novel coping strategies to discuss.

A second limitation of this study was that recruitment of the six older adults was done exclusively through organizations focused on providing low vision services. Although other methods of recruitment were attempted, including optometrists' offices and senior's day

programs, those efforts did not result in any enrolled participants. The existing literature tells us that many older adults with ARVL do not access low vision rehabilitation services for reasons such as cost, lack of access, or being unaware of services (Spafford et al., 2009). As such, the fact that all participants were recruited through organizations such as CNIB, CCB, AEBC, and BALANCE for Blind Adults excluded a large subset of the population who do not access low vision services. Those who access such services may demonstrate more sophisticated coping strategies than if the sample was comprised of older adults who did not access any such services.

6.4 Future research directions and implications

6.4.1 Future research directions

This study unpacked the coping strategies employed by older adults with ARVL to maintain meaningful occupational engagement. When the literature review was conducted, it was determined that psychological coping mechanisms had not been fully explored in the existing research. As such, future research should explore the specific psychological coping mechanisms used by older adults with ARVL, further exploring the ways in which older adults employ emotion focused coping to maintain occupational engagement. Additionally, the differences in coping strategies employed by older adults for different meaningful occupations should be explored further in future research. Though coping is a dynamic, personalized process, having specific examples of how older adults cope to continue engagement in meaningful occupations may serve as a positive and helpful example for other older adults. Older adults in this study struggled with lack of access to information and many felt that they were coping with ARVL on their own. Hearing these stories about older adults in similar situations could be a positive way to share coping strategies with older adults and remind them that they are not alone in their efforts to pursue occupational engagement with ARVL.

During recruitment, my supervisor and I noticed that during our first wave of recruitment, two of the older adults enrolled in the study had been coping with vision loss since childhood, which likely influenced their coping mechanisms following their ARVL diagnosis. Following this discovery, we attempted to recruit older adults who had been more recently diagnosed with ARVL. That being said, future research would benefit from exploring the difference between coping strategies employed by older adults who have been diagnosed with ARVL in late life versus those with previous experience coping with vision loss.

Another trend noted about the study participants was their heavy reliance on low vision services. In fact, all but one older adult was recruited directly from such an organization, and therefore they were familiar with the services offered, many of which focused on developing healthy coping strategies to vision loss. It is important to acknowledge, however, that a large segment of older adults with ARVL either do not have access, or choose not to access, low vision services. In future research, older adults who are not receiving low vision rehabilitation services should be purposively sampled to see how their coping mechanisms compare to those older adults who are receiving such services.

Interestingly, maintaining occupational engagement was framed as both an outcome of healthy coping strategies but also was a means of coping with ARVL stressors for the older adults in this study. Contrary to the research that presents coping strategies employed by older adults to facilitate occupational engagement with low vision (Brennan et al., 2001; Nyman et al., 2012; Smalfeild & Kaldenberg, 2020; Smith et al., 2009), the older adults in this study framed this relationship, at times, as more cyclical, fluid, and bi-directional, where meaningful occupation and coping was both the cause and effect. Future research should seek out information about how meaningful occupation acts as a coping mechanism, so that it may be

integrated further into low vision healthcare and rehabilitation programs. This could help to improve vision-related outcomes for older adults with ARVL. If healthcare professionals are more focused on meaningful occupation, and aware of its various health benefits and power to help cope and overcome low vision barriers, then this information can be shared with their patients, helping them to live a more positive life with ARVL.

6.4.2 Recommendations for vision loss rehabilitation services and health professionals

This study demonstrated the ways in which older adults psychologically, behaviourally, and socially cope with ARVL barriers to maintain participation in meaningful occupation. Though the older adults were thankful for the various programs and services offered by low vision rehabilitation services, there remained barriers to coping that made meaningful occupation difficult to maintain or caused unnecessary psychological distress. To address these barriers, the participants in this study proposed various improvements that could be taken up by groups such as the CNIB, CCB, AEBC and BALANCE to better support their coping given that they are the low vision services most frequently utilized in Canada. These recommendations include:

1. Increased psychological supports surrounding loss of driver's license

One of the most prevalent areas of psychological distress for the study participants was the loss of their driver's license secondary to ARVL. The older adults in this study struggled with how to cope with this loss and, for each participant, it was a sensitive subject, that caused much grief when discussed during the interviews. Many studies detail the psychological distress experienced by older adults with vision loss who can no longer drive (Alder & Rottunda, 2006; Horowitz, 2004; Rudman et al., 2016), yet low vision rehabilitation services fail to provide older adults with sufficient tools to cope with this loss. Western society heavily relies on private automobile transportation, making it difficult for

older adults who have given up their license to learn how to maintain their meaningful occupations without the convenience of a private vehicle. Older adults need to be better supported to inform the adoption of healthy coping strategies to guide the transition to life without a car. In addition, although many of the older adults in this study voluntarily gave up their licenses, without being recommended to do so by a medical professional, low vision rehabilitation services should inform older adults about the risks of driving with ARVL, provide them with possible options for safer transportation, and provide emotional support for older adults who grieve the loss of independence associated with giving up their license.

2. Revamping the Ontario ADP to reflect current low vision technologies

Many of the older adults in this study relied on assistive devices to behaviorally cope with ARVL and maintain meaningful occupation. Although assistive devices are frequently used to support occupation in this group, many devices are costly, making it difficult for older adults to acquire them. The current ADP in Ontario covers 75% of the cost of assistive devices for older adults with ARVL, but it must be on their list of approved devices, which does not always reflect the most current low vision technologies, such as the currently popular device, e-sight glasses, which are not funded by ADP. The older adults in this study discussed many issues with ADP and did not feel that the program sufficiently supported them. For example, even at 75% coverage, the remaining 25% of costs was too high for many older adults, especially when you consider the multiple pieces of technology often needed. Multiple studies detail the cost related barriers that older adults with ARVL face when procuring assistive devices (Elers et al., 2018; Gupta et al., 2021; Manjari et al., 2020; McGrath & Astell, 2016). Moving forward, this study supports the urgent need for the ADP

list to be updated annually to reflect the current needs of people with ARVL, particularly given that it is a frequently adopted behavioral coping strategy.

3. Low vision rehabilitation services improving disseminating of information on coping with ARVL and its impact on occupation

Spafford et al. (2010) produced a qualitative study detailing the reasons why 34 older adults with low vision did not access services provided by low vision service providers. They found that, the most common answer, was that older adults struggled to access services because they were unaware they existed (Spafford et al., 2010). There is a clear disconnect between the older adults and some of the low vision rehabilitation services being offered due to lack of awareness, referral networks, and poor communication between older adults and health care professionals (Chiang et al., 2011), as confirmed by the older adults in this present study. One of the older adults in this study thought that if they had received information about low vision service providers from their doctors as they were being diagnosed, it would have been significantly easier for them to access these services and cope with ARVL. Based on these findings, I am suggesting that low vision service providers build relationships with optometrists in their operating areas, so that they can accurately disseminate information in ways that are ensured to reach the older adult population and help to facilitate coping to continue meaningful occupation.

4. Health care professionals better disseminating information about how to cope with ARVL and its impact on occupational engagement

A sentiment shared by many of the older adults in this study was the lack of support they received with developing healthy coping strategies from their healthcare providers, with only one participant discussing the positive role their Optometrist had in helping them to

develop behavioral coping strategies. Many existing studies detail similar issues in terms of healthcare providers not appropriately teaching their older adult clients with ARVL healthy coping strategies (Brooks et al., 2017; Choi et al., 2020). In addition to teaching older adults about healthy coping strategies, healthcare providers should also, more clearly, understand the link between coping and restricted occupational participation and its link to feelings of loneliness, isolation, frustration, boredom, and inactivity (Nyman et al., 2012). Healthcare professionals should be aware of this and take the time to curate trusting relationships with their older adult clients, such that information about coping could be easily digested by the older adult with ARVL in a safe space.

6.5 A return to reflexivity

Throughout my thesis, I experienced some hardships that I needed to be reflexive about to ensure I maintained sincerity and meaningful coherence of the study. The first of these hardships was the sudden death of my grandmother, who was the inspiration behind this study and the pursuit of my master's degree; and ultimately the person I dedicated this work to. While grieving my grandmother, I was leading narrative interviews with older adults where they shared various stories about coping with ARVL to maintain meaningful occupation, and many of them shared similar struggles and life experiences as my grandmother. During data analysis, I found myself revisiting these stories and listening to the audio-recordings upwards of three times per participant interview, and complex emotions would come up about my own grandmother's death. Personally, this intensified the grieving process for me, making it difficult, at times, to fully immerse myself in the data analysis. To cope with this, I processed my feelings and thoughts reflexively, ensuring I reflected on my grieving process as to not negatively impact the data collection and analysis process. When interviews were completed, I would partake in a self-

debrief where I wrote down any emotions I had that were related to my grandmother, and this helped me to contextualize my own grieving process within the data collection process. Any time I started to develop negative feelings surrounding my grandmothers' death, I would write reflexively and explore these feelings and determine their origin, even outside of interviews, and this allowed me the space to grieve her death as healthily as I could, given the circumstances. Reflexivity allowed me the space to do this properly and ensure I could still produce rigorous and meaningful research.

The second challenge that I was able to unpack reflexively was when hearing stories from some of the older adults, where their ideologies or beliefs directly contradicted with my own. Being a young, black, female in academia, I had certain pre-understandings about sampling from a population aged 65 and older, and I knew that I may come across participants who held values about race and women from the past that would have been more widely accepted amongst their peers. This is something I unpacked reflexively, in great detail, prior to beginning data collection, because I am an outspoken, politically active individual. Outside of the contexts of research, I would never stand by and be silent when exposed to discrimination on any level. That being said, I was not prepared for the emotional toll it took on me to continue fostering positive, healthy researcher-participant relationships with each of the older adults after hearing some shared stories that contradicted my own core values. The reflexive work I had done before the interviews provided me with some preparation for dealing with moments like this in the moment, however, I experienced one situation which left me deeply offended and shocked. This incident had a negative impact on my emotions, requiring a debriefing session with my supervisor and broader discussion with my lab colleagues. To cope in the moment, I pretended as if the comments were not made and this allowed me to continue fostering the positive environment, I

had tried so hard to maintain for each participant, and the interview went along smoothly. After the fact, I was able to unpack further by reflexively exploring my true emotions about the situation. I wrote down everything that I was feeling so that I could be clear minded for future interactions with participants. My supervisor was also able to provide further emotional support and suggested that whatever comment I wanted to make in the moment, I wrote it down in my reflexive journal, which proved to be an effective coping mechanism that I employed in every interview to ensure that the older adults felt comfortable and that I did not feel I was compromising my values any further than I had to.

6.6 Conclusion

This research explored how six older adults with ARVL coped with the stressors of ARVL in ways that supported their continued engagement in meaningful occupation. Three central themes emerged, including: (1) Psychological coping strategies, (2) Behavioural coping strategies and, (3) Social coping strategies. The research findings address gaps in the previous literature by highlighting the various ways in which older adults employ coping strategies, and by exploring the relationship between coping strategies and maintaining occupational engagement; a link that has not been properly explored in other studies. By sharing the first-person, narrative accounts of how older adults are coping in various ways to maintain occupational engagement, this current study may help to inform improved rehabilitation programs for older adults, focusing on a blend of coping strategies to maintain occupational engagement. This study may also help to spread awareness among older adults with ARVL regarding the influence of healthy coping strategies on continued engagement in occupation.

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Appendices

APPENDIX I : Study Flyer

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 the coping mechanisms used to maintain engagement in your meaningful activities.

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

Where: Interviews will be conducted via Zoom or by telephone, if preferred. If social distancing, due to COVID-19, is no longer required, the sessions may take place in-person at a location that is convenient for you, such as your home, in the community, or at Western University.

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

Zakara Stamp, Co-Investigator

Principle Investigator

Colleen McGrath, PhD

APPENDIX II: Telephone Script

Research Project Title: The Coping Strategies of Older Adults with Age-Related Vision Loss:

A Narrative Account

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 one of: Central Optometry, the Canadian National Institute for the Blind (CNIB), the Canadian Council of the Blind (CCB), the Occupational Therapy and Vision Rehabilitation Network (OTVRN) through the Canadian Association of Occupational Therapists (CAOT), the Victorian Order of Nurses, Dearness Home, Kiwanis Senior Center, Horton Street Senior Center, or Hamilton Road Senior Center through a recruitment flyer, email, or newspaper ad.

This telephone script will be used by co-investigator, Zakara Stamp, or the principal investigator, Dr. Colleen McGrath, when a participant calls to inquire about participating in the research study.

Hello, this is Dr. Colleen McGrath's office. This is [**name of the Co-Investigator/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 the study details, I would like to ask you a few questions to confirm your eligibility to participate.

1) Do you have self-identify as having age-related vision loss (including macular degeneration, glaucoma and/or diabetic retinopathy)?

a. _____

2) How long has it been since your diagnosis of ARVL?

a. _____

3) Does vision loss impact your ability to engage in the daily activities that you need to, want to, or are expected to do?

a. _____

4) Are you 60 years of age or older?

a. _____

5) Are you comfortable participating in sessions in either English or French?

a. _____

If the individual answers NO to any of the questions:

Thank you for taking the time to reach out and for answering my questions. Unfortunately, you do not meet the eligibility criteria for this study.

If the individual answers YES to all five questions:

Thank you for taking the time to reach out and for answering my questions. You meet the eligibility criteria for this study. I would like to start by explaining what you will be asked to do if you decide to participate in the study.

This study is being conducted by Zakara Stamp, who is a master's student in the Health & Rehabilitation Sciences program at Western University. This study will examine how older adults with age-related vision loss cope with vision loss in ways that support their engagement in meaningful activities. 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 via Zoom, over the telephone, or in person (only if Public Health measures allow) at a location, date, and time of your choosing. The first meeting, which is a narrative interview will address topics related to the

coping mechanisms you use to maintain your engagement in meaningful activities. The second session will be a semi-structured interview. It will build and expand upon the ideas and responses you share during the first interview. Before the third meeting, the researcher will send you a draft-rendering of your story via either email or a physical copy will be delivered to you (depending on your preference). In the third, and final interview, you will have an opportunity to reflect and share your perspectives on 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, a date and time for the first interview will be booked.*

APPENDIX III: Email Script

Research Project Title: The Coping Strategies of Older Adults with Age-Related Vision Loss:

A Narrative Account

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 one of: Central Optometry, the Canadian National Institute for the Blind (CNIB), the Canadian Council of the Blind (CCB), the Occupational Therapy and Vision Rehabilitation Network (OTVRN) through the Canadian Association of Occupational Therapists (CAOT), the Victorian Order of Nurses, Dearness Home, Kiwanis Senior Center, Horton Street Senior Center, or Hamilton Road Senior Center through a recruitment flyer, email, or newspaper ad.

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

Hello,

My name is Zakara Stampp. I am a master's student in the Health & Rehabilitation Sciences program at Western University. Thank you for your interest in the research study that I am conducting, along with my supervisor, Dr. Colleen McGrath.

In order to participate in this study, you must be 60 years of age or older, self-identify as having age-related vision loss (which includes macular degeneration, glaucoma, and/or diabetic retinopathy), have had your diagnosis for at least 1 year, be comfortable participating in sessions in English or French, and be willing to share your story about the coping mechanisms you have used to maintain your engagement in meaningful activity since your vision loss diagnosis.

This study will examine how older adults with age-related vision loss cope with vision loss in ways that support their engagement in meaningful activities. 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 via Zoom, over the telephone, or in person (only if Public Health measures allow) at a location, date, and time of your choosing. The first meeting, which is a narrative interview will address topics related to the coping mechanisms you use to maintain your engagement in meaningful activities. The second session will be a semi-structured interview. It will build and expand upon the ideas and responses you share during the first interview. Before the third meeting, the researcher will send you a draft-rendering of your story via either email or a physical copy will be delivered to you (depending on your preference). In the third, and final interview, you will have an opportunity to reflect and share your perspectives on 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 given below.

Zakara Stamp

MSc student in Health & Rehabilitation Science

Colleen McGrath, PhD

Assistant Professor, School of Occupational Therapy

Thank you,

Zakara Stamp

APPENDIX IV: Letter of Information & Consent

Project Title: The Coping Strategies of Older Adults with Age-Related Vision Loss: A

Narrative Account

Principle Investigator

Colleen McGrath, PhD

Assistant Professor, School of Occupational Therapy

Co-Investigator

Zakara Stamp, BSc.

MSc student in Health & Rehabilitation Science

1. Invitation to Participate

You are being invited to voluntarily participate in a project aiming to study the coping mechanisms used by older adults with age-related vision loss (ARVL) to maintain engagement in meaningful activities. To participate in this study, you need to meet the following criteria: (1) be 60 years of age or older; (2) have a diagnosis of ARVL (including macular degeneration, glaucoma, and/or diabetic retinopathy); (3) be able to communicate in English or French; and (4) be willing to share your stories about the coping mechanisms you use to maintain your engagement in meaningful activity. A maximum of five 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 2017, vision loss was one of the main contributors to the number of years lived with disability in the Canadian older adult population, aged 65 and older. Impaired vision is commonly associated with significant negative implications on the physical, cognitive, psychological, and social functioning of older adults. Extensive research has demonstrated the detrimental effects of ARVL on older adults' ability to continue to engage in meaningful activity. It is important to focus on meaningful activity engagement because when restricted, activity deprivation can lead to negative effects, such as: psychological distress; social isolation, decreased life satisfaction; and compromised health-related quality of life.

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 (approximately 1-2 hours each) over a period of four months. Each of these meetings will be conducted either over Zoom, the telephone, or in person (if COVID-19 restrictions allow).

Meetings will be arranged 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 question by the researcher, related to how you have used coping strategies in order to continue taking part in your favorite activities since your vision loss. After you have finished telling your story, the researcher will prompt you to provide further detail on specific topics you raised during the storytelling. This session will be audio recorded and transcribed by hand by the co-investigator.

During the second session, you will participate in a semi-structured interview. The purpose of this interview is to generate further detail in relation to the previously shared stories. 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 and transcribed electronically using the NVivo transcription software.

Before the third meeting, the researcher will provide you with a draft of the narrative account made up of the stories you've shared during the first and second session. This narrative account will be mailed to you as a physical copy or sent electronically via email. In the third and final interview, the researcher will ask you to reflect and share your thoughts on the narrative account. This session will also provide you with an opportunity to clarify and elaborate on information that you shared with the researcher during the first two sessions. At this point, any objections to the draft version should be voiced. This session will be audio recorded and transcribed electronically using the NVivo transcription software.

You may receive a copy of the study results via posted mail or electronically via email.

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. That being said, 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. The research team will provide you with an information sheet that details mental health resources available in the London community at the beginning of the study.

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.

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. 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. 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 monitoring purposes.

Your full name, address, postal code, telephone number, and email address will be collected for study correspondence (sending and receiving study documents, communication with the researchers, supporting ongoing data collection). Audio recordings will be collected for data analysis purposes. Age and partial date of birth is collected to ensure participant eligibility in the study as well as for the demographic questionnaire. Gender, race, ethnicity, marital status, number of children, distance away from children, location of birth, name of vision condition, length of diagnosis and visual ability based on the diagnosis will be collected as part of the demographic questionnaire.

All three interview sessions will be audio recorded. In addition, the researcher will take 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. Consenting to participation in this study allows for the use of unidentified quotes obtained during the study in the dissemination of this research.

To protect your identity, a pseudonym 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 pseudonym with your real 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 (or a secure safe in a personal, private office if COVID-19 guidelines restrict access to the school facilities), 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 \$10 honorarium which will be provided in the form of a Tim Horton's gift card.

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 Zakara Stampf.

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 (519) 661-3036, email: ethics@uwo.ca.

11. Risks of Email Communication

Email is not a secure form of communication and therefore is not recommended for the transfer of research data. The only research data that would be emailed to you is a copy of your final narrative account. This narrative account will use a pseudonym and therefore will not identify you. If you would prefer the narrative account, be sent through posted mail, or dropped off at your home, that can be arranged.

12. Use of Third-Party Platforms

The online video conferencing platform, Zoom, will be used if a virtual interview takes place.

Here is a link to Zoom's privacy policy: <https://zoom.us/privacy>. Data collected by Zoom is stored in the home country of the user's account.

NVivo is a qualitative data analysis computer software package produced by QSR International.

It will be used to transcribe audio recordings of interviews and to help with the analysis of the research data. Here is a link to QSR's privacy policy: <https://www.qsrinternational.com/privacy-policy>. Data collected by NVivo is stored on the server in the county closest to the user, in Canada.

Though Zoom and NVivo state they are both safe and reliable platforms who take multiple steps to encrypt data, there are always risks on the internet. Personal data may be subject to a breach with consequences such as database corruption, confidential information leaks or theft of intellectual property.

This letter is yours to keep for future reference.

APPENDIX V: Verbal Consent

Project Title: The Coping Strategies of Older Adults with Age Related Vision Loss: A Narrative Account

Principle Investigator

Colleen McGrath, PhD

Assistant Professor, School of Occupational Therapy

Co-Investigator

Zakara Stampp, BSc.

MSc student in Health & Rehabilitation Science

Verbal Consent

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 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

Name of Participant

Date of Verbal Consent (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Researcher Signature

Date (DD-MM-YYYY)

APPENDIX VI: Written Consent

Project Title: The Coping Strategies of Older Adults with Age Related Vision Loss: A Narrative Account

Principle Investigator

Colleen McGrath, PhD

Assistant Professor, School of Occupational Therapy

Co-Investigator

Zakara Stampp, BSc.

MSc student in Health & Rehabilitation Science

Written Consent

Written consent will be documented by the participant, by checking the appropriate boxes and signing.

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 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

Printed Name of Participant

Participant Signature

Date of Written Consent (DD-MM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

Researcher Signature

Date (DD-MM-YYYY)

APPENDIX VIII: Interview Guidelines

First Interview

Thank you for participating in this research, which will be looking at the coping strategies used by older adults with age related vision loss to maintain engagement in meaningful occupation. In this interview, I would like to hear your story about how you have coped with your age-related vision loss since your diagnosis. You can tell me your story in any way you like, and in any order. Once you are done telling your story, I will ask you some questions, to learn more about certain topics you have shared. Before we start this interview, are there any questions you would like to ask me? [Respond to all participant questions].

Question: Can you tell me the story of how you have coped with your age-related vision loss since your diagnosis?

After the participant is done sharing their story, clarification questions will be asked but only based on the information shared during this session. Sample follow up questions will include:

1. You talked about _____, can you elaborate on that?
2. How does _____ relate to your coping skills?
3. You mentioned *coping mechanism*, can you elaborate on when you have used this in daily life?

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

Second Interview

Randy

1. So, the first question I have to ask to you is, you talked about this fear that you had when first diagnosed and considering the history that you have with your wife, does fear come into play at all when you're maintaining your favourite activities?
2. The second question I have is, so, language is something that seemed very important to you and the way that you use language when you're talking about your visual problems. You specifically said that you like to use the term legally blind. Why are you comfortable with that label?
3. Okay, and then following up with that question, who are you comfortable telling that you're legally blind?
4. Are there certain people that you would prefer to share that with, or no?
5. Okay, and then do you think that when you clarify situations, that is what is helping you to keep participating in going to the store, doing your regular activities? When you clarify and say to people: I am legally blind, please do not mind my eyes, that is what allows you to do that task or activity seamlessly?
6. Do you feel that being judged prevents you from participating in perhaps activities that you like to do just for fun?
7. So, do you find maybe, not bringing attention to your vision loss is a way of coping? Do you not try to bring attention to it so that you can continue on and participate in your favourite activities without having judgement or without having the hustle and bustle or people worrying about you?

8. So, next question, you talked about an old classmate who developed a very negative attitude over the years. Can you explain how you approaching life with positivity and being happy helps you maintain your favourite activities?
9. Can you maybe tell me a story of a time when you had to remain positive and tap into that thought process to do something that was new to you or any meaningful activity?
10. And do you think that staying positive during those times helped you to overcome vision problems?
11. Alright, so something I also wanted to bring up was that you mentioned a few times that you do not want to be mistaken as someone who uses drugs or who is under the influence due to your eyeglasses or to your eye twitching. Can you explain to me a little bit more about that?
12. I want to talk to you about church. How do you think that church and religion play into your coping with vision loss?
13. Can you tell me about a story or a time when you wanted to do something, you wanted to do an activity and vision loss was getting in the way of that and you turned to religion to cope and allow yourself to continue on.
14. Yeah, you mention that you now work from home, was that due to COVID or was that an intentional move to eliminate any obstacles on the way of you getting to work?
15. Okay, my next question is, you talked about certain instances where you're going to avoid disclosing your diagnosis to strangers, but then you talked about other instances where you'll let that person know right away that you have vision loss. So, who are you willing to tell and share that information with?

16. You talked about appearing like a regularly sighted person in the office. Do you think that appearing regularly sighted is a coping mechanism to kind of navigate work or any other activity that you do?
17. Alright, so, my next question is that you talked about taking some online courses and going to seminars and the knowledge that you gained to help you cope. How do you cope with your vision loss to be able to take part in online courses over the computer?
18. You like to learn, and you like to keep learning and stay smart. Do you think that is a coping mechanism in itself?
19. So, you talk about being a very visual person despite your ARVL and I think that's very interesting, and so, I want you to talk to me a little bit more about that. About being visual, despite having vision loss.
20. I know you're not a huge fan of the computer. Can you tell me a story about how you cope to use the technology you can't avoid for work or personal reasons?
21. Okay, I want to explore this relationship that you have with your boss and how he helps you out at work. Do you want to tell me a little bit more about that?
22. So how did this relationship get started then? How did he turn into what it is now? I know that he helps you out so much now, but how did this get started?
23. So, something else you mentioned about work was staying organized and your organizational system. Do you think that this is a coping mechanism to maintain work?
24. Would you be able to maintain work with vision loss if you weren't so organized?
25. Something else that we talked about a little before was you going to a concert. So, what does that look like for you?
26. How do you go and see everything and enjoy the experience with vision loss?

27. I'm wondering, do you have a social network of people that help you to maintain your meaningful occupations and help you to continue doing the things that you love? Do you have people who support you in doing that besides your boss?
28. There's quite a few situations that you talked about where you take on the role of the advocate. Do you think that this plays into a coping mechanism?
29. Mhm, and so this role that you take on as the leader or in a leadership position, do you think that this plays into your occupations?
30. Is being a leader and being an advocate, is this one of your meaningful occupations?
31. Okay, so, I wanted to ask you about your friend. Your, I don't want to call her your girlfriend without you calling her your girlfriend, but I wanted to ask what type of role she plays in your life as far as maintaining your favourite activities cause it seems like you spend quite a bit of time with her, so how does that work?
32. And do you think that being in a relationship or being in a romantic relationship is a coping mechanism for you? Having a partner and having someone to share your life with?
33. So, building on the social aspect of things, I kind of want to talk about service providers. I know you work with Balance; can you talk about how certain service providers help you with coping at all?
34. I know you were talking about the iPhone and how they were gonna help you with that but are there any other situations like that that service providers help you with?
35. So, my next question is about your sister. You mention that you talk to her occasionally, here and there, and that your relationship has defiantly grown over the years. Do you

think this relationship that you have with your sister plays into your coping mechanisms at all?

36. And this sense of family, does this play into coping for you and being closer with them later in life?

37. So, with your sister who is also partially sighted, do you feel a sense of comfort? Is it comforting to talk to someone who has similar issues as you?

38. So, my next question is gonna be about humour. I want to hear about humour and how you use it as a coping mechanism. You're always using humour with me, so I want to know how you use it to cope with AVRL.

39. So, when you use humour in situations with sighted people, do you think it acts as a way to break the ice and make it a more comfortable situation for yourself?

40. Okay, so moving on, how would you say that your coping mechanisms change or differ as you navigate different environments?

41. So, do you think that your coping mechanisms are different at work then they are in the church, or do you think you cope with your vision loss the same in different situations?

42. So, your coping would be different in a new environment then it would be in an environment you already know?

43. You talk about not being accepted by others due to the simple fact that you had vision loss. Can you elaborate on that feeling of unacceptance?

44. So, do you think that not feeling accepted by sighted people stops you from participating in some activities that you might like to participate in?

45. Ok, so, can you tell me a story about a time when another person was judging you or not accepting of you with your vision loss and how you coped and overcame that to continue an activity?
46. So, can you tell me a little bit more about that? When the light was flooding into your eyes and you couldn't see, how did you get home, how did you navigate that situation?
47. Alright, so, my next question is, a little bit ago, you mentioned that your friend was upset with you for getting your emails read to you by your boss and I know you mention that they also had visual problems. Can you tell me a little bit more about this?
48. My other question for you is you talk about the importance of asking for help and how as you've gotten older, this is something that you've really embraced. Who are you willing to ask for help from?
49. Okay, so, do you prefer the help of assistive devices over asking other people?
50. Okay, so back to assistive devices, you talk about your monocular a lot, your telescope. Are there anymore assisted devices that you use to maintain your favourite activities?
51. Do you think that finances play a part in that? Do you think that if you had more spending money you would have more devices? Other than the E-Sight?
52. So, this relationship that you have with Louis, you think that he helps you with some areas that you're lacking in due to the vision loss and you help him as well?
53. Are there any other people in your social network that you could think of that are important?

Pearl

1. So, the first question I have is about your grandchildren. You gave an example of a time when you had trouble reading a story to your great granddaughter at the cottage. And so,

it made me think about how you cope with vision loss to maintain those close relationships that you have with your grandchildren because sight plays into it sometimes?

2. So, if you were in another situation where it was hard to read or where your vision loss got in the way, what would you do to try to cope with that then?
3. Can you think of any other coping mechanisms that you have that I guess you use specifically when it's your grandchildren?
4. Let's talk about some more about how COVID has influenced you in participating in your favorite activities. Has COVID gotten in the way for you?
5. Considering you don't have a lot of support from your other son and your relationship is sometimes strained with your daughter, do you think that the lack of support or the situation or your relationships with your children influences how you cope with vision loss?
6. So, looking back to when you were talking about a situation where your, where you wanted... you had a problem with your computer and you asked your son to help and he said, no. In our moment when he said no, how did you cope with your problem? How did you navigate the computer?
 - a. Did you use the computer?
7. So, how does the strained relationship with your daughter play into you coping with vision loss?
8. OK, so I guess we'll talk about back when you originally received your age-related vision loss diagnosis, when you received that diagnosis, when did your vision problems become separate from your initial vision problems that you had?

- a. How did you notice that your vision was getting worse between the two diagnoses?
9. So, I guess building off of reading, how, what are some ways that you cope with your vision loss to continue being able to read?
10. How do you cope with your vision loss to continue being able to write?
11. So, my other question is, was journaling a coping mechanism for you when you were able to read?
12. So how do you use your iPad to help you cope with age related vision loss?
13. So, what are... what would you say your most meaningful activities are? What are your favorite activities?
14. Okay, so how do you cope with your vision loss to continue taking photos?
 - a. Is it just the iPod and that's easy enough for you to use or do you have to do anything else to make sure you're still getting a good shot?
15. Okay, so when you talk about some of your meaningful occupations, some of them included driving somewhere. Do you remember the circumstances surrounding you losing your license?
 - a. Okay, so when you lost your license, did that affect your ability to cope with age related vision loss?
 - b. Seeing as it made transportation more difficult, did you have to start relying on people?
 - c. How did that affect your coping?
 - d. So, did losing your license affect your ability to maintain social connections and seeing people in person?

16. Because you put that energy in that time into creating your space and having like a positive relaxing space in your home, does that help you cope with vision loss at all?
17. How do your social activities and your social relationships help you to cope with vision loss? Because I know that you are really invested your graduating class of nurses. You do the courses. You met your friend in Asia. You are so involved in so many things. How does that help you cope with vision loss?
18. So, do you think that just ...I guess being able to talk to other people it helps you to cope because you're staying busy and you're staying active, and you feel comforted by others?
19. You talk about helping others and you really are like an advocate for helping your friends and your family when you can tell that they are struggling. Do you find that helping other people, is a coping mechanism for yourself?
20. So, can you tell me a story about a time when you were helping others and when you were being advocate for others, and it helped you to cope with your vision loss?
21. I will just ask you to share anything else that you can think of that can relate to you coping with your vision loss to maintain participation in your favorite activities.

Kim

1. So, the first question I have is, can you tell me a little bit about how you made the decision to stop driving?
 - a. ...when you say that you were planning to give up your license, can you go into some of the things that you did, including moving?
 - b. You said you moved so weren't downtown, what were the other things you did to try to plan for this?

- c. So, when you gave up your license, what was that like for you? When you decided to stop driving, how did that feel?
2. So, how do you navigate the community now?
3. Your vision loss, does that make it difficult to use the bus as you did before?
4. Okay, so the next question I have for you is, I know you talked about how you enjoyed to read and you really like to read books before and now that you've shifted over to audiobooks, have you enjoyed listening to audiobooks?
5. Okay, and when you watch sports on the TV, is it hard to see?
6. Do you use any technology or assistive devices to help you participate in some of the activities that you like doing?
7. So, what do you do then? Tell me about a typical day in life for you!
8. So, when you knit, do you need help to see? Or you can see everything you need to see with the use of your hands?
9. You mention that you had visual challenges all of your life. Can you talk to me about what you mean when you say that?
10. So, do you like to use assistive devices, or do you avoid using assistive devices?
 - a. I know you said you don't like using your glasses and I know you said that you do use a magnifier. If you had access to other assistive devices, would you use them?
 - b. So, do you think not having access to these devices is what's stopping you from using them?
11. My other question is, do you think that because you've had vision loss all your life, you've been blind in one your whole life, that made it easier for you to adjust when you got diagnosed with the macular degeneration?

- a. You said it didn't change much for you, right?
 - b. So, you were prepared because you'd already been blind?
12. So, could you maybe tell me about the circumstances in which you were diagnosed with macular degeneration?
- a. Was it at a check-up? How did they determine this?
 - b. And it didn't affect you much because you were like, okay, I already have vision problems?
13. Okay, so, the next question I had was about your social interactions. So, you mention that in your apartment complex, it's a senior's complex so a lot of people who are older who have health issues. You said there's a general understanding that you have vision problems and people know what to expect there, right?
14. And so, do you think that you have an easier time explaining that to people who are older, people who understand, versus someone who might be younger than you and who wouldn't understand?
15. So, you talk about telling people about your vision loss when you first meet them. Do you do that with everyone when you first meet them? You just let them know?
16. Are there situations when you don't feel comfortable telling someone about your vision loss?
17. Okay. I wanted to ask about your brother. You said he lives in town, but you don't see him a lot, right?
- a. Is there a specific reason for that?
18. Okay, I wanted to talk about this theme of independence that I've noticed. You really value your independence. Do you want to talk a little more about that?

- a. So, you don't like people interfering. Have you had a moment when somebody has been interfering with you?
19. Okay, so, the next thing I wanted to talk about was your interaction with friends. You said you have friends who will drive you places, and you play games with some of your friends. Your social circle. You did say that you don't want to beg for rides, when you go somewhere, you don't want to beg.
20. Do you think that you struggle to ask others for help? Is that something that doesn't come easily to you?
- a. Do you want to talk a little more about that?
 - b. Do you think that is rooted back in independence and in being an independent woman on your own?
 - c. Do you think that there's maybe a reason why you're so – the reason why you value independence so much. The reason why I ask is because I wonder if this is a coping mechanism for you in a way. Is to remain independent and to be very strong. That might help you cope with your vision loss?
21. So, you talk about playing games. You like to play cribbage and what else did you like to play?
- a. So how to manage with playing cribbage? I know you said you had the extra big cards but otherwise, is there anything else you do to try and help yourself out?
 - b. So, you don't have any strategies to sort of help you navigate cribbage other than the big cards? You just see what you can and you're good to go?
22. What is your reluctance in initiating that ask [for a drive]? What is making you reluctant to ask her in the first place?

- a. Do you take taxis often?
 - b. Are they hard to navigate, visually?
23. Do you think that that is your biggest coping mechanism? Just acceptance and being matter of fact?
24. You seem very resilient to what goes on around you. You soldier on no matter what the situation is, no matter whose helping you, who's not helping you – it doesn't matter to you, you get it done. Have you always been resilient or has that just been in the face of vision loss?
- a. I guess you've been blind your whole life, do you think it stems from that or is it truly just a personality trait?
 - b. So, if you weren't resilient, do you think it would make your vision loss harder on you?
25. How do you think that social interactions tie into your coping?
- a. Do you think that being around people, playing games with friends, seeing your daughter, that does interactions help you cope?
26. Yeah, and when you're bored, does that have an effect negatively?
27. I guess my question is what were some of the differences that you noticed in your personal activities, your favourite activities, going from just having the one eye problem to now you have macular degeneration. How was that transition in terms of the things you love doing?
28. Alright, and do you think there's anyone else that we haven't talked about, that factors into this social circle of yours. The social circle of support, because we talked about your

daughter, we talked about your friend, is there anyone else who helps you cope and keeps you stimulated?

- a. Does that bother you?
- b. Do you want more people in your social circle?

29. And do you think that being low energy is preventing you from doing more activities?

- a. So, if you had more energy, you'd be doing more things and your vision loss, how does that factor into your vision loss? Is that a part of it at all?

30. When you talk about losing your license and giving up your car, do you remember what was the final moment or what made you decide that you were going to give this up on your own?

31. So then, are there any other tasks that you would like to do but you don't do because of your vision loss?

- a. I know we talked about bridge, driving – is there anything else that your vision loss stops you from doing?

32. So, you're at a point in time where you don't want to do anything else because you don't have the energy?

Liz

1. So, you mentioned that your mother and your grandmother also had similar vision loss problems and you grew up watching them go through that. Do you think that watching them cope with vision loss over the years helped you to cope with vision loss and maintain your meaningful activities?

2. Do you think you could tell a story or a time when that was true in your life, or when they, or when something that they taught you, or something that they did around you helped you?
3. That's good and so the extra insight from your mom and your grandma, how did that, how do you think that helped you to participate in some of your activities, now that you're losing your vision or now that your vision is affected?
4. So, coping wise, what do you think the biggest thing is that you took from your mother?
5. So, when you're faced with a loss of independence or when you're in a situation where you need to rely on someone else, how do you cope with that?
 - a. And so, can you tell us a story about a time when someone, I guess, got in the way of what you doing what you wanted to do or when you weren't able to be independent and can you tell me how you actually were able to navigate that?
6. So, you feel comfortable asking people or asking strangers for help, when you want to maintain your independence, to continue the activity that you're doing?
7. So, the next question I have was about your optometrist. So, you said that you had a close relationship with him, and he was able to get you in to do your surgeries and your treatments super quick and that was beneficial right?
 - a. So, my question is, having that close relationship with your optometrist and the speed at which you were able to start treating, do you think that that have an effect on how you now cope with age-related vision loss?
 - b. How do you think that it's affected your coping mechanisms?

- c. So, these coping skills that your optometrist is able to provide you with, have you ever had to use one to specifically complete an activity that you really wanted to do?
- 8. So, the next question I have is you mentioned a time when you took the VIA to visit your daughter in Kingston and you did so on your own. How did you navigate that trip on your own despite the challenges with your vision loss?
 - a. Alright and do you think that having the means to go first class makes it easier, or that having the means to do those extra things is a coping mechanism for your vision loss?
- 9. So, you also mentioned times when you would attend fitness classes with your friends and how you really enjoyed being able to interact in the social setting and get out and about with your friends.
 - a. So, how do you cope now with the loss of this meaningful activity? Do you have something that you replace it with or...?
 - b. Okay, so when you're out and about those classes, do you rely on your friends as coping mechanisms to help you out with vision loss?
- 10. Alright and besides your friends, how else do you manage your vision loss, when you're in classes or when you're out and about?
- 11. So, my next question is, when you talked about enjoying crocheting and making little crafts, how do you cope with your vision loss to be able to continue that meaningful activity?
- 12. Can you tell me about a story of a time when you have to cope with your vision loss to be able to continue your travels?

13. Do you have a time when you use the white cane to maintain your activity? When you have to get your white cane out and use it and that was the only way you were going to be able to continue on.
14. So, this technique of memorizing and counting, this would be a big coping mechanism for you?
- a. And is this something that you actively did while you had your vision or something that you just naturally do on your own?
15. So, you talked about camping and how that was a big deal with your family. Does vision loss ever get in the way of that at all?
- a. So how do you cope at all the loss of that meaningful activity?
16. What other assistive devices do you use to help you cope with age-related vision loss?
- a. Have you had any success with your miner's light?
17. Okay so speaking about the three-year-old actually, I guess some of your younger grandchildren or when they were younger, did vision loss ever get in the way of you maintaining that closeness with them?
- a. So, do your grandchildren help you cope them with age-related vision loss?
- b. So, having all of those tasks divided up between the different kids and grandkids, does that help you cope with vision loss?
18. You talk about how you use your cell phone and it's like your lifeline outside of the home and you need it. So, can you tell me a story about a time when age-related vision loss got in the way and your cell phone was able to help you cope?

Morgan

1. Could you tell me a story about a time you used a trick or a coping mechanism that you learned from your husband, to cope with your own vision loss and maintain a meaningful occupation?
 - a. How do you use that technique now that your vision has been worse?
 - b. And do you think that helps you to maintain your favorite activities?
2. Can you share a time when you use ParaTranspo as a means to do one of your meaningful occupations besides work?
 - a. Okay, and do you think that's a reliable service that's allowed you to do those occupations and continue despite vision loss?
3. So, you said that you like to network with other friends who have disabilities. What does this networking look like to you?
 - a. Alright, do these conversations and this way that you've set up your networking now, does that help you to maintain any other meaningful occupations or is that the meaningful occupation in itself?
4. Yes, on the topic of COVID, can you talk about in what other ways COVID has affected your meaningful occupation?
5. So, this feeling, this distrust that you have and the safety of your community due to the lack of, I guess the lack of effort on the end the police force, how does that also come into play with your vision loss?
6. So, the next question I have...yeah, it's actually about the homelessness and the drug related community in the downtown core, and yes, you did just answer that question

because I asked...I was going to ask, when did that get in the way of you completing a meaningful occupation and how did you cope with that, but we just went over it.

7. So, do you think that in a situation like that, you would rely on a stranger or a bystander to help you cope, if that was getting in the way of your occupation?

a. And do you feel comfortable to ask?

8. Okay. So, you said before that you like to be sure before something unpoor happens.

Can you explain what you mean by that?

9. So, I know that you said that you were sighted when that happened, but do you think that that experience has had an effect on you relying on others to help you cope with traveling, now that you have vision loss?

a. And do you feel that this feeling of maybe being taken advantage of, stops you from participating in certain meaningful activities so that you can avoid those feelings coming up?

10. So, the next question I have is about the CNIB. So, you mentioned that they worked with you briefly and that they were able to help you, but can you explain what they were able to do with you?

11. So, you talked about how you enjoy watching Netflix and different movies. How do you cope with your vision loss to be able to continue this meaningful occupation?

12. So, could you tell me a story about a time when your vision loss had a negative effect on your vacation activity and how you were able to overcome that challenge?

13. So, you talked about how you struggle to get that iPod set up properly so that you could use it and you were waiting for either your son or your daughter to come. Then you said

probably not your son...so how do you cope with your vision loss to manage the use of the technology you enjoy?

14. Do you have any psychological coping mechanisms that you used to cope with your vision loss and maintain meaningful occupation?
15. So, you briefly talked about your feelings towards people who are sighted working for vision loss non-profits and I wanted to know if you could expand on that?
 - a. Okay and does that frustration with those groups, ever get in the way of you participating in meaningful occupation?
16. Do you think that your financial freedom has an effect on how you cope with vision loss?
17. Can you tell me about a time you were able to use your sense of humor to cope with vision loss and continue an activity?
 - a. And do you think it's effective?

Sam

1. You talk about your love for photography and that happens to be a very visual occupation. Can you tell me the story of when your vision began to negatively affect your photography and how did you cope to continue that at the time?
2. Okay, so the next question is, you talked about using a visualization technique to be able to see the pictures in your head, despite age related vision loss. Is that a coping mechanism that you use to continue enjoying photography?
3. Can you tell me a story about a time you used your white cane to cope with your vision loss and participate in a meaningful activity?

4. So, you also told the story about you practicing and learning songs for your church choir.
I want to know how you cope with your vision loss to be able to read the songs, memorize them, and then sing them?
5. So, you also talked about going to the library and using the computer to do research or any other thing that you need to do that day. Does your age-related vision loss influence that at all?
6. Okay my next question is, did writing braille become harder for you as your vision loss progressed or not writing braille but reading braille.
7. You talked about the organization system that you set up to be able to pick out a clothing item on your own easily if you need to get dressed for shows. How did you get that set up in the first place?
8. You talked about a fear response that you had when crossing that busy street to get to the Shoppers and I wanted to know if fear got in the way of any of your other meaningful activities at all?
9. You mentioned how you don't think it's practical or necessary to have someone helping you cross the street and that when your neighbors would ask you that that wasn't a practical thing. Did you have a bad experience with a bystander, when asking for help coping with their age-related vision loss to maintain a favorite activity?
 - a. OK, so then I would just want to determine why do you think that it wouldn't be practical or necessary to ask your neighbors for help?
10. Does worrying about appearing as a blind person stop you from participating in meaningful activities at all?
 - a. Do you worry about appearing as a blind person and does that stop you?

11. Can you tell me a story about a time when positivity allowed you to continue an activity in the face of vision loss?
12. So, the next question I have is, you talk about music and how writing songs is a coping mechanism for you. I wanted to talk about psychological coping and how writing music helps you to continue other activities, psychologically.
13. How does religion help you to psychologically maintain other activities?
14. You talked about Wheel Trans very briefly, but are there any other support organizations that you use as well?
15. I asked, are there any other coping mechanisms that you use to help you overcome age related vision loss and maintain your meaningful activities?

Third Interview Questions

1. Does my rendering of your story reflect what you wanted to convey? Does my storyline capture the important aspects of your experience with coping as a result of ARVL?
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 study?

APPENDIX VIII: Demographic Questionnaire

1. What gender do you identify as?
 - a. Female
 - b. Male
 - c. _____ (written if other)
 - d. Prefer not to answer

2. What year were you born in?
 - a. _____ (open response)

3. What is the name of your vision condition?
 - a. Macular degeneration
 - b. Glaucoma
 - c. Diabetic retinopathy

4. How many years have you had your vision condition for?
 - a. _____ (open response)

5. How would you describe your vision abilities based on your diagnosis (example: partially sighted, legally blind, cannot see at night, ability to perceive light, etc...)?
 - a. _____ (open response)

6. How would you describe your ARVL condition onset?
 - a. Gradual
 - b. Sudden

7. What is your ethnicity?
 - a. _____ (open response)

8. What city do you currently live in?

- a. _____ (open response)
9. What is the highest degree or level of education you have finished?
- a. PhD
 - b. Masters
 - c. Bachelors
 - d. Trade School
 - e. College
 - f. High School
 - g. Some High school
 - h. Elementary school
 - i. Prefer not to answer
10. Are you currently married?
- a. Yes
 - b. No
 - c. Widowed
 - d. Prefer not to answer
11. Do you have children? If so, how many children do you have?
- a. _____ (open response)
12. How many of them live within 20km of your home?
- a. _____ (open response)
13. Where were you born?
- a. _____ (open response)

APPENDIX IX: Screening Form

Screening Form

- 1) Do you have a diagnosis of ARVL (including macular degeneration, glaucoma, or diabetic retinopathy)?
 - a. _____
- 2) How long has it been since you were diagnosed with your ARVL condition?
 - a. _____
- 3) Does vision loss impact your ability to engage in your daily activities?
 - a. _____
- 4) Are you at least 60 years of age?
 - a. _____
- 5) Can you participate in an interview in either English or French?
 - a. _____

APPENDIX X: Research Ethics Approval



Date: 30 August 2021

To: Dr. Colleen McGrath

Project ID: [REDACTED]

Study Title: The Coping Strategies of Older Adults with Age Related Vision Loss: A Narrative Account

Application Type: NMREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 01/Oct/2021

Date Approval Issued: 30/Aug/2021 15:50

REB Approval Expiry Date: 30/Aug/2022

Dear Dr. Colleen McGrath

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Interview Guide	Interview Guide	18/Jun/2021	2
Telephone Script	Recruitment Materials	18/Jun/2021	2
Email Script	Recruitment Materials	18/Jun/2021	2
Study Protocol	Protocol	18/Jun/2021	2
Demographic Questionnaire	Paper Survey	13/Aug/2021	2
Recruitment Flyer	Recruitment Materials	13/Aug/2021	3
Newspaper advertisement	Recruitment Materials	13/Aug/2021	2
Email Script (Recruitment Organizations)	Recruitment Materials	13/Aug/2021	1
Letter of Information and Consent Form	Written Consent/Assent	13/Aug/2021	2
Letter of Information and Consent Form	Verbal Consent/Assent	13/Aug/2021	2
Demographic Questionnaire (French)	Translated Documents	13/Aug/2021	1
Email Script (French)	Translated Documents	13/Aug/2021	1
Email Script (Recruitment Organizations) (French)	Translated Documents	13/Aug/2021	1
Letter of Information and Consent Form (French)	Translated Documents	13/Aug/2021	1
Newspaper Advertisement (French)	Translated Documents	13/Aug/2021	1
Recruitment Flyer (French)	Translated Documents	13/Aug/2021	1
Debriefing Form (French)	Translated Documents	13/Aug/2021	1
Telephone Script (French)	Translated Documents	13/Aug/2021	1
Recruitment Script (French)	Translated Documents	13/Aug/2021	1

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
TRAC Response - NVivo	Technology Review document	14/Jun/2021	1

Screening Form	Screening Form/Questionnaire	13/Aug/2021	3
Mental Health Resources	Other Materials	13/Aug/2021	2
Mental Health Resources (French)	Translated Documents	13/Aug/2021	1
Screening Form (French)	Translated Documents	13/Aug/2021	1
Translation Attestation Letter	Translation Certificate	13/Aug/2021	1

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, 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 NMREB 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 NMREB 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 NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,



Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).