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Navigating the "Blind World": The Psychosocial and Occupational Experiences of Parents of Adolescents with Visual Impairments

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Abstract

Using a constructivist narrative inquiry approach, this research study sought to explore how parents of adolescents with visual impairments story their psychosocial and occupational experiences. Participants of the study consisted of four parents who were currently raising adolescents with visual impairments between the ages of 14 to 17. Participants took part in two in-depth narrative interviews, in which they answered several open-ended questions about their experiences of raising their adolescent children who were visually impaired. Participants also participated in a brief concluding interview session, in which they provided feedback on the narrative that I constructed based on their interview responses. A holistic-content analysis (Lieblich et al., 1998) and a thematic analysis (Braun and Clarke, 2006) were performed to analyze participants' narrative accounts. The analyses identified six themes including: 1) *Grief, Uncertainty, and Frustration During the Early Years*; 2) *Identity as An Advocate*; 3) *Enabling Independence and Envisioning the Future*; 4) *Planning Occupations in the Time of Transition*; 5) *Navigating Challenges in Getting Required Support: Frustrations and Successes; and 6) Changed Perceptions within the Context of Societal Misunderstanding*. Findings of this study address the gap in the current body of literature by highlighting the complexity of parents' psychosocial and occupational experiences along the journey of raising an adolescent with a visual impairment and ways in which parents negotiate and make sense of those experiences. The implications of the findings of this exploratory study for future research and low vision rehabilitation practice are also discussed.

Keywords: parenting, psychosocial experience, occupation, visual impairment, narrative inquiry

Lay Summary

In Canada, approximately 88,010 adolescents are living with a visual impairment. Adolescence is a developmental period where many transitions and changes take place, and parents of adolescents with visual impairments often need to navigate unique challenges and parenting tasks along their parenting journey. This research study aimed to understand the experiences of parents of adolescents with visual impairments. Four participants (three mothers and one father) who were currently raising adolescents with visual impairments between the ages of 14 to 17 took part in this study. Participants were interviewed and shared their stories of raising their adolescent children who were visually impaired. Analysis of the participants' narrative accounts revealed six themes including: 1) *Grief, Uncertainty, and Frustration During the Early Years*; 2) *Identity as An Advocate*; 3) *Enabling Independence and Envisioning the Future*; 4) *Planning Occupations in the Time of Transition*; 5) *Navigating Challenges in Getting Required Support: Frustrations and Successes; and 6) Changed Perceptions within the Context of Societal Misunderstanding*. Findings of this study highlight the psychological process, social reality, as well as the important and meaningful parenting tasks involved in the lives of parents of adolescent with visual impairments. Knowledge gained from this study has the potential to inform future research as well as the development and reform of programs and services for adolescents with visual impairments and their parents, within the context of healthcare, social service, and education systems.

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Chapter I: Introduction

This thesis was conducted to examine how parents of adolescents with visual impairments frame and narrate their psychosocial and occupational experiences. I begin this introductory chapter with background information that provides a rationale for why this study needed to be conducted. Next, I define the key terms that will be frequently used throughout the thesis. I then outline the study purpose as well as my research questions. I also position myself as a researcher in this chapter by explaining how I, as a researcher, came to study my topic of interest. I conclude this chapter with an outline of this thesis.

1.1. Background and Significance

The transition to parenthood often involves notable changes in personal and social identity, as well as daily occupations and routines (Nomaguchi & Milkie, 2003; Stein, Foran, & Cermak, 2011). Parenting generally requires adults to spend a significant amount of time and energy caring for, and doing things together with, their children. For parents of both young children and adolescents, this means that they need to coordinate between childrearing-related activities and other paid and unpaid occupations that they need or want to engage in (Orban, Ellegård, Thorngren-Jerneck, & Erlandsson, 2012). In recent years, occupational scientists have come to conceptualize parenting as a relational role that involves a variety of occupations rather than a single occupation (Sethi, 2019). As pointed out by Sethi (2019), parents play multiple interconnected roles in their child's life, such as caregiver, nurturer, educator, protector, and learner.

Since the majority of children are born without disabilities and do not acquire disabilities during their childhood or adolescence, having a child with a disability, such as a visual impairment, is an unexpected life event and is often life-changing for most parents (Jenks, 2005;

King, Scollon, Ramsey & Williams, 2000; Leyser & Heinze, 2001). In the literature, raising a child with a disability has been associated with various adverse consequences for parents, such as heightened risk of depression (Olsson, Larsman, & Hwang, 2008), social isolation (Beresford, 1994), higher levels of marital dissatisfaction (Gau et al., 2012), and greater financial stress within the family (Dabrowska, & Pisula, 2010). It is not until recently that researchers started to examine what may contribute to such adverse outcomes. Various factors, such as maladaptive coping strategies, inadequate support networks, lack of access to financial resources and health services, and social exclusion, have been found to have adverse impacts on the everyday experiences and well-being of parents of children with disabilities (Algood, Harris, & Hong, 2013; Sola-Carmona, Lopez-Liria, Padilla-Gongora, Daza, & Aguilar-Parra, 2016). It also has become evident that the negative outcomes associated with parenting children with disabilities are not inevitable. For instance, findings of several studies indicate that adaptive coping strategies, adequate social support, engagement in personally meaningful occupations, as well as positive encounters with healthcare service providers all serve as buffers against stress for parents who are raising children and adolescents with different types of disabilities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Gupta, & Singhal, 2004; King, King, Rosenbaum, & Goffin, 1999; Stein, Foran, & Cermak, 2011).

In Canada, approximately 88,010 young people between the ages of 15 and 24 are living with a visual impairment (Canadian National Institute for the Blind, 2019). For young people with and without visual impairments, adolescence is a crucial developmental period characterized by rapid physical, cognitive, socioemotional, and relational changes, and signals the transition from childhood into adulthood (Chang & Schaller, 2000; Steinberg & Silk, 2002). Despite their growing independence and desire for autonomy, adolescents have relatively little

knowledge about the world around them, and therefore still require support and guidance from their parents (Chang & Schaller, 2000). For those who are raising adolescents with disabilities, besides the common challenges encountered by parents during this transitional phase, such as intensified parent-child conflict, they often face unique additional challenges, such as difficulties in helping their children navigate the transition between the education system and adult service programs (Hetherington et al., 2010).

In recent years, a number of studies have investigated the psychosocial and occupational experiences and overall adjustment of adolescents with visual impairments (Chang & Schaller, 2000; Kef & Deković, 2004; Pinquart & Pfeiffer, 2013). In addition, a growing body of research has examined the experiences of parents of children with disabilities and their relationship to psychosocial well-being (Algood et al.,2013; Howe, 2006). However, despite this increasing attention on the day-to-day experiences of members of the disability community, parents of children and adolescents with visual impairments remain an under-researched population. Only a few studies have been conducted to examine the experiences and well-being of parents who are raising children with visual impairments, and even fewer studies have addressed the psychosocial and occupational experiences of parents of adolescents with visual impairments. The few studies involving parents of children and adolescents with visual impairments have overwhelmingly utilized a self-report survey design, which limited the richness of the participants' experiences that researchers could capture. Literature on parents' narratives of raising children and adolescents with visual impairments is scarce, with a few notable exceptions (Jenks, 2005; Leyser & Heinze, 2001).

Understanding the subjective experiences of parents of adolescents with visual impairments and how they negotiate those experiences is important. Despite the valuable

knowledge about topics such as vision loss management, accessibility accommodations, and advocacy that many parents of adolescents with visual impairments have, parents' perspectives are often overlooked by the research community. Examining the psychosocial and occupational aspects of those parents' experiences could offer additional insights into the important parenting tasks involved in raising an adolescents with a visual impairment, as well as the success and challenges that the parents experience during this formative developmental period where many notable changes occur. Gaining this knowledge could potentially inform the development of support programs and services for parents of adolescents with vision impairments.

1.2. Present Study

1.2.1. Purpose of the Study

The present study aimed to explore the ways in which parents of adolescents with visual impairments frame and narrate their psychosocial and occupational experiences of childrearing. More specifically, I was interested in understanding the nature of those parenting experiences, as well as how parents negotiate their psychosocial and occupational experiences of raising adolescents with visual impairments.

1.2.2. Research Questions

Guiding research question. The primary research question that guided the proposed study was: "How do parents story their psychosocial and occupational experiences of raising their adolescent children with visual impairments?"

Sub-questions. Based on the guiding research question, this study sought to answer two specific sub-questions including: 1) What are the subjective psychosocial and occupational experiences of parents of adolescents with visual impairments? and; 2) How do parents of adolescents with visual impairments negotiate and make meaning from those experiences?

1.3. Defining the Language Used in This Study

It is important to ensure a consistent understanding of the terms used within this study. As such, I have defined those terms, including *psychosocial*, *occupation, adolescence*, and *visual impairment*, that will be used consistently throughout this study.

1.3.1. Psychosocial. In social science and health science literature, the term psychosocial refers to the interrelations between psychological and social aspects of life (Dammeyer, 2009). In the case of the present study, I take a close look at the combined influence of psychological factors (parents' coping strategies) and social context (e.g., society's attitudes towards individuals who are visually impaired) on the childrearing experiences of parents of adolescents with visual impairments.

1.3.2. Occupation. Within the field of occupational science, there are several widely accepted definitions of occupation, with some emphasizing the individual aspects (Yerxa, 1990), and others highlighting the sociocultural and/or political aspects (Njelesani et al., 2013; Pierce, 2001). This study adopted the definition of occupation proposed by the International Society of Occupational Science (2009) which states that occupation refers to: "the various everyday activities people do as individuals, in families, and with communities to occupy time and bring meaning and purpose to life… things people want to do, need to do, and are expected to do." This definition was employed in this study, since it captures the different levels at which occupations take place, as well as the various reasons that people perform and engage in occupations in various contexts. As pointed out by Wilcock (1993), engagement in occupations goes beyond physical completion of activities and involves an interaction between the body, mind, and spirit (American Occupational Therapy Association, 2017), and therefore includes both observable actions and subjective experiences.

1.3.3. Adolescence. There is no consensus with regards to the age range that defines adolescence. Although it is generally agreed that adolescence begins around age 10 and is marked by the onset of puberty, there are debates amongst scholars regarding when adolescence ends. Some argue that adolescence ends around the age of 19 (World Health Organization, 2018a), whereas others believe that adolescence continues until the age of 24 (Sawyer, Azzopardi, Wickremarathne, & Patton, 2018). Adolescence can be further divided into several distinct phases, including early (10-14-years), middle (15-17 years), and late adolescence (18-22 years; Meeus, Van De Schoot., Keijsers, Schwartz, & Branje, 2010). In this study, adolescents referred to young people who are between ages 14 and 21, individuals who are in early to late adolescence. Age 14 was used as the lower age limit, as that is when most Ontario students (with and without disabilities) start high school. Age 21 was used as the upper age limit, because for individuals with disabilities living in Ontario, age 21 is the maximum age for attending high school (Justice for Children and Youth, 2013).

1.3.4. Visual impairment. According to the World Health Organization (WHO, 2018b), visual impairment, also known as vision impairment or vision loss, can be defined as the best-corrected visual acuity less than 20/40 (i.e. need to stand closer than 20 feet from objects that people with perfect vision can see clearly at 40 feet to have the same visual experience when wearing glasses or contact lenses) in the better-seeing eye. The medical impact of adolescents' visual acuity on their everyday functioning is outside the scope of this proposed study. Therefore, this medical definition of visual impairment only served as a guideline for the proposed study, and instead of measuring adolescents' visual acuities to make sure that they meet this diagnostic criterion for visual impairment, the presence and degrees of adolescents' visual impairment were based on parents' self-report.

1.4. Situating the Researcher

My research interest in the experiences of people with visual impairments and their families was initially sparked by my own experiences as someone who is partially sighted. During my undergraduate training in Psychology and Disability Studies at the University of Windsor, my coursework in Developmental Psychology drew my attention to the topic of parent-child relationship dynamics during the child's adolescence, a developmental phase where many changes and transitions take place. With my personal experiences with visual impairment, I started to wonder, what is parenting an adolescent with a visual impairment like? Do parents of adolescents with visual impairments experience more anxiety and uncertainty during those transitional years? How do they frame and make sense of their parenting experiences? Shortly after I began my graduate studies in Occupational Science, I realized the various activities that parents do are just as important as their emotions and feelings in shaping their lives. With this new perspective comes new questions. For my own parents, I wondered if having to balance tasks, such driving me to school and fulfilling some of my social needs that would have been otherwise fulfilled by my friendships with peers, while working full-time during my early high school years had any implications on their lives. Do other parents of adolescents with visual impairments have similar experiences as my parents, and how do they perceive and negotiate their parenting experiences during those transitional years? After searching the literature and finding very few answers, I decided to tackle those questions in this thesis.

I positioned myself as an insider as well as an outsider in relation to my study participants. I am an insider in the sense that I have lived experience with visual impairment and went through adolescence not long ago, and therefore, was able to easily connect with the participants and could relate to some of the stories that they shared during the interviews,

especially when they talked about their adolescent children. I am an outsider in the sense that I am not a parent of an adolescent with a visual impairment and have never experienced parenthood. I acknowledge that my unique position as an insider and an outsider in this study, as well as my academic background in Occupational Science, Psychology, and Disability Studies impacted the decisions that I made throughout the research process. Those decisions included the research topic that I chose, how I entered the research field, the questions that I asked the participants during the interviews, the lens through which I interpreted participants' narrative accounts, and what I considered important to report in the written thesis.

1.5. Thesis Outline

In Chapter 2, I present a review of the current literature on the experiences of parents of typically developing adolescents, as well as the childrearing experiences of parents of adolescents with visual impairments and other types of disabilities. It should be noted that the majority of the research that I reviewed in that chapter was produced in industrialized Western countries with participants who were educated and from middle-to-upper class backgrounds, and therefore may have limited applicability to other countries. In Chapter 3, I describe the paradigmatic position that underpins this research, the methodology utilized in the study, and the data collection methods and analytical techniques that I employed. Chapter 4 presents the participants' re-constructed narratives, and Chapter 5 demonstrates the thematic results of my analyses of participants' narrative accounts. Finally, in Chapter 6, I discuss my interpretations of the findings, strengths and limitations of the study, and the implications of the findings for future research and low vision rehabilitation practice.

Chapter 2: Literature Review

This chapter presents an overview of the existing literature on different aspects of the experiences of parents of children and adolescents without disabilities, with disabilities other than a visual impairment, and with visual impairments. In the first section of the chapter, I present the research on the psychosocial well-being and occupational transitions experienced by parents who are raising typically developing adolescents. Next, information on the caregiving experiences of parents of children and adolescents with various types of disabilities is presented. Lastly, I review the current body of evidence related to the implication of having a child or an adolescent with a visual impairment on parents' lives.

2.1. Parenting and Adolescent Adjustment

Parenting is a fundamental occupational role in the lives of many adults, which enables them to pass down family values and beliefs to the next generation (Crowe, Duvall, & Gutierrez, 2016). As primary caregivers, parents play a key role in their children's physical, psychological, and socioemotional development (Baumrind, 1991; Bornstein, 2001). For most adults, the transition to parenthood is a life-changing experience. The rewards (e.g., self-identity transformation; increased social integration), as well as the stress (e.g., more housework; heightened frustration and marital conflict) associated with becoming a parent have been widely documented in the literature (Abbey, Andrews, & Halman, 1994; Nomaguchi & Milkie, 2003; Smith, 1999). The significant influences that parents have on their children continues well into adolescence and early adulthood. However, as children move from childhood to adolescence, a series of developmental changes begin to take place, which may drastically influence parent-child relationships, as well as family routines and dynamics, either directly or indirectly (Steinberg & Silk, 2002).

2.1.1. Physical Growth, Cognitive Change, and Parent-Child Relationships. The onset of puberty triggers accelerations in physical growth and maturation, which not only lead to changes in adolescents' self-images, but also serves as a constant reminder for parents that their children are quickly growing up (Steinberg & Silk, 2002). Cognitively, adolescents become much more capable of engaging in abstract and relativistic thinking than ever before. This advanced cognitive development provides adolescents with the foundation to successfully transition into adulthood, and therefore, is beneficial in the long run (Christie & Viner, 2005). In addition, the structural changes and functional reorganization in the developing brain after puberty results in adolescents' heightened sensitivity to the social signals in their environments (Crone & Dahl, 2012; Peper & Dahl, 2013), which in turn, contributes to increased reliance on peer evaluation when determining their self-worth (Blakemore & Mills, 2014). Adolescents, who now have an idea about how the world "should work" and acceptance from their peers is more important than ever before, begin to challenge and reject their parents' values and expectations more frequently and as a result, parent-child conflicts may increase. For parents, those arguments and conflicts with their teenage children may make them feel emotionally overwhelmed, as they may sometimes attribute their adolescents' defiance to their personal failures as parents (Laursen, Coy, & Collins, 1998). Fortunately, for most families, this state of tension is temporary, and is generally resolved as developing individuals form a more realistic and comprehensive view about the world after reaching late adolescence or emerging adulthood (Steinberg & Silk, 2002).

2.1.2. Changes within the Social Realm. In addition to physical and cognitive changes, adolescents and their parents also experience transitions within the social realm. In contemporary Western societies, adolescents spend less time with their parents and more time participating in

social and leisure occupations outside the family with their friends compared to younger children (Barnes, Hoffman, Welte, Farrell, & Dintcheff, 2007). From the perspective of parents, their decreased involvement in their adolescents' social lives and control in how their adolescents spend their free time means that they need to establish new routines and become more involved in other occupations that are meaningful to them, in order to adjust to the shift in their roles as parents (Chapdelaine et al., 2017). Adolescence is also a development period where many young people start dating and engaging in romantic relationships. This change often prompts parents to assess and monitor their adolescents' romantic relationships through setting expectations and rules regarding their adolescents dating behaviours, such as keeping parents informed about their plans and treating their romantic partners with respect (Mounts, 2008). Interestingly, research has shown that parents are more likely to use rules to regulate adolescent girls' dating activities than they do with boys, and mothers tend to be more involved in the rule setting task compared to fathers (Madsen, 2008).

Furthermore, societal expectations associated with the status transitions in adolescence placed on teenagers and their parents may also contribute to heightened stress and anxiety among parents (Steinberg & Silk, 2002). Indeed, some scholars have asserted that societal values and cultural beliefs have far greater influences on adolescents and their parents during this period of transition than the physical and cognitive changes taking place within the developing individuals (Lesko, 2012). In Western culture, adolescents are expected to develop autonomy and to explore different options when it comes to important life decisions, such as personal identity and career paths (Bartle-Haring, 1997; Soenens, & Vansteenkiste, 2005). As noted by Darling and Steinberg (1993), the process of parenting unfolds within a broader sociocultural context. As cultural

agents, parents of adolescents may feel pressured to make sure they are taking the right steps to help their teenage children meet those societal expectations (Lesko, 2012).

    2.1.3. Occupational Transitions. The needs of children change over time as they mature cognitively and socially and develop new skills and occupations (Crowe et al., 2016). The changes that unfold throughout the young person's childhood and adolescence shape the roles that parents play in children's lives and often impact parents' occupations (Crowe, Duvall, & Gutierrez, 2016). In the occupational science literature, adolescence is considered as a transitional phase that involves adapting to new environments, occupations, and routines for both adolescents and their families (Chapdelaine, Shields, & Forwell, 2017; Zeedyk et al., 2003). In North American society, the transition from elementary school to middle school or high school, and the transition from high school to post-secondary education and/or employment both occur during adolescence. In a recent study examining mothers' experiences of parenting adolescents who had recently entered their first year of high school, participants believed that their adolescent child starting high school resulted in changes in family routines and occupational demands for parents (Chapdelaine et al., 2017). For example, participants mentioned that having an adolescent child in high school led to less time spent together with parents and younger siblings as well as changed parent-child communication patterns that resulted from adolescents' decreased self-disclosure and increased smartphone use. Some parents also noted that as their child moved into mid-adolescence and entered high school, they shifted from being controlling to playing a more supporting role in their child's life.

    Indeed, for families with typically developing adolescents, increases in independent living skills and cognitive capacity enable adolescents to engage in a variety of new occupations both within and outside the family. This may, in turn, provide parents with more time and energy

to pursue their own occupations (Crowe et al., 2016). At the same time, these changes may require parents to re-negotiate the balance between parental-monitoring occupations and autonomy-granting occupations (Chapdelaine et al., 2017).

This shift in occupations and time use for adolescents and their parents may further result in a change in parents' occupational identity (Chapdelaine et al., 2017; Spring, Rosen, & Matheson, 2002). Occupational identity is defined by Kielhofner (2002) as "a composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation" (p. 120). As pointed out by Raanaas, Lund, Sveen, and Asbjørnslett (2019), self-identity can be constructed and re-constructed, and expressed through performing daily occupations. During their children's infancy and childhood, the role as a dedicated parent is often central to adults' occupational identity (Cast, 2004). However, as children move from childhood to adolescence, parents tend to become less involved in their children's lives and have less knowledge about their children's daily activities and feelings than they did when the children are younger. With the changes in everyday occupations and time use as their adolescent child experience a series of transitions, the process of re-constructing their occupational identity may unfold for many parents.

Despite the challenges associated with parenting adolescents, and a series of transitions that take place during adolescence, most parents are able to navigate this developmental period successfully. High marital satisfaction as well as engagement in occupations outside the home, have been identified as some of the protective factors that buffer parents of adolescents against stress along their parenting journey (De Rooij, & Gravesteijn, 2018; Kereteš, Brković, & Jagodić, 2012).

2.1.4. Parenting Styles. Parenting style is conceptualized by Darling and Steinberg (1993) as "a constellation of attitudes toward the child and constitute the emotional context for specific parenting practices" (p. 488). Baumrind (1989) identified four distinct parenting styles, characterized along two distinct dimensions: responsiveness and parental control. Those four parenting styles are authoritative (i.e., high in both responsiveness and parental control), authoritarian (low in responsiveness but high in parental control), indulgent (high in responsiveness but low in parental control), and neglectful (low in both responsiveness and parental control; Baumrind, 1989; Darling & Steinberg, 1993).

Marked by high levels of emotional support, reasonably high parental expectations, and appropriate autonomy granting, the authoritative parenting style has been linked with various positive developmental outcomes among children and adolescents. Generally speaking, adolescents who are raised by authoritative parents tend to have better psychosocial adjustment, greater school involvement and academic performance, and lower rates of substance use than their peers who are raised by authoritarian, indulgent, or neglectful parents (Cohen & Rice, 1997; Steinberg, Elmen, & Mounts, 1989; Steinberg, Lamborn, Dornbusch, & Darling, 1992). While recent research has suggested that some cross-cultural variations exist when it comes to the effects of those different parenting styles on the adjustment of adolescents from different ethnic backgrounds, the benefit of authoritative parenting style has been demonstrated across various ethnicities, cultures, socioeconomic statuses, and (dis)ability statuses (Aran, Shalev, Biran, & Gross-Tsur, 2007; Steinberg, 2001; Steinberg & Silk, 2002). Authoritarian, indulgent, and neglectful parenting styles, on the other hand, are more likely to be linked with delinquency, anxiety, and depression in adolescents (Lee, Daniels, & Kissinger, 2006).

The positive impact of authoritative parenting on adolescents' development is not surprising. Authoritative parents can usually find the appropriate balance between autonomy and control, which in turn, facilitates their adolescents' development by providing opportunities to establish independence and to form meaningful relationships with others outside the family, while setting the standards and limits that developing individuals need (Lee et al., 2006). In addition, authoritative parents can often successfully make changes in their parental monitoring occupations (e.g., gradually shifting away from being relatively controlling to a more supporting role as their children get older) to suit children's developmental needs (Chapdelaine et al., 2017). This adaptability is especially beneficial for young people when their capabilities and needs are rapidly changing during adolescence. Furthermore, instead of forcing rules and standards onto their adolescent children, parents who adopt an authoritative parenting styles are likely to engage in family discussions with adolescents when it comes to decision-making and expectation setting. This bidirectional communication style has been shown to promote adolescents' problem-solving skills and psychosocial competence (Milevsky, Schlechter, Netter, & Keehn, 2007).

Parenting styles are determined by a wide range of individual and contextual factors, such as the child's personality, the parents' own upbringing, marital status, the families' access to financial resources and social services, and culture (Lomanowska, Boivin, Hertzman, & Fleming, 2017; Spera, 2005). For example, it has been revealed that for families living in poverty and/or dangerous neighborhoods, parents of adolescents are likely to adopt an authoritarian parenting style. In fact, under those harsh living conditions, this parenting style, which is characterized by high levels of parental control, may actually help the adolescents' development and family functioning (Steinberg, Blatt-Eisengart, & Cauffman, 2006).

2.2. The Experiences of Parents of Children and Adolescents with Disabilities

2.2.1. Implications for Psychosocial Well-Being. The theoretical perspectives and research findings on parenting discussed in the previous section are primarily based on parents of children and adolescents without disabilities. As demonstrated in previous research, the presence of a childhood disability often creates changes in parents' lives as well as in family dynamics (Howe, 2006; King et al., 2000). The onset of disability in a child or an adolescent often contradicts parents' ideal of the "normal" and "perfect" child (Heiman, 2002; Björquist, Nordmark, & Hallström, 2016; King et al., 2000; Leyser, Heinze, & Kapperman, 1996). When reflecting upon their parenting journey, many parents of children and adolescents with disabilities consider the first few weeks and months following their children's diagnosis to be emotional and stressful (Kerr & McIntosh, 2000; King et al., 2000).

Parenting is a dynamic and transactional process that is shaped by the interplay between both parental and child characteristics. Parenting a child with a disability is not an exception to that. In fact, research has suggested that there are considerable similarities between the experiences of parents of children with and without disabilities (Crowe, et al., 2016). However, previous research has indicated that the presence of a disability may add additional challenges to parents' already stressful caregiving experiences. For example, infants and young children with visual impairments tend to have less frequent eye contact with their parents, and more fleeting smiles and emotional expressions, as compared to their sighted peers. Because of this, their parents may feel unsettled or even rejected, especially before they realize that their child has a visual impairment (Howe, 2006).

Interpersonal factors such as close relationships with other family members and support from other parents of children with disabilities have been shown to promote adjustment of

parents of children with disabilities (Kerr & McIntosh, 2000). Moreover, there has been some evidence that as their children get older and reach adolescence, many parents of adolescents with disabilities become more accepting towards their adolescent children's disabilities and less concerned about finding a cure (Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013). As a result, they become more satisfied with their parenting experiences and their lives in general (de Klerk & Greeff, 2011; King et al., 2000).

 2.2.2. Time Use and Engagement in Occupations. As mentioned earlier, the physical and cognitive maturation, as well as increased occupational competence among adolescents often means that parents now have more time and energy to perform occupations other than caring for their children. This pattern, however, may not apply to many parents who are raising adolescents with disabilities. As illustrated by Smith and colleagues (2010), mothers of adolescents with autism spectrum disorders experience more stressful events, and spend more time performing childcare occupations and less time participating in leisure occupations than mothers of adolescents without disabilities. Likewise, a mixed-methods study conducted by Crowe and Michael (2011) demonstrated that, although both mothers of adolescents with and without disabilities spent less time on direct caretaking and supervising occupations as their child gets older, mothers of adolescents with disabilities devoted significantly more time engaging in occupations related to supervising their adolescents and less time participating in social occupations.

 Previous research has shown that adolescents with visual impairments tend to spend more time at home with their parents and less time with their peers than do their sighted counterparts; moreover, adolescents with visual impairments rely more on their parents for transportation than do adolescents without visual impairments (Kroksmark, & Nordell, 2001). For some parents of

adolescents with visual impairments, this means more opportunities to engage in family occupations with their adolescent children. At the same time, spending time with and caring for their adolescents may leave parents with less time and energy to engage in other paid and unpaid occupations (Chang et al., 2000).

Having a child with a disability can also influence family occupations, which are defined as everyday activities shared by two or more family members that are culturally meaningful (Bagatell, 2016). This is not surprising, because many occupations are transactional in nature, and family occupations are collectively shaped by all family members involved (Cutchin & Dickie, 2013). A study involving parents of adolescents with ASD revealed that because of the behavioral changes that often occurred during adolescence for young people with ASD, such as increased levels of aggression, their families often had to alter or give up certain family occupations, such as going to movies together (Bagatell, 2016). Furthermore, for some families of children with physical and/or developmental disabilities, attending appointments with healthcare professionals and social service providers takes up a significant amount of family time throughout the childhood and adolescent years (Goddard, Lehr, & Lapadat, 2000; Heiman, 2002; Jordan, Eccleston, & Osborn, 2007).

Some studies involving parents of adolescents with disabilities suggest that major educational and occupational transitions (e.g., transition from high school to college or the workforce) during adolescence can be especially stressful for some parents (Hetherington et al., 2010; McConnell, 1999; Peña & Kocur, 2013). According to Hetherington and colleagues (2010), this heightened stress and uncertainty can be largely attributed to the marginalization of young people with disabilities and their families, perpetuated by the educational system and other social institutions.

2.2.3. Understanding Parents' Experiences through Narratives. The lives of parents of children and adolescents with disabilities are often reflected in, and can be understood through, their narratives about their childrearing experiences. For example, a study investigating the life stories of parents of children and adolescents with Down Syndrome by King and colleagues (2000) revealed that happy endings were related to higher life satisfaction and subjective well-being, and a sense of closure in the stories was associated with emotional maturity of the storytellers. These findings are in line with previous studies that identified that positive parental attitudes towards a child's disability and proactively advocating for their children's rights, help parents better cope with stress and anxiety associated with raising children and adolescents with disabilities (Leyser et al., 1996; Leyser & Heinze, 2001).

Taking a closer look at previous research examining the childrearing experiences of parents of children and adolescents with disabilities, the findings suggest that those experiences are a mixture of joy, hope, struggles, and concerns (Goddard, Lehr, & Lapadat, 2000; Heiman, 2002; King et al., 2000; Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010). For example, in a study investigating the experiences of parents of children and adolescents with congenital disabilities by Heiman (2002), the majority of the participants reported the need to compromise their social lives in order to care for their children with disabilities, as well as heightened frustration and dissatisfaction associated with their caregiving responsibilities. Most of those parents, however, also demonstrated an overall optimistic outlook for the future and recognized the importance of holding strong beliefs in their children's abilities to thrive. This shows that parents of children and adolescents with disabilities who experience a considerable amount of stress and uncertainty along their parenting journey may still be able to view and frame their parenting experiences through a positive light (Heiman, 2002; King et al., 2000).

Through in-depth individual interviews and focus group sessions with eight mothers and seven fathers of adolescents with cerebral palsy, Björquist and colleagues' (2016) work shed light on the concerns, challenge, resilience, and important parenting occupations involved in caring for adolescents with disabilities. Participants in the study expressed sorrow when their adolescents experienced rejection from their peers, worries about the implications of their adolescents' self-identity formation, and wondered what the future held for their adolescents' following the transition into adulthood. This sense of uncertainty was exacerbated by the task of navigating the complicated healthcare and social service systems and balancing caregiving occupations, medical appointments, transition planning activities, as well as work. Meanwhile, participants developed strategies to cope with the challenges along their parenting journey and to balance their multiple roles and responsibilities. For example, participants described taking turns with their partner at being at work or attending meetings for parents and using the time when their adolescents were at school to engage in activities that they enjoyed (Björquist, 2016).

The narrative accounts of parents of children and adolescents with disabilities also highlight the pervasive impact of social stereotypes and discrimination on their parenting experiences (Goddard, et al., 2000; Kinnear, Link, Ballan, & Fischbach, 2016). This was illustrated in a study seeking to explore parents' views of disability with those who were caring for children, adolescents, and young adults with disabilities using a critical social constructivist approach (Goddard et al., 2000). Interestingly, according to participants' narratives about their parenting journey, collected through focus group sessions, the tragic and dysfunctional discourse on disability was frequently perpetuated by healthcare professionals (e.g., pediatricians, social workers, psychologists) who had the intention to help the children and their families. Many participants felt frustrated by the ways in which their children were perceived and objectified by

professionals when receiving services and intervention. Some also talked about the guilt and sadness that they felt, due to parent-blaming by others, regarding expectations for making sure that their children meet societal norms (Goddard et al., 2000). Those study findings provide a context for understanding the negative emotions that parents of children and adolescents with disability experience in their everyday lives, and suggest that the frustration, sadness, and guilt experienced by those parents are not always the result of their children's impairments. Instead, they could be the product of discriminatory societal attitudes towards the parents (Goddard et al., 2000).

2.3. Parenting Children and Adolescents with Visual Impairments

2.3.1. Parents' Perspectives. Although the parenting experiences of caregivers of children and adolescents with disabilities has received growing attention from healthcare professionals and researchers in recent decades, parents of children and adolescents with visual impairments continue to be an under-researched population. Most research on children and parents in this population has been conducted by low vision professionals, such as social workers, occupational therapists, educational and developmental psychologists (Rainey, Elsman, van Nispen, van Leeuwen, & van Rens, 2016). While these research studies have advanced the body of knowledge on the experiences of parents of children and adolescents with vision loss, the underrepresentation of parents' perspectives and knowledge in the low vision literature may prevent researchers and professionals from gaining a comprehensive understanding of the lives of caregivers of young people with visual impairments (Rainey et al., 2016). Furthermore, existing research on childhood visual impairment has mainly focused on medical and functional aspects (Lupón, Armayones, & Cardona, 2018). In contrast, other aspects that may impact the developmental trajectories of children and adolescents with visual impairments, such as parents'

psychosocial well-being and occupational experiences, have been largely overlooked (Lupón et al., 2018). Nevertheless, the findings of the limited numbers of studies on this topic provide us with a glimpse of the social and psychological reality of those parents.

Most children with visual impairments are born to sighted parents, who know very little about visual impairment and the blind community prior to receiving their child's diagnosis. In mainstream culture, vision is often considered the most important sense for humans. Some scholars have argued that for an average person without a visual impairment, approximately 80% of information learned in everyday life is acquired through vision (Thau, 1991). Therefore, parents who are unfamiliar with the disability culture may have difficulty envisioning their children's lives with limited vision or without vision.

As suggested by Chapdelaine and colleagues (2017), as children enter adolescence, one common strategy for parents to prepare their visually-impaired children and themselves for the transitions and changes, is to engage in information-gathering occupations, such as talking to other parents who have raised or are currently raising visually-impaired adolescents and reading related books. In North America, it is estimated that only 0.5 to 0.8% of children and adolescents are living with visual impairments (National Federation of the Blind, 2019; World Health Organization, 2018b). Because of the relative rarity of visual impairments in childhood and adolescence, it is often difficult for parents of adolescents with visual impairments to meet other parents with similar experiences in their immediate social network. Parent-to-parent support groups, therefore, have become an important modality for parents of adolescents with visual impairments to connect with each other and engage in information-gathering occupations in preparation for their child's transition into adolescence (Law, King, Stewart, & King, 2002).

It is worth noting that the experiences of parents of children and adolescents with visual impairments may vary widely because the causes and the nature of visual impairment vary widely. Some individuals are born with congenital conditions resulting in visual impairments, whereas others acquire visual impairments through illnesses or accidents; some have residual vision which allows them to see colours, faces, and objects held close to their eyes, and others have complete vision loss; some individuals' eye conditions remain stable throughout their lives, whereas some have eye conditions that change frequently (Castañeda et al., 2016). Each child's unique circumstances may shape his or her parent's psychosocial and occupational experiences in a unique way (Jenks, 2005).

Using a mixed-method design, a group of researchers from the United States conducted one of the first studies that explored the perspectives of 130 parents of children and adolescents between ages 0 to 25 who were visually impaired (Leyser & Heinze, 2001). In their responses to the open-ended questions about their parenting experiences, participants expressed concerns about issues such as the family's access to information and services, society's attitudes towards their child, and the child's independence and adjustment. Besides concerns and worries, participants also described the positive aspects of raising children and adolescents with visual impairments. For example, some participants identified their children's progress and accomplishments as their major source of joy and encouragement, and some believed that raising their children who were visually impaired made them become more compassionate and more accepting towards people with disabilities.

For some parents of children and adolescents with visual impairments, their child's functional vision is another source of concern. In a qualitative study conducted by Castañeda and colleagues (2016), parents of children and adolescents with congenital cataracts voiced their

uncertainty and stress associated with their child's changing eye conditions and treatment of the eye conditions. A study involving parents who had finished raising their children with visual impairments painted a brighter picture of the psychosocial experiences of parenting children and adolescents with visual impairments (de Klerk & Greeff, 2011). When reflecting on their parenting journey, although participants reported experiencing some ongoing struggles, their narratives unveiled a process of inclusion for their children and the development of a sense of pride and accomplishment as their children approached adulthood. This process was facilitated by support from immediate and extended family members, spirituality, and help from eye care professionals (de Klerk & Greeff, 2011). de Klerk and Greeff's (2011) study was conducted in South Africa, a country with a more collectivist cultural orientation than many Western countries. For those participants, raising their children who were visually impaired in a collectivist society that highly values family closeness and community, may have been an important contributor to their resilience and optimism.

An autoethnography by Jenks (2005) also shed light on the experiences of parents who are raising children with visual impairments. In her writing, Jenks (2005) looked at her experiences as a mother of a 13-year old boy who was legally blind as well as the narratives of other parents of children who were visually impaired or blind. Connecting the "personal" with the "social", she concludes that the experiences of parents of children and adolescents with visual impairments do not mirror either the medical model or the social model of disability. Rather, they are situated 'somewhere in between' (Jenks, 2005, p. 146). This 'somewhere in between' could be explained by the ecological model of disability (also known as the social-ecological model). Unlike the medical model that focuses on 'individual deficits,' or the social model which is concerned with environmental influences, the ecological model of disability

stresses the joint influences of personal traits and environmental factors on the lives of individuals with disabilities and those of their caregivers (Bricout, Porterfield, Tracey, & Howard, 2004; Llewellyn & Hogan, 2000).

  2.3.2. Adapting to the Changing Needs of Adolescents with Visual Impairments. In the visual impairment literature, and the disability literature more broadly, the term 'children' is often used as an umbrella term to describe individuals who are under the age of 18 (Castañeda et al., 2016). Therefore, the few studies that have tackled the psychosocial and occupational experiences of parents of adolescents with visual impairments have included parents of adolescents as well as those who were raising younger children (Castañeda et al., 2016; Jenks, 2005; Leyser & Heinze, 2001). It is worth noting, however, that parents' psychosocial and occupational experiences often vary considerably depending on their child's developmental stage (Steinberg & Silk, 2002).

  As mentioned previously, adolescence is a transitioning period during which many developmental and contextual changes take place (Steinberg & Silk, 2002). Similar to their sighted peers, adolescents with visual impairments desire to achieve increasingly greater levels of independence and autonomy from their parents (Chang et al., 2000; Rosenblum, 2000). Like parents of adolescents who are sighted, parents of adolescents with visual impairments face the task of enabling their child's independence while providing them with sufficient guidance and support. However, for parents of adolescents with visual impairments, some additional challenges may arise during this process.

  During adolescence, young people start travelling independently and taking public transit on their own more frequently (Steinberg & Silk, 2002). As the presence of a visual impairment often impacts the orientation and mobility (O&M) skills of an adolescent to various extents

(Papadopoulos, Metsiou, & Agaliotis, 2011), parents of adolescents with visual impairments tend to feel more reluctant to encourage their adolescents to travel without parental supervision than those raising adolescents who are sighted. When speaking about their everyday experiences as teenagers living with visual impairments, some of the participants in Rosenblum's (2000) study reported that their parents provided them with less space to practice their independence than they did with their sighted siblings. For instance, due to safety concerns related to their visual impairments, parents would discourage them from travelling to certain places on their own or with their friends. Previous research has suggested that parents who engaged in supervising occupations do so in an effort to protect their adolescents from actual and/or perceived risks, however, doing so may unintentionally hinder the adolescents' social development (Castañeda et al., 2016). Intriguingly, some research has shown that the negative impact of parental overprotection on adolescents' abilities to form close friendships and peer relationships may be stronger for adolescents with visual impairments than for those who are sighted (Pinquart, & Pfeiffer, 2011). As such, negotiating the right balance between autonomy granting and parental monitoring occupations in their parenting practices may pose unique challenges for those who are raising adolescents with visual impairments.

2.4. Conclusion

The review of the existing literature underscores the complexity of the parenting experience of those who are raising adolescents with visual impairments. To date, parents' experiences of raising adolescents with visual impairments has received relatively little research attention. In fact, only one study has carried out in-depth examinations of the narrative accounts of parents of adolescents with visual impairments, and no existing research has specially looked at the psychosocial and occupational aspects of the parenting experiences from the perspectives

of adolescents with visual impairments. Expanding the body of knowledge on the psychosocial experiences of parents who are raising adolescents with visual impairments could help researchers and practitioners better understand the joys, challenges, and needs of those parents, which could, in turn, lead to the enhancement of the lives of this group of parents. To address this gap in the literature, the present study aimed to examine the stories of parents of adolescents with visual impairments in an effort to contribute to our understanding of the psychosocial and occupational experiences of this population.

Chapter 3: Research Methodology and Methods

This chapter presents the methodology and methods employed in this constructivist narrative study. I begin this chapter by detailing the theoretical and philosophical underpinnings of the study, including paradigm, theoretical framework, and the narrative methodology. I then describe how the data were generated and analyzed. Finally, the criteria used to ensure the quality of this study and ethical considerations are discussed.

3.1. Methodology: Narrative Inquiry

3.1.1. Paradigm

According to Filstead (1979), a paradigm can be defined as a "set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organized study of that world" (p. 34). This study was situated within a constructivist paradigm. Proponents of the constructivist paradigm maintain that instead of being a singular and static entity, social reality is constructed by individuals and society and can evolve over time (Finlay, 2006; Guba & Lincoln, 1994; Ponterotto, 2005). In addition, the constructivist paradigm emphasizes the importance of human interactions in shaping realities and knowledge. Therefore, constructivists would argue that in research settings, knowledge is co-constructed by the researcher and his/her participants through their interactions (Ponterotto, 2005).

3.1.2. Guiding Theoretical Framework

Within a constructivist inquiry, the theoretical frameworks that a researcher adopts influence the lens through which he/she views his/her research topic and the kind of knowledge being produced in the study (Grant & Osanloo, 2014). The topic of interest for this study was viewed through the ecological system theory of human development proposed by Bronfenbrenner (1992).

The ecological system theory posits that human development is shaped by the dynamic interplay between personal traits and multiple systems within the environment (i.e., microsystems, mesosystems, exosystems, macrosystems, and chronosystem) throughout the individuals' lifespan (Bronfenbrenner, 1979; 1992). Specifically, the ecological system theory proposes that as the central force of development, the individual interacts with and actively shapes the environments in which he/she functions; at the same time, the various nested systems within the environment also directly or indirectly influence the individual's life course trajectory (Bronfenbrenner, 1979; 1992). The microsystem involves the people and structures that the individual has direct contact with (e.g., immediate family members). The mesosystem serves as the connection between microsystems, such as the relationship between family and school. The exosystem refers to the larger social system that the individual does not have immediate contact with but still experiences its indirect influences. Being the outermost layer of the environment in which the individual functions, the macrosystem consists of the broader sociocultural forces, such as societal norms, cultural values, and political systems. Finally, the chronosystem represents the time dimension of development, such as the transitions that take place over the individuals' life course (Bronfenbrenner, 1992; Darling, 2007; Rosa & Tudge, 2013).

The ecological system theory has undergone continuous refinement since it was first developed four decades ago (Darling, 2007). An important component of the most recent version of the theory is the Process–Person–Context–Time (PPCT) model for studying human development, which is comprised of the four elements that formulate the theory (Lerner et al., 2002). In other words, Bronfenbrenner (2005) believed that just as the developmental process, the person, the context, and time must all be included in the conceptualization of the human

development system, so should all of those components be appraised in research that aims to achieve a deep understanding of human development.

Through the lens of the ecological theory, one would view parenting as a complex process involving not only the bidirectional relationships between parents and children, but also the parents' direct and/or indirect interactions with other individuals within the family, social institutions, and broader cultural context (Lerner et al., 2002). Changes within any of those ecological systems (e.g., family's socioeconomic status, child's disability status) could significantly impact parents' childrearing experiences. With regards to the experiences of individuals with visual impairments and their caregivers, a proponent of the ecological system theory would argue that since the individuals and the ecological systems within their environments are interdependent and all play an active role in the individuals' lives, the experiences of those with disabilities and that of their caregivers cannot be studied in isolation from the sociocultural context in which they are embedded (Darling, 2007; Llewellyn & Hogan, 2000).

Seeing the data through the lens of the ecological system theory, the personal characteristics and developmental trajectories of the parents and their children, the individuals and the immediate environments that participants encounter, the broader sociocultural forces, as well as the influences of time, were all taken into consideration when examining the stories of parents of adolescents with visual impairments. Furthermore, the ecological system theory was employed in this study to shed light on how those elements interacted with each other and how parents of adolescents with visual impairments make sense of their experiences in relation to these elements.

3.1.3. Ontology

Ontology can be defined as the way in which the nature of reality is understood. Broadly speaking, there are two widely accepted and often contradictory ways of understanding our social reality, realism and relativism (Finlay, 2006; Guba & Lincoln, 1994; Ponterotto, 2005). The realist approach views reality as deterministic, predictable, and existing independently from human perception. Proponents of the realist approach would argue that with scientific measures that are rigorous enough, one single 'objective truth' can be discovered (Guba & Lincoln, 1994). The relativist approach is on the other end of the spectrum. According to the relativist approach, multiple equally valid realities exist, as reality is dependent upon the ways in which it is perceived and the sociocultural context it is situated within (Finlay, 2006; Guba & Lincoln, 1994; Ponterotto, 2005).

The ontological position that a researcher chooses to employ is largely driven by his/her research purpose and/or research question. Guided by my research questions and the constructivist paradigm, I choose to adopt a relativist approach while still acknowledging the 'core of facts' that participants' narratives are based on (Lieblich, Tuval-Mashiach, & Zilber, 1998, p. 8). In other words, although I believe that parents of adolescents with visual impairments frame their narratives of their childrearing experiences based on a series of events that have actually happened in their lives, the participants' recall accuracy of those life events is not the focus of the study. Instead, this study concerns the subjective experiences of parents and the meaning-making process, which are both dependent upon the individuals' perceptions and shaped by the historical and cultural context that the individual belongs to. In addition, the stories of those experiences are shaped by the presence of audiences (e.g., family members, friends, researchers). Thus, the relativist approach is particularly suitable for addressing the

research questions of the proposed study. Perhaps more importantly, it is often the life stories that people construct, narrate, and live with that ultimately shape their identity and influence their well-being, rather than the objective events (McAdams, 1993).

3.1.4. Epistemology

Epistemology is concerned with the question of what constitutes real knowledge and how such knowledge can be obtained (Finlay, 2006; Ponterotto, 2005). By adopting a constructivist paradigm position, I acknowledge that both subjective experiences and their meaning are constructed by the protagonists of the life stories at a particular moment in time and are subjected to interpretations. In the case of the present study, although participants' experiences of parenting adolescents with visual impairments provided them with the 'raw materials' to construct their stories, the stories they shared during the interviews were influenced by additional factors, such as the presence of the interviewer and their emotional state throughout the storytelling process as well as their accumulated experiences over their lifetime. In line with my constructivist position, I played an active role as a researcher and took part in the story's co-construction process with the participants through my interactions with them.

More specifically, I interpreted participants' stories and asked them follow-up questions based not only on the parenting experiences that they shared with me but also my understanding about those experiences and the world around me. I recognized that as someone with a congenital visual impairment who went through adolescence a few years ago, and a researcher who was immersed in low vision research, I could form a personal connection with some of the stories that participants shared with me. As a result, my interpretations of the participants' journey of parenting adolescents with visual impairments are likely be different from a researcher with a different background.

3.1.5. Methodology

Mapping onto my ontological and epistemological positioning, the study employed a narrative methodological approach. Narrative inquiry postulates that as human beings, we are natural storytellers (Smith & Sparkes, 2008). Starting from late adolescence and early adulthood, people begin to construct an internal story of the self, based on their significant life events. That internalized life story provides people with unity and purpose and serves as a guide for people to perceive the present and to envision the future (McAdams, 1993). From a narrative researcher's perspective, narratives are not only a way of telling about our lives but also a means of knowing (Richardson 2000). Therefore, a clear path to accessing an individual's inner reality and its connection with the outside world is through listening to the stories that he/she tells about his/her own life (Lieblich et al., 1998). As the content and form of narratives are largely influenced by social and cultural conventions, life story narratives not only mirror the narrators' lived experiences, but also illuminate the sociocultural context to which the narrator belongs (Smith & Sparkes, 2008).

Life-altering events, such as becoming a parent of a child with a disability (e.g., a visual impairment), often challenge people's taken-for-granted assumptions about themselves and the world and require the individual to come to terms with their new life circumstances. A common way for people to achieve this goal is by constructing their life stories, narrating those stories internally and telling them to others (Frank, 1995; McAdams, 1993; King et al., 2000). An implicit assumption of many narrative researchers is that people are inherently meaning seekers who are motivated to make sense of their own experiences through storytelling (Singer, 2004). Previous research has suggested that presence of a sense of meaning, or integration of one's

experiences and of oneself in narratives, is a major characteristic of a well-formed life story (Mclean & Pratt, 2006).

In line with the goal of this study, the central purpose of narrative inquiry is to understand how social actors perceive and make sense of their own social realities (Smith & Sparkes, 2008). As human beings, we live in a world of stories and make meaning from our lives by constructing and telling our own life stories (Mclean & Breen, 2014; Smith & Sparkes, 2008). According to narrative researchers, narratives constitute our inner realities and shape our ways of being (Smith & Sparkes, 2008). In the present study, narratives were used as a tool for parents of adolescents with visual impairments to express their voices and for me to understand the social realities of those parents.

3.2. Methods

3.2.1. Study Context

This study took place in Southwestern Ontario, mainly within London and its surrounding areas. London (population of 383,437 as of 2016) is considered a midsized city. At the time of this study, I resided in London and had made connections with some staff members from the Canadian National Institute for the Blind (CNIB) local offices prior to this study. This made London an ideal location for carrying out the participant recruitment and data collection phases of this study. To date, there has been no statistics on the number of adolescents with visual impairments and their parents who reside in London or Southwestern Ontario. Across Ontario, approximately 681,300 individuals are currently living with some degree of vision loss, and approximately 5.8% of those living with vision loss are in their mid or late adolescence (i.e., between ages 15 and 24; Statistics Canada, 2018).

3.2.2. Participants and Sampling

Participants were recruited from the CNIB in Southwestern Ontario. The study was approved by the research department at the CNIB and the Non-Medical Research Ethics Board (NMREB) at Western University, where the study underwent full ethics board review. To be eligible to participate in this study, potential participants needed to be a biological parent who was currently raising an adolescent (between ages 14 to 21) living with a visual impairment. In addition, since the research interviews were conducted by me in English, the parents needed to understand and communicate in English in order to participate in the study. I specifically focused on parents of adolescents, because I believed that parents who are currently raising adolescents would be more likely to recall their past, as well as current, childrearing experiences than those whose children are already young adults. Age 14 was used as the lower age limit, since the majority of adolescents in Ontario start high school at that age; age 21 was used as the upper age limit, because individuals with disabilities living in Ontario typically complete high school by the age of 21 (Justice for Children and Youth, 2013).

Adoptive parents were excluded from this study, as in most cases, individuals who choose to adopt children with visual impairments are aware of their child's disability status prior to adopting them (Conroy, 2018). The ways in which adoptive parents perceive and story their childrearing experiences are, in turn, likely to differ considerably from those of biological parents of children with visual impairments.

There were no exclusion criteria with regards to gender, ethnicity, and age of the parents. This helped to ensure diversity among the participants and would, in turn, increase the conceptual generalizability and transferability of the findings (Tracy, 2010). Using purposive sampling, which entails selecting the sample based on the research purpose and certain

characteristics of the population instead of probability (Abrams, 2010), I aimed to invite stories

from individuals who shared experiences of parenting adolescents with visual impairments.

The recruitment phase took place between October 2019 and January 2020, during which

four parents who were currently raising adolescents between the ages of 14 to 17 with visual

impairments were recruited. Potential participants received a recruitment email (See Appendix

B), along with a study flyer (See Appendix C), sent by the CNIB on my behalf. In order to reach

a wider audience, a hard copy of the study flyer was also posted at the CNIB London

Community Hub office (i.e., an accessible community space where those living with visual

impairments and their family members can participate in CNIB-run social events and receive

assistive technology training). The sample size of the present study was in line with the

expectations of a narrative study and allowed adequate time for in-depth individual interviews,

which in turn, helped enhance the richness of the narrative data collected and the depth of the

analysis (Abrams, 2010). I chose to partner with the CNIB for participant recruitment because it

is the largest non-profit organization serving individuals with vision loss and their families in

Canada. Moreover, given the tight timeline for a Master's thesis, recruiting from a reputable

organization that has contact information for a number of parents of adolescents with visual

impairments was a practical and relatively non-time-consuming approach.

3.2.3. Study Design and Procedure

This study incorporated the Biographic Narrative Interview, which included a lightly

structured interview and a semi-structured follow-up interview (BNI; Wengraf, 2001). Following

the completion of the two BNI sessions, participants were invited to take part in a feedback

session, where they had the opportunities to review my analysis of their stories and provide their

feedback (See Appendix E for the detailed interview protocols for each interview session). The

BNI sessions were audio recorded, transcribed verbatim, and took place at locations of the

participants' choosing (e.g., a private conference room/office space where the participant works,

research lab space at Western University).

All participants completed the two BNI sessions. Three of the participants completed the

BNI sessions in-person and one participated via Zoom (i.e., a virtual platform for hosting video

conferences and teleconferences), due to the distance between the city where she resided and

London. Two out of four participants completed the feedback session via Zoom due to the

impact of COVID-19. The feedback session was not audio-recorded or transcribed. Participants

received a $10 Amazon gift card for their time and participation in each interview session of the

study.

Lightly Structured interview. The first BNI was lightly structured and took

approximately 60- 80 minutes to complete. Before the interview began, participants reviewed the

consent form (See Appendix D). They were encouraged to seek clarification from me if they had

any questions or concerns about the study. During the interview, participants first completed a

brainstorming exercise, in which they were instructed to develop a timeline of their journey of

parenting their child with a visual impairment (See Appendix E; Leung, 2010). During the

timeline construction exercise, participants placed their memorable parenting experiences, such

as high points, low points, turning points, as well as other significant events related to raising

their children with visual impairments, along a timeline. Participants then answered the question:

"Can you tell me about your experiences of raising an adolescent who has a visual impairment?",

using the timeline that they had constructed as a guide. During the storytelling process,

participants were encouraged to freely discuss their experiences and to provide as many details

as they were comfortable sharing. The purpose of the first interview was to collect and

understand participants' overall stories of being a parent of an adolescent with visual impairments.

During this time, I listened to the participant's story with minimal interruptions. I also made note of any key words, phrases, or stories that I wanted to follow up on. After finishing telling their story, I sought more information on particular aspects of the story by asking such open-ended questions as "Can you tell me more about X" or "Can you tell me about a time when you felt Y". At the end of the first interview session, participants filled out a brief demographic questionnaire with questions such as their age, gender, ethnicity, marital status, and type and degree of their child's visual impairment (See Appendix F).

Semi-structured Follow-Up interview. The semi-structured follow-up interviews took place two to six weeks after the first interviews and were approximately 45-60 minutes in length. The purpose of this interview was to develop a more insightful understanding of participants' occupational and psychosocial experiences of raising their adolescent child with a visual impairment.

A research assistant transcribed the first interview session. As I listened to the audio recordings of the first sessions and read through the transcripts, I developed more in-depth and specific questions for the second interviews based on the stories that each participant had shared. Those questions varied from participant to participant. For example, if advocating for their child was a theme that a participant frequently brought up during the first interview, during the second interview session, I would ask him/her open-ended questions such as "Can you give me a few examples of when you played a role as an advocate for your child?"

Towards the end of this semi-structured interview, all participants answered a few reflective questions, pre-set by me, about their experiences of parenting adolescents with visual

impairments (e.g., Has being a parent of a child with a visual impairment changed you as a person and your beliefs about people with visual impairment? If so, in what ways?).

Feedback Session. Following the completion of the BNI sessions, I performed preliminary analysis on the interview data collected to date and wrote up a narrative based on each participant's parenting experiences. Approximately one month after the completion of the second BNI session, participants were invited to take part in the feedback session. The invitations, as well as a copy of their personal re-written narratives, were sent to participants via email. For participants who did not respond to the initial invitation email, I sent them a follow-up email asking if they would be interested in taking part in the feedback session. Since this concluding phase of data collection took place during the COVID-19 pandemic, and all of my participants were working in the healthcare sector during that time, only two participants were able to complete the feedback session by the end of May 2020.

Both participants who participated in the feedback session took time to read over the re-written narrative and provided written feedback prior to the final interview session. Participants' written feedback either suggested no changes or only a few grammatical edits to the quotes that I presented in the personal narrative. Neither participant suggested any changes to the content of the narrative. The feedback sessions took place approximately a week after the invitation email and the narrative were sent. Each feedback session took about 15 minutes.

3.3. Ethical Considerations

Similar to many other narrative studies, narrative ownership was an ethical concern for the proposed study. Situated within a constructivist paradigm where reality is co-constructed by the researcher and the participants and dependent upon individuals' interpretation of the world around them, there could be multiple, and perhaps equally valid, interpretations of the stories that

have been shared. Therefore, the study raised the question of whether the participant's or the researcher's version of the story was more credible. How the researcher approached this question had important ethical implications (Symthe & Murray, 2000). To address this concern, it was made clear to the participants at the beginning of each interview and in the consent form that the researcher's interpretations of their stories may be different from their own. In addition, as mentioned previously, participants had the opportunity to review the stories about their parenting experiences that the researcher constructed based on their interview responses, during the last interview session. This process of bringing the data and findings back to participants may have helped to enhance narrative ownership for participants.

Furthermore, participation in the present study could pose psychological risks to the participants, as the psychosocial and occupational experiences of raising adolescents with visual impairments are very personal by nature and may be considered a sensitive topic by some participants. I was aware that talking about those experiences could make some participants feel vulnerable and elicit some unpleasant emotions. To mitigate this potential psychological harm, participants were provided with a list of psychological counselling resources at the end of the study. In addition, process consent (Symthe & Murray, 2000) was practiced in this study. Specifically, I asked the participants at various stages of the interviews if they wished to continue to be in the study and reassured them that they could withdraw from the study at any time without penalty.

How to exit the research scene without causing harm to the participants was another potential ethical concern that I took steps to address prior and during the data collection. I was aware that by virtue of being someone with a visual impairment and a member of the blind community, talking with the participants as an interviewer could make some participants feel a

sense of emotional connection with me. There was a possibility that this connection could continue after the study ended. To minimize the potential harm caused by the researcher (i.e., myself) leaving the research scene, participants were informed in the consent form and at the beginning of data collection, that their participation in the study involved three interview sessions, and they would not be contacted for reasons unrelated to the purpose of the study, either during or after the study was complete. With these protocols in place, ethical issues related to me as a researcher or the research process causing psychological distress or emotional harm to participants did not arise during or after the study.

3.4. Data Analysis

Participants' narrative data collected in the present study was analyzed using a combination of holistic content analysis (Lieblich et al.,1998) and thematic analysis (Braun and Clarke, 2006). The holistic content analysis involved viewing each participant's story as a whole while focusing on the plot presented by the story during the analysis (Lieblich et al.,1998). The thematic analysis involved identifying common patterns and themes across four participants' stories that are related to my research question. A primarily inductive (i.e., bottom-up) approach was utilized to analyze the narrative data. The data analysis process was also driven by my theoretical framework, the ecological system theory. The data analysis process took paces in four stages, which are described below.

3.4.1. Transcription and Data Cleaning. In preparation for the data analysis, each BNI session was transcribed immediately following its competition. The interviews were transcribed by a research assistant in order to accommodate the tight timeline of this master's thesis project. I acknowledge that by having a research assistant transcribe the interviews instead of transcribing them myself, I may have missed the opportunity to be fully immersed in the data

and to discover emerging patterns and themes from participants' stories prior to conducting the narrative analysis. Moreover, I am aware that participants' changes in tone of voice and pauses in speech could not be fully captured within the interview transcripts. To compensate for this limitation, I listened to each audio recorded interview multiple times before performing data analysis (Lieblich et al. 1998). While listening to the audio recorded interviews, I also read through the corresponding transcripts to check their accuracy.

I then cleaned the interview transcripts. Specifically, major grammatical errors were corrected, and repeated words that did not express any meaning were removed, for the purpose of clarity. In order to protect the identity of those individuals mentioned within the transcripts, all names mentioned in the interview transcripts were replaced with pseudonyms. Among the two participants who took part in the feedback interview session, one chose the pseudonyms for herself and her child, and the other gave me permission to choose the pseudonyms for her and her child. For the two participants who I could not get in touch with after the second BNI session, I picked the pseudonyms for them and their children.

3.4.2. Holistic-Content Mode: Generating Themes from Individual Transcripts. This stage of the analysis began with familiarizing myself with the data, by listening to the audio recorded interviews and reading through the interview transcripts. During this active reading/listening phase, I jotted down notes about the data (e.g., my interpretations of the significance of a particular life event to the participant, and my observations of the ways in which the participant made sense of an experience). In addition, I highlighted the content in the transcripts that I considered meaningful, interesting, or prominent in the participant's story. The note-making process at this stage was causal and observational rather than systematic.

Once I became familiar with the data, I began to analyze the content systematically through generating initial codes. Codes are labels that highlight certain features of the data that are potentially relevant to the research question (Braun & Clarke,2006). An example of a code noted in many of the interview transcripts is *promoting independence in adolescent child*. The coding process was done by hand in a Microsoft Word document. The process involved identifying portions of the data that were significant and potentially relevant to my research questions, taking note of the content associated with each code through colour coding the text. This process was repeated until the transcript was fully coded and all relevant content was marked. Some of the codes were descriptive, staying close to the story content and mirroring participants' words; others were interpretive, integrating my interpretations and extending beyond what participants said.

Then I put the participant's interview data from the two BNI sessions side by side, reviewing the coded data from both transcripts. Upon reviewing the data from two interviews as a whole, I combined the existing codes that shared similar unifying features into themes and identified the storylines of the narrative data. The within-story themes created were each assigned a title that conveyed their central meaning. All transcripts were coded following this procedure.

3.4.3. Re-writing the Narratives. The next step of data analysis involved re-writing the stories told by participants during the interviews into personal narratives. As noted by Lincoln and Guba (1985), people often do not tell their stories in a linear manner (Creswell, Hanson, Clark Plano, & Morales, 2007; Lieblich et al. 1998). Therefore, to start this narrative re-writing process, I re-examined each participant's interview transcripts from the two BNI sessions and organized the story in chronological order. When re-writing the narratives, I focused on

participants' contributions during the interviews, and used a combination of the themes that I had generated as well as the storylines that I had identified as a guide to frame the narratives. My theoretical framework, the ecological system theory, also came into play at this stage of analysis. In particular, I highlighted how various components in participants' lived environments (e.g., families, social service providers, the school system, cultural context) shaped their parenting experiences, as well as how they asserted influences on their environment as parents (e.g., advocating for their child). I took the role as a narrator and an observer in the re-constructed personal narratives and wrote those narratives from the third-person point of view.

3.4.4. Identifying Themes across the Data Set. After the central themes were generated from interview transcripts and participants' personal narratives were re-constructed, I started to generate the overarching themes across data sets using thematic analysis (Braun & Clarke, 2006). Specifically, I explored the relationships between the themes that I had created and considered how this list of themes across stories could work together to tell "an overall story about the data" (Braun & Clarke, 2006, p. 65). I then examined the potential themes in relation to the coded data, the whole data set, and the research question. At this stage of the analysis, certain themes identified within individual participants' narrative accounts were modified or discarded (Braun & Clarke, 2006). This final phase of data analysis generated six overarching themes, which will be presented in detail in Chapter 5.

My Master's thesis supervisor and I both participated in this final stage of the data analysis process. After analyzing the narrative data from all participants' interviews, I emailed the data analysis summary of each participant's interview responses to my thesis supervisor, who had reviewed all the interview transcripts beforehand. Those summaries included the list of themes that I had generated from each participant's story and corresponding exemplar quotes.

Next, my supervisor and I each read through all four summaries and generated the overarching themes across the data set. After we both completed this process on our own time, we held a two-hour meeting to discuss the major themes that we had identified. Towards the end of the meeting, we reached agreement regarding the most prominent themes emerging across the narrative data. The purpose of having two researchers analyzing the data was not to a find the single 'truth' in the data. Instead, this practice, referred to as co-reflexivity, aimed to ensure that the data was analyzed rigorously and allowed the researchers to take a step back and reflect critically on the assumptions that they bring to the table (Moore, Noble-Carr, & McArthur, 2016).

3.5. Data Management

All participants and their adolescent children were referred to by pseudonyms to ensure confidentiality. The written and audio data collected during the study (e.g., the timelines drawn by participants, audio recorded interviews, and participants' demographic information) were stored in a locked filing cabinet in my thesis supervisor's student lab at Western University. The electronic data were stored on a password protected computer. All data will be kept for ten years after the completion of the study. After this time, the written data will be shredded and disposed, and the audio and electronic data will be permanently deleted.

3.6. Quality Criteria

In order to ensure the quality of the narrative research study, a number of quality criteria as proposed by Tracy (2010) were employed. These criteria include:

- **Rich rigour**: A qualitative study that meets the criterion of rich rigour is characterized by complexity and abundance in the use of theoretical constructs, data and time in the field, sample, research context, and data collection and analysis processes (Tracy, 2010). In the case of the present study, the three-phase interview design and the amount of time that I

spent interviewing and interacting with the participants enhanced the richness of the

narrative data collected. Moreover, to ensure rigour, data collection and analysis

procedures that I employed were based on established theories and coding procedures.

- **Sincerity**: Sincerity is linked to authenticity and genuineness. It means that the research

  is characterized by the researchers' honesty and transparency about their background,

  assumptions, and goals, as well as about how these factors shape the research process.

  Self-reflexivity (i.e., "honesty and authenticity with one's self, one's research, and one's

  audience"; Tracy, 2010, p. 842) and transparency (i.e., "honesty about the research

  process"; Tracy, 2010, p. 842) are two of the means for achieving sincerity. I actively

  engaged in self-reflexive practice by keeping a reflexive journal throughout the research

  process. In the reflexive journal, I documented and evaluated how my own academic

  background, biases, motivations, and my interactions with participants may have shaped

  my research. To achieve transparency, I provided my rationale for important research

  decisions, such as inclusion/exclusion criteria for participant recruitment and the research

  methodology that I chose to adopt. In addition, I documented how challenges and

  unforeseen circumstances, that arose during the research process, were addressed.

  Sincerity was also achieved through the utilization of co-reflexivity during the data

  analysis process.

- **Credibility**: Credibility is concerned with the trustworthiness and plausibility of the

  research findings (Tracy, 2010). One way in which a researcher can achieve credibility in

  qualitative research is through thick description. Thick description requires researchers to

  attend to the complexity and the situated nature of their data and to support their research

  findings with abundant details. In order to achieve thick description in the present study,

findings of the study are illustrated in subsequent chapters by both exemplar quotes from the participants' interview responses and my interpretation of the data. The context in which the data generation takes place was also accounted for and described in the research report when appropriate. Credibility of this study was further enhanced through member reflection (Tracy, 2010), which involved bringing the narrative, which was constructed by the researcher based on the interview transcripts as well as my preliminary analysis of the narrative data, back to the participants and giving them the opportunity to review and modify their responses and to offer feedback about my interpretations of their narratives, during the final interview session.

3.7. Conclusion

This chapter outlined the theoretical and philosophical underpinnings of this study, as well as research methodology and analytical methods employed in this study. The next chapter will present the personal narratives that I constructed based on my analysis of the parenting experiences that the participants shared with me during the interviews.

Chapter 4: Participants' Narratives

In this chapter, I present the narratives I constructed based on the analysis of the stories that participants shared during the interviews. Basic demographic information of the participants and their children, as well as some contextual information regarding the interviews, are integrated into the narratives.

4.1. Olivia's Narrative

Olivia, the mother of a 17-year old girl who is partially sighted, was my first participant. Olivia and I agreed to meet at her workplace for the research interviews. Olivia's daughter, Chloe was diagnosed with a significant visual impairment at age 6 and was a grade-12 student at the time of the study. Olivia and her partner (Chloe's dad) have another child, a girl who is two years older than Chloe. At the time of this study, Chloe and her older sister were living with their parents.

When I thanked Olivia for taking the time to participate in my study before our first interview, Olivia replied by saying that she was happy to help out and was glad to see research involving parents of adolescents with visual impairments being done. She added that Chloe really wanted her to participate and share her experiences after learning about my study. From the brief conversation that I had with Olivia before I turned on the audio recorder, I could feel that both she and her daughter were passionate about advocating for people with visual impairments.

The Early Years: Emotional and Academic Struggle

Chloe was diagnosed with significant vision loss at age 6, but Olivia's journey as a parent of a child with vision loss began a few years before the diagnosis:

"I always suspected there was a problem. At 3 or 4 she – you know, I'd point to the sky and I'd say, 'Look at the plane or the bird' and she would be like, 'Where?' Or 'Look at the dog,' and 'Where?'"

The world of vision loss was new to Olivia and her family. She described receiving the diagnosis as "scary", and for her, those early years were "very difficult" in many ways. For example, when Chloe was younger, Olivia spent a lot of time and energy trying to figure out the services and resources that she and her daughter were entitled to. Moreover, she had to constantly advocate for appropriate accommodations for Chloe in school settings. Many of those advocacy efforts did not immediately lead to desirable outcomes:

"It [Chloe's visual impairment] is almost like an invisible disability kind of thing. You really have to be on the teachers, you always have to be aware of what's happening- always- because they [the teachers] will forget large prints still and that really made Chloe feel like she wasn't important, because she would say, 'Well you know if I was in a wheelchair would they make me take the stairs?'"

"I used to meet with the teachers at the beginning of every semester and it still wasn't enough. It still wasn't enough."

Those early years were challenging for Chloe as well. Olivia recalled that between the ages of seven and eleven, her daughter "was pretty angry at like, God, because she went to Catholic school. Why would God do this to her?" Olivia also shared that her daughter felt lonely and frustrated. Recalling a clinic visit, Olivia emphasized her daughter's sense of being alone:

"We went to the [name of the eye clinic], we actually saw a neuro-ophthalmologist and it always seemed to be cataract day, so we never saw any paeds. So Chloe really felt like, 'Hey, am I the only kid?'"

In addition, teachers' lack of awareness of vision loss during those early years resulted in insufficient accommodations for Chloe at school, which affected Chloe's academic performance:

"... [the lack of proper accommodations at school] made her struggle academically, because she's not given the same tools, it didn't level the playing field. She was definitely at a disadvantage. So that makes it difficult, too."

Olivia was thankful that Chloe did not have any health issues besides vision loss, and she tried to help Chloe recognize the fact that she was an amazing child despite her vision impairment. However, watching her daughter struggle emotionally and academically made Olivia feel heartbroken as a parent.

Lake Joe Summer Camp: A Turning Point

For Olivia and Chloe, attending Lake Joe summer camp (i.e., a summer camp for people living with vision loss and their families run by the CNIB) when Chloe was 12 years old was what changed everything. Olivia considered participating in Lake Joe Family Week program as a turning point for Chloe and for herself as a parent:

"I can't imagine where we would be today without Lake Joe. It would be a significantly different story, I think."

Describing her experiences at Lake Joe elicited a lot of emotions. The emotional support and the resources that Olivia received from Lake Joe were significant to her, especially in the context of inadequate support from some of her family. Olivia explained that despite her husband being supportive of Chloe and her, some other family members "don't believe that Chloe deserves, and they have told Chloe that they don't think it fair that she asks for accommodations. You know, they have, they have never made any kind of effort to anything, they think she just needs to suck it up and move on."

Olivia added that prior to attending the Family Week at Lake Joe Summer Camp, she and her partner, as well as Chloe had never met other families with similar experiences. Being the only ones in their social network who were parenting a child who was partially sighted often left Olivia feeling like they were fighting a battle alone. Connecting with other participants and staff members with visual impairments who were independent and successful at the summer camp opened the door to a new world and provided Olivia and her partner with a sense of reassurance that Chloe would be capable of living a fulfilling and productive life:

> *"It gets me emotional because it was amazing. We saw people that were successful, independent, everything, you know, instead of my family saying, 'Oh, well she shouldn't do that" or 'She can't do that.' Here [at Lake Joe] we're seeing, 'Yes, she can. We knew those people existed, we just didn't know where they were, and we couldn't find them, we couldn't even find them here in [the city where Olivia and her family resided], even through the CNIB. We tried to get them in camps; they just weren't here. I don't know, so and Chloe wasn't seeing it and we needed to prove to her, you know, that no, just because this is what it is. It doesn't matter. You're still good to go."*

Olivia and her partner had always believed in Chloe's potential. However, being able to finally back up their confidence in their daughter, using the stories of those living with similar conditions that they met at Lake Joe summer camp was empowering to them. For example, meeting a yoga instructor who was completely blind at Lake Joe gave them the hope that Chloe would be able to have a fulfilling career in the future:

> *"You know, we can back up our words like, Vivian is there teaching yoga and she's completely blind. Like how is that possible? But it happened, it was great."*

In addition, connecting with parents who were living with visual impairments themselves allowed Olivia and her partner to see the possibility of their daughter having a satisfying family life as an adult:

"Yeah, it was really good to talk to other parents, and it wasn't just kids that were visually impaired or partially sighted. Sometimes it was the mom or the dad, you know, like look at them raising a family."

Olivia believes that the experiences at Lake Joe summer camp were transformative for Chloe, too. Taking part in a variety of activities and connecting with other people living with visual impairments at the summer camp built up Chloe's self-confidence, gave her a sense of belonging, and enabled her to have a more positive outlook on life:

"It's where she [Chloe] says: 'Mom, I have found my people.' And she didn't mean blind people or partially sighted. She meant independent, successful, amazing people. That was really the first time she's ever met people like her that were amazing, so I think that's what really changed. It was really inspiring to her to see, now if they can do it so can I."

To give back to the community that once transformed her, Chloe went back to Lake Joe to work as a camp counsellor at age 16 and is planning to do it again this year. Olivia hoped that her daughter would inspire other people who were blind or partially sighted:

"So now, Chloe's a camp counsellor there [at Lake Joe]. So she's hopefully she's inspiring other people."

Becoming and Being an Advocate

As my interview with Olivia progressed, her passion for advocacy stood out to me even more. Indeed, her narrative conveyed how she took on the identity of being an advocate and how this developed over time.

Since Chloe was first diagnosed with a visual impairment, advocacy has become a big part of Olivia's life, and she believes that being a parent of a child who is partially sighted is what has made her become the advocate that she is today:

"[...] I feel like there was never a lot of restful times. It's always been, advocating, worrying, getting stuff ready, trying not to drop the ball. Juggling, making sure that she is supported and making sure my other one is supported, because for us, it was so important that in order to level the playing field we as parents, or me really, I had to work really hard to do that and to teach her how to help level her own playing fields for her future. I certainly was not the advocate then and I am now."

Olivia emphasized that she has never stopped advocating for Chloe. She noted that despite having strong advocacy skills for her age, Chloe still lacks knowledge that is needed to navigate the complicated health service and education systems on her own. For example, Olivia recalled a recent challenge Chloe faced:

"Chloe just did the Casper test for university. Just booking that is an ordeal, and then if you need accommodations they have to be in 3 weeks before, has to be signed by a medical professional, and it's just like, no other 17 year old kid has to figure this out."

Olivia further explained that because of Chloe's young age, she is more likely to be taken advantage of than someone who is older:

"I am definitely advocating –because she's young, she's not the strong advocate that I am because I don't care [what other people think of me]. She still does, you know? So I find – and I find people take advantage of that and that really ticks me off too."

Olivia's advocacy work goes beyond levelling the playing field for her daughter. In fact, Olivia has recently spoken at a fundraising event to raise awareness of visual impairment. She

said that being an invited speaker at a big event like that was out of her comfort zone, however, she felt that she needed to set an example for her daughter. Olivia added that she was grateful for that opportunity to stand up for what she believed in:

"Because I always, I always push Chloe, like sorry I don't care that you're partially sighted, you need to get a job in my house. Like that's just the way it is… it wouldn't be fair if I didn't get out of my comfort zone and do this for her. Similar, when I talked about when I as at the [name of the eye clinic], I saw a Mom with a child the same age as Chloe. I know that Chloe would want me to introduce myself and share my story because that's what we do, we advocate… I felt really proud to stand up for what I believe in. It's a whole different path than I thought we would ever be on, you know. I was pretty happy to do it."

From Olivia's perspective, one of the major challenges along her advocacy journey has been the lack of professional resources and supports for parents of children and adolescents with visual impairments:

"[…] at no fault of CNIB, I just don't think that we [parents of children with vision loss] know what our rights are. Nobody has taught us how to advocate. There's no real big resources on that. It's just us doing it, day gig, you know."

In addition to advocating for Chloe, Olivia has been taking steps to teach Chloe how to become a self-advocate. She has done so by actively involving Chloe in advocacy efforts related to her own care:

"Like when we write email, she's always copied on everything. At meetings at the school, she's always there. Just always being a part of everything, she's always participated even

if I write an email, she's copied on it. Copied on everything, she's always been part of her

care,"

Olivia said that her advocacy efforts are not understood and supported by some of her extended family members:

"It was very difficult when you have my in-laws saying, that she didn't think it was fair that we were asking to have the cash register raised, [at the restaurant where Chloe used to work], a small accommodation. And she in fact told them that if it was her, she would make sure to only hire 100 percent healthy people, so having gone through that and then getting that from your grandma when you're 15 is devastating. Devastating for all of us, because we just can't allow it, and it just puts such a divide in our family, because we cannot allow Chloe to see that we condone that kind of philosophy in life."

Although Olivia finds not having support from her family, other than her partner, is challenging at times, she chooses to continue to stand up for what she believes in and being an advocate for her daughter:

"When you don't get that support [from your family], you start thinking, am I crazy, but no I'm not. I'm going to continue on."

Olivia viewed her efforts in advocating for Chloe and teaching Chloe self-advocacy skills as paying off. For example, now the teachers at Chloe's high school are more accommodating to her needs, and Chloe has become a good advocate for herself and her needs. When I asked her if she still felt the need to constantly be aware of what was happening in her daughter's school now, Olivia answered:

"Less so now, because Chloe is a great advocate. And actually after many years of emails and trying to get resolutions and everything, now, if Chloe has a teacher doesn't

follow, like doesn't give her a large print, basically Chloe is pretty independent, but she

does require a large print out or a large book or an audiobook. If the teacher doesn't

come prepared and she doesn't get it at the same time, she is allowed to rate a teacher or

write an email to the principal and then the principal comes right away. Yeah, so that's

how and she's probably only done it twice because now the teachers know"

Enabling Independence and Letting Go

As a parent, Olivia hopes that Chloe will lead an independent life and become a

productive member of society in the future. She has been working towards this goal by creating

opportunities for Chloe to gain and practice independent living skills both within and outside

home:

"I always say my kids probably got to do more because of Chloe than had they both been

sighted, because we had to prepare her more for life. She had to be independent. Like my

kids were already taking the city bus at 11 and 12 going all over the city, probably

because I knew she had to be ready."

Like many other teenagers, Olivia views Chloe as eager to build her own independence

and explore different opportunities. At age 15, she began working part-time outside school.

Unfortunately, Chloe's experiences in the workplace did not start off on a positive note:

"At age 15, she started working at [her previous workplaces], where they treated her

terribly, terribly. 'Clean the bathrooms, empty the garbage,' just terribly. Like everybody

was rude to her; it was a terrible time."

Olivia recalled that despite being treated unfairly at her previous workplaces, Chloe

would not quit and tried to prove herself as an employee, but she was not provided with the

accommodations needed to succeed at those two workplaces. Olivia knew that Chloe wanted to

work and had the right to work just like everyone else, and she was devastated by the fact that

Chloe was not given the opportunity to thrive. Olivia said that at that low point in Chloe's life,

she did her best to support her daughter. Although it was hard for her to watch Chloe experience

workplace discrimination as a teenager, she believed it was important to support her child's

decision and to allow her to experience the positives as well as the negatives in those

environments:

> *"We just tried to support her. And you know, even working at [name of the restaurant], it*
>
> *was very hard to let her go in but know that they were kind of bullying her around, but*
>
> *she needed to do that. I needed to let her do that."*

Thankfully, Chloe has had some positive experiences at other workplaces, which showed

Olivia the difference that positive attitudes towards those with vision loss and an inclusive work

environment could make in her child's life:

> *"[Chloe's current workplace] has been amazing so she still works [there] [...] Basically*
>
> *she asked, 'Hey, I'm legally blind, could you maybe raise the cash register or so?' That*
>
> *manager was like, 'Oh, okay' and put a box under it and never really thought anything of*
>
> *it, like just very casual. She works all stations. She does dressing, ovens, cashier,*
>
> *everything. Like they are amazing."*

Letting her daughter explore the outside world and be as independent as possible does

come with worries and concerns for her daughter's safety. Olivia noted that these concerns are

not entirely the result of Chloe's visual impairment, as she experiences similar worries for both

of her children at times:

> *"I do it with both of them [the children], like I worry. I don't know, if they were going to*
>
> *go on a road trip with a girl guides to Canada's Wonderland, well I worry because what*

if they're not, if they don't. What if Chloe gets lost and she can't find them, you know? I

always know to keep track of where she is."

However, Olivia does not think that she should let her fear deprive Chloe of opportunities

with regards to moving towards her independence:

"I tried not to let the fear of her riding her bike, like my fear of worry about her not being

able to see the curb or see a bump or whatever, deprive her of riding a bike, although I

kept her safe as much as I could. That's just one example, I couldn't let my fear deprive

her. I couldn't wrap her in bubble wrap and say 'oh you can't go out, you can't try to get

a job, you can't get hurt. No, you need to go through all that.' "

Olivia noted that her partner's support and reassurance had made the process of enabling

Chloe's independence much easier:

"I had to keep reminding myself that thank God for my husband, Chloe's dad, who says,

'It's nothing we can't handle. Like everything is good; she's fine, relax.' So that makes it

– because I'd be like, 'Oh my God, have we got this?' and he be like, 'We got it.'"

Chloe will be starting her university studies in the next academic year. In preparation of

this upcoming transition, Olivia has toured the university campus with Chloe to learn about the

resources that were available. Also, Olivia believes that Chloe's previous work experiences as

well as the independent living skills that she has learned and practiced at home have prepared her

well for the transition from high school to university life:

"I definitely think letting her be a camp counselor at 16 at Lake Joe helps [...] [When

Chloe worked at Lake Joe], she's really living independently when she's out there in a

somewhat controlled environment, so I think that's helping prepare her. Like I said, she's

been working since she was 15, she been taking the bus, she cooks, she knows how to eat

and cook, she can take care of herself. She's been a gone for weekends by herself. She

could survive."

In Olivia's eyes, Chloe has grown into an independent teenager and a great self-advocate. She recognizes the importance of continuing to support Chloe, but she believes that she now needs to shift from a more controlling parenting style to a more permissive parenting style. Olivia added that as Chloe is currently doing well in school, holding a part-time job, and had gone away to work at Lake Joe as a camp counsellor for ten weeks, now is the time for her to start letting go as a parent:

"[…] there comes a point where I feel like at this point, I don't know. Like you have to

start trying things and we're here to catch you,

This was illustrated in a recent instance where Olivia took the opportunity to let Chloe make her own decision:

"[…] Chloe said, 'Oh – because we're going to a play on a Thursday' – and she goes,

'Well I have school the next day but maybe I won't go.' And I said, 'Well I'll write you a

letter.' She goes, 'You will?' 'Of course I will, if that's your decision,' you know?'"

Olivia considers her current parenting style as permissive. She further explained:

"[…] because she [Chloe] is a really great kid. I already did a lot of work before when

she was younger, so I don't know. I heard one time that they said a lazy parent is busy, so

I wasn't lazy and now I can relax, you know, because I did it. I don't know what else."

Towards the end of my second interview with Olivia, our conversation was brought back to Lake Joe, a place that represented a significant chapter in her and her daughter's lives. When I asked her what advice she would give to a parent of a child who was recently diagnosed with a visual impairment, she responded:

"I definitely think I'm still going to say you need to go to Lake Joe, because I think it really will help you to see what the potential is."

Olivia also wanted to let other parents of children living with visual impairments know that despite the ups and downs throughout the journey, things will be okay:

"[…] it will be okay, and it will be. You'll find your groove. You'll learn how to advocate."

4.2. Brandon's Narrative

Brandon is the father of a 14-year old girl who is legally blind and a pre-teen boy without visual impairment. At the time of the study, Brandon was working as a social worker. For the interviews, we decided to meet in a private conference room at his workplace over the lunch break. Brandon's daughter, Erica, is a Grade 9 student with oculocutaneous albinism. Erica's parents are no longer together, but Erica spends time regularly with both of her parents and has a close relationship with them. She has a younger brother who is a pre-teen without visual impairment.

Brandon expressed his excitement about being in my study and said that he looked forward to hearing about the findings of the study after it is completed. As I chatted with Brandon before our first interview, I could tell that he is a very involved father in his daughter's life. His friendly and warm demeaner also stood out to me.

Learning to Parent in the World of Vision Loss

Brandon recalled that when Erica was first born, he and Erica's mom (his partner at the time) noticed right away that her hair was really blonde and that her skin tone was very fair. "But then we noticed, I guess about 2 to 3 months, that she started having nystagmus, that the eyes going back and forth. Then shortly thereafter she was diagnosed with oculocutaneous albinism."

Brandon said that when the optometrist delivered Erica's diagnosis to him and Erica's mom, the process felt rushed. In addition, after providing the diagnosis, no one followed up with them to provide information or resources regarding raising a child with low vision. This lack of support from health professionals exacerbated the grief and uncertainty that they had already been feeling:

"Even just after the diagnosis, it was just, it was just so plain. It was just like 'Oh your child is blind and has this, and that's it. Thank you have a nice day.' Right? So there was no connection to CNIB. There were no resources, no nothing. It was just 'Oh this is what it is, and you know thank you and next.' At least that's what is felt like for us. I remember being in the parking lot and looking at my wife and just crying, because it was just you know, well this changes everything, right, because we just didn't know what to expect or how this was going to impact Erica."

As a piece of advice to health professionals working with parents whose child is newly diagnosed with a visual impairment, Brandon hoped that the doctors and other health professionals would "take their time" when delivering the diagnosis:

"Like it may not be a big deal for them [the doctors], because they give this diagnosis maybe 3 or 4 times a week, But, really take their time and empathize with the parent [...] It would be helpful if doctors took time or at least said here's a list of resources that you might find useful to connect with in the future."

Brandon and Erica's mom did not have any experiences with parenting a child with a visual impairment prior to Erica's birth. Reflecting on how they managed those early years with minimal support from health and social service professionals, Brandon said that the whole

experience "was very much trial and error." Brandon illustrated this with the example of how he learned to guide his daughter safely when they would walk together:

"What I really noticed is that quickly in my parenting career is definitions from sidewalk to the curb, that step down, I learned that. She fell, and of course I learned quick, and of course it broke my heart, because she was a little three-year-old, skinned her knee and scuffed her chin. But it was a memorable moment for me, knowing that I have to, you know, be aware of this stuff just as she is a very young child."

Brandon noted that the techniques to help Erica navigate her environment that he learned over time have now become second nature:

"[…] I can't expect Erica to just walk behind and follow me, because she might trip or fall so, it's kind of just having her walk side by side with me and even now we walk arm in arm and I'll just say, "hey there's a curb,' or 'step up,' or 'step down.' It's second nature but when I was first parenting, it wasn't."

Due to her albinism, Erica is light sensitive. From my conversation with Brandon, I could tell that over the years, he and Erica's mom have developed creative strategies to help their daughter manage the impact of her light-sensitivity on her everyday life. This was illustrated in how they encouraged Erica to wear her sunglasses when she was younger:

"She was very light sensitive, so we had to get her to wear sunglasses a lot of the times, especially outside and she hated it. Being a toddler, she would pull them off and throw them away, not wanting to do it. So just looking at ways we can make it fun for Erica to wear her sunglasses, we would sing a song that she still remembers today."

As Erica got older, Brandon also learned how to accommodate Erica's light sensitivity when planning family leisure activities. For example, instead of going to the beach with Erica

during the day when it was sunny and bright outside, Brandon would go to the beach with his teenage daughter at night and spend some quality time around a campfire:

"The beach is another thing where it is bright and sunny, the land and the sand is different, so she doesn't like walking on that as much. But at nighttime it's great. So that's what we decided to do when we go to the beach. We are going to go at dusk and going to have a campfire and just kind of sit and enjoy. Yeah, so it's just learning as you go. "

Beyond Visual Impairment

Besides a visual impairment, Erica is also living with anxiety. Brandon recalled that Erica's anxiety started when she was in grade 3:

"I'm thinking about, was it grade 3? She started having these really anxious and worried thoughts [...] she is a very anxious child and worries about things. She has gone to counselling for anxiety but has been a struggle for her starting at grade 3."

Brandon added that despite having received counselling services, anxiety continued to impact Erica's life, especially during the adolescent years:

*"Erica is also a teenager now, she's 14, and she doesn't like being told what to do. *laughs* Like any teenager, right? [...] and sometimes she almost like self-handicaps, just because she isn't using the tools that the counsellor has asked to help with her anxiety, and it is kind of limiting her ability in high school, especially now because she just started grade nine, to make new friends and to be more social."*

Brandon believes that his career as a social worker has helped him greatly when it comes to parenting an adolescent living with anxiety, since he has a good understanding of what anxiety entails. However, he noted that Erica's anxiety does have an impact on him as a parent:

"Because I want the best for Erica, and I see her limiting herself with these experiences, right? Like she's not, well she is getting better, but before, she was like 'I don't want to go on the school trip, because it's something different and I don't want to do it,' Or 'I don't want to talk to people, because they might not like me.'"

Brandon recognizes the importance of helping his daughter reframe those anxious thoughts when needed:

"And then it's kind of reframing those thoughts, like 'maybe they are thinking that you're not wanting to talk to them not because you are shy but because you are a jerk, but you aren't a jerk, and you will never know, so you just have to go up and say hi." Right?'"

Brandon said that to this day, he still wonders to what extent Erica's anxiety is related to her visual impairment and whether her anxiety is just a typical part of being a teenager:

"I always wonder, how much [Erica's anxiety] is related to the vision loss, and not navigating the world, and not seeing it as well as others, or is it the anxiety or is it both? I don't really know. Or is it just being a regular teenage girl and having those feelings, too, right? So it's just so hard."

Brandon also acknowledged that he does not know what it is like to be a high school student who has low vision and is visibly different in 2020, and as a parent he is trying his best to be understanding and be empathetic towards his daughter:

"And it is true, like I don't know what it's like to be someone in high school with low vision but, she is pretty centered out, right. Like she has a cane, her hair is white, and she can't help, but be different, but that sometimes it's hard for a child, any child, especially for a teenager, so we are especially mindful of that."

Brandon noted that because of Erica's noticeable differences, some of her peers only see her disabilities and ignore her many other qualities. He illustrated this with a recent conversation that Erica had with another student at her school:

> *"Even last week or so, she met someone who was a few grades older than her, and she [the other student] was like, 'oh, you're the blind girl in grade 9.' And she [Erica] was like 'yeah, well it hurt, because I am so much more than that.' And I'm like 'yeah but you are! That's something like saying 'I'm the fat guy at work,' that it doesn't feel good. No, you are so much more than that."*

Indeed, Brandon firmly believes that Erica is much more than her disabilities, and in his eyes, Erica is a typical teenage girl in many ways:

> *"So Erica is a typical teenager, she doesn't like getting up early in the morning. She needs some extra, I guess, encouragement to get out of bed. She likes to stay up late which doesn't help as well. She likes to be on her phone. […] When she's at home and knows the environment you don't notice anything right? You don't notice any limitations, it's just Erica."*

Like many other teenage girls her age, Erica enjoys painting and singing. Brandon said that Erica does those two activities very well, and he is proud of her as a parent:

> *"And one thing she's really good at and I'm proud of is that she paints. She does great landscape paintings and great portrait paintings. I think she paints almost every other day. So that's something I'm really proud of. She also sings. She has gotten up in front of a large group and has sung and yeah, like she's doing good."*

Balancing Multiple Roles as a Parent: An Advocate, a Teacher, and a Protector

During the interviews, Brandon noted that one of his priorities as a parent is to advocate for a more accessible learning environment for his daughter. He explained:

"There are many times I think when you just have to let people know. The school system is number one, and I don't want to say on the teachers, but you just have to remain in contact with the teachers a little more, I think. Having a child, if you are a parent of a child with low vision, because Erica won't say anything either."

Brandon added:

"I think one of the biggest things is that we [Brandon and Erica's mom] had to advocate for, was getting tape on the stairs and tape on the middle of the doorways, like fluorescent tape just to put up so Erica could see those definitions."

In addition to playing the role as an advocate for his daughter, Brandon has taken steps to teach Erica to become a better self-advocate at school. He explained that at this point, Erica is a good self-advocate with "people she feels safe around", such as family members, friends, and teachers that she was familiar with, but when she is around teachers who she does not know well, she can be shy and reluctant to ask for what she needs. To help Erica overcome this fear of advocating for herself in those situations, Brandon keeps reminding her that it is ok to ask for help when she needs it:

"We try to instill those values, because people don't know what you need unless you say something. I tell her that all the time. She would say her teacher didn't help her with this, and I would say 'well did you ask?' She would say 'oh no I didn't.' 'Well then just ask, and it's ok.'"

I wondered if his career as a social worker has positioned Brandon well as an advocate for Erica. In response to my question, Brandon said:

"Oh I think so. I often say that I had two different lives, before I went to school and started my career, I was a 'blue collared worker', because I didn't understand the values and differences of others. I was that person who would not really think about that stuff. I think having that understanding or even that foundation of understanding is key to many different life experiences and thinking about life. I wish everyone had the opportunity to one year of liberal arts education to broaden their mind."

Currently, a lot of the worries and hopes that Brandon has for Erica and her future are centered around whether she will be able to lead an independent life:

"I think my biggest thing for that future for Erica is will she be independent and able to live this life without me? Without us? Like I think that's the biggest thing that any parent worries about, is that if something happens to me, will my kids be ok? And I think that's the biggest thing I worry about. [...] will she be able to do something that she loves, and will she be able to be independent?"

Brandon said that Erica is in the process of learning how to take the bus and how to walk home [from school]. […] but she is a little reluctant to do that, because it is something that is new, and anything new with Erica is scary, and she doesn't like doing it." He added:

"I tell her that when you do it the first time it is going to be awkward and scary. But if you do it a couple hundred times after that it will be easy, and you just have to learn your way around. No one is good at anything right off the bat."

Encouraging independence in Erica does come with concerns for her safety. Brandon acknowledged that as a parent, he is "protective" of his daughter:

"And me being a parent, I am very- I don't want to say daddy bearing, but I am very

protective of Erica and also my other son. But I am more protective of Erica just because

I think she has a harder time sometimes because of those [her physical] differences."

Brandon further illustrated his negotiation between independence and safety with a recent

instance where he saw his daughter with her friends when he was out running errands:

"I was [out] doing something and I saw Erica walk down the street with a bunch of

friends on Main Street and I was like 'Oh man.' It kind of just hit me, ok she's out and

doing something this is great, but God I hope she doesn't fall. […] It's just going through

those things in my mind, like oh she doesn't have her cane, but there are friends there,

what if the friends ditch her?"

Brandon added that, at the moment, he realized that he should not be engaging this

catastrophic thinking, but he could not help but worry about his daughter as a parent of a

teenager with low vision:

"It's just that catastrophizing thinking, right? Even though I know I shouldn't do it, but

what if those friends are jerks and all of a sudden, they leave her. How will she find her

way home? Does she have her phone with her? Should I pull-over and ask? But I didn't

because I don't want to embarrass her either, but when it's that extra thinking I just think

that we have to have being a parent with a low vision child, and I want to make sure she

is safe, too."

For Brandon, teaching Erica how to make her own decisions and to take responsibility for

those decisions is another important aspect of guiding her towards independence. This was

illustrated in one instance where Brandon let Erica make the decision on the use of assistive

technology and be accountable for that decision:

"There have been some incidences in the past where even with her [assistive] technology, it's like Erica, you are going to get behind if you don't use your technology. She doesn't, and then we spend the whole weekend doing homework. This is like, you can make whatever decision you want, but you have to be accountable for the decision you make. Sometimes we let her make the decisions she wants to do but they aren't that great."

Brandon emphasized that similar to encouraging his daughter to practice her orientation and mobility skills and to travel independently, teaching her to be a better decision-maker involves finding a balance between autonomy granting and parental supervision:

"It just a balance. I wouldn't let her do anything that would cause her harm, but I would let her do something that would cause her more work and frustration, as long as she learns from decisions she made."

Brandon believes that it is important for Erica to not only be independent but to have goals in her life, because "you can learn a lot from achieving goals but also from failing." Observing Erica doing the activities that she enjoys has created teachable moments for him to instill this value:

"So right now, she is big into painting and she paints every other day. You can see the progress in her paintings, at the beginning, they weren't that great, but even though I thought they were fine, until now. So she can see the progress of doing something over and over again and can see the outcome of experience, and just explaining to her that nobody is good at something the first time they do it, that's just impossible to happen. You have to do something a thousand to ten thousand times to get good at it. So just instilling that it's ok to fail and it's ok to not be great at some areas, but you still need to try."

Thinking About the Future: Worries, Hopes, and Plans

Erica started high school not long ago. Brandon noted that being a young high schooler with a visual impairment, Erica does not want to appear different: "it's just hard in high school being young and being different. Everything she is doing now is to fit in." Brandon noticed that some of the strategies that Erica uses to fit in with her peers have in fact hindered her ability to access and learn course material at school. For example:

"She is given tools [e.g., assistive technology] at school to use, but she doesn't want to use them because she doesn't want to seem different, even though she is…So I think these next few years are going to be hard on Erica."

Brandon shared that he has been working on making this transition into high school smoother for Erica by being supportive of her and normalizing the challenges that she is currently experiencing or might experience over the next few years:

"High school is kind of hard for everybody. I didn't have a great time in high school, and I found my people and what I wanted to do in college and university. […] so I'm just really trying to encourage Erica, and sure these years are tough, but you aren't the only one feeling like this. Everyone feels this way in high school, whether you are different or not."

Projecting ahead, Brandon realizes that when Erica gets older, she will be spending more time with her peers and possibly start having romantic relationships. He spoke about his concerns for Erica's safety when she starts dating:

"It would be hard especially when Erica gets 19-20, and goes on a date, and I didn't think about this until now, but she would never notice if someone slipped something in her drink. I know that's catastrophizing, and that's me thinking of worst-case humankind,

and I hope no one would do that. But those thoughts do come up, so I just hope that she picks her friends wisely, and that she surrounds herself with people who are trustworthy and that she can depend on."

During my interviews with Brandon, I could tell that Erica's employment prospects is another source of concerns for him. When speaking about his wishes for Erica in the future as a parent, Brandon said:

"If I had a crystal ball and could look, I would love for Erica to be self-sufficient and working and doing something she really loves. Like any parent, I just want her to be happy. If she has to apply for ODSP or any kind of disability benefit that's fine, but I just want to make her sure that this life is worth living"

Brandon explained that he has worries about Erica's employment prospect partly because of her visual impairment and partly because of the lack of job opportunities in the field that she is currently interested in:

"Like she's such a great kid and can do really a lot of good. […] I just think it will be hard for her to find her way, because she is very much an artsy type person and loves the arts and loves singing and doing that. And just that's a hard business to even begin for a person who has no vision impairment."

Brandon has been thinking about what he could do as a parent to help Erica along the process of entering the workforce. He shared that right now, he is thinking about the possibility of opening a small business and offering Erica the opportunity to work for him:

"Even thinking about my profession and what I do. I was thinking is there a way I can open up a small business and then have Erica come in and do work for me, and that way we can make sure she has full employment and that security moving forward."

Brandon added that Erica seems to be on board with this idea, and they have started taking steps to make this plan a reality:

"Actually next year, they have small business grants that are available for high school kids. So we are starting to prepare a small business plan for that to get that kind of interest going in developing a small business, and what we can do to make that happen."

At the same time, Brandon recognizes the importance of not being overprotective of Erica. Once again, he emphasized the need to strike a balance between enabling independence in his daughter and protecting her against the challenges in life:

"I also don't want to coddle or be that helicopter parent always over her shoulder making sure she's ok. So, it's definitely a balance."

Reflecting on his parenting journey, Brandon said that his experiences of raising his daughter with low vision has allowed him to see disabilities and other differences as a normal part of the human experience and to better connect with people from all walks of life:

"When I wasn't really exposed to anyone who was different from myself, I always thought of those people having significant difficulties or they might need a lot of assistance. I wouldn't see them; I would see the impairment or the visual impairment. But now, with Erica, I don't even notice her eyes moving or her nystagmus anymore, because she's just Erica, she's just a person. So I think that changed my values for sure, and my ability to just go up and talk to people."

4.3. Jenifer's Narrative

Jenifer is the mother of a 17-year old girl with visual impairment. She was working as a personal support worker at the time of this study. Unlike my other participants whose children were diagnosed with a visual impairment at a young age, Jenifer's daughter, Pam, started

experiencing significant vision loss less than a year prior to this study. At the time of this study, Pam was a grade 12 student who had lost full vision in her left eye and still had some functional vision in her right eye. She is currently living with her parents and her brother who is five years younger than her.

Jenifer and I decided to meet at a private meeting room at Western University for our interviews. From on my brief conversation with Jenifer before the first interview, I could sense that Jenifer was still processing her daughter's sudden vision loss, but it was clear to me that Jenifer was supportive of her daughter and was trying her best to help her daughter navigate the transition to her life with vision loss.

The Loss and the Grief

In our first interview, Jenifer began telling her story by sharing how Pam started losing her vision unexpectedly ten months ago. Jenifer recalled that Pam has always had vision problems. Shortly before her third birthday, she had surgery for her crossed eyes. Pam wore strong prescription glasses afterwards, but before her vision began deteriorating suddenly, she could still see with her glasses and was able to get her driver's license. April 30, 2019 was when everything changed for Pam:

> *"She woke up, and she couldn't see out of half of her left eye. From there, we went through all these testing. They [the doctors] couldn't find anything. They didn't know what was going on. August 11th, she lost seventy five percent vision in her left eye, and it went to 50 percent vision in her right eye. In the left eye, it was completely blurry, so even the 25 percent she did have, it was pretty much useless to her. So from there, January 12th of this year, she lost full vision in her left eye and still 50 percent in her right eye."*

Pam's vision loss was not only unexpected and sudden but progressive in nature. Processing and adjusting to this unexpected loss was an emotionally overwhelming experience for Pam and Jenifer. During our first interview, Jenifer expressed the grief that she had been experiencing over the past ten months:

"As a parent, you feel helpless. As a mom watching your kid trip over everything, you just want to pick them up. When they are adolescents, they are17. It's 'mom, stay away. Mom, I've got this. Mom, I've got this.' And then you walk by, and she's crying in her room because she's frustrated with what she can't do now. What she's lost."

In addition, Pam's deteriorating vision made it much more difficult for her to do the activities that she used to enjoy, such as play ringette and cooking:

"Watching her give up stuff she used to like, she used to play ringette and not competitively, but on a team. And she gave that up because of safety concerns [related to her vision loss]."

Jenifer noted that not all her parenting experiences following Pam's vision loss were negative. For example, the fact that Pam has been excelling academically at school after she lost her vision did give Jenifer a sense of hope and relief:

"On the opposite end, I didn't expect her to do so well in school this semester because of how much she's lost since April. And she's blown me away. She's always been B plus A minus kind of. She is honor student in all four classes. She is top in all of her four classes, but not even just a little bit. She's getting like ninety fives in most of her classes, and I wasn't expecting that."

Managing the Uncertainty and the Guilt

Jenifer shared that the doctors have yet to figure out what condition Pam has that has caused her vision loss. This uncertainty has added another layer of challenge for Jenifer and Pam. Jenifer added that Pam would be going through further testing to determine what was going on with her eyes: "And that scares us, both of us. I don't know what to say to her and make it better. When we first started this in April, we were always told it was temporary. Now, at this point, even though nobody said anything, we've accepted that it's permanent," Jenifer said.

Without having a definitive answer regarding the cause of Pam's vision loss, Jenifer wondered if she had done something that caused her daughter's condition. She explained that when Pam was doing research on her own recently, she found out that the eye surgery that she received when she was three could have caused an infection which led to her current vision loss. Jenifer acknowledged that letting her daughter receive the surgery when she was younger was the best decision she could make based on the information that had been given at the time, and she knew that Pam was not angry at her for making that decision. Still, Jenifer could not help but feel a sense of guilt at times:

> *"It's a decision I made way back when, that could have resulted in this. […] When she first told me, I'm like, I'm a horrible person. […] And then I had to realize, here's my information I was given. I made the best decision at the time, because when I did the surgery, if I didn't do the surgery because of how bad her strabismus cross-eyed was, she would have lost her vision sooner."*

Currently, Jenifer does not know whether Pam's vision will continue to deteriorate. In addition, Pam's vision can often fluctuate throughout the day, which impacts her ability to perform certain tasks, such as reading. In my first interview with Jenifer, she expressed the

worries she felt about implications of Pam's vison loss on her future, especially her employment

prospects:

> *"At this point. Yes, she's got 20/20 vision in half her right eye. But if she loses any of that*
>
> *or she has eye strain where, you know. She reads good in the morning, but halfway*
>
> *through the day, it's gone. So what does that [Pam's deteriorating vision] mean for her?*
>
> *Can she work part time? Can she work? I'm still trying to figure these things out. I know*
>
> *she has to figure them out on her own, but I want to. She asks me these questions and I*
>
> *don't have answers. I feel like there's not enough answers out there to help with that."*

Jenifer added that Pam was concerned that both people with and without visual

impairments might not accept her, because not only does she have vision loss, she does not know

why she lost her vision:

> *"Like she's been to the CNIB hub [a community space where the CNIB hosts events and*
>
> *programs for those with sight loss and their families]. And she really liked it. But her fear*
>
> *is, people won't accept her, because she doesn't know the reason why she's lost her*
>
> *vision, so she's kind of in that limbo where she doesn't think people with vision loss will*
>
> *accept her because she doesn't know why. And people who are normal in their eyes won't*
>
> *accept her because she has that vision loss."*

Although Jenifer was trying her best to empathize with her daughter and to understand

what she was going through, she recognized that without experiencing the loss first-hand, she

could not completely understand what life is like for Pam to lose her vision suddenly during her

teenage years:

> *"I'm hoping that she meets people that kind of help and understand what she's going*
>
> *through. I've tried, but I'm not on that same level. I don't know what it's like to lose my*

vision, suddenly. I don't know what it's like to have to learn differently. You have to worry

about that. So I struggle. I'm scared of the future."

Jenifer said that she has yet to meet other parents whose child lost their vision in their

adolescent years. She felt that she and her husband were navigating this whole experience alone,

and this sense of isolation was emotionally overwhelming for her at times:

"I'm alone, like I talk with my husband [about my feelings and challenges], but it [this

unexpected loss] sucks, you know. You have one vision of what you wanted in life and

then it totally throws you for a loop when you have stuff like this happen."

Jenifer believed that it would be easier for her as a parent if her family's experiences with

vision loss was more common and if she could connect with other parents who had similar

experiences:

"I think if there was a lot more people there were that were out there dealing with the

same situation, I think it would help. Because right now I feel like I'm with my husband,

we're doing it on our own. We have no knowledge of what we're going through. It's kind

of like blind leading the blind,"

Re-Introducing Independence and Learning to Do Things Differently

Jenifer considers Pam as independent and mature for her age, both prior to and after her

vision loss. However, Jenifer noted that after Pam lost her vision, she had to re-learn how to

perform many everyday tasks independently, such as using a knife, taking the bus, and going to

the mall. Furthermore, as a parent, Jenifer had to re-establish the balance between encouraging

independence in her daughter and protecting her against harm:

"When your kids are growing up, you're always trying to push them to be independent. And that's what I did up until April, like 'take the bus, go to the mall.' […] It takes me so much to do that now, because I'm so scared of something happening to her."

Jenifer added that she noticed that Pam's dependence on her parents and younger brother became "more prominent." For example, rather than going to the mall by herself, Pam would choose to go there with her brother:

"I find she and her brother are very close, so she's always constantly if she wants to go to the mall, it's like, 'Jayden, you want to go to the mall with me?' It's never her going by herself because she's too afraid to do that."

Jenifer also recognized that as a parent who was relatively new to the world of vision loss, she was still in the process of figuring out when to offer help to her daughter and when to step back:

"I struggle with where do I back off? Where do I let her figure this out? Where is it acceptable? Or where do I say, "You know what? If you need me to do that, it's okay."

Through our conversations during the first interview, it was evident to me that Jenifer was still trying to find the right balance between pushing Pam to be as independent as she could and being protective of her. As Jenifer noted, the sudden change in Pam's ability to perform everyday tasks independently following her vision loss has led to changes in their parent-child relationship dynamic:

"I want to baby her. I want to. I want to. 'You want to live here for the rest of your life. Okay.' Ten months ago, I'd be like, 'okay, you're 18. Get the heck out.' You know, like it [Pam's vision loss] has changed the whole dynamic of how I think, you know, that's underprepared."

Despite the challenges that she has encountered in the process of balancing independence and safety concerns, by the time I first spoke with Jenifer, she had already taken some major steps to re-introduce independence in Pam's life. For example, in terms of orientation and mobility (O&M) skills and independent living skills (ILS), Jenifer connected her daughter with the staff from the CNIB and utilized the professional support and resources provided by the organization, such as O&M lessons.

Looking back, Jenifer believes that the CNIB has been a huge help for Pam along her path of regaining independence. Jenifer illustrated this in our second interview with a recent instance where Pam learned how to confidently navigate her high school co-op placement site with the help of an O&M instructor from the CNIB:

"Like when she went to [the hospital where her co-op placement site is], I think she went twice to [name of the hospital] and had a tour with them [staff from the CNIB]. Then she was like 'I got this,' and now with going to [name of the hospital] for a co-op, she's been everywhere in [name of the hospital], because there are 3 X-ray clinics, and she has to show people where to go. [...] She doesn't need me. I think that was a big help having the CNIB step in and do that because it pushed her, she wanted to show people that she could do it. I'm a lot more aware of what is out there for her."

However, she shared that utilizing those services provided by the CNIB and letting those resources be helpful was initially hard for her as a parent. "[…] because I didn't know how to accept that. As a parent, you're always a person that provides everything for your child. And accepting that there's somebody better to do that for your child was very hard," Jenifer explained.

Jenifer added that with the help of the CNIB, Pam is also working on getting back to activities that she enjoys, such as cooking, ringette, and skating:

"She now cooks once a week. Some of the activities like skating and ringette, she likes. So now we skate once a week at a free skate. Next year, because she's 18, ringette has an 18+ fun league. I don't know if she will be able to do it, but we are going to try because she loves ringette and misses that."

It is evident that Pam has made some remarkable progress in getting back to the activities that she enjoys. In addition, Jenifer and Pam have found strategies that allow Pam to engage in those activities safely:

"She is skating amazing right now, she's back to skating at full capacity of what she was before she lost her vision and her comfort wise. When we go for the free skate, it's not busy so she's not maneuvering around 50 million people, she's moving around like 30. So she's able to. And the cooking, she's cutting up more stuff. If it's fine stuff like onions, we don't do that yet, we aren't there yet. But we do peppers and potatoes and that sort of thing. I asked her if she wants a knife that does that, like a ball with a knife on it, but she's like 'no', she's just using the regular knife. I make her wear a glove."

Jenifer believes that being independent entails more than the ability to travel independently and take care of oneself. She emphasized that self-advocacy is another important aspect of independence for Pam, especially after her vision loss. Jenifer hopes that Pam "can be her own voice." To guide Pam towards this goal, Jenifer has been teaching Pam how to speak up for herself and creating opportunities for her to practice those self-advocacy skills. For example, when she and Pam go to doctor's appointments, instead of talking to the doctor on her daughter's behalf, Jenifer would encourage Pam to speak with the doctor directly:

"When we go to doctor's appointments, I'm working with her and I talked to her before. I work with her because I want her to be her voice. So, before an [doctor's] appointment,

it's like, okay, we're going to this appointment. This is what it is. This is what you need to

tell them. And then I step back."

Jenifer further explained that as a personal support worker, working with people with

disabilities, she has noticed that people have the tendency to treat those with disabilities as less

of a person because of their impairment. For example, in the context of a medical appointment,

rather than talking directly to the person with a disability who is there for the appointment, health

professionals tend to talk to the support person who does not have a disability. Jenifer hopes that

letting Pam speak for herself will allow more people to see her beyond her visual impairment:

"I work with people with disabilities, and I see it all the time. So for me it's now, when I

go to a doctor's appointment with her especially, or things like that, if they start talking

to me, I'm just like 'look it's her appointment. I'm just here so she understands

everything you are saying.' She knows everything that's wrong with her so she can speak.

So I just believe that it gives her that voice to say 'I'm not a disabled person, I am a

person.'"

From Jenifer's perspective, for her soon-to-be adult daughter, leading an independent life

also involves making informed decisions related to her own care. Jenifer noted that throughout

the process of seeking answers for Pam's condition and regaining independence following her

vision loss, she has been guiding her daughter to make informed decisions for herself as much as

she can:

"And this whole process, it's always been her decision. Do you want to go see this

doctor? Do you want to have this test done? Do you want to have this test? It is her

decision because at the end of the day, she turns 18 soon. I'm trying to let her, as much as

I want her to do all this. It's her decision. So I'm not saying I don't influence it. I do. I give her my opinion, but I also say I will respect her opinion."

Seeing the Light at the End of the Tunnel

For Jenifer, adapting to the new normal after Pam's sudden vision loss has been a process that she and Pam are still working through. However, throughout my second interview with Jenifer, which took place a-month-and-a-half after our first interview, it was evident to me that Jenifer has moved to a point where she now accepts her daughter's vision loss and feels more hopeful about her daughter's future:

"It does take time, and for me it took a lot of time, because my daughter went through changes where her vision got worse. So every time it got worse, I would have to work through that stage. Now I'm at a point and I'm hoping, that I've accepted it. I can't change what has already been changed. I can accept what the future holds."

Jenifer considers support from her family and friends as a major source of help that got her through the dark moments and brought her to where she is today:

"A lot of family support, a lot of friend support and my husband. Instead of internalizing it, I speak about it. I don't speak about it with her [Pam] around, but I do speak about it and my frustrations. Sometimes I am asking for advice from those people, other times I'm just getting it out and saying this really sucks, I don't know how to deal with it. It helps because knowing that people understand, like they all know my daughter and they all understand how she was before and knowing what I'm going through."

Jenifer added that although she still encounters challenges in her parenting experiences sometimes, with the social support from her family and friends, she now feels that those low points are not as overwhelming as they were before:

"We still have our obstacles, but they aren't mountains anymore, like they are bumps.

Like last week, she fell pretty bad, and so I've been helping her with her scuffs. That's a

bump to me. It's not like she lost all her eyesight if she fell, so it's just knowing what's

out there for me. Like if I need advice, I'll ask my mom and if I need somebody to listen to

then I'll ask my husband or my friends."

Jenifer noted that another source that helped her move forward along her parenting

journey is the professional support from the CNIB. She explained that because of the guidance

from the staff at the CNIB, she now feels more comfortable with parenting her daughter with

vision loss and encouraging her to step out of her comfort zone. She added that participating in

activities and events organized by the CNIB has also increased Pam's confidence and interest in

trying new things:

"She did the rock climbing with one of the CNIB staff. […]. Since she tried it, she is

trying new things. [...] It started us in the process of trying new things. Like she's done

the painting, she did the art therapy. So now she is trying more things. I think it [the

CNIB] has helped us along this path. It has gotten us to the point where we are now

comfortable parenting her. I'm not saying I'm 100% because I'll never be there, but you

know, knowing it's ok to push her, it's ok if she gets mad at you. Before I was just like, oh

my gosh she's mad at me. I got to fix this. But now, it's like she's mad at me, we'll get

over this tomorrow. It has shown me tools to cope."

Pam will be starting college next year. As Jenifer moves towards a more accepting

attitude towards Pam's vision loss, she has also been doing what she can as a parent to prepare

her daughter for the transition from high school to college life. She noted that although Pam will

not move away from home during her college years, she has arranged campus tours with the

CNIB O&M instructor to help Pam familiarize herself with the college campus layout. Jenifer is also looking into helping her daughter get the academic accommodations in place at the college that she will be attending:

> *"I've set up with CNIB so they will help tour with her. Once she gets her schedule, they are going to keep on touring with her so she can get used to it. […] The other thing I am doing is, we are setting up disability things. I am asking for a scribe for her because some days for obvious reasons or a recorder."*

At the same time, Jenifer has taken steps to make sure that Pam is ready for this transition herself as well. For example, she shared that since becoming an X-ray and MRI specialist has always been Pam's dream, she encouraged her to get co-op experience at a local hospital this year, Jenifer hopes that by gaining work experiences in a hospital setting, Pam will be able to not only become more prepared for college life but also explore her interests and get closer to her dream:

> *"I've prepared her on the opposite end, we've done co-op at an x-ray clinic at [name of the hospital]. That way she knows she can do what she's going for."*

Towards the end of our second interview, Jenifer noted that through receiving vision rehabilitation services and participating in CNIB-run Child and Youth programs and Sports and Recreation programs, she and Pam have been able to meet and connect with people who do not let their vision loss define what they can and cannot do. This experience has given both of them a renewed understanding of what it means to live with a vision loss:

> *"Meeting people that don't see vision loss as an impairment, they see vision loss as, I may not be able to do this, but I can do this, this and this. When she lost her vision in August, I was petrified that she was going to have to give up her dream, and I was*

worried where that was going to send her. whether it was going to send her into a turmoil

[…]. I didn't know how that would affect things. So showing her that she can do it has

given her a whole new eyesight, sort of speak, because vision impairment is not an

impairment, it is just a setback. It's not the end of the world basically."

Looking back at her journey since her daughter's vision changed last year, one piece of advice that Jenifer has for other parents whose child may be newly diagnosed with vision loss is that grieving is a normal part of the adjustment, and it is ok to let yourself experience the grief:

"To know that it's ok to be upset and mad at the world. You will get past that. It is a loss,

and to accept it like that, and then move on from that."

Jenifer also wanted to let others know that this process may be full of ups and downs, but there is a light at the end of the tunnel:

"It's difficult to work through, but as you have seen since the last time I've spoken with

you, I'm at a positive place in my life where you've seen me as I'm still working through

it. I'm still getting better, and there's a light at the end of the tunnel."

4.4. Lauren's Narrative

Lauren is the mother of a 17-year old girl with a visual impairment. At the time of this study, Lauren's daughter, Ruby, was a Grade 12 student who has light perception. Ruby is currently attending a school for students with visual impairments but had previously attended mainstream public school up until grade 8. Shortly after Ruby switched from the mainstream school that she attended to her current school, her family moved from their previous city to the city where the new school is located. Ruby lives with her mom and stepdad and has a brother without visual impairment, who is seven years older than her.

Due to the distance between the city where Lauren resides and where I was located, we

decided to hold the interviews with Lauren through video conference calls. Lauren was my final participant but was the first participant who I interviewed via virtual technology. Lauren seemed to be very involved in her daughter's education. Before I turned on the audio recorder, she shared some of her concerns regarding her daughter transition to post-secondary education, mostly around academic accommodations and campus accessibility.

A Path to the Diagnosis of Vision Loss

Lauren recalled that her daughter, Ruby, was born with a left eye infection which the doctor treated with antibiotics and Prednisone drops. Lauren added that during her pregnancy, she was prescribed Prednisone orally to treat existing health issues. She was later informed by a pharmacist that Prednisone could cause blindness. Lauren said that although she was not sure if that information was accurate, she still felt a sense of guilt, wondering if she had done something that caused Ruby's vision loss, which was diagnosed three years later:

> *"I think as a parent, it's the guilt I feel. What did I pass on? Did I do something by taking the Prednisone, if I didn't, would it still have happened? Was it something to do with the eye drops? I think as a parent you want to fix things."*

Lauren said that when Ruby was three years old, the doctor found out that she did not have any vision in her left eye. At a young age, Ruby had to face the challenges with some of her everyday activities brought on by the significant visual impairment:

> *"[...] she would walk into door frames. She had no depth perception at all. And then in nursery school, she had no peripheral vision, she would get hit by toys, the teachers set goals for her not to get hit."*

As Ruby's vision kept declining in both eyes, Lauren and Ruby spent a lot of time attending hospital visits and doctor appointments, trying to figure out what condition Ruby

had and the appropriate treatment plan for her eye condition. Some of their experiences with health professionals during that time were positive, but many interactions were not so pleasant:

"I had a bad experience with one of the doctors at [name of the hospital], accusing Ruby of making up her vision loss. She didn't answer, so the doctor accused her of being deaf as well. Anyway, lots of tests, MRIs [...] But on the positive side we did meet some nice doctors, a wonderful doctor at [name of another hospital], and Ruby ended up with a really nice neuropthalmologist doctor."

Experiences at the Mainstream School: Discrimination and marginalization

Ruby entered the mainstream public school system after nursery school. Lauren considered Ruby's experiences at public school challenging, both for Ruby and for herself as a parent. She explained that because the teachers at Ruby's school, at the time, were not experienced with teaching students who had visual impairments, many of them were not accommodating with respect to both Ruby's academic and social needs. Although Lauren was trying to be understanding towards the teachers, it was hard for her to watch her child experience the discrimination perpetrated by the teachers and the school.

For example, Lauren remembered when the school got Ruby her vision resource teacher, "they [the school] literally put her in a closet with the teacher, and they said they didn't have any teaching space, and they put her in a supply closet. She couldn't find the closet to go over her lesson, and she was isolated from the other students. It was really hard to watch her go through this as a parent, because she was having to drop all her favorite subjects."

Lauren recalled that despite being quite an active teenager, Ruby had to drop gym class,

because the teachers could not accommodate her. She had to drop Art for similar reasons. Ruby

was forced to drop out of French as well, since the mainstream school that she was attending

could not find a teacher for her. "By about grade 7 or 8, she was just taught math and science,"

Lauren said.

Lauren added that one teacher, in particular, was frustrated that she needed to spend

extra time enlarging course materials for Ruby. That teacher went further and made hurtful

comments, which made Ruby feel bad about needing academic accommodations that she was

entitled to:

> *"One teacher, Ruby will never forget this, she slammed down the enlarged work on*
>
> *Ruby's desk and said to her: 'I wasted my entire break enlarging this for you!'.*
>
> *This made Ruby feel terrible."*

Lauren remembered feeling angry and disappointed at that teacher's behavior when

Ruby told her about that experience. From her point of view, someone who went into teaching

should be there to help their students, instead of making students feel bad for something that

they could not control. Lauren added:

> *"It [the incidence] bothers me still to this day. My daughter will talk about it, and I*
>
> *think it will stick with her for the rest of her life that someone would do that."*

Lauren said that out of all the teachers that Ruby had in the mainstream school, there

was one teacher who was interested in learning about what he could do to provide better

accommodations for Ruby. Unfortunately, that was not representative of attitudes held by

the majority of the teachers:

> *"There was, out of all of them, one teacher who basically gave her the time of day.*
>
> *He was her science teacher, and when a group from the School for the Blind] came*

and brought a CCTV and different tools that Ruby can use...He was the only one

who was interested in any way."

Ruby was also bullied by other students at school. Lauren recalled that the other

students "would take her [Ruby's] cane and they would throw it on the playground, so

she couldn't find it. They would smash it against walls."

To make matters worse, when Lauren brought the situation to the school principal's

attention, she and her daughter barely received any support. Rather than taking actions to

address bullying behaviours, the principal suggested that Ruby should go from classroom to

classroom to explain her vision loss to her peers:

> *"I went to the principal, no support. His idea was for Ruby to go by herself, she was*
>
> *very anxious at that time, to go by herself from classroom to classroom and explain*
>
> *her vision loss. She said: 'I can't', she was terrified."*

Lauren recognized the importance of advocating for her daughter and pushing for

changes in the school system. However, having to fulfill other responsibilities in life meant

that she could not spend endless amounts of time and energy on advocacy work. Lauren

explained that besides having to stay on top of Ruby's medical appointments, she and Ruby

were going through a series of transitions. For that reason, she chose not to pursue the case

further after several unsuccessful attempts of pushing the school to take actions to address the

bullying that was going on:

> *"I was starting a new job, we've moved, and Ruby was starting at a new school, I*
>
> *didn't want to battle that one out and as a parent, you need to choose your battles. It*
>
> *was hard enough to go to doctors' appointments and specialists all the time. "*

Lauren noted that in addition to Ruby's negative experiences at school, she did not

receive much support from the CNIB local office at the time. Lauren added that the social and health service providers, outside the field of vision loss rehabilitation, that they encountered were not able to provide Ruby with the support she needed to cope with the fear and anxiety associated with her changing vision condition:

"As far as social services, any kind that we tried from social workers, to psychologists and psychiatrists, had no idea, they had no clue. They could not help Ruby at all, work through any kind of feelings or fears. It was very disappointing. They kept turning it around on her, a lot of people would say it's her fault, or she chose to lose her vision, and she's making it up in her head."

New City, New School, New Chapter

Seeing how Ruby was struggling in the mainstream school, a social worker suggested Lauren consider the School for the Blind, in a small urban city in Southwestern Ontario. Although Lauren had never heard of the school before, she decided to let Ruby give it a try. Lauren recalled Ruby's first day at the School for the Blind:

"Ruby had a trial there, and on the first day she said: 'I fit in here, I belong.' And she's finally found a group of people with some understanding, so she refused to go back to her other [previous] school"

Her positive experience at the School for the Blind led Lauren to decide to switch schools for Ruby halfway through grade 8. Lauren said that the teachers from the mainstream school voiced doubts or even negative views of the School for the Blind, but she believes that she made the right decision by sending her child to her current school:

"[…] they [teachers at the mainstream school] said it [the School for the Blind] is not very good for the children to go there, because it's like living in a fake world. So

I said maybe Ruby needs that. To be honest with you, it was the best decision that we

could have made."

Ruby's new school was not located in the city where the family lived, so after

commuting back and forth for a while, Lauren's family moved to the city where the School

for the Blind was located. Lauren said that not only is the new school a better fit for Ruby

compared to the previous school, the services that they received from the CNIB are also much

better. She described the staff members at the local CNIB office in her current city as

"supportive and outwardly amazing". With the help of the CNIB, Ruby was able to

significantly improve her independent living skills (ILS), such as doing laundry and

preparing meals, as well as her orientation and mobility (O&M) skills.

Lauren added that the staff from the CNIB local office also helped Ruby arrive at a

turning point by recommending that she get a guide dog:

"Her O&M instructor [from the CNIB] noticed that when Ruby petted her cat or

bunny her anxiety reduced drastically. She said: 'have you ever thought of getting a

guide dog?'"

Ruby was 13 at the time. Being a guide dog handler was new territory for Lauren and

Ruby, but because of Ruby's love for animals, they decided to give it a try. The process of

getting a guide dog went much more smoothly than Lauren had anticipated, and since Ruby

started working with her guide dog as a team, Lauren noticed that her daughter has become

more confident and independent:

"[…] when she was walking [with her guide dog], her speed was faster, her shoulders

were more relaxed. She walked at a much quicker pace with her dog compared to a

cane. I think she enjoyed the freedom with being more independent and more free with

the dog. She naturally has a quick pace which she couldn't do with the cane."

Lauren believed that for Ruby, this confidence and newfound freedom associated with being a guide dog handler went beyond the ability to travel independently. The guide dog provided Ruby with much needed companionship, and working with her guide dog increased her confidence when interacting with others:

"I guess [the guide dog was] like a companion, but it was just a transformation, and even to this day, the principal and vice principal and all the teachers at the school, had a girl come halfway through grade 8 who said nothing, labelled as shy, to now a girl who won't stop talking."

Lauren considers Ruby getting a guide dog as a transformative experience for her as a parent, too. Lauren explained that after Ruby started working with her guide dog as a team, she felt much more comfortable stepping back and letting her daughter go out on her own:

"[…] because I noticed that people noticed her more. He [the guide dog] is a big black lab, he's quite substantial in size where drivers tend to notice. I think they saw her more with the dog as well so I just felt better, because she's still learning street crossings and at least he has eyes to help her look for cars, I did let her go and let her have more freedom because of the guide dog."

With the inclusive environment at her new school, the support from the CNIB, and the transformation that her guide dog brought to her life, Ruby now has more opportunities to participate in various extracurricular activities and community events. Lauren shared some of Ruby's recent accomplishments in those activities that she felt proud of as a parent:

"The school got her into tandem cycling, and last year in 2019 she won the gold for Ontario and then went on to win it for Canada. […] The CNIB has supported her

advocating for herself, and she did a wonderful speech the other year for Night

Steps [i.e., a fundraising event hosted by the CNIB], a lot of speeches at schools on

awareness about visual impairment, about guide dogs, and even how to talk to

someone with a visual impairment."

Lauren attributed many of the positive changes in her daughter's life to the support

from the CNIB, and she said that as a parent, she feels especially thankful for the CNIB's

help:

"This girl who said nothing and who was terrified is now someone who can stand up

in front of a crowd and speak. I thank CNIB for that."

Worries and Hope in the Present, Concerns and Anticipations for the Future

"She [Ruby], I find, still went through that same rite of passage that all teenagers

do. When I was a teen, about 1000 years ago, I felt invincible. I think that's how she feels

and is desperate for independence." When speaking about the present, Lauren noted that

like many adolescents her age, Ruby currently has a strong desire for independence.

Lauren explained that from her perspective as a parent, letting her daughter explore

the world independently involved a constant negotiation between safety and independence:

"You realize as a parent you can't keep your child in a bubble. You have to let them

go. She's not little anymore. She grew up."

The process of enabling her daughter's independence certainly comes with worries.

This was illustrated in an instance when Ruby first started practicing her O&M skills in the

neighbourhood:

"She thinks it's funny. When she first started going around the neighborhood with her

cane, I was that parent who followed her. She just thinks that it's the funniest thing.

Now I don't, I cut the apron strings. She goes on walks on her own."

Lauren added that at this point, she trusts that Ruby has the O&M skills necessary to allow her to travel independently, but her worries come from uncertainty about what could happen in her daughter's environment:

"It's not so much her that I don't trust, but it's the other guys. The crazy driver turning the corner and not seeing her."

When reflecting on her experiences of parenting Ruby, Lauren noted that her worries for Ruby's safety may not be entirely the result of her vision loss. Some of her worries could be because she is a female. This was apparent to her when she compared the experiences of parenting Ruby and Ruby's older brother:

"I can tell you the difference between her and her older brother, he doesn't have a visual impairment, so I didn't worry much, but then again maybe I didn't because he's male. I'm not sure."

Lauren said that currently, she has been trying to manage her worries for Ruby and to step back as much as she can as a parent by placing more trust in her daughter's ability to safely navigate her environment:

"I still worry but I've let go a lot and trusting that she's learned routes, and it's easier nowadays with her cell phone. There's so many apps and stuff now that she can figure out where she is, like what street if she takes a wrong turn."

Lauren also expressed a constant feeling of being on guard when she would go out in public with Ruby and her guide dog, wondering if something negative, such as a restaurant or a cab turning them away because of the presence of Ruby's guide dog. Lauren added that although such scenarios have never happened, she remembers one instance where Ruby's

guide dog was distracted by another dog that was off leash when he was working:

> *"It's happened where a dog comes running up to her and starts jumping on her*
>
> *guide dog and he spins her around and she gets disoriented. She gets upset and then*
>
> *I do, it's like a domino effect."*

Lauren acknowledged that constantly feeling on guard is tiring, and that society's negative attitude towards Ruby's visual impairment has intensified this feeling. From Lauren's perspective, this negative societal attitude is oftentimes manifested in people's stares and comments in public:

> *"The staring of people, I mean Ruby can't see them looking at her, but it started out*
>
> *when she had a cane. I think it's society's attitude that someone who is blind would be*
>
> *an 80-year-old, because it's to do with age. […] they still ask Ruby, is she training her*
>
> *guide dog? Is she an instructor? And she said, 'No, he's my guide dog.' But it's this*
>
> *attitude, first of all, people are shocked I think when they see even little tiny kids with*
>
> *canes, and I still think there's that shock of how can a young person, a child or teen,*
>
> *have a visual impairment."*

Lauren noted that the stares and comments from others bother her as a parent and she hopes that people would give her daughter the respect and privacy that she deserves. When I asked Lauren how she copes with this uncomfortable feeling when being stared at, she answered:

> *"I never tell Ruby at the moment. I hide those feelings from her because she doesn't*
>
> *need to know anything about that. But yes I think that I would be talking to a friend*
>
> *about it and venting would be my strategy."*

Lauren said that she does not usually confront people who stare at or make

inappropriate comments about Ruby, but she does advocate for her daughter if needed. This was illustrated in a recent instance where she talked to a group of girls who blocked Ruby's path when they were walking in public:

> *"Well one time I did [talk to them]. A group of seven girls walking hand in hand in the mall were blocking the pedestrian traffic. They would not move out of the way. They waited and stood there, and I made a comment that they can see and get out of the way and she [Ruby] can't, I would appreciate it if they could move."*

Lauren added that when she does advocate for her daughter, she usually takes the time to explain to people why she is saying something:

> *"[...] usually I explain why to people. I don't ever want to come across as bossy, so I usually give a rationale as to why I am saying something. For the most part, people are pretty nice."*

When asked to give a piece of advice to a parent of a child who recently got diagnosed with a visual impairment, Lauren emphasized the importance of playing the role of an advocate for a child with a visual impairment again:

> *"I don't really know if it matters the age, a 2-year-old, to a 12-year-old, to a 22-year-old. It's still an impact. So I think regardless of the age that a person either doesn't have vision, loses vision, whatever happens to be the case, it still impacts them a lot, and it's still something that they have to go through. So I think, advocating as much as you can so they don't have to go through it alone."*

Ruby will be finishing up grade 12 this year. Lauren said that her daughter is thinking about going into psychology or social work and has checked out programs at several universities and colleges. "So I thought, do something you are interested in, you've worked in

school hard enough. She's a very intelligent girl. I just worry about the barriers that she will have to face and as we all know there's good and bad teachers out there," Lauren added.

Another source of Lauren's concern about Ruby's transition from high school to university life centers around accessibility of the course materials and academic accommodations. This issue was apparent when Ruby took a high school online course last summer. Moving forward, Lauren is also worried about her daughter's employment prospects after graduating from university:

> *"She tried to take an online course, but it wasn't in the right format, so she spent the entire month of July advocating for herself and she got further and further and further behind. So I'm just concerned, what's it going to be like for her at university? Will they have things in the right format, will it be a struggle? Then projecting ahead, will she get a job? Will anyone want to hire her?"*

To prepare for the transition to university, Ruby has toured a few university campuses to learn about the campus environment and academic programs. Lauren added that Ruby has already decided to take a year off after high school to complete a co-op before starting university. Lauren respects her daughter's decision and hopes that the co-op experience will make Ruby's transition from high school to university life smoother:

> *"I need to listen to how she is feeling, and she doesn't feel like she's ready to jump right off into university then I need to respect her request to do a co-op prior to going. I think it will increase her confidence more, because she's in a world right now where students are either blind or visually impaired and then changing to a different environment of everyone being sighted will be a challenge. I think she has to be ready for that."*

For Lauren, her daughter's positivity has been a tremendous help that has supported her through all the ups and downs along her parenting journey:

> *"You know you can't fix it [Ruby's visual impairment], but with her attitude, she's just so upbeat and is a happy person and has a great sense of humor. I need to have the same attitude too. We just have to keep each other up and happy."*

4.5. Conclusion

This chapter featured the re-constructed narratives of participants' experiences of parenting an adolescent with a visual impairment. In Chapter 5, I will present the thematic results from the analysis of the narrative data.

Chapter 5. Thematic Results

In Chapter 4, the narratives of the four parents of adolescents with visual impairments were presented. In this chapter, the basic demographic information of the participants and their adolescent children, as well as the overarching themes generated through the process of engaging in holistic-content analysis and thematic analysis are presented. In order to protect participants and their children's confidentiality, pseudonyms have been used. The names of people and places have been removed from the quotes presented in this chapter. The pseudonyms of the participants and their adolescent children used in this chapter are the same as the ones used in the presentation of the narratives in the previous chapter. The pseudonyms and demographic information of participants and their adolescent children are presented in *Table 1* below. As shown in *Table 1*, participants who took part in the present study were parents who were between the ages of 39 and 50. Three of the parents were mothers; and one was a father. Although this study was open to parents of both adolescent boys and girls with visual impairments, all four participants who took part in the study were raising adolescent girls who were either partially sighted or had some light perception at the time of their participation. One adolescent was diagnosed with a visual impairment as an infant, two received the diagnosis in their early childhood, and one was diagnosed during her adolescence. All participants identified as Caucasian, completed post-secondary education, and had one other child who did not have a visual impairment. Three participants were married, and one was living with her common-law partner at the time of the study.

Table 1: Demographic Information of Participants and their Adolescent Children

Participant's Pseudonym	Olivia	Brandon	Jenifer	Lauren

Child's Pseudonym	Chloe	Erica	Pam	Ruby
Participant's Relationship to the Child	Mother	Father	Mother	Mother
Participant's Age	44	43	39	50
Child's Age	17	14	17	17
Participant's Gender	Female	Male	Female	Female
Child's Gender	Female	Female	Female	Female
Child's Level of Vision	Partially Sighted	Partially Sighted	Partially Sighted	Some Light Perception
Child's Age When Diagnosed with A visual Impairment	6	0	17	3
Participant's Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian
Participant's Level of Education Completed	Post-Secondary	Post-Secondary	Post-Secondary	Post-Secondary
Participant's Marital Status	Married	Married	Married	Common Law
Number of Siblings That the Child Has	1	1	1	1

Six major themes were identified from the narrative data. These overarching themes

include: 1) *Grief, Uncertainty, and Frustration During the Early Years*; 2) *Identity as An*

Advocate; 3) *Enabling Independence and Envisioning the Future*; 4) *Planning Occupations in*

the Time of Transition; 5) *Navigating Challenges in Getting Required Support: Frustrations and*

Successes; and 6) Changed Perceptions within the Context of Societal Misunderstanding.

5.1. Grief, Uncertainty, and Frustration During the Early Years

During the interviews, all participants described the overwhelming emotions that they felt

after their child was initially diagnosed with a visual impairment. Common reactions in the

initial stage following diagnosis were related to grief and uncertainty. In later stages, as parents

faced barriers to obtaining supports and accommodations for their child, frustration came to the

fore as a common emotion.

Participants experienced grief and uncertainty about the possible implications of the

diagnosis on their child's life. This was illustrated by Brandon's recollection of his response

when his daughter, Erica, was first diagnosed with a significant visual impairment when she was

a few months old:

> *"I remember being in the parking lot and looking at my wife and just crying, because it*
>
> *was just- you know, well this [the diagnosis of a visual impairment] changes everything,*
>
> *right, because we just didn't know what to expect or how this was going to impact*
>
> *Erica."*

Unlike other participants whose child was diagnosed with a visual impairment at a young

age, Jenifer's daughter, Pam, lost her vision suddenly and unexpectedly less than a year prior to

the study at the age of 17. In my first interview with Jenifer, she spoke about how the sense of

helplessness and grief that she was experiencing was exacerbated by the sudden onset of her

daughter's vision loss:

> *"As a parent, you feel helpless. As a mom watching your kid trip over everything, you*
>
> *just want to pick them up. When they are adolescents, they are 17. It's 'mom, stay away.*
>
> *Mom, I've got this. Mom, I've got this.' And then you walk by, and she's crying in her*
>
> *room because she's frustrated with what she can't do now. What she's lost."*

For Jenifer, it was especially heartbreaking to watch Pam give up the occupations that she

previously enjoyed due to her sudden vision loss:

"Watching her give up stuff she used to like, she used to play ringette and not competitively, but on a team. And she gave that up because of safety concerns [related to her vision loss]."

Some participants also expressed a sense of guilt that they felt as a parent, wondering if they had done something that could have caused their child's visual impairment. For example, Lauren wondered if the medication that she took during her pregnancy, or the eye drops that doctors prescribed to treat her daughter's eye infection when her daughter was a baby resulted in her daughter's vision loss later in life, even though she was unsure if there was any scientific evidence that supported these speculations:

"I think as a parent, it's the guilt I feel. What did I pass on? Did I do something by taking the Prednisone, if I didn't, would it still have happened? Was it something to do with the eye drops? I think as a parent you want to fix things."

The children's personality characteristics also played a role in shaping participants' responses to their grief about their child's vision loss. For instance, Jenifer and Lauren noted that their daughters' positive outlook on life, in the face of uncertainty and challenges, greatly helped them as parents cope with the uncertainty of their child's vision loss:

"You know, so for her to go through this process [of searching for an answer about the cause of her vision loss] with a positive outlook has helped me through. As a parent, you're supposed to be the strong person. I've accepted. I'm not. Some days I am, but she's the stronger one in our relationship." -- Jenifer

"I follow her lead as much as I can on being positive. She really focuses on what she can do, not what you can't. Yeah, she had always said she wanted to drive a car, she can't. But other than that, there's a lot that she still can do." -- Lauren

After their children reached school age, the school system became a major source of frustration for participants. As Olivia explained, she used to feel the need to constantly be in touch with the teachers at Chloe's school, because some of them would forget to provide Chloe with the accommodations that she needed to succeed academically, which not only affected Chloe's academic performance but also made her feel that she was not as important as her peers:

> *"You really have to be on the teachers, you always have to be aware of what's happening always because they'll forget large prints still and that really made Chloe feel like she wasn't important because she would say, 'Well you know if I was in a wheelchair would they make me take the stairs?'"*

Lauren and her daughter, Ruby, had particularly negative experiences with the mainstream school system. After Ruby was assigned a resource teacher, she was deprived of opportunities to participate in classroom learning and was segregated from her friends, because the school "could not accommodate her":

> *"The way they treated her when they got her resource teacher, they literally put her in a closet with the teacher. And they said they didn't have any teaching space, and they put her in a supply closet. She couldn't find the closet to go over her lesson, and she was isolated from the other students. It was really hard to watch her go through this as a parent, because she was having to drop all her favorite subjects. She's quite active and she had to drop gym, they can't accommodate her. They dropped out of French because they couldn't find a teacher. They had her drop art. […] by about grade 7 or 8, she was just taught math and science."*

Lauren added that Ruby also experienced bullying from her peers at the mainstream school that she used to attend. When she brought this issue to the principal's attention, she was disappointed at his inaction in addressing the other students' bullying behaviours:

> *"The kids were mean, she got bullied. They would take her cane and they would throw it on the playground so she couldn't find it. They would smash it against walls. I went to the principal, no support. His idea was for Ruby to go by herself from classroom to classroom and explain her vision loss. And yeah I see she said "I can't", she was terrified."*

Lauren shared that switching from the mainstream school to a School for the Blind, halfway through grade 8, was what changed things for the better for Ruby, because that was where she finally found a sense of belonging. Lauren recalled her daughter's first day at her current school:

> *"Ruby had a trial [at the School for the Blind], and on the first day she said: 'I fit in here, I belong.' And she's finally found a group of people with some understanding, so she refused to go back to her other [previous] school"*

5.2. Identity as An Advocate

Advocacy was another common thread across participants' experiences of parenting an adolescent with visual impairment. Parents described their advocacy efforts within various contexts, such as the school setting and social service system. In addition, they spoke to how they developed their identity as an advocate for their child, and how important this was within current systems. Parents emphasized the occupations they did that made up becoming and being an advocate. They also noted the importance of teaching their children to become self-advocates, particularly as their children aged into adolescence.

All of the participants spoke about the things that they have done and/or were currently doing to advocate for their child with vision loss. For Brandon, the school setting was where he primarily took on his advocacy role:

"There are many times I think when you just have to let people know. The school system is number one, and I don't want to say on the teachers, but you just have to remain in contact with the teachers a little more, I think. Having a child, if you are a parent of a child with low vision, because Erica won't say anything either."

Brandon added that advocating for an accessible campus environment for his daughter was a priority for him as a parent. This was taken into consideration in the planning process when he and Erica's mom chose a high school for their daughter:

"One of the biggest things that we had to advocate for was getting tape on the stairs and tape on the middle of the doorways, like fluorescent tape just to put up so Erica could see those definitions. We also toured a lot of high schools before Erica chose the high school, to make sure that the one that she went to was the best suited to her mobility. Whether it's getting up or down flights of stairs or using the elevator. We wanted to really make sure that the school was on board."

Olivia noted that although Chloe was a great self-advocate for her age, she still needed to play the role as an advocate in her daughter's life, because oftentimes, the education and social service systems were too complicated for a teenager to navigate. She illustrated how this was a recent challenge that Chloe faced when arranging accommodations for an important test that she would be taking:

"Chloe just did the Casper test for university. Just booking that is an ordeal, and then if you need accommodations they have to be in 3 weeks before, has to be signed by a

medical professional, and it's just like, no other 17 year old kid has to figure this out.

How is she supposed to figure this out? So she can't. You know she doesn't know anything

about assistive devices program. […] You know like they just can't do it on their own.”

When asked to offer advice to other parents with similar experiences, both Jenifer and
Lauren highlighted the importance for parents to advocate for their child with a visual
impairment as much as they could:

“Make the best decision for your child, and if you don't like something, change it and if

it's something not working at school, change it. Be your child's best advocate.” -- Jenifer

“Speak up as much as you can for your child. […] I don't really know if it matters the

age, a 2-year-old, to a 12-year-old, to a 22-year-old. It's still an impact. So I think

regardless of the age that a person either doesn't have vision, loses vision, whatever

happens to be the case, it still impacts them a lot and it's still something that they have to

go through. So I think, advocating as much as you can so they don't have to go through it

alone.” -- Lauren

For Olivia, being an advocate for her daughter and other people with visual impairments
has not only become a big part of her life, but also part of her identity:

“[…] I feel like there was never a lot of restful times. It's always been, advocating,

worrying, getting stuff ready, trying not to drop the ball. Juggling, making sure that she

is supported and making sure my other one is supported, because for us, it was so

important that in order to level the playing field, we as parents, or me really, I had to

work really hard to do that and to teach her how to help level her own playing fields for

her future. I certainly was not the advocate then and I am now.”

Furthermore, from my conversations with Olivia, it was clear that Chloe and Olivia have formed a collective identity as advocates for people who are blind or partially sighted:

"[...] when I talked about when I as at [name of the eye clinic], I saw a Mom with a child the same age as Chloe. I know that Chloe would want me to introduce myself and share my story because that's what we do, we advocate."

All participants believed that it was important that their adolescent became good at self advocacy and shared that they have been taking steps to instill self-advocacy skills in their child. Olivia, for instance has been working on teaching Chloe how to advocate for herself by actively involving her in advocacy efforts related to her own care:

"Like when we write emails [to the teachers or optometrist], she's always copied on everything. At meetings at the school, she's always there. Just always being a part of everything, she's always participated even if I write an email, she's copied on it. Copied on everything, she's always been part of her care,"

Jenifer took a similar approach in teaching her daughter how to become a self advocate. She has been using daily activities, such as going to doctor's appointments, as an opportunity to encourage Pam to practice her self-advocacy skills:

"When we go to doctor's appointments, I'm working with her and I talked to her before. I work with her because I want her to be her voice. So, before an appointment, it's like, Okay, we're going to this appointment. This is what it is. This is what you need to tell them. And then I step back."

Jenifer further explained how her experiences as a personal support worker influenced her decision on letting her daughter "be her own voice" in medical appointments:

"I'm not always going to be there for every little thing. I can guide her when I am around, but I think that not just being a blind individual, but everyone should learn that [self-advocacy] skill. But I think she needs it more, because people tend to either treat people less of a person because of her disability, and I've seen it in my own life [as a personal support worker], or they talk to the other person. So, like if I were to go to a doctor's appointment, they would talk to me instead of her, when it's her appointment. So I believe that her speaking on her behalf, gives her that voice that she needs."

Brandon related his emphasis on advocacy along his parenting journey to his career as well. He noted that his education background in Social Work and his career as a social worker positioned him well as an advocate for Erica:

"I often say that I had two different lives, before I went to school and started my career [as a social worker], I was a 'blue collared worker', because I didn't understand the values and differences of others. I was that person who would not really think about that stuff. I think having that understanding or even that foundation of understanding is key to many different life experiences and thinking about life. I wish everyone had the opportunity to one year of liberal arts education to broaden their mind."

Brandon also discussed that he has been focusing on instilling self-advocacy awareness in his daughter by teaching her that it is ok to speak up for herself and ask for help when needed:

"We try to instill those values, because people don't know what you need unless you say something. I tell her that all the time. She would say her teacher didn't help her with this, and I would say 'well did you ask?' She would say 'oh no I didn't.' 'Well then just ask, and it's ok.'"

5.3. Enabling Independence and Envisioning the Future

Their adolescent child's independence is a topic that all four participants frequently discussed during the interviews, when talking about the present, as well as when anticipating the future. Along their parenting journey, participants continuously negotiated the balance between promoting independence in their adolescents and ensuring their safety and well-being. While actively creating opportunities for their adolescents with visual impairments to build their physical and psychological independence, participants took steps to protect them from potential harm in the environment. Projecting ahead, participants also shared their concerns related to their adolescent's financial independence and employment prospect.

All participants in this study expressed their hope that their adolescent child would lead an independent life, in the near future, and discussed their constant negotiation between encouraging independence in their adolescent child and ensuring their child's safety. As Lauren said:

> *"It's just that realization of a parent you can't keep your child in a bubble. You have to let them go. So it's just trusting things have been hard for me because I mean she's not little anymore. She grew up."*

In addition, Lauren acknowledged that the search for independence was very much in line with what a teenager would typically want at this developmental stage, regardless of whether he/she had a visual impairment or not:

> *"She [Ruby], I find, still went through that same rite of passage that all teenagers do. When I was a teen, about 1000 years ago, I felt invincible. I think that's how she feels and is desperate for independence."*

Participants were proactive about creating opportunities to allow their children with vision loss to learn and practice their Independent Living Skills (ILS) and Orientation and

Mobility (O&M) skills. They believed that doing so would better prepare their children for the challenges that they may face in the future. This was evident in Olivia's narrative account:

> *"I always say my kids probably got to do more because of Chloe than had they both been sighted, because we had to prepare her more for life. She had to be independent. Like my kids were already taking the city bus at 11 and 12 going all over the city, probably because I knew she had to be ready."*

However, for participants in this study, encouraging independence and autonomy in their adolescent child with a visual impairment did come with worries and fear about their child's well-being. Brandon illustrated this when describing the thought process that he went through when seeing Erica walking down the street with her friends when he was running errands recently:

> *"I was [out] doing something, and I saw Erica walk down the street with a bunch of friends on Main Street and I was like 'Oh man.' It kind of just hit me, ok she's out and doing something this is great, but God I hope she doesn't fall. [...] It's just going through those things in my mind, like oh she doesn't have her cane, but there are friends there, what if the friends ditch her? It's just that catastrophizing thinking, right? Even though I know I shouldn't do it [...], but it's that extra thinking I just think that we have to have being a parent with a low vision child."*

Brandon pointed out that his worries about Erica's safety are not only due to her low vision, but also stem from the fact that she is a female:

> *"Being a female is difficult in this world, because you have to be more aware of who you are with and if you will be safe with these people. I think even being a female with low vision would be a little more hard as well, because you want to make sure you are safe*

and with people you trust, and if you do need help they aren't going to leave you

hanging."

Lauren shared that she too, was concerned about the influence of her child's gender on

her well-being:

"I also worry because she's female, and her stepdad had said the same thing. He goes

'you know what even if you didn't lose your vision, your mother would still be the same

way worried." Young girl and walking. Like she doesn't care if she walks night or day. I

care."

To mitigate the risks that might come with their adolescent child's growing

independence, participants have been teaching their child how to protect themselves in case of an

emergency. For example, Jenifer described how she was working on instilling self-defence

knowledge and skills in Pam to ensure her safety:

"There's always been someone looking out for her because she's that little girl. So that's

what I'm afraid of it. Will she be able to do something, a) because of her vision loss and

b) because this [how to defend herself in case of an emergency] is not in her knowledge.

Like we've talked about it and everything else, but sometimes I'll say, 'punch me just on

my hands,' so I can make sure she knows how to punch."

Olivia noted that despite the worries that she had when promoting Chloe's independence,

she did not want to let her fear deprive her daughter of opportunities with regards to moving

towards her independence:

"I tried not to let the fear of her riding her bike, like my fear of worry about her not being

able to see the curb or see a bump or whatever, deprive her of riding a bike, although I

kept her safe as much as I could. That's just one example, I couldn't let my fear deprive

her. I couldn't wrap her in bubble wrap and say 'oh you can't go out, you can't try to get

a job, you can't get hurt. No, you need to go through all that.'"

Participants recognized that for their adolescent child with a visual impairment, being an independent person entails more than having the abilities to take care of oneself and travel independently. They considered making informed decisions for oneself and taking responsibility for those decisions to be another crucial aspect of independence. All participants described instances where they encouraged their child to make decisions for themselves. For example, throughout the process of adjusting to Pam's vision loss, Jenifer supported Pam to take the lead and make her own choices at each step, from the kind of eye tests that she would like to get done to the types of visual aids that she wanted:

"She's very light-sensitive. I've seen her struggle with the light, so I said, 'why don't we buy you some glasses at this point and buy you prescription sunglasses?' She wears a sunglass like a clip on all the time now. So why don't we just buy your sunglasses, wear sunglasses all the time? Why don't we just buy a [pair of] prescription sunglasses because they're stronger, right? But it had to be her decision, so I suggested it, and I waited, waited, waited, waiting while she came out. And she goes, "I've thought this through. And I think that would be a good idea.'"

"And this whole process, it's always been her decision. Do you want to go see this doctor? Do you want to have this test done? Do you want to have this test? It is her decision because at the end of the day, she turns 18 soon. I'm trying to let her, as much as I want her to do all this. It's her decision. So I'm not saying I don't influence it. I do. I give her my opinion, but I also say I will respect her opinion."

This parenting approach was shared by Brandon, who spoke about how he would sometimes allow Erica to make her own decisions even when it did not align with what he would have wanted for her. To Brandon, teaching his daughter how to make responsible choices was sometimes more important than protecting her against the negative consequences of her decisions, as long as those decisions did not cause her harm:

> *"There have been some incidences in the past where even with her [assistive] technology, it's like Erica, you are going to get behind if you don't use your technology. She doesn't, and then we spend the whole weekend doing homework. This is like, you can make whatever decision you want, but you have to be accountable for the decision you make. Sometimes we let her make the decisions she wants to do but they aren't that great. It just a balance. I wouldn't let her do anything that would cause her harm, but I would let her do something that would cause her more work and frustration, as long as she learns from decisions she made."*

Participants also recognized that financial independence is essential to living an independent life as an adult in Canadian society. Therefore, their adolescent child's employment prospects were another focus when they talked about the future. At the time of this study, Jenifer did not know if Pam's vision would continue to deteriorate. She expressed her concerns related to the uncertainty of her daughter's vision condition and its implications for her future employment prospects:

> *"At this point. Yes, she's got 20/20 vision in half her right eye. But if she loses any of that or she has eye strain where, you know. She reads good in the morning, but halfway through the day, it's gone. So what does that [Pam's deteriorating vision] mean for her? Can she work part time? Can she work? I'm still trying to figure these things out. I know*

she has to figure them out on her own, but I want to. She asks me these questions and I

don't have answers. I feel like there's not enough answers out there to help with that."

Some of the participants' worries for their adolescent child's employment prospects appeared to stem from the barriers that their child was currently facing, or had encountered, in the past. For example, Lauren's daughter, Ruby, would be graduating from high school this year and has checked out several university programs in Psychology and Social Work. In the interview, Lauren expressed her concerns about her daughter's transition to post-secondary education as well as her employment prospects after completing university/college. Lauren explained that she was worried that Ruby might encounter similar challenges that she had experienced in the past, such as not receiving the accommodations that she needed, in her future education and employment:

> *"She tried to take an online course, but it wasn't in the right format, so she spent the*
>
> *entire month of July advocating for herself and she got further and further and further*
>
> *behind. So I'm just concerned, what's it going to be like for her at university? Will*
>
> *they have things in the right format, will it be a struggle? Then projecting ahead, will*
>
> *she get a job? Will anyone want to hire her?"*

5.4. Planning Occupations in the Time of Transition

Ruby, Chloe and Pam would soon be transitioning from high school to university/college. Also, Erica recently went through a transition from elementary school to high school. As such, preparation and anticipation for transitions to a new chapter in life was a frequently discussed topic among participants. In order to prepare their adolescents for the transition points, participants engaged in various planning occupations within and outside the school setting, such as arranging O&M skill training services for their adolescent and setting up academic

accommodation at the school that their adolescent would be attending. Some participants noted the contributions of vision loss rehabilitation service providers and education professionals in this transition planning process.

It was clear that participants have taken steps to help their child prepare for the transition that they would be experiencing within the education system. For Jenifer, part of the transition planning involved collaboration with vision loss rehabilitation service providers. She shared that she has connected Pam with the O&M instructor from the local CNIB office who would tour the college campus with her and help familiarize her to the campus layout. In addition, Jenifer planned to help her daughter set up the academic accommodations that she needed before she starts college next year:

> *"I've set up with CNIB so they will help tour with her. Once she gets her schedule, they*
> *are going to keep on touring [the college campus] with her so she can get used to it. [...]*
> *The other thing I am doing is, we are setting up disability things. I am asking for a scribe*
> *for her because some days for obvious reasons or a recorder."*

Similarly, Olivia's daughter, Chloe, would be starting university in the upcoming academic year and intended to pursue a career in Nursing. In preparation for this new chapter, Olivia toured the campus of the university that Chloe wanted to attend with her and spoke with the director of the Nursing program to make sure that its nursing program was a good fit for her daughter's career goal:

> *"We actually went [to the university that Chloe has applied to] and met with the assistant*
> *director [of the Nursing program] and the senior counsellor, who was so above and*
> *beyond that they gave us this meeting and let us go down to the simulation lab to see if*
> *Chloe could see, and that kind of stuff. So yeah, they were amazing. Told her there was a*

place for her, maybe not in the OR or the ER but Chloe's aware of that. But she just

wants to do patient care."

Olivia further noted that she felt confident that the independent living skills that Chloe has developed and the work experiences that she has gained over the past few years have positioned her well for the transition from high school to university life:

> *"I definitely think letting her be a camp counselor at 16 at Lake Joe helps [...] [When*
>
> *Chloe worked at Lake Joe], she's really living independently when she's out there in a*
>
> *somewhat controlled environment, so I think that's helping prepare her. Like I said, she's*
>
> *been working since she was 15, she has been taking the bus, she cooks, she knows how to*
>
> *eat and cook, she can take care of herself. She's been a gone for weekends by herself. She*
>
> *could survive."*

Participants further highlighted the importance of listening to their adolescent child's input and respecting their feelings and decision when planning for the transition points. For example, Lauren shared that Ruby had decided to take a year off after high school to complete a co-op prior to starting university. She explained that she respected her daughter's decision and believed that the co-op experience would increase Ruby's readiness for the transition from an environment where visual impairment is seen as the normal to a world where most people do not have a visual impairment:

> *"I need to listen to how she is feeling, and she doesn't feel like she's ready to jump right*
>
> *off into university then I need to respect her request to do a co-op prior to going. I*
>
> *think it will increase her confidence more, because she's in a world right now where*
>
> *students are either blind or visually impaired and then changing to a different*
>
> *environment of everyone being sighted will be a challenge. I think she has to be ready*

for that."

This theme of being supportive of their adolescent in the time of transition was also evident in Brandon's narrative account. Brandon anticipated that the transition from elementary school to high school would be challenging for his daughter, because of her noticeable differences due to her albinism. He spoke about how he was working on making this transition smoother for Erica by being emotionally available for her and normalizing the challenges that she was currently experiencing or might experience in the near future:

> *It's just hard in high school being young and being different. Everything she is doing now is to fit in. She is given tools at school to use, but she doesn't want to use them because she doesn't want to seem different, even though she is. […] I think these next few years are going to be hard on Erica. High school is kind of hard for everybody. […] So I'm just really trying to encourage Erica, and sure these years are tough, but you aren't the only one feeling like this. Everyone feels this way in high school, whether you are different or not."*

In addition to providing emotional support for his daughter, Brandon recognized that Erica would eventually face the transition from the education system to the workforce. Therefore, he had started thinking about what he could do as a parent to make the transition to the workforce smoother for his daughter. Brandon shared that he was currently thinking about the possibility of opening a small business and offering Erica the opportunity to work for him and had began working with Erica to make this plan a reality:

> *"Even thinking about my profession and what I do. I was thinking is there a way I can open up a small business and then have Ab come in and do work for me, and that way we can make sure she has full employment and that security moving forward. […] Actually*

next year, they have small business grants that are available for high school kids. So we

are starting to prepare a small business plan for that to get that kind of interest going in

developing a small business, and what we can do to make that happen."

5.5. Navigating Challenges in Getting Required Support: Frustrations and Successes

This theme highlighted the role of informal support from family and friends, as well as

formal support from the CNIB and health professionals outside the field of vision loss

rehabilitation in shaping participants' experiences of parenting their adolescent with a visual

impairment. Participants spoke about how the presence or absence of informal support made a

difference to their parenting experiences. In addition, participants noted the significance of

institutional support from the CNIB in their lives as parents and the mixed experiences regarding

receiving support from health professionals outside the field of vision loss rehabilitation.

Participants also voiced the need for more opportunities to connect with other parents who were

also raising children or adolescents with visual impairments.

For some participants in this study, emotional support from loved ones, such as family

members and friends, was a main factor that helped them through the challenging moments

following their child's vision loss. This positive impact of family and friend support was

demonstrated in Jenifer's narrative account:

"A lot of family support, a lot of friend support and my husband. Instead of internalizing

it, I speak about it. I don't speak about it with her [Pam] around, but I do speak about it

and my frustrations. Sometimes I am asking for advice from those people, other times I'm

just getting it out and saying, 'this really sucks, I don't know how to deal with it'. It helps

because knowing that people understand, like they all know my daughter and they all

understand how she was before [losing her vision] and knowing what I'm going

through."

In contrast to Jenifer, Olivia did not receive adequate support from her family, except her

husband, throughout her parenting journey. For example, she shared that Chloe's grandparents

did not support her and her husband advocating for Chloe, and did not believe that it was fair for

Chloe to request the accommodations that she needed to succeed academically or at her part-time

job:

"It was very difficult when you have my in-laws saying, that she didn't think it was fair

that we were asking to have the cash register raised, [at the restaurant where Chloe used

to work], a small accommodation. And she in fact told them that if it was her, she would

make sure to only hire 100 percent healthy people, so having gone through that and then

getting that from your grandma when you're 15 is devastating. Devastating for all of us,

because we just can't allow it, and it just puts such a divide in our family, because we

cannot allow Chloe to see that we condone that kind of philosophy in life."

Olivia highlighted that participating in the CNIB-run family week program at Lake Joe

summer camp, when Chloe was 12 years old, transformed Chloe and herself, as a parent, in a

positive way. She viewed the summer camp experience as a turning point for her daughter as

well as her husband and herself, especially in the context of a lack of family support. Olivia

explained that through the Lake Joe summer camp, they had the opportunity to meet people with

visual impairments who were "successful and independent" for the first time. For Olivia and her

husband, connecting with people like Chloe who were already living a fulfilling and productive

life, reassured their confidence in their daughter and was an empowering experience that they

had never had before:

"It gets me emotional because it [the summer camp experience] was amazing. We saw

people [with visual impairments] that were successful, independent, everything. You

know, instead of my family saying, 'oh, well she shouldn't do that" or 'she can't do that,'

here [at Lake Joe] we're seeing, 'Yes, she can. We knew those people existed, we just

didn't know where they were, and we couldn't find them, we couldn't even find them here

in [the city where Olivia and her family resided], even through the CNIB. We tried to get

them in camps; they just weren't here. I don't know, so and Chloe wasn't seeing it and

we needed to prove to her, you know, that no, just because this is what it is. It doesn't

matter. You're still good to go."

Jenifer and Lauren also spoke about the institutional support their children received from

the CNIB and expressed their gratitude towards the organization. For example, Jenifer

highlighted the role of CNIB in helping Pam get her independence back after her sudden vision

loss:

"Like when she went to [the hospital where she was doing her co-op], I think she went

twice to [the co-op site] and had a tour with them [staff from the CNIB]. Then she was

like 'I got this,' and now with going to [name of the hospital] for a co-op, she's been

everywhere in [the hospital], because there are 3 X-ray clinics, and she has to show

people where to go. [...] She doesn't need me. I think that was a big help having the

CNIB step in and do that because it pushed her, she wanted to show people that she could

do it."

Jenifer added that support from the CNIB helped her greatly as a parent as well. The

guidance from the staff at the CNIB not only made her more comfortable with approaching tasks

related to re-introducing independence in her daughter's life, but also provided her with the tools
to cope with the grief associated with parenting an adolescent with vision loss:

> *"I think it [the CNIB] has helped us along this path. It has gotten us to the point where*
> *we are now comfortable parenting her. I'm not saying I'm 100% because I'll never be*
> *there, but you know, knowing it's ok to push her, it's ok if she gets mad at you. Before I*
> *was just like, 'oh my gosh she's mad at me. I got to fix this'. But now, it's like she's mad*
> *at me, we'll get over this tomorrow. It has shown me tools to cope."*

Lauren, on a similar note, discussed the positive impact of the CNIB on her daughter's
life as well as her parenting journey. She shared that Ruby's O&M instructor helped her arrive at
a turning point in her life, by suggesting she get a guide dog. Lauren believed that becoming a
guide dog handler not only increased Ruby's independence but also provided her with the
emotional support that she needed:

> *"The CNIB [staff from the local office], on a positive note, was so supportive and*
> *outwardly amazing and really increased her cane skills and suggested she got a guide*
> *dog. And ever since she got a guide dog, her anxiety decreased, she came out of her*
> *shell."*

Participants' experiences with healthcare and social service providers outside the field
of vision loss rehabilitation were mixed. Lauren spoke about her negative as well as positive
experiences with physicians when seeking a diagnosis for Ruby's vision loss when she was
younger:

> *"I had a bad experience with one of the doctors at [name of the hospital], accusing*
> *Ruby of making up her vision loss. She didn't answer, so the doctor accused her of*
> *being deaf as well. Anyway, lots of tests, MRIs [...] But on the positive side we did*

meet some nice doctors, a wonderful doctor at [name of another hospital], and Ruby

ended up with a really nice neuro-ophthalmologist doctor."

In terms of social services outside the field of vision loss rehabilitation, Lauren said that Ruby was dismissed by service providers, such as social workers and psychologists, that she encountered:

"As far as social services, any kind that we tried from social workers, to psychologists

and psychiatrists, had no idea, they had no clue. They could not help Ruby at all,

work through any kind of feelings or fears. It was very disappointing. They kept

turning it around on her, a lot of people would say it's her fault, or she chose to lose

her vision, and she's making it up in her head."

Similarly, Brandon recalled that when Erica was initially diagnosed with a visual impairment, he felt that the entire process was rushed, and that the healthcare professionals did not follow up with him and Erica's mom to provide any resources or connect them with the CNIB:

"But even just after the diagnosis, it was just, it was just so plain. It was just like "Oh

your child is blind and has this and that's it, thank you have a nice day." Right, so

there was no connection to CNIB, there was no resources, no nothing. It was just

"Oh this is what it is, and you know thank you and next." At least that's what is felt

like for us."

Although having a peer support network can be helpful for parents raising children with disabilities, participants in this study either did not know any parents of children with sight loss or knew of only a few parents with similar experiences in their social circle. As a result, they sometimes felt alone on their parenting journey. As Jenifer pointed out:

"I think if there was a lot more people there were that were out there dealing with the same situation, I think it would help. Because right now I feel like I'm with my husband, we're doing it on our own. We have no knowledge of what we're going through. It's kind of like blind leading the blind,"

Reflecting on his parenting journey during the early years, Brandon wished that he had access to more information regarding parenting a child with low vision. He added that a handbook written specifically for parents of children with visual impairments would have provided him with a better understanding of his daughter's developmental trajectory and relieved the sense of uncertainty he felt as a parent back then:

"I just wish there was a handbook or something, right? That would've just give us not a sense of hope, but a sense of understanding of what to expect when you are raising a child with low vision. They have a book for what to expect when you are expecting, and I'm sure they have a book for how to raise a child, but it would've been great to have something that just says that if your child has low vision, this is what you can expect, and these certain milestones. That would've been great. That would've been really handy to have."

Likewise, Olivia pointed out that there was a lack of resources to support parents advocating for their children with visual impairments:

"At no fault of CNIB, I just don't think that we know what our rights are. Nobody has taught us how to advocate. There's no real big resources on that. It's just us doing it, day gig, you know."

5.6. Changed Perceptions within the Context of Societal Misunderstanding

Participants touched base on how individual and societal perceptions of visual impairment impacted them as parents and their adolescent child. They also discussed how raising an adolescent with a visual impairment changed their beliefs about people who are blind or partially sighted.

Some participants emphasized that despite their child's visual impairment, they considered their child as a typical teenager in many ways. This was demonstrated in Brandon's description of his daughter, Erica:

"So Erica is a typical teenager, she doesn't like getting up early in the morning. She needs some extra, I guess, encouragement to get out of bed. She likes to stay up late which doesn't help as well. She likes to be on her phone. […] When she's at home and knows the environment you don't notice anything, right? You don't notice any limitations, it's just Erica."

Brandon, however, realized that not everyone could see Erica beyond her visual impairment. He illustrated this with a conversation that Erica recently had with one of her peers at school:

"Even last week or so, she met someone who was a few grades older than her, and she [the other student] was like, 'oh, you're the blind girl in grade 9.' And she [Erica] was like 'yeah, well it hurt, because I am so much more than that.' And I'm like 'yeah but you are! That's something like saying 'I'm the fat guy at work,' that it doesn't feel good. No, you are so much more than that."

Pam's relationships with her peers were impacted by her visual impairment, too. As Jenifer noted, her daughter lost many of her friendships after her vision deteriorated, since her friends did not feel comfortable interacting with her anymore:

"Like her friends won't go to the mall with her because they don't know how to walk around the mall with her. And it's simple as walk on her left side, but she can't get that through their head. It's like, 'we don't want to babysit you,' so she's just gotten to the point where I'll just go to the mall with my mom."

Pam was at a point where she has lost most of her vision, but has yet to find out the cause of her vision loss or received any kind of formal diagnosis. As a result, Jenifer added that her daughter felt out of place in both the low vision and sighted communities when she first lost her vision. She did not feel legitimized in the low vision community because she did not have an official diagnosis and worried that people with normal sight would not accept her either:

"Like she's been to the CNIB hub [a community space where the CNIB hosts events and programs for those with sight loss and their families]. And she really liked it. But her fear is, people won't accept her, because she doesn't know the reason why she's lost her vision, so she's kind of in that limbo where she doesn't think people with vision loss will accept her because she doesn't know why. And people who are normal in their eyes won't accept her because she has that vision loss."

Societal attitudes towards visual impairments was another powerful force that influenced participants' experiences of parenting their adolescent child with sight loss. For example, Lauren shared her observation that people tended to view visual impairment as a disability associated with old age and were often shocked when they came across a young person with vision loss, especially if he/she has visible signs of visual impairment, such as a white cane or a guide dog. Lauren further explained that for Ruby and herself, those negative societal attitudes that the general public held towards those with visual impairments were most evident through the stares and comments they received when walking in public spaces:

"The staring of people, I mean Ruby can't see them looking at her, but it started out when she had a cane. I think it's society's attitude that someone who is blind would be an 80-year-old, because it's to do with age. […] they still ask Ruby, 'is she training her guide dog? Is she an instructor?' And she said, 'No, he's my guide dog.' But it's this attitude, first of all, people are shocked I think when they see even little tiny kids with canes. And I still think there's that shock of how can a young person, a child or teen, have a visual impairment. It's like people are staring when we walk by. I still feel like going out into society, it's still seems fresh. Like it seems like it's a world we are still navigating together."

In addition, Lauren pointed out that the negative societal attitudes towards vision loss were often manifested in subtle ways, such as the language that people use in everyday life:

"Like even my coworkers, they don't say things on purpose, I know that. But I find I'm very sensitive now if someone says, 'oh I couldn't find a word on the page. I must be blind.' I have heard it this last year, I don't know how many times, how many people are saying 'oh I must be blind.' You know I just feel like yelling at them and saying,' you're lucky you're not.' You know? But I know it's in the society and people just say these things."

Participants further believed that raising an adolescent with a visual impairment helped to change their perceptions of people with visual impairments as well as disability more broadly. Brandon, for instance, shared that raising his daughter with low vision allowed him to see disability as a 'normal' part of the human experience and to form connections with people from all walks of life:

"When I wasn't really exposed to anyone who was different from myself, I always

thought of those people having significant difficulties or they might need a lot of

assistance. I wouldn't see them; I would see the impairment or the visual impairment. But

now, with Erica, I don't even notice her eyes moving or her nystagmus anymore, because

she's just Erica, she's just a person. So I think that changed my values for sure, and my

ability to just go up and talk to people."

Likewise, Jenifer highlighted that her experience of parenting her daughter, who lost her

vision suddenly during her teenage years, opened her eyes to what people living with visual

impairments are capable of accomplishing:

"It's opened my eyes as a parent, because I had this label that people with vision loss

couldn't do as much as they can. I hate myself for it, because I work with people with

disabilities but a lot of the people I work for don't work, so it broaden my horizons. I

always wanted to push my daughter to do more, obviously, but now broaden my horizons

that she can achieve more than what I expected."

5.7. Conclusion

The themes and the subthemes presented above highlighted the different aspects of

participants' psychosocial and occupational experiences along their parenting journey. In the

next chapter, I will conclude the present study by discussing my interpretations of findings and

relating them to the ecological system theory, as well as current and future research.

Chapter 6: Discussion

This study investigated the psychosocial and occupational experiences of four parents of adolescents with visual impairments. In this final chapter, I discuss the findings of the present study in the context of existing research and my theoretical framework. I also examine the strengths, limitations, and implications of the study findings. First, I explore the findings in relation to previous research which has focused on parents' experiences of raising children and adolescents with visual impairments and other types of disabilities. The discussion of the findings in this section are organized based on the central themes identified in this study as well as chronology of participants' parenting experiences. Next, I present my interpretations of the finding through the lens of the ecological system theory. The strengths and limitations, as well as the implications of the present study are then discussed.

6.1. Connecting Study Findings to Previous Research

  6.1.1. *Psychosocial Adjustment Following a Child's Diagnosis and the Role of Social Support*. In the present study, participants discussed the overwhelming emotions that they experienced following their child's visual impairment diagnosis, with grief and fear being the two most prominent feelings. This is in line with previous findings that parents of children with disabilities, such as visual impairment (Leyser & Heinze, 2001), hearing loss (Jackson, Traub, & Turnbull, 2008), and Down Syndrome (King et al., 2000), often felt intense sorrow and a sense of uncertainty about the future when they first received their child's diagnosis. Intense grief after initially learning about one's child's disability seems to be especially common among parents who do not have disabilities themselves, possibly because for those parents, their child's disability is in sharp contrast with the mainstream ideal of a "perfect child/teenager" and shatters

their assumptions about the future for their child that they may have envisioned (Janoff-Bulman, 1992; Scorgie, Wilgosh, & Sobsey, 2004).

In addition, findings from this study illustrated the sense of guilt that the participants felt about their adolescents' visual impairments, although they were aware of the lack of scientific evidence indicating that they did anything that would have caused the vision loss. Although not previously noted in the limited number of research studies involving parents of children and adolescents with visual impairments, the sense of guilt experienced by parents has been widely documented in the broader disability literature (Findler, Jacoby, & Gabis, 2016; King et al., 2000). As pointed out by Goddard and colleagues (2002), this sense of guilt that many parents of children with disabilities experience may be better understood within the context of the social discourse based on the medical model of disability, in which parents are deemed at fault when their child is born with or acquires a disability, either due to hereditary reasons or poor prenatal care.

Although participants reported that negative emotions such as grief, guilt, and frustration were still a part of their parenting journey at times during the interviews, all of them noted that they had come to terms with their adolescent's condition and were able to view grief as a 'normal' part of the experiences of parents who are raising a child with a disability. Participants' narrative accounts further demonstrate that social support from family and friends can have a major positive impact on the lives of parents of children with visual impairments, especially during the time of initial distress following their child's diagnosis. The importance of support from family members, friends, and community for parents of children and adolescents with disabilities has been widely shown in earlier research (de Klerk et al., 2011; Rentinck, Ketelaar, Jongmans, & Gorter, 2007). As highlighted in the present study, such support from loved ones

may not always be present, which could partly be attributed to the stigmatizing attitudes towards disability and/or the lack of understanding of parents' situation. When social and emotional support from loved ones is inadequate or altogether absent, the psychological distress associated with parenting can be buffered by high-quality professional support and connecting with other parents with similar situations or people with similar disabilities as their children. For example, in this study, several participants shared that guidance from the CNIB considerably mitigated their feelings of uncertainty, grief, and frustration along their parenting journey. Furthermore, one participant, who did not receive adequate family support, shared that through connecting with other parents of children with vision loss and adults with similar conditions to her daughter, she was empowered as a parent and became more confident about her daughter's abilities to lead a fulfilling life.

  6.1.2. Engaging and Finding Meaning in Advocacy Occupations. Findings of this study also revealed the significance of advocacy-related occupations in participants' lives as parents of adolescents with visual impairments. All four participants devoted significant amounts of time and effort towards advocating for their adolescent children in various settings. The school system, for example, was where three of the participants focused the majority of their advocacy work. This is consistent with Chang and colleagues' (2000) in-depth qualitative study in which adolescents with visual impairments identified parental advocacy efforts in the school system as a key form of support that they received. In addition to advocating for their adolescent child with vision loss, all participants in the present study had been increasingly focusing on teaching their adolescents to become self-advocates. They believed that solid self-advocacy skills would help offset the challenges that their adolescents would likely face in their future education, employment, and other aspects of their daily lives.

Taking on the role of advocate, and instilling self-advocacy skills in their adolescent children with visual impairments, required participants to stay up-to-date with the current services and resources available in order to navigate the complex and fast-changing education, social service, and healthcare systems. Similar to findings from past research (Hetherington et al., 2010), participants in this study reported that institutional support and professional resources related to advocating for an adolescent with vision loss were hard to find. As a result, participants sometimes experienced a sense of isolation, feeling that they were fighting the battle alone. It is worth noting that one participant's advocacy occupations, in particular, moved beyond speaking up for her daughter who is partially sighted and extended into empowering other people with visual impairments, through participating in activities such as giving public presentations to raise awareness about vision loss. This progression from advocacy at the personal level to activism at the broader sociocultural level was also described in earlier occupational science research concerning fathers of children with disabilities (Bonsall, 2014). Furthermore, the participant considered that her transition to becoming a parent of a child with a visual impairment made advocacy occupations a central aspect of her parenting experiences and her identity. This supports Raanaas and colleagues' (2019) observation that expected and unexpected life transitions often lead to change in meaningful occupations, which in turn, contributes to the re-creation of self-identity.

Taking a closer look at participants' stories, the narrative data further suggested that participants' advocacy occupations in their everyday lives as parents were largely dictated by the barriers that their adolescent children with vision loss encountered in their physical and social environment. For example, issues including inadequate academic accommodations, inaccessible campus environments, as well as discrimination from teachers and other students at school were

highlighted as some of the main reasons that led to participants' advocacy work within the school system. One participant noted that she had been consciously focusing on teaching her daughter to speak up for herself outside of school, because she believed that this skillset would give her daughter a better chance to let her voice be heard in a society where the general public tends to hold the assumptions that people with visual impairments are less capable or intelligent than those without visual impairments. The important teaching role that parents play along the journey of being allies for their adolescents has also been documented in research involving parents of adolescents with learning disabilities (Barnard-Brak, & Fearon, 2012; Smith, English, & Vasek, 2002).

6.1.3. Independence Vs. Safety: Negotiating a Delicate Balance. Contrary to some of the previous work suggesting parents of children and adolescents with physical disabilities tend to be overprotective (Holmbeck et al. 2002; Manuel et al. 2003), parents in the present study actively promoted independence in their adolescents with visual impairments. Participants acknowledged that the increasing desire for independence and individuality is a normal and healthy part of the transitions taking place during adolescence, regardless of the presence of a visual impairment. Therefore, they considered promoting physical and psychological independence in their adolescents would be beneficial for their development. Participants reported creating opportunities to help their adolescents build and practice their independence, such as encouraging them to work part time and letting them make decisions related to their own care. Some also explained that while they recognized the challenges that their adolescents may face in the independence-building process due to their visual impairments, they discouraged their adolescents from 'playing the victim'. The participants' emphasis on independence-promoting occupations may be shaped by the North American cultural context in which autonomy,

individuality, and productivity are highly valued, especially during adolescence and emerging

adulthood (McElhaney & Allen, 2012).

Institutional support from the CNIB was identified by participants as having a positive

impact on their adolescents' path towards independence, especially regarding independent living

skills (ILS) and orientation and mobility (O&M) skills. Participants described how the ILS

specialists and O&M instructors from the CNIB taught their children how to perform

occupations such as cooking, taking the bus, and going to the mall safely and independently, and

how these increased ILS and O&M skills helped them to feel more comfortable letting their

adolescents perform those occupations without parental supervision. This emphasis on the

impact of vision loss service providers on the psychosocial and occupational experiences of

adolescents with visual impairments and their parents differs from previous research in which the

role of physicians and optometrists was the primary focus (Castañeda et al., 2016).

In line with the qualitative findings from Leyser and colleagues' (2001) work examining

the parenting experiences of a larger and more diverse group of parents of children and

adolescents with visual impairments, participants in this study expressed worries for their

adolescents' safety and well-being. Specifically, functional limitations caused by adolescents'

visual impairment and risks within the outside environment were both major sources of concern

for participants when trying to enable their adolescents' independence. It should be noted that the

adolescents' gender was another factor that shaped participants' worries and concerns for their

adolescents' safety. Some participants recognized that being a young female could be

particularly challenging in today's society because of the prevalence of gender-based

discrimination and violence and believed that the combination of their adolescents' gender and

visual impairment status may make them particularly vulnerable when performing some of the

occupations typical for their age, such as going on walks at night, going to house parties, and

dating. This novel finding indicates that the experiences of parents of adolescents with visual

impairments may be driven by factors in transaction with their child's disability status and calls

for the utilization of an intersectionality approach (Mullings & Schulz, 2006) when studying the

occupational experiences of this population. An intersectionality approach posits that biological

and social categories, such as gender and (dis)ability status, are not separate but mutually

defining dimensions of an individual's identity, which need to be examined together in order to

fully understand his/her experiences.

Chang and colleagues (2000) noted that during this time of transition, parents of

adolescents with visual impairments often feel the need to negotiate a delicate balance between

parental-monitoring occupations and independence-promoting occupations. This was consistent

with findings from the present study, in which participants performed parental-monitoring

occupations while giving their adolescents space to practice and enjoy their newfound

independence. Two participants, for instance, recalled following their adolescents with vision

loss when they first started walking around the neighbourhood independently using their white

cane. Participants discussed how they tried to not let their own fear for their adolescents' safety

deprive them of opportunities to move towards independence. They accomplished this by placing

trust on their adolescents' abilities to navigate their environment. In addition, similar to the

literature involving parents of adolescents without sight loss (Chapdelaine, 2017; Spring et al.,

2002), some study participants identified open parent-child communication as key to finding the

right balance between autonomy-granting and parental-monitoring. Specifically, they explained

how having the knowledge about where their adolescents were going and/or whom they were

with helped to relieve their worries when their adolescents went out on their own or with their

friends. Although balancing parental-monitoring and independence-promoting is not a task unique to parents who are raising adolescents living with visual impairments, their path of finding this balance is often complicated by the conflicting societal expectations for adolescents with disabilities as well as additional safety concerns associated with their adolescents' vision loss. As demonstrated by Powers, Hogansen, Geenen, Powers, and Gil-Kashiwabara (2008), on the one hand, within the context of North American culture, society generally expects parents to promote independence and individuality in their adolescent children. On the other hand, the belief that adolescents with physical disabilities should refrain from taking risks to ensure their safety is still a prevalent assumption in society.

6.1.4. Preparing for Future Transitions Through Planning Occupations. Besides encouraging independence and autonomy, parents in contemporary North American society are expected to navigate through a series of tasks with their adolescents, such as exploring future education and career options and establishing social networks, in preparation for the transition into adulthood (Powers et al., 2008). In this study, since all participants' children with visual impairments had either recently gone through a transition or would soon be experiencing a transition specifically within the education system (e.g., from high school to university), parenting occupations related to transition planning were considered a priority by participants. The transition planning process requires parents, educators, service providers, and adolescents to engage in a coordinated set of activities aimed to facilitate the adolescents' transition within the education system or from school to the workforce (Hetherington et al., 2010).

Similar to the parents interviewed by Chapdelaine and colleagues (2017), and as part of the overall planning process, participants in the present study engaged in various types of information-gathering occupations prior to the transition point. For example, participants whose

adolescents would be transitioning to post-secondary education and the participant whose

daughter recently started high school reported researching the campus accessibility and/or

academic program setups in order to decide if the school was best suited to their adolescent's

accommodation needs, mobility, and/or career interest. Chapdelaine and colleagues (2017) have

demonstrated that parents' information gathering process often involves activities such as talking

to other parents going through similar transitions and finding resources online or through

education professionals, such as teachers. However, as shown in the present study and past

research (Jenks, 2005; Leyser, 2001), because of the low prevalence of visual impairment among

adolescents, parents who are raising adolescent children with visual impairments often have no

connections or only very few connections with other parents of adolescents with visual

impairments in their social network. Furthermore, professional resources that facilitate the

transitional planning process for adolescents with visual impairments are relatively scarce, and

obtaining those resources often requires parents to navigate the fast-changing education and

social service systems (Lindsay Menna-Dack, Sanford, and Adams, 2015). Those barriers

undoubtedly add an extra layer of complexity for parents of adolescents with visual impairments

when performing information-gather occupations during the transitional phase.

     To make the transition to their new environment smoother for their adolescent children

with visual impairments, participants engaged in planning tasks such as making arrangements

with student accessibility services at their adolescents' new school to set up proper academic

accommodations and utilizing the support from the CNIB to help their adolescents become

familiarized with the new campus layout. Performing these types of planning tasks when

children experience a transition in the education system represents an important aspect of

parents' occupational experiences regardless of the presence or absence of a visual impairment

(Baric, Hemmingsson, Hellberg, & Kjellberg, 2017; Chapdelaine et al., 2017). However, it is worth noting that unlike parents of adolescents without sight loss, the planning occupations discussed by participants in the present study predominantly focused on meeting the adolescents' accommodation needs and involved frequent interactions with vision loss rehabilitation service providers. When engaging in those planning occupations, participants actively involved their adolescents in the process and took their input into consideration. This has been shown to be beneficial for post-transition outcomes, such as mental health and emotional wellbeing, academic performance, and self-advocacy skills, in adolescents with other types of disabilities, such as Autism Spectrum Disorders (ASD; Nuske, Rillotta, Bellon, & Richdale, 2019). Providing their adolescents with emotional support while engaging in the process of preparing for upcoming transitions was another key aspect of participants' parenting experience. For example, when the adolescents felt unsure about their abilities to form meaningful relationships with their peers at their new school, or about whether they could reach their career goal, parents would encourage them by offering reassurance about their worth and abilities.

When thinking about the future, it was evident that many of the participants' concerns and hopes were centered around the employment prospects for their children. In line with the literature, participants recognized that the benefits of participating in paid work involve not only financial independence but also meaningful social connections with others (Lindsay et al., 2015; McConnell, 1999). Participants hoped that their adolescents with vision loss would work in a field that they love and find a sense of purpose through a fulfilling career in the future. However, they also worried about the availability of employment opportunities for their adolescents because of the functional limitations associated with their visual impairment, as well as the possibility of discriminatory attitudes and practices on the part of the employer or colleagues in

the workplace. Participants' concerns about their adolescents' employment prospects are validated by current statistics regarding the employment status of Canadians who are blind or partially sighted. According to a recent report by Statistics Canada (2017), among working age Canadians with visual impairments who are between the ages of 25 and 64 years, only 54% are currently employed. This rate is considerably lower than the national average (80.1%) and is also lower than the average employment rate amongst working age Canadians with all types of disabilities (59.4%). As pointed out by Lindsay and colleagues (2015), the discrepancy between the employment prospects for youth with visual impairments and their sighted peers may not only be attributed to the lack of independence and life skills among some of the youth, but also due to system-level barriers such as inadequate disability awareness among employers and the lack of funding and policies to enhance such awareness.

6.2. Linking the Findings to the Ecological System Theory

The psychosocial and occupational experiences of the four participants in this study were shaped by diverse and interacting components within the micro-, meso-, exo-, macro-, and chronosystems outlined in the ecological system theory (Bronfenbrenner, 1992). At the same time, however, participants also actively asserted their influence as parents of adolescents with visual impairments, thereby impacting their environment over the course of their adolescent children's development.

Within the microsystem, which refers to the individuals and institutions that the participants have direct interactions with (Bronfenbrenner, 1992), it was evident that factors such as the adolescent child's attitude towards their visual impairment, as well as the presence or absence of social support from family members and friends, shaped aspects of participants' parenting experiences, including their emotional responses to their child's visual impairment

diagnosis and how they negotiated the balance between parental-monitoring and independence

promoting occupations. For example, two of the study participants spoke about how their

adolescents' positive attitudes towards their visual impairments provided them with a sense of

comfort when they faced uncertainty and setbacks along their parenting journey; one participant

whose daughter had a visual impairment and anxiety learned to help his daughter reframe the

anxious thoughts that she had in everyday life, such as the fear of travelling independently.

Furthermore, it was clear that participants' career and workplace played a role in shaping their

values about visual impairment and the parenting occupations that they considered important and

meaningful. Interestingly, all study participants were working in healthcare in some capacity,

which likely influenced their willingness to participate in this study. In addition, most of the

participants noted that their work experience and previous academic training in healthcare or

social service-related fields made them more attuned to the challenges and systemic barriers that

their adolescent children had encountered or were likely to encounter in the future and made

them more passionate about advocating on behalf of their children's needs.

Not surprisingly, the interconnection between the microsystems (i.e., the mesosystem;

Bronfenbrenner, 1992) impacted their experiences of parenting their adolescents with visual

impairments as well. For instance, the majority of the study participants expressed that their

adolescents' ILS and O&M skills improved considerably as a result of collaborations with the

vision loss rehabilitation staff at the CNIB. This positive change subsequently increased

participants' level of comfort in encouraging their adolescents to try new occupations, such as

cooking and travelling to the mall on their own. Likewise, the interplay between the resources

and support available at the CNIB, and the adolescents' career goals, accommodation needs, and

readiness for transition into high school/post-secondary education collectively shaped the types of occupations that participants engaged in during transition planning.

Similar to past research utilizing the ecological system theory in occupational science and other related fields (Lindsay et al., 2015; Lynch, Hayes, & Ryan, 2016), the present study illustrated that the exosystem, which refers to settings that are not immediately experienced by the participants but ultimately affect their microsystem (Bronfenbrenner, 1992), also played a role in shaping participants' psychosocial and occupational experiences of raising an adolescent with visual impairments. For example, the healthcare practice models in Ontario had significant influences on their experiences when they sought a diagnosis and/or medical treatment for their adolescent children's vision conditions. Specifically, some of the participants mentioned that because their optometrists were not able to spend enough time providing them with information regarding the implications of their child's visual impairment after giving the diagnosis, their grief and uncertainty about the future were exacerbated. Furthermore, for some participants, the lack of communications between optometrists and vision loss rehabilitation service providers resulted in delays in receiving the much-needed professional support from the CNIB. Similarly, despite not being a part of the decision-making process within the school system, the decisions made by the school and the teachers, such as academic accommodation arrangements, impacted the adolescents' experiences at school, which in turn, dictated parents' advocacy occupations.

The present study confirms findings from recent research showing that the micro-, meso- and exosystems are situated within, and driven by, the broader macrosystem (i.e., sociocultural context; Lindsay et al., 2015). An in-depth examination across participants' stories further demonstrated the ways in which societal attitudes towards visual impairment and individuals with sight loss, embedded within the mainstream Canadian culture, impacted participants'

experiences as parents of adolescents with visual impairments. In addition, participants themselves reflected on how their own views and beliefs about visual impairment were challenged and transformed through their parenting experience through working against their internalized negative attitudes towards disabilities and impairments. For some participants, this change shaped their family relations and led to questioning by family members who held stigmatizing attitudes towards those with visual impairments. In addition, participants pointed out that due to the general misconception that visual impairment is almost always associated with old age, visible signs of visual impairment in young people often invited unwanted attention from strangers, which primarily manifested through stares and comments. This is in line with Rosenblum's (2000) work, in which adolescents who were blind or partially sighted shared that their visual impairments sometimes made them stand out among their peers even when they did not want the extra attention from others. One parent in this study expressed the constant feeling of being on guard as a parent when walking with her daughter in public because of the negative public perceptions of children and adolescents with visual impairments. Similar concerns were also reported in Goddard and colleagues' (2000) study with parents of children and adolescents with various types of disabilities. In particular, some of the participants in Goddard and colleagues' study expressed their constant worries about their children being labeled or judged by health professionals, school staff, or other parents, because of their diagnosis.

In addition, findings of this study highlighted how the chronosystem, which is concerned with the role of time, and expected and unexpected transition over the participant's life course (Rosa & Tudge, 2013), influenced participants' parenting experiences and how they perceived and framed those experiences in their stories. For example, participants' narrative accounts illustrated that as their children got older, their parenting approaches and occupations changed

accordingly. Some reported that when their adolescents with vision loss were younger, they took a more controlling parenting approach, focused on advocating for their children, and engaged in more parental-monitoring occupations. However, as their children transitioned into adolescence and became more capable of navigating the world independently and advocating for themselves, participants took a more permissive approach, engaged in more autonomy-granting occupations, and emphasized more on creating opportunities to allow their adolescents to take the lead and be their own voice. The impact of the chronosystem on participants' experiences of parenting an adolescent with a visual impairment was also manifested in the change in their identity and beliefs about what living with a visual impairment means for their children over time. This process of change was especially apparent for the participant whose daughter lost her vision more recently, at the age of 17. During my first interview with the participant, she expressed the overwhelming uncertainty about the future, wondering if the sudden onset of a visual impairment would send her daughter into turmoil and if her daughter would have to give up her dream of becoming an X-ray and MRI specialist because of her vision loss. However, one-and-a-half month later, the participant noted in the second interview that she now had a more positive outlook on her daughter's future and viewed visual impairment as a setback in life that requires adjustment instead of the end of a fulfilling life. As pointed out by Bonsall (2014), whose study focused on parents of children and adolescents with disabilities, this change often takes place through a process of reflecting on their past experiences and re-envisioning the future for both their children and themselves.

Furthermore, it is worth mentioning that for all study participants, becoming a parent of a child or an adolescent with sight loss was an unexpected life transition; however, participants psychosocial and occupational experiences varied because of the difference in the timing of the

onset of their adolescent child's visual impairment. Unlike other participants whose children were diagnosed with visual impairments during early infancy or early childhood, Jenifer's daughter acquired a visual impairment suddenly in her late adolescence, during a critical period for independence building and identity formation (Erikson, 1968). Since Jennifer's daughter had formed her identity as a person without a disability and had learned to perform everyday occupations independently with her sight, forging a new 'disabled' identity with her daughter and re-introducing independence to her daughter became tasks that were unique to Jenifer in this study. According to Forber-Pratt, Lyew, Mueller, and Samples (2017), when people acquire a disability, they often simultaneously negotiate their physical impairments and the social meaning assigned to those impairments in order to form an identity around disability.

Lastly, in line with the ecological system theory, this study demonstrated that participants were not just passive recipients of their environments (Darling, 2007). Instead, they actively took steps to promote the development of their adolescent children with visual impairments and asserted influences on their environment through taking on various roles, such as educator, advocate, and protector. By engaging in education and career planning occupations with their adolescents during their formative years, participants sought to build their adolescents' confidence and increased their readiness for transitions in the future. Likewise, by advocating for their adolescent children with visual impairments, and/or people with visual impairments in general, participants may have contributed to positive changes at the macrosystem level, through challenging current public perceptions and societal attitudes towards individuals with sight loss.

6.3. Strengths and Limitations

This study has several strengths, with the first being methodological coherence. To answer my research question, "How do parents story their psychosocial and occupational

experiences of raising their adolescent children with visual impairments?", I situated the present study within a constructivist paradigm, which asserts that individuals construct their social reality through experiencing the world around them and reflecting on their experiences. The multiple in-depth interview design, guided by the narrative methodology, was in line with my paradigmatic position in the sense that it created room for study participants to construct and lead their stories and allowed me to capture how participants' stories about their parenting experiences unfolded in the moment. Finally, the holistic-content approach to data analysis enabled me to examine the participants' narratives as a whole, as well as the broader sociocultural context within which the narratives were constructed.

A further strength of the present study is related to the similarity of my background to that of the participants' children and my connections with the CNIB as a client and an employee. As a person with a visual impairment who went through the transition from adolescence to adulthood only a few years ago, I was able to quickly form a trusting relationship with all study participants and to generate rich data during the interviews. Furthermore, although I did not work directly with parents of adolescents with visual impairments as an employee at the CNIB, my work experiences at the CNIB and my experiences as a client of the organization allowed me to form a good understanding of the context of the participants' stories when they discussed their experiences with the services and programs offered by the CNIB during the interviews.

At the same time, I acknowledge that sharing a similar background with participants' adolescent children and being a client as well as an employee of the CNIB could also be a potential limitation of this study. Participants' knowledge about me as a person with a visual impairment, who was pursuing her Master's degree, was likely to influence the experiences that they chose to share with me during the interviews. Also, my work experiences with the CNIB

meant that I may have been attuned to ask questions that were more positively oriented regarding CNIB services during the interviews. In addition, because of my personal experiences with visual impairment, I had pre-existing assumptions about participants' parenting experiences and might have prioritized my own beliefs when re-constructing participants' personal narratives. As mentioned earlier, sending the re-written narratives back to participants for feedback was used as a strategy to mitigate this potential limitation. Also, as a narrative researcher adopting a constructivist paradigmatic position, I do not view the participants' interview responses or my interpretations of their narrative accounts as the single truth representing their parenting experiences. Instead, I recognize that what the participants shared with me was only a "snapshot of an evolving story that changes throughout the life course" (Lieblich et al., 1998, p. 45). As such, I believe that my background as a young researcher living with a visual impairment contributed to the co-constructed narratives of the participants' experiences of parenting their children with visual impairments in the context of this study.

The lack of demographic variability of participants and their adolescent children is an additional limitation of the study. All four study participants and their adolescent children with vision loss were Caucasian with a middle-class background. In addition, parents involved in this study have lived in Canada all their lives, completed post-secondary education, had two children (including one with sight loss), worked in healthcare or social service related sectors, and were either married or in a common-law relationship. Since findings of this study were largely driven by specific participants' experiences and stories, this homogeneity regarding participants' backgrounds prevented me from learning about the experiences of parents with other ethnocultural and educational backgrounds, marital statuses, and career paths. Similarly, as mentioned earlier, all of the adolescent children mentioned in the narrative interviews were

teenage girls. As a result, the aspects of the psychosocial and occupational experiences of parents of adolescent boys with visual impairments remain unexamined.

Another limitation of this study is that not all the interview sessions with participants were conducted in-person, as initially anticipated. As mentioned in Chapter 3, due to the distance between my city and the city where one of the participants resided, as well as the travel restrictions due to the COVID-19 pandemic, one narrative interview session and two feedback sessions were conducted virtually via Zoom. Although the participant who completed the interview sessions virtually was elaborative during the narrative interview sessions and the interviews yielded rich data, it is possible that better rapport with the participant could have been established and the interviews might have been more natural and spontaneous had they been conducted in person (Lo Iacono, Symonds, & Brown, 2016). In addition, for reasons related to the COVID-19 pandemic, two participants were unable to participate in the final session where participants commented on the narrative account, which means that I do not know whether they believe that the narratives that I re-constructed based on their stories represented their experiences of parenting an adolescent with sight loss.

6.4. Implications

6.4.1. *Directions for Future Research*. This exploratory study expands on the existing body of work pertaining to the experiences of parents of adolescents with visual impairments. Using a narrative inquiry, I was able to carry out an in-depth examination of the psychosocial and occupational experiences of four parents of adolescents with visual impairments. Findings of this study challenge the popular belief that being a parent of an adolescent with a visual impairment is primarily a stressful experience, thereby providing a starting point for future research and practice.

As previous studies have indicated, gender may be a particularly important social factor shaping the transition imperatives for both adolescents and their parents among adolescents with various types of disabilities (Hogansen, Powers, Geenen, Gil-Kashiwabara, & Powers, 2008; Powers et al., 2008). Given that information, future research would benefit from researching the psychosocial and occupational experiences of parents of adolescent boys with visual impairments. Larger scale research could also be conducted with parents of adolescent boys and those of adolescent girls with visual impairments to compare and contrast the experiences of these two groups of parents, as well as investigate the interplay between parents' gender and adolescents' gender in shaping the parents' experiences. As noted by Powers and colleagues (2008), compared to parents of adolescent boys, parents of adolescent girls are more likely to engage in parental-monitoring occupations and tend to discourage their adolescents from participating in occupations that promote autonomy and independence due to safety concerns during the transitional years. In addition, adolescent girls generally receive more emotional and career support from their parents and other adults during the transition planning process but have fewer opportunities to participate in paid occupations than their male counterparts, because of gender stereotypes (Powers et al., 2008). The existing research certainly points to differences, but applied within the context of vision impairment would be a helpful contribution to the existing literature.

Also, upon reviewing the literature for the present study, it came to my attention that research concerning the experiences of parents of children and adolescents with visual impairments has been primarily conducted with Caucasian parents from middle class backgrounds, and the voices of immigrant parents from other ethnocultural backgrounds and socioeconomic (SES) status have been largely neglected. A recent study conducted by Hon, Sun,

Suto, and Forwell (2011) has suggested that the parenting experiences of Chinese-Canadian immigrant mothers of adolescents with developmental disabilities were often influenced by the changes in types of caregiving occupations and stressors associated with moving to a new country, as well the cultural values of their home country. For immigrant mothers of adolescents with developmental disabilities, language barriers, lack of knowledge of where to access services and programs, altered work schedules after moving to a new country, and the task of navigating an unfamiliar education system and culture were all added challenges to their parenting experience (Hon et al., 2011). Past research has documented the impact of SES on the experiences of parents of adolescents with disabilities as well (Emerson, 2003; Park, Turnbull, & Turnbull, 2002). It has been noted that poverty can lead to a lack of funds for accessing healthcare and social services that children and adolescents with disabilities could greatly benefit from and results in heightened marital conflicts between parents (Emerson, 2003; Park et al., 2002). In addition, long work hours associated with low SES means that parents may have less time available to engage in advocacy occupations or help their adolescents with disabilities with transition planning (Murray, 2003). Therefore, future research in occupational science could examine the occupational experiences of immigrant parents and parents with lower SES who are raising adolescent children with visual impairments in order to unpack how those parents' experiences and occupational engagement are shaped by immigration, ethnic or cultural background, and/or SES.

6.4.2. Implications for Practitioners. Findings from this study have relevance for healthcare practitioners, education professionals, and social service providers working with parents of adolescents with visual impairments. Overall, participants expressed satisfaction with the vision loss rehabilitation services that they and their adolescents received. However,

participants acknowledged a lack of resources pertaining to advocacy and the lack of

opportunities to connect with other parents of adolescents with visual impairments, both of

which highlight the demand for advocacy-skill training programs as well as support groups for

parents of children and adolescents with sight loss. Furthermore, the widespread

misunderstanding and negative societal attitudes towards those living with visual impairments

revealed in this study underscores the need for the development of programs and policies to raise

public awareness about visual impairment. As revealed in a systematic literature review by

Lindsay and Edwards (2013), one way to achieve a more inclusive social environment and

enhanced public awareness about visual impairment is through a better integration of disability

awareness education content into school curriculum.

In this study, the school setting emerged as an important site for advocacy for

participants. Findings demonstrated the lack of understanding of the academic and social needs

of students with visual impairments amongst education professionals, as well as inadequate

campus accessibility in mainstream public schools. The lack of understanding and knowledge

about the implications of visual impairment on students' education, on the part of education

professionals, calls for the reform of teachers training programs within the education system. As

suggested by previous research, a heavier emphasis on special education and diversity training as

well as more exposure to learners with visual impairments may offer a good starting point to

enhance teachers' readiness to work with students with visual impairments in the mainstream

classroom setting (Shippen, Crites, Houchins, Ramsey, & Simon, 2005). In addition, school

boards and educators could integrate universal design concepts into curriculum design and

course planning to remove barriers to learning for students with a wide range of needs, including

those with visual impairments (Basham & Marino, 2013). At the structural level, more

government funding and resources allocated for enhancing accessibility in mainstream school settings may allow schools and teachers to foster a more inclusive learning environment for children and adolescents with visual impairments (Biewer et al., 2015).

With regards to healthcare, the barriers that participants encountered as parents of adolescents with visual impairments suggest that current healthcare practices in Ontario may need to be re-evaluated and modified to better support parents of adolescents with vision loss. Specifically, findings of this study underscore the importance for health professionals to take time and communicate the child's diagnosis in an accessible way when talking to parents and provide them with information, resources, and referrals related to raising a child with a visual impairment following their child's diagnosis. Parents' need for information from healthcare professionals was also voiced by parents involved in Speedwell, Stanton, and Nischal's (2003) work, whereby the authors suggested that a lack of post-diagnosis information for parents could potentially be addressed by the placement of information booklets, about the different aspects of visual impairment in children and adolescents, at hospitals and eye clinics. Moreover, the delay in referrals from optometrists to the CNIB that was frequently experienced by participants and their adolescents with vision loss calls for more in-person as well as virtual collaborations between healthcare providers (e.g., doctors and optometrists) and vision loss rehabilitation service providers, in order to enable better communications between these stakeholders.

6.5. Conclusion

This study examined the psychosocial and occupational aspects of four parents' experiences of raising adolescents with visual impairments. Utilizing a narrative methodology and a combination of holistic-content approach and thematic analysis, themes centering on psychological adjustment, advocacy, promoting independence, transition planning, formal and

informal social support networks, and societal attitudes towards visual impairments were identified from the narrative data. Findings of this study address a gap in the current body of literature by highlighting the complexity of parents' psychosocial and occupational experiences along the journey of raising an adolescent with a visual impairment and ways in which parents negotiate and make sense of those experiences. This study has direct implications for future research within and outside the field of occupational science and has the potential to inform the re-imagination and subsequent development of services and programs designed for parents of adolescents with visual impairments.

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Appendices

Appendix A: Research Ethics Approval

Western Research

Date: 23 September 2019

To: ███████████

Project ID ███████

Study Title: Navigating the "Blind World": The Psychosocial and Occupational Experiences of Parents of Adolescents with Visual Impairments

Short Title: The Psychosocial and Occupational Experiences of Parents of Adolescents with Visual Impairments

Application Type: NMREB Initial Application

Review Type: Full Board

Meeting Date: 06/Sep/2019

Date Approval Issued: 23/Sep/2019

REB Approval Expiry Date: 23/Sep/2020

Dear ███████████

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 must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Demographic Questionnaire	Interview Guide		
Email Recruitment Script	Recruitment Materials	02/Aug/2019	
Email Recruitment Script for the CNIB	Recruitment Materials	02/Aug/2019	1
In-Person Recruitment Script & Telephone Script	Oral Script	02/Aug/2019	1
Interview Protocol & Example Interview Questions	Interview Guide		
Letter of Info & Consent- Revised	Written Consent/Assent	18/Sep/2019	
Study Flyer-Revised	Recruitment Materials	18/Sep/2019	

Western 🛡

Appendix B: Email Script for Recruitment

The staff from the CNIB London office will follow this email script when they make initial contact with the potential participants on the researchers' behalf.

<u>**Subject Line: Invitation to participate in research**</u>

Hello,

You are being invited to participate in a research study conducted by Ms. Peiwen (Lily) Cao from the Health and Rehabilitation Sciences Program and Dr. Colleen McGrath from the School of Occupational Therapy at Western University. The study seeks to explore parents' experiences of raising adolescents living with visual impairments. If you choose to participate in this study, you will take part in three individual interview sessions, in which you will mark your memorable parenting experiences on a timeline sheet and answer several questions about your experiences of raising your child who is living with a visual impairment. The first interview session will take 60-90 minutes to complete, and the other two interview sessions will each take 45-60 minutes of your time. You can participate in this study in person or through virtual technologies (e.g., Zoom, Skype) at a location that is convenient to you.

Your participation in this study has the potential to contribute to the scientific knowledge that may inform the development of intervention programs and services for children and adolescents with vision loss and their families. In order to participate in this study, you need to currently be a biological parent of an adolescent with a visual impairment who is between ages 14 and 21. In appreciation of your time and participation, for each of the interview sessions that you take part in, you will receive a $10 Amazon gift card. This study is being conducted as partial fulfilment of the requirements of Ms. Peiwen Cao's Master's Degree in Health and Rehabilitation Sciences, under the supervision of Dr. Colleen McGrath.

Participation in this study is voluntary. If you decide to not participate it will have no effect on any services that your child may receive from the Canadian National Institute for the Blind (CNIB). If you would like more information about this study or would like to receive a letter of information about this study, please contact one of the researchers at the contact information provided below.

Thank you,

Ms. Peiwen (Lily) Cao

Western

Parents' Experiences of Raising Adolescents with Visual Impairments
Participants Needed for a Research Study

Are you a parent of an adolescent with a visual impairment?

Is your child between the ages of 14 and 21?

Would you like to reflect on your parenting journey and share your experiences?

If **yes…**

We want to hear your story!

You are being invited to participate in a research study conducted by Ms. Peiwen (Lily) Cao and Dr. Colleen McGrath from the School of Occupational Therapy at Western University, exploring the everyday childrearing experiences of parents of adolescents living with visual impairments.

If you agree to participate, you would:
- ✓ Participate in three individual interviews, in which you will mark your memorable parenting experiences on a timeline and answer several questions about your experiences of raising your adolescent with a visually impairment
- ✓ Fill out a brief questionnaire that collects basic information such as your age, gender, and type and degree of your child's visual impairment.

Each interview session will take 45-60 minutes to complete**.**

In appreciation of your time and participation, you will receive a $10 Amazon gift card for each of the interview sessions that you take part in.

For more information, please contact Ms. Peiwen (Lily) Cao ▓▓▓▓▓▓▓▓ or Dr. Colleen McGrath ▓▓▓▓▓▓▓▓

Western 🛡

Appendix D: Letter of Information and Consent

Project Title: Parents' Experiences of Raising Adolescents with Visual Impairments

Principal Investigator

Additional Research Staff

1. **Invitation to Participate**

    You are being invited to participate in a research study exploring the everyday childrearing experiences of parents of adolescents living with visual impairments, because you are currently a parent of an adolescent between the ages of 14 and 21 who has a visual impairment.

2. **Why is this study being done?**

    In this study, we seek to explore the childrearing experiences of parents of adolescents living with visual impairments. For children and adolescents, parents are important figures in their lives and have a big impact on their development. In Canada, more than 4,000 clients served by the Canadian National Institute for the Blind (CNIB) are children and adolescents. Adolescence is a time period for rapid change, for both children and their parents. During this transitioning period, parents of adolescents with visual impairments may encounter unique joys and challenges along their parenting journey. In addition, although many parents have gained valuable knowledge and insights related to visual impairment and the blind community from their own experiences of parenting children and adolescents with visual impairments, their voices are rarely represented in the visual impairment literature. Therefore, it is important for researchers to develop a deeper understanding of the stories of parents of adolescents with visual impairments.

3. **How long will you be in this study?**

Your participation in this study will involve three individual interview sessions which will take place over the course of approximately a month and a half. You will take part in the second interview one to two weeks after the first interview and will take part in the final interview session approximately one month after the second interview. The first interview session will take 60-90 minutes to complete. The second and the third interview sessions will each take approximately 45-60 minutes of your time.

4. What are the study procedures?

If you agree to participate in the study, you will take part in three individual interviews. The interviews will take place at Western University or at your own home, depending on your preference. To fully capture the stories that you share with us, all interviews will be audio recorded. Before the first interview begins, you will review the consent form and will be encouraged to seek clarification from the researcher if you have any questions or concerns about the study. During the first interview, you will be asked to mark your memorable parenting experiences (positive, negative, and turning point events) on a timeline. You will use the timeline that you construct as a guide to talk about your experiences of raising your children who are visually impaired. At the end of the first interview session, you will fill out a brief demographic questionnaire that collects information such as your age, gender, ethnicity, marital status, and type and degree of your child's visual impairment.

Approximately one to two weeks after the first interview, you will take part in a semi-structured interview, in which you will answer more specific and in-depth questions about your experiences of parenting your child with a visual impairment. Most of the interview questions for this second session will be based on your responses to questions asked during the previous interview session. Towards the end of the second interview session, you will answer a few reflective questions, pre-set by the researchers, about your experiences of parenting your adolescent with a visual impairment.

The researcher will analyze your responses from the first and the second interview before inviting you to participate in the final follow-up interview. You will be invited to take part in the follow-up interview approximately a month after the second interview session. During the follow up interview, you will have the opportunity to review the life course timeline you have constructed and to modify the timeline (e.g., add/take out information) as needed. You will also be given a copy of the narrative that the researcher constructed based on the experiences that you shared during the previous two interviews. You will be invited to review those materials and offer your feedback. The materials will be provided to you prior to the follow-up interview, either electronically or in hard copy, depending on your preference.

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

By participating in this study, you may experience some emotional discomfort when discussing your experiences of raising your children with visual impairments. However, if negative feelings do arise, they are expected to be mild and temporary. You may refuse to answer any questions and can refuse to disclose any information during the interviews if you feel uncomfortable doing so. You are also free to withdraw from the study at any time with

no negative consequences. In addition, you will be provided with the contact information of several local counselling services at the beginning of the study.

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

By participating in this study, you may learn new insights about yourself and your experiences of parenting your children with visual impairments.

7.   Can participants choose to leave the study?

You are free to decide whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any point without any negative consequences. Your participation or non-participation in this study, along with your choice to stay in or withdraw from the study at any time, will have no impact on any services that you and your child may receive from the CNIB. You will be provided with your unique participant ID number linked to your interview responses and will have the option to remove your data from the study any time before the study is published. If you wish to have your information withdrawn from the study, please contact the principal investigator or the co-investigator.

8.   How will participants' information be kept confidential?

All information collected about you and your children during this study will be kept confidential to the extent permitted by law. While the co-investigator of this study is an employee at the CNIB, all information collected about you and your children will only be used for the purpose of the study. No other members of the organization will be made aware of who has (or has not) participated in the study, and no information collected during the study will be disclosed to other members within the organization. You will be provided with a participant ID number to ensure confidentiality. Signed consent forms, as well as the list linking your participant ID number with your name and contact information, will be stored separately from other study materials in a locked filing cabinet in the co-investigator's student lab at Western University. The audio recordings of the interview sessions will be transcribed by a research assistant, who will be required to sign a confidentiality agreement. Once the audio recordings have been transcribed, they will be deleted. Transcribed data will be de-identified. Only the principal investigator, co-investigator, and the trained research assistant will have access to the data collected from the study. All written data will be stored in a locked cabinet in the co-investigator's student lab, and all electronic data (e.g., electronic copies of the interview transcripts) will be stored on a password protected computer. All data will be kept for seven years after the completion of the study. After this time, the written data will be shredded and disposed, and electronic data will be permanently deleted. Raw data will be stored and identified only by the ID numbers. Furthermore, you will not be individually identified in any publications or presentations that may stem from this research; only aggregated data will be presented. All quotations presented will be anonymous and will in no way be linked back to you.

9.   Are participants compensated to be in this study?

You will receive a $10 Amazon gift card for your participation in each of the interview sessions. For completing the study (all three interview sessions), you will receive a total of $30 worth of Amazon gift cards.

10. Exclusion criteria
You are not eligible to participate in this study if you are an adoptive parent of an adolescent with a visual impairment, or if you are parenting an adolescent with multiple disabilities.

11. What are the rights of participants?
Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time, it will have no effect on the services that your child receives from the CNIB.

We will give you new information that is learned during the study that might affect your decision to stay in the study.

You do not waive any legal right by signing this consent form.

12. Whom do participants contact for questions?
If you have any questions and/or concerns about this study, please feel free to contact the principal investigator: **Dr. Colleen McGrath** or the co-investigator: **Ms. Peiwen Cao**

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

This letter is yours to keep for future reference.

13. Consent

Project Title: Parents' Experiences of Raising Adolescents with Visual Impairments

Principal Investigator

Additional Research Staff + Contact

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research

☐ **YES** ☐ **NO**

_____   _____   _____
Print Name of Participant   Signature   *Date (DD-MMM-YYYY)*

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

_____   _____   _____
Print Name of Person   Signature   *Date (DD-MMM-YYYY)*
Obtaining Consent

Appendix E: Interview Protocol

Interview Session 1

Thank you for taking part in this study. During this interview session, you will talk about your personal experiences of parenting your adolescent child with vision loss. There are no right or wrong answers to the questions asked in this interview. Do you have any questions for me before we get started? *[Interviewer answers any questions that the participant has]*

In thinking about your experience specifically, I would like to start with developing a timeline of your journey of parenting an adolescent living with vision loss. On the timeline, I would like you to mark the events that are memorable and defining to you along your parenting journey. I will help guide you through this exercise.

[Researcher hands timeline sheet to participant and guides participant through the life course timeline construction exercise]
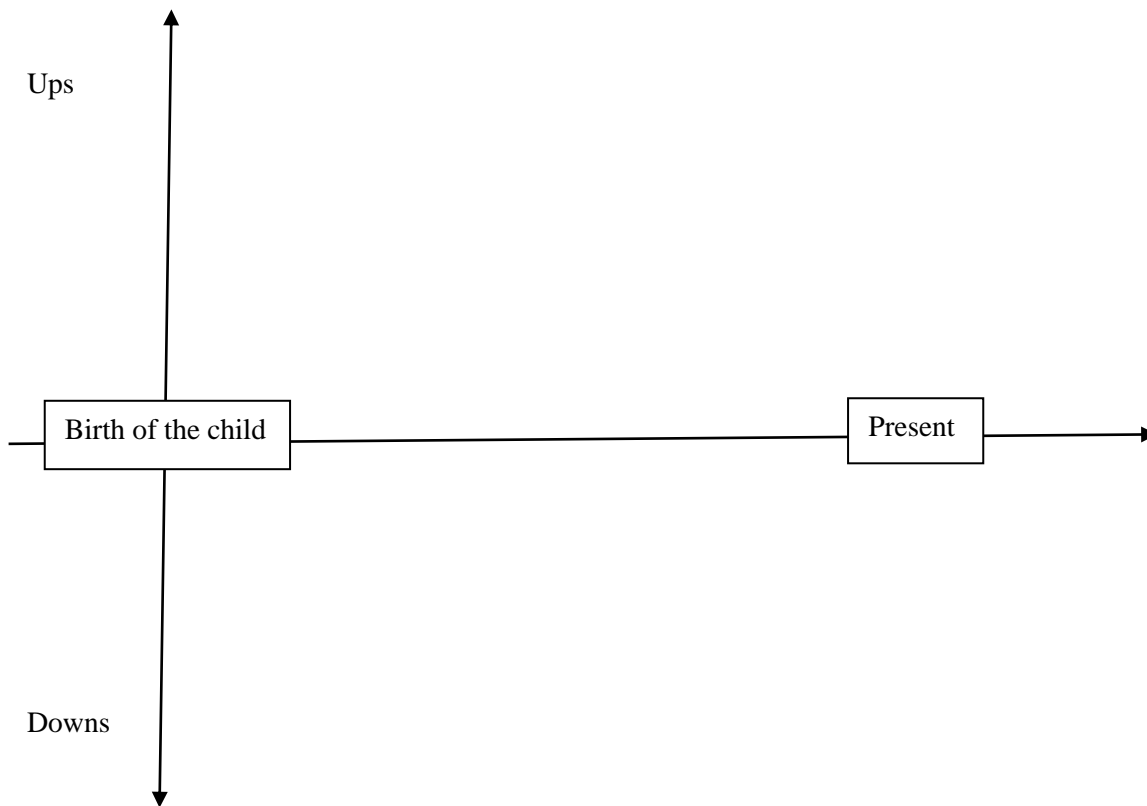
Can you tell me about your experiences of raising an adolescent living with a visual impairment? You can use the timeline you have constructed as a guide when you tell your story. Please feel free to start wherever you like. I will listen first and will not interrupt.

Follow-up questions

1. Have you identified all the ups and downs of your parenting journey that you wish to share with me on the timeline? *[Researcher asks this question after participant finishes constructing his/her timeline]*
2. You mentioned that *[insert the part of the participant's response that stands out to the interviewer],* can you tell me more about that?
3. What do you mean by *[insert the point that the interview wish that the participant can further elaborate further]*?
4. Can you give me an example of when you felt *[insert experience here]*?

Interview Session 1 – Timeline Sheet

Please use the space below to construct your timeline of parenting your child with vision loss. On this timeline, please mark the ups and downs that are memorable and defining to you along your parenting journey.

Ups

Birth of the child   Present

Downs

Interview Session 2

Olivia

During the previous interview, you shared some of your experiences of raising your adolescent child who is partially sighted. In this interview, I will ask you a few more specific and in-depth questions about your parenting experiences. The first few questions were developed based on the stories that you have shared during the last interview, and the final three questions were written by me and are being asked to all the participants. This interview will take approximately 45-60 minutes to complete. Do you have any questions for me before we begin?

Childhood and Early Adolescence
1. Towards the beginning of the last interview, you talked about the need to be "careful" and "be aware" when Chloe was growing up. Can you tell me a bit more about that? Do you still feel like that now?

2. You mentioned that Chloe felt "angry", "frustrated" and "lonely" when she was younger. As her parent, how did that affect you? How did you try to manage those feelings?

Lake Joe
1. Looking back at the stories that you have shared with me in the last interview, it seems that talking about your experiences at the Lake Joe Summer Camp when Chloe was 12 evoked a lot of emotion for you. Can you tell me why attending Lake Joe summer camp was such a significant experience?

2. You talked about how participating in Lake Joe Summer Camp transformed Chloe when she was 12. Do you think it was also a transformative experience for you as a parent?
   - *[If yes]*- In what ways was the experience transformative for you?

3. Outside of Lake Joe camp, what support do you receive as a parent of an adolescent who is partially sighted?

Advocacy
1. In the previous interview, you discussed the importance of advocating for your child who is partially sighted. Can you give me a few examples of when you played the role of an advocate for your child?
   a. What did you do to advocate for your child?
   b. What was the result?
   c. What were you thinking and/or feeling at that time?

2. As a parent, how are you teaching Chloe to advocate for herself? Why is this so important to you?

Mid and Late Adolescence
1. In the first session, you talked about Chloe's experiences at several workplaces. For example, you mentioned her time at [her previous work places] was challenging because people bullied her and treated her terribly. Alternatively, people at [her current

workplace] were accommodating and amazing. How did these experiences impact you as a parent?

2. You spoke a bit about not wanting your fear to deprive Chloe of opportunities. Can you tell me more about that?

3. You mentioned being an invited speaker for a fundraising event for Lake Joe. Can you tell me a bit about that? Why is participating in these types of events important to you?

4. You mentioned in the first session about how important it was for Chloe to "not play the victim" and "not feeling sorry for yourself." Why were these such important lessons?

5. You spoke about Chloe's future (going to [name of the university] for nursing, living independently, etc.). What steps have you taken as a parent to help ensure that Chloe is ready for this next step?

Preset Questions

1. Has being a parent of an adolescent who is partially sighted changed you as a person and your beliefs about people with visual impairments?
   - *[If yes]*- In what ways?
   - *[If not]*- Why has it not changed your beliefs?

2. If you could give a parent of a child who just got diagnosed with a visual impairment advice, what would that be?

3. What piece of advice would you have wanted when Chloe was first diagnosed with a visual impairment?

Brandon

During the previous interview, you shared some of your experiences of raising your adolescent child with low vision. In this interview session, I will ask you a few more specific and in-depth questions about your parenting experiences. The first few questions were developed based on the stories that you have shared during the last session, and the final three questions were written by me and are being asked to all the participants. This interview will take approximately 45-60 minutes to complete. Do you have any questions for me before we begin?

Positive Event on the Timeline

1. On the timeline that you developed during the last session, you marked Erica's Grade 8 graduation as one of the positive moments for you as a parent. Can you tell me more about that experience?
a) What was the event like?
b) What were you thinking and feeling?

Early Years and Advice for health professionals

1. In the previous interview, you mentioned that as a new parent, you did not receive adequate support and information from doctors and other parents in similar situations after Erica was first diagnosed with a visual impairment. How did you and Erica's mom manage in those early years where little resources were provided?

2. Looking back, if you could give a piece of advice to health professionals working with parents of children who recently got diagnosed with a visual impairment, what would that be?

Independence

1. You spoke about some of your worries for Erica's future as she moves towards independence. What are some strategies you have tried to help prepare her and yourself for a future when she might live on her own or go off to school?

2. You discussed how you've been teaching Erica to set goals for herself. Why do you think that it is important to instill these values?

3. As a parent, how do you negotiate the balance being protective and enabling her independence?

Advocacy

1. You said in the last interview that Erica is a good advocate for herself. How did she become a self-advocate? (What role did you play in this process?)

2. Do you think your career as a social worker positioned you well as an advocate for your child?

Preset Questions

4. Has being a parent of an adolescent who has low vison changed you as a person and your beliefs about people with visual impairment?
    - *[If yes]*- In what ways?
    - *[If not]*- Why has it not changed your beliefs?

5. If you could give a parent of a child who just got diagnosed with a visual impairment advice, what would that be?

6. What piece of advice would you have wanted when Erica was first diagnosed with a visual impairment?

Jenifer

During the previous interview, you shared some of your experiences of raising your adolescent child who has a visual impairment. In this interview session, I will ask you a few more specific and in-depth questions about your parenting experiences. The first few questions were developed based on the stories that you have shared during the last session, and the final three questions were written by me and are being asked to all the participants. This interview will take approximately 45-60 minutes to complete. Do you have any questions for me before we begin?

Advocacy

1. In the last interview, you spoke about how you were teaching Pam to speak up for herself and wanting her to be her own voice. Can you tell me why you believe that instilling the self-advocacy skill in her is important?

2. Can you tell me a time when she used her advocacy skills?
   - What was the event like?
   - What was the result?

Emotions and Feelings

1. During the previous interview, you mentioned that the ups and downs associated with your daughter's changing vision condition over the past 10 months made you feel helpless at times. How have you managed those feelings of helplessness?

2. You mentioned that sometimes you felt like you have done something that made Pam lose her eyesight. Do you think this feeling influences how you parent her?

Independence

1. You said in the previous interview that Pam was going to [name of the college] next year. What are some of the steps that you are taking or plan to take to help her get ready for this transition?

2. Have you and Pam thought up any strategies that would allow her to get back to the activities she enjoys, such as cooking (given her fear of using a knife)?

3. In the last session, you mentioned that since Pam's vision declined, you are more concerned about her safety (like the people that could be around her when she goes out on her own). Can you tell me more about that?

4. How do you manage some of those fears you have for her safety?

Preset Questions

1. Has being a parent of an adolescent who has a visual impairment changed you as a person and your beliefs about people with visual impairment?
   - *[If yes]*- In what ways?
   - *[If not]*- Why has it not changed your beliefs?

2. If you could give a parent of a child who just got diagnosed with a visual impairment advice, what would that be?

3. What piece of advice would you have wanted when Pam was first diagnosed with a visual impairment?

Lauren

During the previous interview, you shared some of your experiences of raising your adolescent child who has a visual impairment. In this interview, I will ask you a few more specific and in-depth questions about your parenting experiences. The first few questions were developed based on the stories that you have shared during the last interview, and the final three questions were written by me and are being asked to all the participants. This interview will take approximately 45-60 minutes to complete. Do you have any questions for me before we begin?

Guide Dog

1. In the previous session, you mentioned that ever since Ruby got a guide dog, her anxiety decreased, and she came out of her shell. Is it fair to say that getting a guide dog was a real turning point for her?
   - **[If yes]**- Do you think that her guide a guide dog was a turning point for you as a parent as well?

Sense of Guilt

1. You spoke about the guilt that you felt as a parent, wondering if you had done something to cause Ruby's visual impairment. Do you think this sense of guilt impacts how you parent your daughter?

Experiences at Mainstream School

1. During the last interview, you talked about Ruby's experiences of being bullied by other kids when she attended the sighted school. How did those situations of her being bullied affect you as a parent?

2. You spoke about the negative experiences that Ruby had with the teachers at the sighted school, like when the teacher slammed the enlarged documents on her desk. When she told you about those experiences, what was your reaction as a parent?

CNIB and Independence

1. You mentioned that the CNIB has supported Ruby advocating for herself. Can you tell me a time when she used the support from the CNIB or the skills that she had learned from the CNIB to advocate for herself?

2. You mentioned that the CNIB has helped improve Ruby's independent living skills and orientation and mobility skills. Do you find that with the skills that she now has, you feel more comfortable stepping back and letting her do things like cooking and travelling independently?

3. Has CNIB provided you with programming specific to parents of children or adolescents with vision loss?
   - *[If yes]* Have you taken advantage of any of those opportunities?

4. Has the support that Ruby receives from the CNIB evolved over her life?

Transition into University

1. You mentioned that Ruby is finishing up grade 12 and has checked out different university programs. Are there any specific strategies that you or Ruby have taken to prepare her for the transition from high school to university?

Anticipation

1. Towards the end of the last interview, you spoke about the feeling of being on guard and anticipating something bad to happen, like a restaurant might turn Ruby away because she has a guide dog. Is that constant feeling of being on guard tiring?
   - How do you manage that?

Preset Questions

1. Has being a parent of an adolescent who has a visual impairment changed you as a person and your beliefs about people with visual impairment?
   - *[If yes]*- In what ways?
   - *[If not]*- Why has it not changed your beliefs?

2. If you could give a parent of a child who just got diagnosed with a visual impairment advice, what would that be?

3. What piece of advice would you have wanted when Ruby was first diagnosed with a visual impairment?

Interview Session 3

1. Do you think the story that I wrote based on your interview responses from the last two sessions reflects your experiences of parenting your child who has a visual impairment?
   - Do you think the themes that I generated from your story captured some important aspects of your parenting experience?
   - Overall, do you think that my interpretations of your story represent your experiences of parenting your child who is visually impaired?

2. Would you like to add or take out anything from the story that I wrote?
3. Do you have any other thoughts on my interpretations of your story?

Appendix F: Demographic Questionnaire

Please respond to the following questions (where applicable):

Age (in years): _____

What is you gender _____

Which ethnic category(ies) best describes you?
___Aboriginal (North American Indian, Metis, or Inuit)
___Arab (e.g. Lebanese, Palestinian, Egyptian, Iraqi, etc.)
___African
___Caribbean
___Caucasian
___East Asian (e.g. Chinese, Korean, Japanese, etc.)
___Filipino
___Latin American
___South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
___Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
___Mixed/Biracial (please specify) _____
___Other (please specify) _____

Which of the following best describes your marital status? (check one)
___ Single
___Married
___ Divorced
___Separated
___Widowed
___Other (please specify) _____

Please mark the category that best represents your annual household income (check one)
a.	___ <$10,000	e. ___ $50,001 - $70,000
b.	___ $10,001 - $20,000	f. ___ $70,001 – $90,000
c.	___ $20,001 - $30,000	g. ___ $90,001 - $110,000
d.	___ $30,001 - $50,000	h. ___ >$110,001

___ prefer not to answer

What is the highest level of education you have completed?
_____ a) some high school   _____ d) completed college or university
_____ b) completed high school   _____ e) post-university degree
_____ c) some college or university

What is your employment status?

_____ a) full time   _____ b) part time
_____ c) unemployed   _____ d) prefer not to answer

What is your child's age? _____

What is your child's eye condition (e.g., glaucoma, congenital cataracts)? _____

At what age was your child diagnosed with visual impairment? _____

Is your child' eye condition congenital or acquired?
___ congenital   ___acquired

Which of the following best describes your child's degree of visual impairment?
___ Partially sighted   ___Has some light perception   ___Completely blind
 ___Prefer not to answer

Does your child have any siblings?
___ yes   ___no

If yes, how many siblings does he/she have? What are their ages?

_____

Curriculum Vitae

Peiwen (Lily) Cao

Education

2018-Present **Master of Science in Health & Rehabilitation Sciences - Occupational Science**, Western University, London Ontario
2013-2018 **Bachelor of Arts in Psychology with Thesis, minor in Disability Studies**, Graduated with Distinction, University of Windsor, Windsor, Ontario

Research Interests

Psychosocial adaptation following life-changing events, emotional and physical well-being of individuals with visual impairments and their caregivers, mixed-method research design, social determinants of health

Work Experience

2019-Present **Coordinator, Foundation Programs**, Canadian National Institute for the Blind
2019 **Research Assistant**, Department of Psychiatry, Western University
2018, 2019 **Teaching Assistant**, School of Occupational Therapy, Western University
- OT 9641 - Enabling Occupation through Assistive Technology (Graduate Course)

2016-2018 **Research Lab Coordinator**, Department of Psychology, University of Windsor

Research Experience

2019 **Research Assistant**, Department of Psychiatry, Western University
- Learning from a Failed Implementation of Team-Based Chronic Disease Management: Implementation Evaluation

2019 **Qualitative Data Coder**, Department of Psychology, University of Windsor
- "Narrative Coherence of Child Maltreatment Memories in Adults" (Doctoral Dissertation Project)

2018-Present **Co-Investigator**, Faculty of Health Sciences, Western University
- "Navigating the 'Blind World': The Psychosocial Experiences of Parents of Children with Visual Impairments" (Master's Thesis)

2017-2019 **Co-investigator**, Life Memories Lab, University of Windsor
- "The Role of Culture in Shaping the Retrieval, Recollection and Salience of Shared Memories in Emerging Adulthood"

2017-2018 **Primary Coder**, Emotional Competence Research Group, University of Windsor
- "What Do Stories Say? Exploring the Narratives of Adults with a History of Child Maltreatment"

2017-2018 **Research Coordinator**, Life Memories Lab, University of Windsor

- "Investigating a Silent Epidemic on Women's Health: The Impact of Canadian Women's Diagnostic Experiences with Polycystic Ovarian Syndrome on Health, Longevity, and Quality of Life"

2016-2017   **Research Coordinator**, Life Memories Lab, University of Windsor
- "The Impact of Relationship Defining Moments on Relationship Satisfaction and Personal Well-being in Emerging Adulthood"

2016-2017   **Principal Investigator**, Department of Psychology, University of Windsor
- "Seeing It Through My Eyes and Remembering It My Way: Transformative Life Event Memories in Young and Midlife Adults with Early-onset Blindness" (Undergraduate Honours Thesis)

2015   **Data Transcriber**, Women's Enterprise Skills Training of Windsor Inc.
- "Women`s Financial Preparedness: Bridging the Divide in Windsor-Essex"

Certifications and Training

2018   Successful Completion of the Teaching Assistant Training Program (TATP), Center for Teaching and Leaning, Western University, 2018

2017   Power without numbers: The underappreciated art of qualitative research, qualitative research method workshop

2016   Jane Loevinger's Ego Level Development Coding Workshop

2015   Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Certificate

Academic Conference Presentations

Oral Presentation
Cao, P., & Soucie, K. (2017). "*Seeing it through my eyes and remembering it my way: Transformative life event memories in young and midlife adults with early-onset blindness*. Poster presented at the UWill Discover undergraduate research conference at the University of Windsor

Poster Presentations
1. Zhu, N., Soucie, K., **Cao, P.,** & Hakim-Larson, J. (2019). *"Examining coherence, meaning, and redemption in emerging adults' Narratives of childhood maltreatment".* Poster presented at the Society for the Study of Emerging Adulthood (SSEA) Conference, Toronto, Canada
2. Samardzic, T., Reaume, C., **Cao, P.,** Soucie, K., Ly, C., & Citron, N. (2019). *"Fostering social support and sense of belongingness through shared social experiences: The moderating role of acculturation".* Poster presented at the Society for the Study of Emerging Adulthood (SSEA) Conference, Toronto, Canada
3. Zhu, N., **Cao, P.,** Soucie, K., & Hakim-Larson, J. (2018). *"What do stories say? Exploring the narratives of adults with a history of child maltreatment".* Poster presented at the Canadian Psychological Association (CPA) Annual Convention, Montreal, Canada
4. **Cao, P.,** & Soucie, K. (2017). "*Seeing it through my eyes and remembering it my way: Transformative life event memories in young and midlife adults with early-onset blindness".* Poster presented at the Canadian Psychological Association (CPA) Annual Convention, Toronto, Canada

Manuscript in Preparation

Zhu, N., Soucie, K., **Cao, P.,** Soucie, K., & Hakim-Larson, J. Examining coherence, meaning, and redemption in childhood maltreatment Narratives

Manuscript Under Review

Cao, P., Soucie, K., & Ly, C. Transformative life event narratives in young and midlife adults with early-onset blindness: An interpretive phenomenological analysis. Manuscript under review in *The Qualitative Report*.

Sibbald, S., Maskell, R., **Cao, P.,** & Law, B. Learning from a failed implementation of team-based chronic disease management: Implementation evaluation. Manuscript under review in *Implementation Science Communications*

Volunteer Experience

2018	**Proctor** for undergraduate Psychology courses (02-46-224 | Developmental Psychology: Adolescence, 02-46-230 | Social Science Research Methods)
2017-2018	**Research Assistant** for the Emotional Competence Research Group (ECRG) at the University of Windsor
2016-2017	**Volunteer** for the Psychology Colloquium Series at the University of Windsor
2015	**Student Research Assistant** at Women's Enterprise Skills Training of Windsor Inc. (WEST) of Windsor
2013-2014	**Committee Member** of Accessibility Planning Committee at the University of Windsor
	Presenter at the second annual Accessibility Awareness Day event in March 2014 | Stephanie Cragg, Stasha Todorovic, Allan Angus, Matthew Pok, & **Lily Cao**. *"Creating an Accessible Community"*
2013-2014	**Volunteer** for the Disability Studies Student Association (DSSA) at the University of Windsor

Awards and Recognitions

2018	Faculty of Arts, Humanities and Social Sciences Dean's Honour Roll
2017	Faculty of Arts, Humanities and Social Sciences Dean's Honour Roll
2017	Undergraduate Research Experience Grant. *The role of culture in shaping the retrieval, recollection and salience of shared memories in emerging adulthood*. K. Soucie & **P. Cao**. Internal Grant. University of Windsor, $2,000, 2017-2018. Awarded
2017	Canadian Psychological Association (CPA) Certificate of Academic Excellence
2017	Third place in the division of Faculty of Arts, Humanities, and Social Sciences at UWill Discover undergraduate research conference
2016	Pernod Ricard/Hiram Walker (formerly Allied Domecq) Scholarship $500
2014	Faculty of Arts, Humanities and Social Sciences Dean's Honour Roll