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Families’ Experiences Raising a Child With Optic Nerve Hypoplasia

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FAMILIES' EXPERIENCES RAISING A CHILD WITH OPTIC NERVE HYPOPLASIA

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ABSTRACT

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Optic nerve hypoplasia (ONH) is a leading cause of childhood visual impairment. Children with ONH are at significantly increased risk for a number of concomitant neurological and behavioral problems. This study applied phenomenological qualitative research methods to investigate the experiences that parents of children with ONH have with raising their child. Twelve parents of children with ONH were interviewed. Three major categories emerged from the data: (a) resiliency of parents who have children with ONH; (b) strategies that families of children with ONH use; and (c) connections that support families of children with ONH. The categories and associated themes are discussed as well as implications for future research efforts and recommendations for practitioners. The findings of this study indicate that parents value child-centered planning and creative problem solving to meet their children's needs. Furthermore, children with ONH need routines, consistency, and structure to support their development.

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CHAPTER I

INTRODUCTION TO THE STUDY

Background

I have spent many years teaching students who have optic nerve hypoplasia (ONH). Many of my students with ONH have enjoyed interacting with music. If you observe me in a braille lesson with a student who has ONH, you're likely to find me singing instructions while modeling the task. I am 20 years into my career, and my understanding and curiosity about the unique developmental needs of children with ONH continue to grow. The parents of my students have also reported being mystified and intrigued by their children's unique perseverations, sensory-seeking, and self-stimulatory behavior. Over the past two years, I have presented at several international conferences on the topic of ONH. The teachers of visually impaired (TVIs) who have attended these sessions have shared that they need more ideas and support for educating students with ONH. There are no established curricula or empirical resources specifically targeting the developmental and educational needs of students with ONH.

Individuals with ONH have varying degrees of vision loss and ability to integrate and use information from their senses. Children with ONH frequently demonstrate perseverations and aversions that influence their educational and social performance (Bahar et al., 2003). My students were often challenged to execute fine motor tasks, and their attention to nuances in the auditory environment frequently prevented them from focusing on the task at hand. The educational and developmental needs of children with ONH are complex.

One of my first students was Shanna (pseudonym) who had a diagnosis of ONH. Shanna demonstrated many challenging and defiant behaviors. Shanna's educational team determined that her behaviors, not her visual impairment, prevented her from accessing classroom materials. I was the only special education teacher who provided direct services to Shanna, and I was at a loss for strategies to use when working with her. Except for an extremely supportive classroom teacher and one remarkably humorous colleague, I felt isolated and worried about Shanna's progress. The challenges I faced with Shanna were the beginning of a trend in my career. After many years of experience providing direct instruction to students with visual impairments, I developed confidence for working with students who have challenges similar to Shanna.

I began my career educating students with visual impairments as an orientation and mobility (O&M) instructor. My first job was serving as both an O&M instructor and a TVI. I completed the required coursework to become licensed as a TVI in Colorado while I performed the responsibilities of the position I was learning to fulfill. In addition to the ordinary learning curve for first-year teachers and a particularly challenging student, I joined a team that had a poor leadership structure and lacked adequate administrative support.

While uniquely experienced by me, the stories of my career roots and first challenges on the job are not an anomaly in my profession (Meador, 2015; Pogrund, 2017; Pogrund & Cowan, 2013). There remains a decades-long shortage of educational professionals to serve students with visual impairments. Many special education teachers, including TVIs, are hired by administrators eager to staff a hard-to-fill position (Cross, 2016; Pogrund, 2017). However, without a dedicated mentor and a local professional support system, problem-solving educational approaches to students with challenging needs can feel futile. When children with visual impairments have challenges that fall outside the scope of blindness-related developmental needs, educational teams look to the TVI to provide answers, guidance, and support for those additional needs.

Shanna and her unique learning needs puzzled me to the point of lost sleep. My memories of problem-solving tactics to engage Shanna in academics (learning braille, in particular) remain clear and powerful, still today. I sought suggestions and searched for strategies to help me be successful in educating Shanna. However, few of my efforts resulted in my student making academic growth. Over the years, I have met many other TVIs who have experienced similar problems throughout the course of their careers, and I have instructed many students with ONH who have challenges in addition to their visual impairment.

I began my career feeling relatively skilled at collaborative work with colleagues and parents of my students. However, my capacity for relating to parents of children with complex learning needs became substantially enriched after I became a stepmother to Avery, who has both Fragile X and autism spectrum disorder (ASD). Initially, Avery's needs at home trumped my ability to consider suggestions for his educational team. Ultimately, I expected Avery to generalize things faster than he was able. Avery, my husband, and Avery's mother taught me that I would have to change some of my expectations in order to partner with other family members to support Avery.

Avery's unique needs require that his care providers and educators provide consistent and predictable structures with minimal interruptions to routine. As I helped to parent Avery, I reflected on how many of my students with ONH had behavioral traits similar to youth who have ASD. Many of my students with ONH have had sensory processing and learning challenges; these students struggled with transitions between activities, they perseverated on preferred stimuli, and they exhibited social rigidity. Initially, I set short-term goals that were too difficult for Avery. I wondered if I had done the same for my students with ONH. I wrestled with my belief that teachers should have high expectations of their students, especially for students who have disabilities!

Frequently, TVIs are the lead service provider for students with visual impairments. As the lead provider and professional expert on the educational team, TVIs assume responsibility for setting expectations for students with visual impairments. My university training and relationships with adults who have visual impairments taught me that high expectations are necessary to level the employment playing field for individuals with visual impairments. When my students with ONH were left alone or engaged in self-stimulation, they appeared to be perfectly happy. Problems came when I tried to re-direct these students' attention or engage them in one of their non-preferred tasks (traditional academic work has been a non-preferred activity for most of my students with ONH). As an advocate for children and adults with visual impairments, I maintain high expectations for my students' growth and independence skills. Yet, setting and holding high academic and social expectations for my students who have ONH continues to be a conundrum.

There are no research-based interventions specific to children with ONH. I have relied on collaborative conversations with parents and educational professionals to assist me in developing approaches to meet the needs of my students with ONH. These conversations help me identify the hopes and expectations that my students' parents have for their children; I use what I learn from parents to help me collaboratively design and update goals, objectives, and accommodations for my students' individualized education program (IEP). I have also looked to professional resources from other fields, such as occupational therapy, to provide ideas for interventions that target the multi-faceted needs of learners with complex sensory needs.

Because of my experiences working with students with ONH and conducting research on challenging student behaviors throughout my doctoral program, I was interested in developing an educational literature base with resources for special education teams and families of children with ONH. I wanted to learn about and share the strategies and suggestions that teachers and parents of children with ONH recommend for meeting their children's educational needs. My desire to develop strategies to support the population of students with ONH is reflected by many other professionals and parents.

A school for the blind in the western part of the United States recently convened a professional learning group on ONH for educational professionals and parents of children with ONH. Over 80 people joined the first two collaborative webinars. The response to the school's efforts and conversation threads from social media groups for parents of children with visual impairments and TVIs indicates a growing need for resources and an established body of research literature investigating and documenting the unique educational needs of children with ONH. The increasing prevalence of visual impairment due to ONH further suggests that empirical evidence and published strategies for supporting students with ONH are needed (Hatton et al., 2013; Ryabets-Lienhard et al., 2016). Learning from families, the people who know their children the best, was a logical starting point. This study investigated families' experiences with support systems to raise their children with ONH and strategies that families use to support the unique developmental needs of their children with ONH.

Significance of the Study

Optic nerve hypoplasia is a leading cause of childhood visual impairment (Hatton et al., 2013; Kong et al., 2012; Ryabets-Lienhard et al., 2016). In addition to deficits in visual functioning, individuals with ONH are at increased risk of additional disabilities, including intellectual and behavioral challenges. Students who have visual impairments due to ONH often have exacerbated sensory needs because their visual disability is frequently accompanied by significant neurological problems (Ryabets-Lienhard et al., 2016). These complications lead to an increased risk for concomitant executive functioning, sensory integration, and self-regulation problems; 71% of individuals with ONH exhibit behavioral challenges (Ryabets-Lienhard et al., 2016). Additionally, there are documented behavioral similarities between individuals with ASD and ONH (Ryabets-Lienhard et al., 2016; Williams et al., 2014).

There is a body of literature documenting behavioral similarities between some children with visual impairment and children with ASD (Butchart et al., 2017; Williams et al., 2014). In 2011, Absoud et al. estimated the percentage of students with severe congenital visual impairment and ASD to be 11-40%**.** In addition to the prevalence of concomitant ASD and visual impairment, the two leading causes of childhood visual impairments, cerebral visual impairment and ONH, are both neurologically based conditions that have implications for executive functioning deficits (Garcia-Filion & Borchert, 2013; Merabet et al., 2017). Formerly, ocular conditions that involved only malformations in the structure of the eyes accounted for the majority of childhood visual impairment. With increasing numbers of students presenting with neurological visual impairments, the educational needs of students with visual impairments are changing (Garcia-Filion & Borchert, 2013; Hatton et al., 2013; Hozjan, 2017; Merabet et al., 2017).

The intensity of impact stemming from the concomitant challenges associated with ONH signalizes that many students with ONH need specialized interventions targeting self-regulation. Other than a master's thesis on music therapy with one student who has ONH, there were no documented empirical attempts to collect data on interventions and practices specific to learners with ONH (Wooster, 2016). The limited educational research on ONH is focused on the cognitive and behavioral characteristics of the children (Ek et al., 2005; Pring & Ockelford, 2005). Furthermore, despite high comorbidity rates of endocrine dysfunction and developmental delays in this population, there are no clinical practice guidelines available for the evaluation and treatment of children with ONH (Ryabets-Lienhard et al., 2016).

Optic nerve hypoplasia is increasing in prevalence and is a prominent cause of childhood visual impairment. Separate census studies from Sweden, Canada, and the United Kingdom each revealed that the prevalence of ONH has increased substantially since the 1980s (Ryabets-Lienhard et al., 2016). In the largest demographic study of young children with visual impairments in the United States, Hatton et al. (2013) collected data on children in 28 states, and ONH ranked in the top three most prevalent conditions causing visual impairment; the incidence of ONH in young children had increased in prevalence to 11.4%, up from 7.6% in 2001 and 9.7% in 2007

To date, all research on ONH has been epidemiological or focused on the defining behavioral features and concomitant medical complications associated with ONH. We know that ONH is increasing in prevalence and that children with ONH are likely to have additional medical and behavioral challenges, but we lack evidence of what is working to mitigate these challenges (Ryabets-Lienhard et al., 2016). The educational field of visual impairment has no systematic approach to providing collaborative educational and therapeutic programming for children with ONH, nor does the field know what strategies families are currently employing to support the developmental needs of their children with ONH. Due to the increasing prevalence and concomitant complexities of ONH*,* an investigation into the experiences that families of children with ONH have with navigating support systems while supporting the developmental needs of a child with ONH was warranted (Hozjan, 2017; Ryabets-Lienhard et al., 2016).

Statement of the Problem

The prevalence of ONH has increased and there are no targeted interventions, documented strategies, or published research for meeting the unique developmental and educational needs of children with ONH (Garcia-Filion et al., 2008; Ryabets-Lienhard et al., 2016). There is evidence that educational teams are experiencing difficulty addressing the concomitant educational, sensory, and behavioral challenges associated with ONH (Bahar et al., 2003; Rundle Kahn, 2018; Rundle Kahn & Conroy, 2019; Sabine, 2019; Wooster, 2016). Social media forums for parents of children with ONH, requests for consultations to ONH consulting (a consulting business run by an adult who has ONH), and the response to online parent and educator groups for ONH suggested an urgent need for literature addressing the complications of educating a child with visual impairment due to ONH (C. Sabine, personal communication, June 17, 2019; R. Clark, personal communication, January 20, 2020). Currently, there are no guidelines or curricula to assist families and educators in supporting and providing services to children with ONH. Individuals with ONH, families, and educational teams need an established research base to guide the development of interventions for children with ONH.

Purpose of the Study

A diagnosis of ONH has significant implications for comorbid developmental delays (Ryabets-Lienhard et al., 2016; Williams et al., 2014). As a collective field, educators and researchers of visual impairment need to learn about family-initiated strategies that are working to improve short- and long-term outcomes for children with ONH. There are no peer-reviewed studies on family or educator experiences implementing strategies and interventions to meet the needs of children with ONH. Stakeholders need to know what is currently working to support children with ONH. This study aimed to document and represent the experiences that parents of children with ONH have with meeting their child's developmental needs. Through a review of literature, parent interviews, parent and researcher reflections, and analysis of the data, the purpose of this study was to establish the beginnings of an educational research literature base on ONH. The Individuals with Disabilities Education Act (Individuals with Disabilities Education Act [IDEA], 2004) requires collaborative family partnerships and the use of research-based interventions (IDEA, 2004). Providing a synthesis of the experiences and strategies that families use to support their children with ONH, the results of this study may serve to establish an educational research base for addressing ONH.

All children who qualify for special education services as a child with a visual impairment receive special education assessments and IEPs. However, the types of educational programs and intervention curricula that are available for children with visual impairment and concomitant disabilities vary. There are no specially designed interventions to meet both the visual and developmental needs of children with ONH. Similar to children with ASD and visual impairments, many children with ONH have challenging behaviors and difficulty with sensory integration (Ek et al., 2005; Ryabets-Lienhard et al., 2016). Without the benefit of sight, modeling, prompting, and cueing must occur through verbal and physical prompting. The consideration of the unique educational and developmental needs of children who have visual impairment concomitant with additional challenges is critical for designing a free and appropriate public education program (IDEA, 2004). Likewise, special educators are beholden to employ and document their use of research-based practices when working with students (IDEA, 2004). There are no evidence-based practices that are designed specifically for children with VI who also have ASD.

Under the IDEA of 2004, the disability category of *visual impairment, including blindness* is defined as an impairment in vision that even with correction adversely affects a child's educational performance. While the IDEA definition of visual impairment defines eligibility criteria for special education services, the level of services needed by a child with ONH is highly individualized and dependent upon each student's unique learning needs. Some students with ONH may thrive in the general education environment, while other students will need a highly modified day with intensive adult support throughout the day.

To access their environment and receive an education to prepare them for the transition to adulthood, students with ONH who have significant visual impairments have to acquire skills to compensate for their vision loss. The additional challenges that many students with ONH possess may influence their educational teams' decisions around educational placements and service delivery. These challenges may also influence families' approaches to supporting their children throughout home life and family routines. The complex developmental needs of students with ONH combined with a lack of educational intervention research targeting students with ONH indicates that educators, families, and individuals with ONH need resources for educational approaches to meet these students' needs.

Literature suggests that many children with ONH have behaviors similar to children with ASD, but no interventions or peer-reviewed empirical research on providing educational or therapeutic services to children with ONH, or families of children with ONH, exist. This study investigated strategies that families and educational teams are using to support the education and development of children with ONH. The purpose of this exploratory study was to document family experiences with support systems for their children and to learn about family-initiated strategies that are working to improve short- and long-term outcomes for children with ONH.

Students, parents, and educators may benefit from the establishment of a formal literature base that addresses the unique learning needs of children with ONH. This study targeted families, the people who know their children best. I conducted interviews with parents and analyzed data from the interviews into a formal synthesis. By establishing the foundation of an educational research base that illustrates perspectives on the unique needs of children with ONH, I hoped to provide families, teachers, and other researchers with multiple perspectives to consider when approaching instruction and supporting the development of children with ONH. To show different perspectives and experiences with supporting children with ONH, I interviewed multiple parents and cross-analyzed the responses of each of the participants for outliers and similarities.

Research Questions

To better understand the experiences and expertise of the families and educators who support students with ONH, I proposed the following research questions:

Q1 How are families of children with ONH experiencing support systems for raising their children with ONH?

Q2 What strategies are families using to support the developmental needs of their child with ONH?

Definitions of Terms

The following terms are defined for use in this study.

Developmental needs: All children have developmental needs and milestones to reach to progress through childhood (California Department of Education, 2000). Developmental needs may include cognitive, social-emotional, speech and language, and fine and gross motor skill development.

Educators/service providers/educational service providers: These terms include public school teachers, private therapists, and related service providers who are not medical care professionals.

*Families: "*Families may be a family of origin, an adopted family, or a family comprising people who are not biologically related" (Beach Center on Disability, n.d.). For this study, primary caregiver may include acting stepparents who are not officially married or related by birth to the child with ONH. I used the term families to indicate the relationships that the participants define as family relationships.

Individuals with Disabilities Education Act: The Individuals with Disabilities Education Act (IDEA) is the federal law that mandates the provision of special education programs for children ages 0-21 who have disabilities. The current iteration of the IDEA was last amended in 2004.

Individualized education program: An individualized education program (IEP) includes both the individualized programming and the written plan for the program that is to be delivered to children ages 3-21 who have disabilities (Understood, n.d.). The IEP is designed through a collaborative process of assessment and planning with the special education team (including parents/caregivers of the child). Children with disabilities, ages birth to 3, may qualify for an Individualized Family Service Plan (IFSP).

Self-regulation: Self-regulation skills are tactics humans use to control impulses, soothe emotional upsets, and garner focus, to achieve short- and long-term goals (Blair & Diamond, 2008; Kramarski, 2018; Zimmerman, 2008).

Support systems: For this study, I define support systems as the relationships and services that work to help the child's parents and care providers with raising the child. The study participants will identify the support systems that they experience (University of North Carolina Chapel Hill, n.d.).

Visual impairment, including blindness. Visual impairment, including blindness is the named disability category in the IDEA (2004) for students who meet the qualification criteria for visual impairment. Some stakeholder groups advocate for the exclusive use of the term *blindness*. However, the two terms are frequently used interchangeably, with *visual impairment* being the preferred term of academic journals. *Visual impairment* is the terminology used by the Federal Government's Office of Special Education Programs.

List of Acronyms

The following acronyms are used throughout this study.

- ASD: Autism spectrum disorders
- ECC: Expanded Core Curriculum for the blind
- ONH: Optic nerve hypoplasia
- IDEA: Individuals with Disabilities Education Act
- TVI: Teacher for students with visual impairments
- O&M: Orientation and mobility

- ABA: Applied behavior analysis
- BCBA: Board certified behavior analyst

Conclusion

In this chapter, I introduced the study through a presentation of background information and defining the problem that I addressed. The purpose and methodology of the study were defined, as well as key terms and acronyms that are used throughout the study. A review of the literature, the methodology I applied, findings from the study, and a discussion follow.

CHAPTER II

REVIEW OF LITERATURE

Prevalence of Optic Nerve Hypoplasia

There are many different causes of childhood visual impairments. Some etiologies of visual impairments are stable from their onset at birth, and other eye diseases are progressive, with vision declining at various rates. Diabetic retinopathy (a complication of diabetes) and age-related diseases such as macular degeneration are the leading causes of visual impairment among adults in the United States (Centers for Disease Control, 2015). Cerebral visual impairment, ONH, and retinopathy of prematurity are the three leading causes of childhood visual impairments in developed countries (Kong et al., 2012; Ryabets-Lienhard et al., 2016). Optic nerve hypoplasia is diagnosed by an ophthalmologist upon observation of underdeveloped optic nerves in one or both eyes. Unlike ocular etiologies that are exclusively rooted in malformations in the structure of the eye, ONH and cerebral visual impairment have dysfunctional neurological associations (Garcia-Filion & Borchert, 2013; Zuidhoek, 2015). An ONH diagnosis should trigger neurological and endocrine testing for associated problems (Garcia-Filion et al., 2008). It is important to consider the implications of neurological malformations because children with visual impairments and no additional disabilities have been shown to have a developmental trajectory average in comparison to their non-disabled peers (Ferrell, 2006). However, two of the three leading causes of childhood blindness have neurological associations.

The IDEA defines visual impairment for special education services at a specific threshold of impact, and visual impairment is a low-incidence disability category. Reports on the total number of children with visual impairments in the United States vary dramatically. Data collected from each state and practices for data collection on students with visual impairment amongst states are often disparate, if even existent (Schles, in press). The 2018 annual report from the American Foundation for the Blind reports that 63,501 children met or function at the definition of blindness for the purpose of instructional materials (American Printing House for the Blind, 2018). However, the figures provided by the American Printing House for the Blind should be interpreted with caution because they are dependent upon reporting and data collection practices of the professionals who provide educational services to children with visual impairment in each state.

The *American Community Survey* is a national survey that provides disability statistics for research and policy review. The *American Community Survey* relies on self-reported responses to the following question: “Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?” (Cornell University, 2018). The number of reported non-institutionalized individuals, aged 0-20, with visual disabilities in 2018 was 715,700: less than 1% of the total population. Even without specific quantitative criteria on the survey, visual impairment emerged as a low-incidence disability. There are clear discrepancies in the way data on prevalence are both defined and collected. Neither the American Printing House for the Blind or the *American Community Survey* disaggregates data on visual impairments by specific visual conditions.

Etiology-Specific Data

Two surveys that attempt to capture etiology-specific data are *Babies Count* and the *ONH Registry Study (*Babies Count, n.d; The Vision Center at The Children's Hospital Los Angeles, n.d.). *Babies Count* is a national registry for young children with visual impairments, ages birth-36 months. According to their website, 15 states are now participating in the annual *Babies Count* survey. The latest published *Babies Count* data set from 2017 cited ONH as second in prevalence to cerebral visual impairment as the leading cause of childhood visual impairments (Babies Count, n.d.).

The ONH Registry Study is a large medical research initiative managed by The Vision Center at The Children's Hospital in Los Angeles. *The ONH Registry Study* is described as a long-term prospective study, and the registry provides data for many of the genetic and epidemiological studies that are cited in this paper. Dr. Mark Borchert has been the lead investigator for ONH on the research team at The Vision Center at The Children's Hospital in Los Angeles (The Vision Center at The Children's Hospital Los Angeles, n.d). The research team at The Vision Center uses the prevalence data on ONH cited in the Kong et al. (2012) report (B. Brown, personal communication, March 20, 2020). The website for The Vision Center reported that the ONH registry is being used to track functional outcomes of registered individuals as well as their visual, endocrine, and cognitive/neurological abilities (The Vision Center at The Children's Hospital Los Angeles, n.d).

Causes and Risk Factors for Optic Nerve Hypoplasia

Studies are currently underway to investigate the genetic variants involved with ONH. So far, no definitive genetic associations have emerged (Borchert & Garcia-Filion, 2008; Garcia-Filion & Borchert, 2013). While several studies have explored maternal recreational drug and alcohol use as indicators for ONH, these have been small case studies with unsubstantiated transferability for the larger population. Currently, young maternal age and primiparity (firstborn child) are the two identified risk factors associated with ONH (Garcia-Filion & Borchert, 2013; Ivy & Hatton, 2018). Medical experts believe that ONH is a multi-factorial disease, and the term s*yndrome* is employed to indicate the groups of symptoms that often accompany a diagnosis of ONH (Borchert & Garcia-Filion, 2008). A brief discussion on the terms used to name ONH is warranted. Suggestions for abandoning the term septo-optic dysplasia follow.

Septo-Optic Dysplasia and Optic Nerve Hypoplasia

Many children with ONH receive a diagnosis of *septo-optic dysplasia.* The term septo-optic dysplasia derives from an early case study that attributed the agenesis of the septum pellucidum to a syndrome that encompassed visual deficits (Garcia-Filion & Borchert, 2013). Due to discrepancies in nomenclature and self-reporting, if individuals with a diagnosis of septo-optic dysplasia are not included in the total counts of children with ONH, there may be more children with ONH than are currently identified.

Over the past 30 years, the diagnosis of septo-optic dysplasia has been used interchangeably with ONH. Presently, leading ONH medical research teams encourage abandoning the use of the term septo-optic dysplasia because this name is believed to be clinically misleading and inaccurate (Garcia-Filion & Borchert, 2013). The absence of septum pellucidum does not appear to have any impact on biological functioning. Furthermore, research efforts have demonstrated that malformation of the septum pellucidum is not implicated with hypopituitarism, a prevalent and defining condition associated with ONH (Garcia-Filion & Borchert, 2013). Throughout this study, the nomenclature ONH will be used, and the term ONH will encompass any cases of septo-optic dysplasia that are referenced.

The Syndrome of Optic Nerve Hypoplasia

Most individuals with ONH are impacted bi-laterally (in both eyes), and more than 80% of bilateral cases result in legal blindness. Individuals with ONH may have additional, secondary visual conditions. Superimposed cerebral visual impairment, refractive errors, and strabismus may accompany ONH. Bi-lateral ONH and agenesis of the corpus callosum are correlated with the behavioral or developmental abnormalities present in 71% of individuals with ONH. A diagnosis of ONH poses a high risk of hypothalamic-pituitary dysfunction, intellectual disabilities, obesity, and ASD (Ryabets-Lienhard et al., 2016). Vision represents just one component of the syndrome of ONH, and the visual system is complex.

There are many steps along the biological pathway of transmitting and processing visual information. The cornea protects the lens, which bends to allow light to travel to the macula, where the retina receives information about the light, shape, and figure of the image before transmitting that image along the pathway of the optic nerve. Beyond the optic nerve lies a myriad of infrastructure that is responsible for processing visual information as well as interpreting and triggering regulating response mechanisms to proprioceptive, tactile, auditory, vestibular, and olfactory information (Dutton, 2015). Both voluntary and involuntary responses to each of these sensory experiences account for humans' interactions with the world. Children with ONH are at risk for challenges with processing sensory information (Ryabets-Lienhard et al., 2016).

Individuals with ONH are likely to have hypothalamic and pituitary abnormalities (Garcia-Filion & Borchert, 2013). The associated challenges with pituitary and endocrine dysfunction in ONH may be more impactful than the resulting visual impairment. It is important to consider that the hypothalamus controls the limbic system, which is responsible for emotions and memory. The hypothalamus also regulates functions of the pituitary gland, and the pituitary gland is responsible for secreting hormones into the bloodstream (Panawala, 2017). Clinical reviews report that approximately 30% of children with ONH have difficulty regulating their sleep cycle, compounding the risk for comorbid physiological and behavioral difficulties (Rivkees et al., 2010; Ryabets-Lienhard et al., 2016). The clinical implications of insult to the hypothalamus are significant and beyond the scope of this paper. Notably, many children with ONH have pituitary and hypothalamic dysfunction that requires the care of a comprehensive medical team, including endocrinologists (Ryabets-Lienhard et al., 2016).

The complex implications of deficits in visual processing concomitant with dysfunction in the body's general processing system adds layers of complexity to both the biological and functional needs of children with ONH. Due to the multiple and significant health-related implications of an ONH diagnosis, experts encourage a multi-disciplinary approach to medical care and treatment for individuals with ONH (Garcia-Filion & Borchert, 2013). Subsequently, these recommendations imply that educational programming requires the expertise of multiple special education professionals for the majority of students with ONH. To support and teach children with ONH, practitioners and families need strategies beyond traditional compensatory approaches for educating with visual impairments. Specialized tactics are required to support the behavioral and developmental needs of children with ONH. Furthermore, research efforts have demonstrated that many children with ONH exhibit characteristics observed in children who have ASD (Williams et al., 2014).

Autism and Optic Nerve Hypoplasia

Considerable attention has been given to the prevalence of autistic-like behaviors in children with visual impairments (Butchart et al., 2017). There is a body of literature documenting behavioral similarities between some children with visual impairments and children with ASD (Absoud et al., 2011; Andrews & Wyver, 2005; Butchart et al., 2017; Gense & Gense, 2005; Williams et al., 2014). Estimates for the population of children with visual impairments who have ASDs are higher than those of the general population. In 2011, Absoud et al. estimated the percentage of school-aged students (5-21) with severe congenital visual impairment and ASD to be 11-40%.

The complexities of diagnosing ASD in students with visual impairments are also well documented. Concerns about diagnosing ASD in the population of students with visual impairments span a range of considerations. There is evidence that ASD is over-diagnosed in young children with visual impairments because their behavioral characteristics often mirror characteristics of children with ASD (Butchart et al., 2017). Concurrently, there are arguments that ASD is under-diagnosed due to a lack of validated protocols and trained professionals to evaluate children with visual impairment for ASD (Butchart et al., 2017; Williams et al., 2014).

Repetitive behavior, echolalia, obsessions, and hypersensitivities are among the behavioral characteristics associated with both ONH and ASD (Fink & Borchert, 2011). There is a positive correlation with ASD diagnoses in children with ONH who have a severe visual impairment (Ryabets-Lienhard et al., 2016; Williams et al., 2014). In a prospective study, Williams et al. (2014) investigated modifying ASD measures to screen for ASD in children with ONH. Their results demonstrated statistical agreement with clinical ASD diagnoses using the modified protocols (Williams et al., 2014). However, no further work has been done to validate the use of the modified protocols. Due to similar and associated behaviors of students with ONH and ASD, efforts to document strategies and interventions for children with ONH may eventually help with designing programming for other children with visual impairment and ASD. Children with visual impairment and ASD and children with ONH (with and without ASD) are at increased risk for challenges with self-regulation.

Self-Regulation and Optic Nerve Hypoplasia

There is evidence indicating that children with visual impairment apply emotional self-regulation skills differently than sighted children. In a causal-comparative study, Salimi et al. (2016) found that the cognitive strategies applied to regulate and modulate expressions of emotions after an upsetting incident by sighted participants were more numerous and more varied than participants with visual impairments. There were significant differences in the number and types of strategies between sighted participants and those with visual impairments. The participants with visual impairments applied fewer strategies for self-regulating emotions. Salimi et al. (2016) suggested that challenges with self-regulation for managing emotions may be a more disabling factor than a visual impairment. These findings, coupled with the additional developmental needs and incidence of hypothalamic dysfunction in children with ONH, suggest that educators and families need to target self-regulation skills development in children with ONH.

Early Development of Self-Regulation

The literature on early intervention for children with visual impairments stipulates that adults must create intentional opportunities for exploration, facilitated play, and language development in young children with visual impairments (Chen, 2014; Ferrell, 2011). Teachers of visually impaired who work in early intervention provide insight and support to the child's family, and the early education team, on how visual impairments can affect the development of skills across domains (Anthony, 2017; Chen, 2014). Children who have delays concomitant to

ONH need developmentally appropriate supports in many areas. For example, children with severe visual impairments and ONH are at risk for challenges with social-emotional attachments (Chen, 2014; Dale & Salt, 2008; Sonksen & Dale, 2002).

Families and caregivers must nourish emotional attachment through touch, sound, and intentional opportunities for bonding with a child who may not respond to traditional stimulation. There is substantial empirical evidence supporting a positive correlation between maternal emotional bonding and a child's healthy self-regulation mechanisms (Laible, 2004; Thompson et al., 2003; Thompson et al., 2013). Thus, the development of foundational self-regulation skills in children with ONH necessitates that caregivers of infants with ONH provide deliberate opportunities for connecting and bonding with their children (Sonksen & Dale, 2002).

Individuals with ONH have varying needs related to the development of language and socialization skills to support their self-regulation. Children who have ONH and significant developmental delays experience barriers to opportunities for social engagement with peers and family (Bahar et al., 2003; Sabine, 2019). Vygotsky posited that socially mediated development of self-regulation occurs in tandem with the internal milieu and of the individual (1978). Children with significant visual impairment and concomitant challenges of ONH lack natural and important reinforcement opportunities for the development of early self-regulation skills (Cho & Palmer, 2008; Rogers & Puchalski, 1984).

The development of self-regulation processes for students with ONH necessitates consideration of social, neurological, and educational environments. Stake (1995) wrote: "Human construction of knowledge appears to begin with sensory experience of external stimuli. Even in the beginning, these sensations are immediately given personal meaning" (p. 100). Children with visual impairments need targeted supports to help them develop self-regulation skills. As they experience and construct the meaning of the world without the input of sight, children with ONH employ self-regulation tactics unique to their sensory perceptions and developmental levels. Home and school settings provide different social and environmental demands, whereby a child with ONH constructs meaning through their interactions with other people and their surroundings.

School-Based Services for Children with Optic Nerve Hypoplasia

The IDEA of 2004 is the law mandating that children with disabilities receive a free and appropriate public education. Educational needs are the measures by which a child qualifies for special education services under the IDEA. *Visual impairments, including blindness* is one of 13 disability categories in the IDEA. A medical diagnosis of ONH does not mean that a child will automatically qualify for an IEP. However, it is highly probable a child with ONH child will need educational interventions and specialized instruction to receive a free and appropriate public education (IDEA, 2004).

The IDEA defines visual impairment, including blindness as “impairment in vision that, even with correction, adversely affects a child’s educational performance” [§300.8(c)(13)]. In addition to cognitive thresholds and academic achievement, special education teams assess and determine students’ needs in social-emotional, communication, mobility, and adaptive skill domains. Special education teams use assessment information to design instructional supports and educational goals for students who qualify for special education services. Special education teams include educational professionals and parents of the child with disabilities; these teams are supposed to collaboratively determine the type of program that will provide the most educational benefit to the child (IDEA, 2004).

Educational programming for children with visual impairments may occur at a specialized school for students with visual impairments or through the child's local public school system. Residential schools were the original model for formally educating children with visual impairments. However, students with visual impairments are now more likely to receive services through their local public schools (McMahon, 2014). Therefore, increasing numbers of children with ONH are entering their local public education systems, and there are no research-based interventions specific to the syndrome of ONH. While providing important insights into the prevalence and associated complications of an ONH diagnosis, the literature base lacks practical strategies for supporting the developmental and educational needs of children identified with ONH.

Teachers of the visually impaired are likely using strategies for educating students with multiple disabilities when they work with students with ONH. Some of the strategies recommended for students with visual impairments and multiple disabilities include: using a functional curriculum to prepare students for life in their greater community, providing instruction in natural daily routines, and fostering communication through labeling materials in the environment, and using accessible calendars and materials (Zatta, 2016). Combining approaches for students with multiple disabilities and instructional techniques to support the unique sensory needs of children with ONH may provide a specialized methodology for educating this population.

Educational Literature on Optic Nerve Hypoplasia

The Blind Children's Center in Los Angeles published a brief guidebook on suggestions for supporting children with ONH (Mendiola et al., 2005). Members of the multidisciplinary team at the center wrote this guidebook. These same individuals also authored a practitioner's paper on using a multidisciplinary approach to support children with ONH; the paper summarized the suggestions that are detailed in the guidebook (Bahar et al., 2003). Over many years of work with preschool children with ONH, the authors identified a list of traits and strategies that they have applied to support their young students. Among the characteristics cited in this paper are problems with cognitive skills, speech, motor delays, tactual and auditory sensitivities, transitions, restricted food preferences, avoidance of social interactions, and profound distractibility. The strategies and motivational techniques the authors used include swinging, allowing for wait time, predictable routines, and the use of rhythms and music during instructional time (Bahar et al., 2003).

Music and Optic Nerve Hypoplasia

Musicality and visual impairments share a long and fond history. The earliest established schools for blind children taught piano and voice lessons (Spungin & Huebner, 2017). Significant differences between heightened auditory perception and musicality in individuals with congenital blindness versus those who have later onset blindness have been detected (Gougoux et al., 2004). Researchers attribute this phenomenon to early neuroplasticity and the reallocation of neural resources that occur in cases of congenital blindness. Furthermore, a propensity for auditory perseverations and musical interests and abilities in children with ONH appears prominently in the published literature as well as in social media forums (Bahar et al., 2003; Pring & Ockelford, 2005; Wooster, 2016).

Pring and Ockelford (2005) investigated the association and relationship of musical interest in children with ONH. Their study was inspired after parents attending a workshop reported that their children with ONH have a high interest in music. Pring and Ockelford’s results demonstrated that children with ONH have a significantly higher interest in music than do their sighted counterparts (2005). Additionally, several individuals have documented and published personal experiences that describe music as a positive variable that can, at times, mitigate challenges associated with behavioral characteristics of ONH (Lewis, 2008; Wooster, 2016).

Sabine (2019), Wooster (2016), and Lewis (2008) each articulated a connection with musicality and an ONH diagnosis. In a timely editorial piece, Sabine (2019) documented his personal experiences with ONH. Juxtaposing his perfect musical pitch and memorization of area codes with his challenges in mastering skills such as dressing himself and tying his shoes, Sabine (2019) provided a personal window into the many nuances of characteristics that may accompany ONH. Sabine, an active member of the National Federation of the Blind, called on his fellow *Federationists* to support the diverse and additional needs that many individuals with visual impairments have, including people like him, with ONH (2019). During a personal interview, Sabine cited the child music prodigy, Rex Lewis-Clack, as an example of the profundity of exceptionalities in children with ONH (C. Sabine, personal communication, October 25, 2018).

Rex Lewis-Clack is a musical savant who has both ONH and ASD. Lewis-Clack rose to fame after being featured in an episode of CBS's *60 Minutes* in 2003. Cathleen Lewis, Rex's mother, provided a personal testimony to the joys and challenges of raising Rex through early childhood and school years (2008). Despite his miraculous musical ability, Rex suffered developmental delays with communication, self-regulation, and social skills. Rex's mother invested countless hours advocating for innovative avenues to support and improve the prognosis for Rex's multiple special needs. Ultimately, music provided an avenue for Rex to attain his developmental milestones.

Wooster (2016) documented approaches for incorporating music to support a student with ONH through transitions and daily routines. While implementing action research for a master's degree, Wooster (2016) accounted a case study of her experiences working as a paraprofessional for a child who has ONH. The student in Wooster's thesis was a second-grade girl who demonstrated characteristics of behavioral and communication challenges. *Mary* is the name given to the child in Wooster's report. Mary had obvious gifts related to absolute pitch, playing piano, and rote memorization. Wooster and Mary's TVI also suspected that Mary had ASD. Incorporating music provided Wooster with a motivational teaching tool for Mary. Wooster (2016) asked if the relationship between musicality, ASD, and ONH could provide a lens for developing interventions and strategies to support children with ONH. She used her questioning as a springboard for a therapeutic music curriculum for students with ONH. Unfortunately, to date, no one has documented and published their implementation of Wooster's (2016) therapeutic music curriculum for students with ONH. However, there is evidence that music should be considered as a tactic for helping students with ONH to develop critical social, emotional, and academic skills.

Optic Nerve Hypoplasia and the Expanded Core Curriculum

Social and emotional skill development is an important consideration in The Expanded Core Curriculum (ECC) for students with visual impairments. The ECC was introduced to the field of visual impairment to address the skills that students with visual impairments need, specific to their disability, but may not acquire through a public education focused exclusively on the general academic curriculum. It is relevant to address the ECC in this section of the paper because many parent support groups and TVIs use language and rationale from research and white papers on the ECC to drive the design for service delivery to students with visual impairments (Huebner et al., 2004; Lewis & Allman, 2014; Sapp & Hatlen, 2010). The ECC for students with visual impairments encompasses the following domains: (a) compensatory access, (b) sensory efficiency, (c) assistive technology, (d) orientation and mobility, (e) independent living, (f) social interaction, (g) recreation and leisure, (h) career education, and (i) self-determination.

Mastery of skills in literacy and the ECC are positively correlated with post-school success (McDonnall, 2011; Wolffe & Kelly, 2011). Students with visual impairments face a dire statistical likelihood of obtaining and maintaining future employment. The average rate of unemployment for individuals with visual impairment hovers around 60-65%, a dramatic difference compared to the Bureau of Labor Statistics' reports of a 10% civilian unemployment rate in the general population during the last recession (Bell & Mino, 2015; Bureau of Labor Statistics, 2012.). Therefore, the value of early assessment and interventions targeting appropriate literacy skills and instruction in the areas of the ECC are important for all children with visual impairments (Chen, 2014). Some students acquire new skills quickly with limited direct instruction; other students need explicit instruction in each area of the ECC and may never reach full independence. A student with ONH is likely to need direct instruction in a broad scope of ECC skills. Some of ECC skills fall in the domain of home and self-care, yet both TVIs and families of students with visual impairments report a lack of time and resources for teaching ECC skills (McKenzie & Lewis, 2008; Yarbrough et al., 2019). Understanding supports that families provide to their children with ONH during their daily home routines may help innovate approaches for infusing ECC skills practice throughout the academic school day.

The evidence that TVIs and families are challenged to provide instruction in areas of the ECC indicates that students may be lacking instructional supports for developing critical life skills (McKenzie & Lewis, 2008; Yarbrough et al., 2019). Students with ONH who are at risk for complex developmental delays may need support from multiple providers to address areas of the ECC (Bahar et al., 2003). No research on the ECC for students with ONH could be located. Many of the skills in the ECC were formerly taught in specialized schools for learners with visual impairments. However, as previously discussed, the majority of students with visual impairments are now educated in their local schools while living at home. While specialized schools for students with visual impairments are increasing their offering of outreach services, no published curriculum guidelines for students with the ECC and children with ONH could be located (DeMario & Caruso, 2001; McMahon, 2014;).

Conclusion

In this chapter, I have summarized the research literature on the unique needs of children with ONH. Children with ONH represent a growing proportion of the population of students with visual impairment (Garcia-Filion & Borchert, 2013; Hozjan, 2017). In addition to ocular concerns, individuals with ONH are likely to have hypothalamic dysfunction, problems with cerebral wiring, and malformation of the corpus callosum (McCulloch et al., 2010). Each of these risk factors and associated symptoms have implications for biological processes and functional behaviors. Special education needs are affected by these biological processes and functional behaviors. Subsequently, educational progress and medical prognoses are entwined for many children with ONH.

A diagnosis of ONH is likely to indicate concomitant neurological problems that warrant a comprehensive medical team including a neurologist and an endocrinologist. A child with the diagnosis of ONH is also likely to need an IEP that is supported by multiple special education providers. Some children with ONH have no functional vision and may need to learn to read braille, while other children with ONH will be able to access and read print. As with other students who have visual impairments and multiple disabilities, a multi-disciplinary educational approach to providing special education supports to children with ONH and their families is recommended (Bahar et al., 2003; Sabine, 2019).

This exploratory research study was designed to provide an avenue for parents of children with ONH to voice their experiences and share their expertise of tactics to support their children. I hope that the shared experiences (including both the successes and sorrows) of the parents I interviewed will inspire new ideas, catalyze research efforts, and support the difficult decisions that educational teams and families have to make when determining support structures for children with ONH. I want to know what is working for parents of children with ONH and gather ideas for to best support children with ONH and their families.

CHAPTER III

RESEARCH METHOD

Introduction

Throughout my career, I have worked with many students who have ONH. Most of the students with ONH whom I have taught have had challenges with self-regulation, classroom behavior, and socialization skills. As the TVI for these students, I frequently served as the case manager and special education team leader. It was my responsibility to lead the special education teams, including school providers and family members, through the process of developing the students' IEPs. While leading teams through decision-making and program implementation, I was often expected to coordinate and conduct educational assessments and to design interventions to mitigate my students' off-task behaviors in order to increase their academic growth.

The challenges my former students with ONH experienced inspired me to conduct deeper investigations of interventions and support strategies for students with ONH. Even though ONH is one of the most prevalent causes of childhood visual impairment in the United States, my review of scholarly literature yielded limited documentation of suggested approaches for supporting students with ONH and no research-based interventions specific to students with ONH (Wooster, 2016). As a TVI, I have used my expertise and intuition, as well as suggestions of colleagues and families, for support and ideas to improve outcomes for my students with ONH. As a doctoral student, I have continued my line of inquiry into the complexities of meeting the educational needs of students with ONH. This study represents a significant area of interest for me: one that also has deep social meaning for people who care for and work with children who have ONH (Moustakas, 1994).

Optic nerve hypoplasia is increasing in prevalence in developed countries, and there is a paucity of literature suggesting functional interventions to support children with ONH (Borchert & Garcia-Filion, 2008; Ivy & Hatton, 2018). I have focused my previous research efforts on the expertise of TVIs and the experiences of adults who have ONH. However, my experiences as both a TVI and a stepmother to a son with a disability remind me that parents know their children best. Parents are invaluable members of their children's educational teams. Parent perspective and reflection on the process that they use to support their children with ONH can serve to provide expert guidance to future researchers and educators for students with ONH.

The goals of this exploratory qualitative study were: (a) to investigate and share experiences that families of children with ONH have had with various support systems, and (b) to provide a scholarly account of family-initiated methods and approaches that are being used to improve short- and long-term developmental goals for children with ONH. Through exploring, contrasting, and synthesizing multiple families' experiences with raising and supporting their child with ONH, I hoped to contribute to the initial body of educational research on ONH. It is important to me that my research embodies stories of the lived experiences of families who are raising children with ONH. These stories may serve as valuable references and support to other parents of children with ONH. Furthermore, family-initiated strategies for managing challenges with ONH may help researchers, teachers, and other families identify interventions that target the complex needs of students with ONH.

The following research questions guided my inquiry:

Q1 How are families of children with ONH experiencing support systems for raising their children with ONH?

Q2 What strategies are families using to support the developmental needs of their children with ONH?

Theoretical Framework

Constructivism was the theoretical framework for this study. Constructivism is defined both as an epistemological paradigm and a theory of learning (Lohmeier, 2018). Epistemology is the study of knowledge (Merriam-Webster, n.d.), and theories of learning are concerned with why and how people acquire knowledge (Bigge & Shermis, 1999). As a theory of learning, constructivism posits that knowledge is gained through observation and experiences with the world. Educational constructivists descend from the developmental psychology theoretical frameworks of both Piaget and Vygotsky; these psychologists studied how children develop in the context of their peers and the environment (Hyslop-Margison & Strobel, 2007). I believe that an individual's interactions with peers and environments are immitigable elements of childhood development. Likewise, parents construct knowledge and understanding of their children through observation and their interactions.

Constructivism acknowledges that people derive meaning from interaction with objects and the environment as well as through social interactions. Interactions and interpretations create meaning for constructivists (Crotty, 1998). I have spent 20 years observing and informally analyzing how relationships appear to influence children with ONH. Frequently drawn toward adult interactions, children with ONH often approach social relationships with peers in a manner that is challenging for their peers to engage and reciprocate. Like many children with special needs, children with ONH may be socially isolated from their neuro-typical peers. The interactions that families have with their children occur across a variety of environments and domains. Therefore, studying approaches that parents use with their children who have ONH provides valuable perspectives for educators who work with these children.

I have tried a variety of methods to engage students who have ONH, but I have not studied the approaches that parents of children with ONH use to engage their children. As they experience and construct meaning of the world without the input of sight, children with ONH employ strategies for interacting with people and objects that are unique to their sensory perceptions. The formative experiences of children with their families shape their conceptual understandings of the environment and their relationships. “Even in the beginning, these sensations are given personal meaning” (Stake, 1995, p. 100). Therefore, constructivism provides a natural lens for organizing and synthesizing parents’ perspectives on their experiences raising children with ONH.

The literature on ONH exists primarily in the realm of medical/diagnostic, assessment, and epidemiological studies. A constructivist approach to studying ONH allows for the inclusion of both important medical implications as well as the lived experiences, reflections, and conveyed feelings of people who are raising a child with ONH. Constructivism allowed me a way to gather and analyze data documenting the shared experiences of families while acknowledging my own experiences and assumptions as a teacher and researcher. Throughout the research process, I maintained a journal that documented my thoughts and perspectives. I referred to this journal throughout my organization and analysis processes to help me construct an ethical representation of my participants’ experiences (Creswell, 2007; Lahman, 2017). Bridling of my biases through my researcher stance, hypotheses, and the reflections captured through my research journal will be discussed in the following sections. My hope is that this study will be used to help support the needs of individuals with ONH, their families, their educators, and their care providers.

Research Genre: Phenomenology

The purpose of my inquiry was to gain an understanding of families' experiences with supporting the special needs of their children with ONH. I wanted to answer questions that are relevant to the phenomenon of challenges associated with ONH. I applied the qualitative method of phenomenology for investigating my research questions. A phenomenological research approach involves studying the experiences and perspectives of people who have lived a shared phenomenon (Moustakas, 1994).

I used data from parent interviews for this inquiry. Interviews are acknowledged as a common primary data source in phenomenological research (Merriam & Tisdell, 2015). After listening to and studying the accounts of my participants, I identified experiences that were common among the participants as well as experiences that were unique to individuals. An understanding of parents' experiences raising children with ONH is needed to help guide the development of support for families, inform educational practices, and identify areas of need for future intervention studies for children with ONH.

The phenomenon I investigated was families' experiences parenting children with ONH. I conducted semi-structured, in-depth interviews with 12 parents of children with ONH, collected follow-up reflections, and maintained a researcher journal throughout my study. I established and maintained open lines of communication with my participants throughout the study. I describe the study design and methodology in the following sections.

I designed this study through a set of four hypotheses that provided the conceptual framework for the study (Stake, 1995). While I did not test my hypotheses through experimental design, I held these hypotheses as I designed and conducted this study. Sharing my hypotheses is meaningful because my discipline-specific experiences allowed me to design and interpret the data of this study (Merriam & Tisdell, 2015). Articulating these hypotheses is a component of my efforts to recognize and bridle my presumptions. Bridling is an active process of allowing the data (participants' description of their experiences) to speak for itself while acknowledging that the researcher brings preconceived ideas and experiences to the research process (Vagle et al., 2009).

I recognize that meeting the educational needs of children with significant visual impairments involves more than simply designing and providing academic support. Research and teaching experience have helped me identify that many children with ONH have complex behavioral and sensory needs. The complexities of raising and supporting a child with ONH indicate that a collaborative therapeutic and educational model, encompassing both educational and physical needs, is necessary. However, I hypothesized that:

H1 Families' experiences with school and medical teams would portray isolated and disjointed models of support.

Children with ONH are likely to have developmental delays in addition to their visual impairment (Ryabets-Lienhard et al., 2016). There are compounding implications for intensive support needs for children who have visual impairments and additional developmental delays. The ECC for students with visual impairments defines the repertoire of skills that students with visual impairments need, specific to their visual disability, but may not acquire through an education focused exclusively on academic curricula. Research indicates that TVIs are not utilizing parent relationships, especially in the non-academic areas of the ECC (Yarbrough et al., 2019).

I also hypothesized that:

H2 Families of children with ONH have limited time and resources to support their child's development of skills in the areas of the ECC.

H3 Families of children with ONH employ creative and individualized support strategies to guide their children through daily routines in the home.

Due to the nature of developmental delays that commonly accompany a diagnosis of ONH, challenges with self-regulation skills are likely to exacerbate students' developmental needs. Classroom settings within the school environment have the added complications of multiple students and demands for executive functioning for work tasks. Therefore, I hypothesized that:

H4 The unique dynamics of a home environment (familiar and safe environment) may provide a setting in which children with ONH can comfortably acquire and practice skills that may eventually be transferred into a less controlled and busier environment.

These four hypotheses guided the methodology of my research design. These hypotheses also conveyed the professional biases that I brought to the project that I had to bridle while allowing the data to lead my inquiry and findings (Merriam & Tisdell, 2015; Vagle et al., 2009).

Methodology

Participants

Twelve families of children with ONH were included in the study. The ages of the children with ONH were 6 to 14 years old. I recruited participants who had recent experiences parenting a child who receives school-based special education services. I set the minimum age at 5 because I wanted the child to be exited out of early intervention and established with school-based services. Early intervention support services are primarily focused on home-routines and are, therefore, different than school-aged services that focus on academics (Ely & Ostrosky, 2018). The maximum age was set at 18 because I wanted the participants to have current experience with school-based services. Participants were recruited throughout the United States based upon the following inclusionary criteria: (a) they are the parent/primary caregiver for a child who has a medical diagnosis of ONH, (b) the child's visual impairment is significant enough that he/she qualifies for special education services as a child with visual impairment, and (c) the parents/primary caregiver have concerns, in addition to the visual impairment, about their child's development.

The purpose of the study was to gain an understanding of families' experiences with supporting the special needs of their children with ONH. Because children with visual impairments and no additional disabilities develop differently than children who have additional challenges, inclusionary criteria for the study required that the children have developmental disabilities and/or behavioral challenges in addition to their ONH. However, due to the added complexities of development experienced by children who are non-verbal and who have significant physical limitations, families of children who are non-ambulatory and/or non-verbal were excluded from participation in this study.

Eleven of the 12 participants are mothers of children with ONH. The 12th interview was with both parents of the child, and both of these parents participated in follow-up correspondence. The parents of the child who interviewed as the dyad have taken turns as roles as the primary care provider for their child. Each of the 12 children who are represented in the study received early intervention and attended preschool. See Table 1 for demographic information about the children of the parents who were interviewed. I included this data in order to describe attributes and diagnoses of the children who are represented through the parent interviews. This table includes information about additional disabilities and primary literacy media of the child. Literacy media refers to the sensory channels that children with visual impairments use to access written language and environmental information. Literacy media is a primary consideration in educational and daily living skills instruction because some children with visual impairment learn tactually, while others may be auditory or visual learners. Knowledge of a child's literacy media is helpful for understanding how the child learns and experiences their environment.

Table 1

Child Demographics

Age	Gender	State	Literacy Media	Additional Disabilities
10	M	CO	Braille, auditory	Hypopituitarism
9	F	WA	Print/large print	Sensory processing disorder
13	F	CO	Print/large print, auditory	Epilepsy
7	F	CO	Braille, auditory	ASD, growth hormone deficiency, diabetes insipidus
14	M	UT	Print/large print, auditory	Panhypopitiuitarism, epilepsy, developmental delays
12	M	NC	Braille	Hypopitiuitarism
6	F	CO	Braille, auditory	Hypothyroidism/cortisol dependent
11	F	CA	Braille	Growth hormone deficiency, hypothyroidism
7	M	TX	Print/large print, braille	Panhypopitiuitarism, ASD, primrose syndrome, FRIES
10	M	TX	Braille, auditory	Diabetes insipidus, panhypopituitarism, seizure disorder, schizencephaly, polymicrogyria
8	F	TX	Braille, auditory	Polymicrogyria, panhypopituitarism, diabetes insipidus, ASD, developmental delay
14	F	MS	Braille	Glaucoma, retinal detachment, sensory perception disorder, hypothyroidism

Recruitment

Initial recruitment began with posting a recruitment letter (Appendix B) to Facebook groups for parents of children with ONH. The Magic Foundation, a foundation for individuals with endocrine problems, allowed me to recruit participants through their Facebook parent group. I also submitted several email announcements to the professional email list of the Association for the Education and Rehabilitation for Blind and Visually Impaired. I asked a network of professionals to share the recruitment notice with families who met the inclusion criteria for the study. Additionally, I shared recruitment materials with my professional network of colleagues and through the National Leadership Consortium for Sensory Disabilities newsletter and Facebook page.

The response rate to my recruitment postings was slow at times. I noticed that I got immediate responses after the initial posts, but I had to continually update the posts in order for people to see them. Early in the recruitment process, when the response rate was especially slow, I consulted with a friend who works in philanthropy; she encouraged me to re-word my recruitment flier in a way that would better encourage people to participate. I changed my flier to include statements about why and how this research can help children with ONH. I had over 30 people respond in total, but there was attrition between initial responses and later responses to my follow-up prompts asking them to complete the demographic questionnaire. One respondent completed the demographic questionnaire, but did not respond to any of my four inquiries to interview.

Sampling

Purposeful sampling is frequently employed in qualitative phenomenological research because it allows the researcher to select individuals who are especially knowledgeable about the phenomenon of the study (Creswell & Poth, 2017; Merriam, 2009). I wanted to learn about the experiences of people who are experts and can reflectively articulate their experiences (Moustakas, 1994). Purposeful sampling allowed me to use social media to recruit participants.

By actively recruiting participants who met the inclusion criteria, I developed a sample that best represented the experiences of parenting a child with ONH who has additional challenges (Patton, 2002).

Data Collection

Institutional Review Board (IRB) approval was obtained before soliciting participants. The IRB application included the purpose of the study, details of the study methodology, and safeguards for participants (including purpose, background, and consent forms). Ethical research standards were followed, and a copy of the IRB approval letter was placed in the appendices of this manuscript (Appendix A).

During the recruitment phase, individuals who were interested in participating were directed to email me with any questions. I screened potential participants to ensure that they met the inclusion criteria through a brief Google Form survey. When someone did not meet the inclusion criteria, I emailed them to explain why. Individuals who met the inclusion criteria received a follow-up email from me that contained a link to the Google Form safeguards and consent and demographic survey (Appendices C and D). Once participants agreed to the safeguards and consent, they progressed to the demographic survey. In the demographic survey, I included a few questions about the preferences and characteristics of the child because I knew that I would not have the opportunity to meet or observe the child. This information helped me to understand the child through the parents' lens, and made the interviews a bit more personal. After participants completed the demographic survey, a recorded semi-structured telephone interview was scheduled using an interview protocol (Appendix E).

Interviews

Researchers use interviews to learn about things that we cannot observe and experiences that have happened in the past (Patton, 2015). I wanted to learn about parents' past and present experiences, so I developed an interview protocol to address my primary research questions. After I wrote the questions, I revised them and reviewed them with an adult who has ONH and runs an ONH consulting business. I also piloted the interview questions with a parent of a child with ONH and a peer reviewer. These individuals reviewed the questions for content and flow before the first formal interview. The questions were designed to be open-ended to allow participants to provide additional feedback and information they deemed relevant to the study and their experiences (Merriam & Tisdell, 2015). Participants had the opportunity to provide feedback on the interview questions and add comments about the content and structure of the tool. However, no participants provided feedback on the questionnaire itself.

Preliminary demographic information such as the child's age, degree of visual impairment, additional disabilities, and family demographics were gathered during the pre-interview phase via an online Google Form survey. Participants confirmed their demographic information and provided verbal consent before the interviews began. All of the interviews were recorded and submitted for transcription services to a professional transcription company.

The primary data source for this study was semi-structured phone interviews with parents of children who have ONH. The interviews were scheduled for a time that was convenient for the participants and were recorded using Google Voice. The average length of the interviews was 43 minutes. The longest interview lasted 57 minutes, and the shortest interview was 25 minutes long. I used an interview guide for each of the interviews and if parents had questions regarding things that were outside the focus of my study, I offered an alternative time to talk to them. Two participants wanted to talk after their interviews about braille literacy, and one participant wanted to discuss educational opportunities for her daughter as the family was preparing to relocate.

Participant Reflections

To honor the participants as an active part of the research process and provide additional opportunity for feedback, participants were asked to reflect on their interviews (Patton, 2015). Acknowledging that some people may feel more comfortable speaking, rather than writing, I offered the option to provide reflections through a follow-up conversation. I sent a follow-up email within two days of the interviews to summarize my main ideas from the interview and ask the participants if they had any lingering thoughts or reflections that they would like to share. Five participants responded, but only one participant offered a reflection after the interview and wanted to include some additional information to their interview.

I planned to include the participants' initial reflections in my data analysis by triangulating the reflections with the interviews and my researcher journal. With such a low reflection response rate from participants after the interviews, this aspect represents a limitation of the project that will be discussed in a later section. This low response rate also prompted me to consider approaches that I could use to get responses to my requests for second-level member checking.

Member Checking

All participants were invited to provide feedback on the interview process and share any additional thoughts they might want to share through a follow-up email correspondence 24-48 hours after the interviews. In the email prompt for feedback and reflections, I shared what I thought were the main ideas and themes from the interview. I also asked if the participants had any lingering thoughts or ideas that came to mind that they would like to share to add to their interviews. Five participants responded to my follow-up email and summary, and only one person wanted to add reflections or additional information to their interviews.

In a further effort to gather feedback on my final analysis, I shared my analysis tree (a visual representation of the themes and findings) and updates on my progress with the participants. I invited the participants to provide feedback on my final analysis. Every participant responded to my final analysis; several participants shared some additional thoughts on the analysis. I discuss their feedback in my findings section.

In addition to feedback on the final analysis, I asked participants if they would be willing to respond to two additional prompts. The prompts were related to the COVID-19 pandemic and things that make their children happy. I decided to add these prompts because my data collection occurred during the COVID-19 pandemic. Although the focus of my research was not specifically related to the pandemic, I wanted to allow my participants to voice their experiences with supporting their children through this unique time. Ultimately, I wanted the children's and families' experiences during COVID-19 to be documented. I also wanted to explore the activities that their children pursue for pleasure because I think these activities can help inform interventions for children with ONH. Unlike the first-level member checks, every participant responded to this second-level checking and shared a response to the prompts. The final prompts and the participant responses will be discussed in the findings section.

Methodological Transparency:
Researcher as an instrument

Qualitative research acknowledges that the researcher is an integral component of the entire research process (Brantlinger et al., 2005; Trainor & Graue, 2014). I brought unique perspectives and biases to both the design and methodology of this project. I took care to honor the unique perspectives and experiences of my participants while acknowledging my expertise

(Lahman, 2017). I have experience working with children who have ONH, an intuitive sense of the needs of children with ONH, and experience with scholarly research on the topic of ONH. However, while I am both a teacher of students with visual impairments and a step-mother to a son who has special needs, I am not a parent of a child who has ONH. Throughout the recruitment and research process, I offered full disclosure of my background and research agenda to my participants. When participants had a question about school services or wanted to discuss something in addition to the research study, I asked them to hold those questions aside until the interview was completed.

Researcher Journal

During the data collection and analysis process, I maintained a research journal that contained notes with my reflections on the interviews and a reflection on the preliminary and final analysis process. I documented instances in which I felt that my biases were blocking my progress with the analysis. I wrote about how I felt after the interviews and what stood out to me as the primary take-aways from the interviews. I maintained a researcher journal to describe and reflect upon my coding process with reflexivity and contemplation (Lahman, 2017).

As I began to analyze and construct codes that emerged from the raw data, I consulted with an expert peer reviewer who has experience in both qualitative research and working with families of children who have visual and hearing impairments. In addition to sharing transcripts and coding notes with the peer reviewer, I referred to my journals to help me organize my thoughts and process with the peer reviewer. Journaling helped me process some of the emotions that I felt after the interviews. In this way, journaling supported my efforts to bridle my personal responses to the interviews, which helped me stay true to the participants' stories as I began coding.

Data Analysis

After the interviews were conducted, I sent an email to the participants with an overview of the main ideas that I interpreted from their interviews. I asked them if their main ideas were captured in my brief initial summary. After the interviews were transcribed, I went back and listened to the recorded interviews while reading the interview transcripts. This step ensured that the transcriptions were accurate, and it helped immerse me in the data. As I reviewed each interview and considered the feedback from my participants, I revisited my research journal to add any additional thoughts about the interviews. During this stage, I began organizing and refining my thoughts on the data (Merriam, 2009). I documented and maintained a record of my changed perspectives and new ideas that occurred as a result of the review step. My research journal helped me synthesize my understandings and served to provide documentation for an audit trail.

Qualitative researchers use the terms *bracketing* and *bridling* to indicate efforts to support trustworthiness and dependability in the research process. The concept behind bracketing and bridling is that the researcher asserts and states their personal biases and holds their biases aside to mitigate the influence of personal bias during analysis. I chose to use the term *bridling* for my efforts because I believe that my biases can never be fully suppressed, only identified and honored as a different perspective (Moustakas, 1994). I aimed to honor the experiences of my participants by bridling my inclination to assert my professional biases into the data organization and analysis (Moustakas, 1994). I practiced reflexivity by continually documenting my thoughts in my research journal.

Coding Process

Coding, a task of phenomenological reduction, involves describing how one consciously sees and interprets things (Moustakas, 1994). Coding was an interactive and iterative process that included my work to categorize and organize the data and to synthesize feedback from consultation with my peer reviewer (see peer review section for details). Initially, I planned to use software to assist with the coding and peer review process. However, I found myself resisting any additional use of technology during the pandemic. After consultation with my peer reviewer, I decided to use paper, pencil, and highlighters to conduct my analysis. I printed the transcripts and organized them into a large 3-ring binder with dividers. This method freed me from screen-fatigue and allowed me to read and annotate by hand. For correspondence with the peer reviewer, we used email, Microsoft Word documents, and Google Docs.

During the first phase of analysis, I identified the large, over-arching themes that I interpreted from the interviews. I wrote notes on these themes and shared these notes with my participants in the first phase of member-checking. Next, I reviewed the interview transcripts to check their accuracy. As I reviewed the transcripts, I wrote down the salient, descriptive phrases from the interviews and took notes about the phrases in the margins of each of the transcripts.

The transcript margin notes evolved into my initial list of codes during the third and open-coding phase of the analysis (Strauss & Corbin, 1990). During this stage, phrases had more than one code assigned. The peer reviewer and I met after we each coded two of the interviews. With assistance from the peer reviewer, I generated an initial list of codes. I continued this open-coding process as the interview transcripts arrived, and I created charts with notes about the code categories that emerged from each transcript. The charts helped me visualize the categories of codes. Next, I identified prominent and lesser categories and began to highlight connections and outliers in the transcripts. I worked with my peer-reviewer during this process; we met by phone or Zoom three times to established inter-reviewer agreement on descriptive terms that I used to organize the data.

After we identified and labeled categories from the transcripts, I established a code chart to help streamline my analysis (Creswell, 2014; Saldana, 2009; Tesch, 2013). The code chart assisted me as I defined thematic categories as codes. Through charting, I began to visualize inclusion and exclusion criteria. I moved the charts from my whiteboard and notes into a codebook, and I used participant quotes to illustrate assigned codes (Creswell, 2014). The codebook served as a tool to help me maintain consistency with organization during my analysis. I structured my codebook to include the code name, definition, and quotes/examples from the data (DeCuir-Gunby et al., 2011)

In the next phase of the analysis, I returned to the transcripts and began to condense, abbreviate, and combine the broader topics into the descriptive codes that I assigned in the codebook. I highlighted unique outliers and bracketed these outliers from the common themes (Saldana, 2009). During this axial coding process, I clustered and coded the themes into categories that provided a constructive framework to address my research questions (Moustakas, 1994; Strauss & Corbin, 1990). This phase helped me to identify relationships between the codes. I continued to review the coded transcripts multiple times as I organized the categories into major themes. The peer reviewer and I discussed that several of the themes were saturated, meaning that multiple families had indicated similar responses. Saturation of themes suggests that the sample size was adequate for the study (Fusch & Ness, 2015). Further description of the coding and thematic organization is presented in the next chapter.

Ultimately, responses that strayed from the research questions were excluded from interpretation in the final analysis phase. Direct quotes from the participants that suggest new ways for understanding experiences with parenting a child who has ONH are included. The conclusions that I drew from the themes that emerged from the iterative coding and organizational process are supported through direct interview quotes as well as participant and researcher reflections.

Credibility and Trustworthiness

Credibility and trustworthiness are constructs that qualitative researchers use to ensure that we are researching what we aim to study (Brantlinger et al., 2005; Merriam, 2009). Methods used to ensure credibility and trustworthiness include triangulation, member-checking, peer/colleague examination, expert examination, researcher stance/hypotheses, and prolonged engagement in the field (Eisenhart & Howe, 1992). Except for prolonged engagement in the field (meaning prolonged periods of time with the participants in the field), I employed each of these tactics to ensure credibility and trustworthiness throughout my study. The following sections describe how I established credibility and trustworthiness.

Triangulation

Triangulation involves using multiple sources of data to ensure credibility in the data analysis phase (Brantlinger et al., 2005; Creswell, 2014). While interviews served as my primary data source, the cross-analysis of participant reflections and feedback, peer-review discussions and summaries, and my research journal provided additional triangulated data to provide support for credibility (Brantlinger et al., 2005). These four sources of data (interviews, participant reflections, peer-review discussions, and research journal), as well as additional follow-up correspondence with the participants, provided substance for cross-examination and triangulation in this project.

Member Checking

In addition to providing evidence of credibility to the research design, member checking throughout this project was critical to the integrity of the research (Brantlinger et al., 2005). Member checking occurred in several phases of this project. First, each participant had an opportunity to review and provide feedback on my initial summary of over-arching emergent themes. During this early analysis phase, I completed a brief journal entry immediately after the interviews. My researcher journal and the additional notes that I took while reviewing the recordings provided me data for the initial thematic outline of each interview. These initial thematic outlines were brief written outlines summarizing the over-arching big ideas that I interpreted from the data. I shared this primary thematic outline with each participant via email after the interviews.

In addition to reviewing the primary thematic overview of the interviews, each participant was invited to provide a written response to a reflection prompt after the interviews. I provided the participants with a prompt, via email, asking if there was anything additional that they thought about after the interview that they wanted to share. Only one participant provided a reflection response after their interview. I also asked participants to be involved in second-level member checks by providing feedback and validation or refutation on the conclusions that I drew (Brantlinger et al., 2005). I received a 100% response rate on the second-level member checks. It was my objective to ensure that each participant felt that his or her experiences were accurately represented throughout all phases of the project, including the analysis phase (Creswell, 2014). The participants' final responses are captured and discussed in the following results section.

Peer/Colleague Examination

Peer examination supports validity in qualitative research (Creswell, 2014). I selected a peer-reviewer who has experience with qualitative research and also has deep experience and familiarity with special education (as both a parent of children with special needs and a researcher). In addition to engaging a peer-reviewer for the interview protocol development phase, I worked with this individual to review my data organization, thematic coding process, and final analysis. The peer reviewer was involved in multiple steps throughout the analysis and final discussion phase. Peer examination also occurred through the process of reviewing my proposal and research stages with the members of my dissertation committee (Merriam, 2009).

The following steps outline the peer-review process during my analysis phase. A secure electronic account was used to store and share transcripts and coding discussions with the peer reviewer. First, we each coded two transcripts and collaboratively discussed our coding process and the big ideas that we derived from the transcripts. There were a few terms and sections that we coded differently. However, when we spoke, we discovered that our meanings were similar and we had simply used different words to describe our interpretations of the data. Through our conversation, we came to consensus on the terminology we would use, while looking at the transcripts we had coded.

After I reviewed all of the transcripts for big ideas and outliers that were related to my research questions, we met again and I shared my initial analysis framework with my peer reviewer. We had a conversation about how there was probably going to be some overlapping between the categories with the themes that were emerging. We also discussed how the data were similar and saturated in many areas for many of the interviews. We talked about how categories can hold themes that are divergent from one another. As I entered the open-coding phase, I used feedback from my peer reviewer to clarify the emergent categories. This process helped provide validation because she was able to help me conclude that we had reached saturation when we found repetitive themes within the data. I journaled, documenting my personal reflections on the discussions during our intercoder agreement process (Creswell, 2014). I consulted with my peer reviewer during the axial coding phase of clustering and drawing connections between the codes (Strauss & Corbin, 1990). The results of the peer-review consultations are discussed in the results and conclusions section of this paper (Brantlinger et al., 2005; Creswell, 2014).

Ethical Considerations

Participants self-selected into this study and were under no pressure or requirement to participate. Each participant had an opportunity to self-select a pseudonym that was used in the reporting. All recordings and transcriptions were stored on a password-protected computer, in password-protected accounts. Transcriptions were downloaded from the transcription company and placed into documents that were stored on my secured computer. The binder with the paper transcripts and my notes were stored in a locked cabinet at my home.

During the peer review process, the transcripts were stored and accessed through password-protected email accounts. The peer-reviewer agreed, through a promise in writing, to protect the security of the transcripts and any personally identifiable information that was included about the participants in the transcripts. All personally identifiable materials will be destroyed three years after the study is completed. Participants were allowed to defer answering any questions in the interview (although none did).

This project qualified for exempt status through the IRB because the project was designed to pose minimal to no risk for the participants. At all times through the design and planning of this research, I endeavored to create a project that honored the experiences of families raising children with ONH. Even though interviewing parents of children should pose no more than minimal threats to the parents' vulnerability, I acknowledged that all persons are vulnerable (Lahman, 2017). As such, I was committed to a conscientious and compassionate approach to listening to each of my participants. I honored my participants with beneficence throughout the data collection, analysis, results presentation, and reflection stage of this project. I recognized that even though there would be no direct contact with children, the parents of these children may be vulnerable to grief and suffering due to the hardships of raising a child with a significant disability. If participants asked me for resources to assist them with parenting their child, I offered follow-up communication to assist them with locating support.

This project aimed to provide a deeper understanding of the support needs that children with ONH possess. I want to suggest ways to best support these children by identifying strategies that work for their families. Throughout the analysis and writing of my findings, I strove to ensure that my participants felt that their voices were accurately represented. I hope that this research will serve to establish a foundation for educational research in ONH and that it will support the development of interventions to mitigate the challenges associated with ONH.

Conclusion

Children with ONH represent a unique subset of the total population of children with special needs. Most children with ONH have problems, in addition to their visual impairment, that require specialized medical and educational care. Families, educators, and care providers of children with ONH need strategies and support for meeting these children's needs. Children with ONH need targeted and individualized approaches to support their development. Additionally, there are characteristics of ONH that are commonly expressed, and these characteristics should be addressed through targeted interventions and support strategies.

Parents of children with ONH have expertise and knowledge about their child's needs. This study investigated families' experiences with parenting and raising children with ONH. Twelve semi-structured interviews were conducted to collect data on parent perspectives of raising children with ONH. The interviews provide a window of understanding into the challenges that families have to address to support their children as well as the strategies that are working for these families as they support their children. The themes that were derived from the interviews were investigated and summarized through the lens of the research questions. The analysis of responses along with participant and researcher reflections provides educators, researchers, and families with suggestions for interventions and strategies to improve models of service delivery for children with ONH.

CHAPTER IV

RESULTS

The purpose of this study was to explore, understand, and represent the experiences that parents of children with ONH have with meeting their child's developmental needs. Twelve semi-structured interviews with parents of children with ONH were conducted. Eleven of the participants were mothers, and one of the interviews was with both the mother and father of the child. The following research questions guided my inquiry:

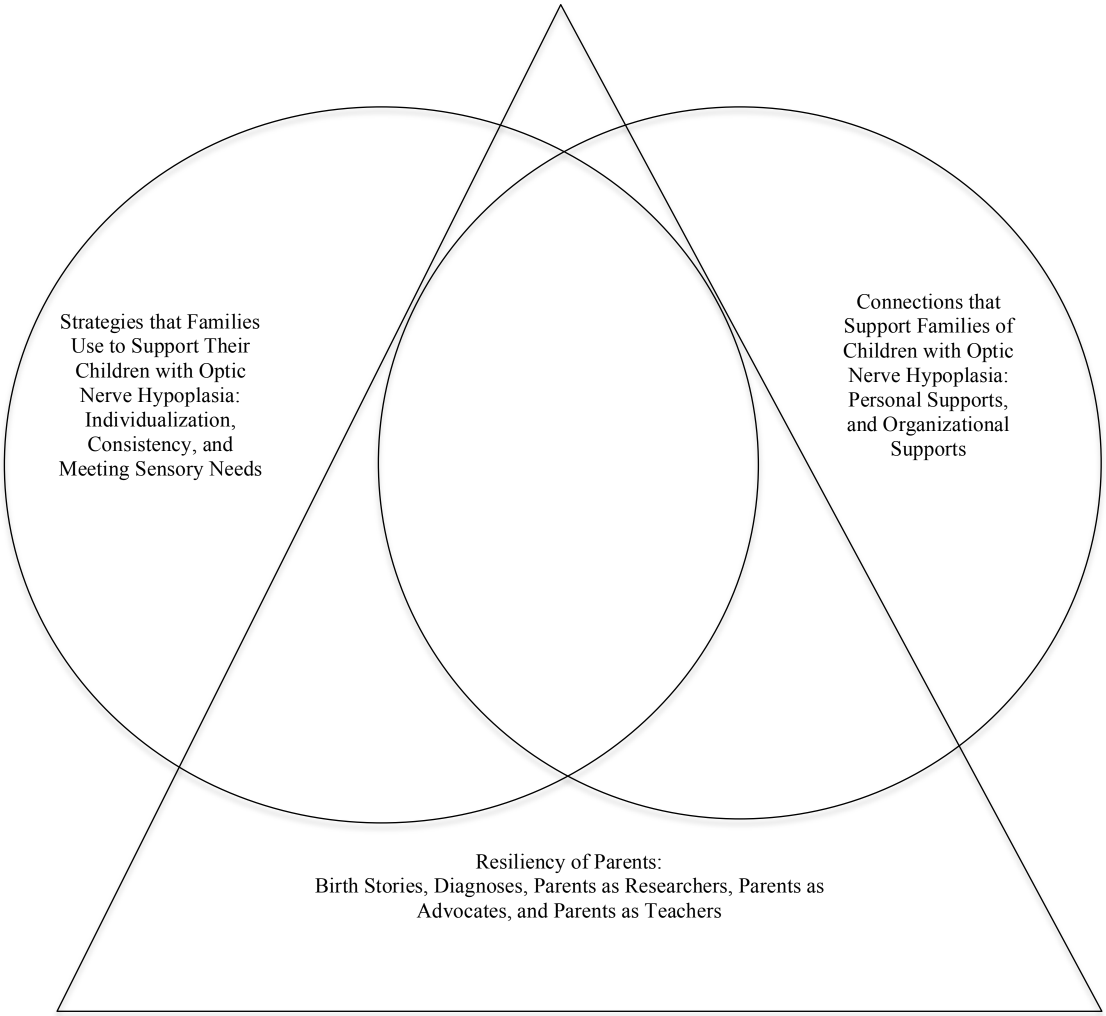
Q1 How are families of children with ONH experiencing support systems for raising their children with ONH?

Q2 What strategies are families using to support the developmental needs of their child with ONH?

This chapter exhibits the key findings that I derived from the interviews and follow-up communication with the participants. Through the processes of transcript analyses, personal journaling, conversations with my peer reviewer, and member checking, three major categories emerged from the data: (a) resiliency of parents who have children with ONH; (b) strategies that families of children with ONH use; and (c) connections that support families of children with ONH. These three categories each relate directly to the research questions. A visual representation of the thematic analysis follows.

Figure 1

Organizational framework for the thematic analysis of parents' experiences raising a child with optic nerve hypoplasia.



Note. This visual representation exhibits the relationship between the three major categories and their related themes. Resiliency emerged as a cornerstone category that has overlapping characteristics and relationship with the other two major categories of strategies and connections.

The strategies that families of children with ONH use to support their children, and the connections that support families of children with ONH are categories that exist, in large part, because of the parents' resiliency. Another way of depicting the relationship of the categories and themes is to envision the image of a tree with roots that grow deep underground. With this image in mind, the tree’s root structure and base of the trunk symbolize the category of resiliency. The trunk of the tree separates into two major branches. Those two branches represent connections and strategies. Continuing with this analogy, the limbs of the branches are the themes and subthemes of the categories. The following discussion describes the findings depicted in the preceding figure and analogy.

In the next sections, I discuss the categories and the themes and subthemes that are nestled within the categories. The categories and themes are exemplified through specific details, including quotes and thick descriptions. When individual quotes or stories are highlighted, the participants’ pseudonym is used. At other times, I use terms such as *the participants* or *the parents.* At the end of this chapter, I return to the research questions and articulate how the categories and themes reveal critical insights to the research questions.

Resiliency of Parents who Have Children with Optic Nerve Hypoplasia

All of the participants in this study described their experiences with persevering through the challenges of parenthood with a tone of hope. Their children’s births, followed by their diagnoses of ONH, launched the parents into unique care provider roles for their children. The (a) experiences with their children’s birth and (b) diagnoses, succeeded by the three major roles of: (c) parents as researchers, (d) parents as advocates, and (e) parents as teachers, formed the five themes that emerged within the major category of resiliency of parents who have children with ONH.

Recently, terms such as resiliency, growth mindset, and grit have gained attention. Researchers and speakers, Angela Duckworth and Carol Dweck, have articulated the relationship of these traits to academic and personal success (Duckworth et al., 2007; Yeager & Dweck, 2012). In some literature, resiliency is defined as a component of grit. Certainly, there is overlap in the semantics of these words. For the sake of clarity in this discussion, I define resiliency as:

> The psychological quality that allows some people to be knocked down by the adversities of life and come back at least as strong as before. Rather than letting difficulties, traumatic events, or failure overcome them and drain their resolve, highly resilient people find a way to change course, emotionally heal, and continue moving toward their goals. (*Psychology Today*, n.d.)

In one example of how the parents exemplified resiliency, Baysan described how she accepts her daughter's unique needs and how coming to terms with the implications of raising a child who has a severe visual impairment helped her move forward to support her child:

> Most people look at me and go, "You wouldn't want her to see?" Well, that's not what I mean. I love her for who she is. I accept her for who she is, and this is her life. And this is my life. So I can either take it, or I can let it just debilitate me to the point of not being able to function, which means I will not be a very good parent if that were to happen.

Birth Stories

For the participants in this study, resiliency started with their child's birth story. The birth stories represent the hope and expectations that the families had for their baby's future life. These stories mattered to the parents, and I chose to begin by sharing one of the birth stories I heard.

> She's my second baby girl, and I just had this feeling that something wasn't quite right. I don't know. I guess it was God's way of preparing me for what I was going to be facing. Little did I know that what I was going to be facing wasn't what I thought I was going to be facing. At worst, I thought it was going to be, okay, she's going to have a congenital

> cataract, which run in my family. . . . Yeah, but I just had this feeling in the gut of my stomach . . . and I couldn't figure out why, or what was going on. And I picked up the phone and called one of my friends who's a pastor. And originally he is from Nigeria. And I picked up the phone and I calmly said, "Okay, I need for you to name this baby for me." And he said, "Give me a minute." And within less than 5 minutes he called back, and said, "You shall call her . . . which means she who encourages and comforts." And that's exactly what she does, even with the challenges we go through with her. She is definitely my little shero. . . . I would not change anything about that child, vision problems or not. (Baysan)

The birth stories are related to the hope the parents had for their babies. That hope was evident even as the parents expressed feelings of sadness and worry that they carried after they received the initial diagnosis of ONH. In addition to recognizing that many medical professionals don't know much about ONH, a majority of the parents relayed that their child's diagnosis was delivered harshly and without much information. Parents who were able to access a children's hospital received more comprehensive information and supportive early care than those who were not near a children's hospital. The parents began resource gathering after their child's birth and diagnoses.

Diagnosis of Optic Nerve Hypoplasia

Most children with ONH are not diagnosed at birth. They are diagnosed later, when they are several months old. The initial diagnosis for the participants frequently came on the heels of the detection of significant endocrine problems. Sally described:

> He was hospitalized for his endocrine issues at about three months old. And the endocrine doctor said, "Hey, most kids who have this have a visual impairment." A

> pediatric ophthalmologist came in and did a consult. He literally looked over Ian, he did some sort of exam, as much as you can do on a three-month-old, he wrote the acronym O-N-H, he wrote [name of preschool for children with visual impairments] on a piece of paper, and essentially walked out.

Erin shared a similar experience: "The ophthalmologist we saw handed us a post-it note and told us to go home and Google it and to come back in six months and that Pippa, at best, would be legally blind." Many parents reported using Google to search for information on their child's diagnosis. When parents were near a hospital with specialists, they received a connection to support agencies for early intervention. Elizabeth, who lived in a rural area, shared that she appreciated receiving a phone call from their doctor after they got home from the hospital: "I was very appreciative of that, but it just felt like we were very much alone, and I didn't realize that there were other families out there."

Every child is different and after the diagnosis, it was hard for families to get concrete information. There isn't much information available on ONH, and what is available can be hard to sift through. Many parents referred to Dr. Borchert's research and work on ONH. Several of the families had participated in Dr. Borchert's research studies and had very positive experiences working with Dr. Borchert, who was described as "hands down amazing and [he] gave us a whole different light as far as what our destination would look like." Ultimately, all of the parents had to work hard to gather information about ONH after their child's birth and diagnosis. These parents quickly became researchers, advocates, and teachers.

Parents as Researchers

After the diagnosis, the parents began looking for answers; they changed their course and began resource gathering. The parents were curious and driven, and they wanted to know what the diagnosis meant. There was limited literature available on ONH, and the parents described frustration with the sparsity of information. The participants shared that the physicians who provide medical care for their children with ONH were also learning about the condition and what it means for those children. Families who had a connection to a nurse, physician, or special educator expressed that having those connections was helpful.

As the parents gathered information, they began learning that ONH encompasses more than just the eyes. Alexa's son was diagnosed after an emergency visit to the hospital when he was 28 days old. She described asking what an ONH diagnosis meant:

> And she (the head neurologist) said, "You know, the brain is very plastic. It adapts." She said, "You don't know what it'll mean. We don't know what it'll all mean." And I said, this is one of those strange moments where we go to the hospital to fix the things, right, and they were telling me, well, we can't fix it. This is a hospital so you need to fix it.

Another mother shared that she "didn't have the heart" to look things up on her own and that having a friend who was willing to take on the early research helped her.

The parents quickly began learning about how children with ONH have different visual and developmental outcomes. They learned that some children with ONH have endocrine problems and others do not. Megan shared about her initial research efforts after a doctor gave her the name and contact information of another mother who had a child with ONH:

> It took me some time to work up the courage and desire to want to talk about it. But, I did eventually call her. But, I was unaware of the spectrum part of ONH and how varying it can be. And so, when I talked to this other mom, her daughter had some vision loss. And she was in the third grade, I think. And so, when she was talking through all the things that her daughter was able to do and all of the things that the school was providing for her, like

> the CCTV and just a bunch of different things . . . and there's quite a lot of difference between visual impairment and complete blindness and all of the stages in between that. And so, what this woman had given me, an impression of what it would be like that her daughter could see. And it was very different from what my reality then became because Olivia doesn't have usable vision. And so, I think that was hard to adjust to, having that expectation of only having spoken to one other person that had dealt with it. . . . I think it's all about . . . a lot about expectations and when your expectations are set for one thing. I mean, to start with, you expect to have a baby that can see. And then . . .

Megan's reflection demonstrates both the hope and frustration that the parents experienced as they navigated the diagnosis and what it would mean for their child. The most supportive diagnoses came along with connections to early intervention services. However, the experiences with referrals to early intervention services varied greatly.

Parents as Advocates

Some parents had to advocate for early intervention services, especially families who lived outside of a metropolitan area. Elizabeth stated that she fought to get services for her son and when the first therapist arrived, the therapist would not provide services because Elizabeth's family was not on Medicaid, "So, that's what we experienced. I had a kind of breakdown that day because I had worked so hard to get her to my house." Another parent felt defeated after she called the state school for the blind in her area and got no information on early intervention from the agency; she was told to call back when the child reached preschool-age. Advocacy was a theme throughout the interviews, beginning in the child's early years and rooted in the parents' research efforts and what they learned about how individuals with ONH have varying outcomes and characteristics.

The parents had to be resilient to continue to advocate for their children throughout the stages of childhood development. Elizabeth summarized:

> I feel like you have to keep pushing with this diagnosis. Just because somebody tells you, “No,” or “That’s not how this works,” the best thing that I’ve found is to ask yourself, “Why wouldn’t it work?” And do some extra research. Because what I found is that doctors don’t know a lot about this condition and sometimes they don’t like to be asked questions. And so we, as parents, we have to strategize and figure things out, what our kids need compared to the other population and work on it as a case-by-case. . . . I feel like you have to be your own advocate, and you cannot expect someone to guide you by the hand because no one is going to do that because it’s just so rare and it’s just so different for each child.

There is a lot to learn about a diagnosis of ONH. Alexa recounted how she walked into a preschool for children with visual impairments after her son was diagnosed. It was there that she began learning about both blindness and advocacy. Her son’s early intervention O&M instructor taught her about how blindness is a low-incidence disability, and that families and educators have a responsibility to advocate and make people aware of blindness. Alexa recounted her major take away from the O&M instructor’s advice:

> People can’t get used to it [blindness] if you hide your blind children away, or blind people don’t go out of the house, or things like that . . . that’s the only way to get people aware of blind people in general . . . no one’s going to make changes that benefit the blind community if they don’t see any blind people.

The participants’ learning and early advocacy work paved the way for their ongoing advocacy efforts as their child moved into the public school system.

Advocacy in the School Years

The transition from early intervention to school-based supports marked an instance when parents had to increase their advocacy. The shift to school also meant a shift away from the community that parents built with their early intervention providers and teams. As Molly put it. "There was a lot of support in EI, then once you get to school age, it doesn't feel like a community anymore." Many parents shared that the transition to school-aged services felt difficult.

Most of the parents expressed experiencing challenges to get their child the services they need at school. Mabel summarized her advocacy approach: "You need to be the parent that says, 'Uh-uh, I want this.'" Matt recalled a battle with his child's school to have his daughter's access needs addressed after she began acting out in school. The child's school was not providing accommodations for tasks that required visual skills:

> We got this scary email saying that she broke pencils and turned over a chair. . . . So, I asked "Well, what was she doing? What was the environment?" We started asking a whole bunch of questions. . . . Any time they asked her to do a vision-based task, she was in meltdown. Come to find out, she's blind, like I kept saying.

These parents had to teach their child's school about accommodating their child's needs. Several families expressed feeling that the school team drove the outcome of the IEP process. Most of the participants emphasized the importance and value of parents being active members of the IEP team. Half of the participants described how they have had to continue to advocate for the appropriate educational setting for their child. Sarah articulated her ongoing advocacy work to keep her child in the general educational setting at school:

> Our life skills classes are glorified daycare and I'm like, no. . . . Yes, she's behind her peers. Yes, I will tell anybody that. She is behind her peers. But, she is learning. She is growing. She is progressing, and I'm not going to let you stop that.

The participants shared that advocacy work can take a remarkable amount of time and energy.

Parents as Teachers

The parents reported that they work with their children on daily living skills around the house. The daily living skills they mentioned included: tooth brushing, cooking, dressing, and toileting. Teaching these tasks required that the parents analyze and provide direct instruction for their children in the home. The parents developed individualized methods for moving their children through the daily routines.

Thinking outside the box and trial and error were listed as the two predominant approaches for developing strategies to teach their children. More than ever during the COVID-19 pandemic, parents mentioned the stress of having to play teacher to their child with ONH. Ultimately, the parents reported that difficulties with juggling multiple kids' needs, online/remote learning, and technology problems, while the stress of worrying about their child's regression felt heavy. An additional section on the parents' experiences during the COVID-19 pandemic will be discussed further at the end of this chapter.

The parents expressed that they have to be resolute with their expectations and that it is important to treat their child with ONH as they would treat any child. They stated that they have to hold their child accountable and provide discipline. One mother revealed a personal struggle that she has had with her son's challenging behavior; she feels she has to bend her principles when imparting consequences because he doesn't understand consequences the same way as her other children. In fact, several parents mentioned that striking a balance of tough love, while maintaining integrity for their own sense of what is right, was hard.

Teaching children can be taxing, and the parents of children with ONH have additional challenges to manage as they juggle teaching and raising their children. Erin reflected:

> Sometimes she's just not in the mood to learn anything new or be independent in a new way. And so, she would much rather just have me do it for her, or she gets mad when I try to help her or instruct her. And sometimes, I'm not in the mood to explain to her how something needs to be done. Because I know how to do it. And even as a parent, for any kid, it's easier to do it myself than teach them how to do it.

Additionally, participants shared feelings that their kids are often harder for them, pushing more boundaries than they do with their teachers. Alex reflected on supporting her daughter during remote learning: "It puts parents in a position to be the teachers, and kids are worse with their parents in general."

The parents reported having to be both creative and structured in their approach to supporting their children's development. These demonstrations of the parents' resiliency, followed by their creativity and innovation, show how the parents used their research, advocacy, and teaching skills to develop strategies for raising their children. Matt was the only parent who explicitly expressed the importance of patience, but patience was certainly implied by all the parents I interviewed. Matt stated that he needed:

> Patience with her, patience with systems, patience with doctors that are learning alongside you. . . . Patience with appointments because you have to have a specialist that's four hours away . . . just patience as a human, in general.

Patience, hope, and tenacity carried the parents as they developed approaches to support their children with ONH.

Strategies That Families Use to Support Their Children With Optic Nerve Hypoplasia

The parents I interviewed repeatedly highlighted that each child is an individual. What works for one child with ONH doesn't necessarily work for other children with ONH. The phrases "think outside the box" and "trial and error" came up in many of the interviews. The families emphasized that they had to try a variety of approaches and suggestions to find tactics that worked to meet their child's needs within the context of their family life. The child's need to touch in order to learn without vision came up a few times. Mabel shared that some people don't understand the ways that blind children access the world: "Somebody was just so worried about him touching things and getting through his vision issues. . . . He just had to learn how to be blind. I don't know how to say that, but he has to learn to be blind."

In addition to adjusting to the learning styles of their children, the families reported that they have had to structure their home and work lives differently than they had originally planned. Several of the parents mentioned that they felt fortunate that one of the parents could be a homemaker. Two of the participants mentioned the gratitude that they felt when they were able to resign from their jobs because their spouse received a substantial raise. One single mother in the study reported that her son travels to another state to spend the summer with his grandparents so that she can maintain her job. The intensity and demands of parenting a child with ONH required that the parents developed personalized strategies that work within the context of their family, to approach short- and long-term goals with their child.

When the families find something that works to help support their child, they generally stick to that approach. The participants shared that they have to pick their battles and choose when to focus on a particular task. Erin described how she considers the expectations she sets for her daughter and how she weighs that against "how much do you want to poke at her and make her do stuff that makes her uncomfortable and causes more behaviors?" Other parents shared this same sentiment, and many expressed the importance of the child having a space in the home where they can spend time alone.

Several parents commented on how the home environment and schedule are very different from school. These parents have had to institute more rigid scheduling at home to emulate the level of structure that the child receives in the school day. Many of the children in this study, especially the children who have a diagnosis of ASD, were reported as being inflexible and rigid in their preferences and needs for routine. Overall, three themes emerged under the category of strategies to support their child's developmental needs: (a) individualization, (b) consistency, and (c) meeting sensory needs. Details of these themes and suggestions from the parents follow.

Individualization

The theme of each child being unique and needing support and daily structure that is different from siblings and other same-aged children was prevalent in the interviews. Furthermore, what works for one child with ONH does not necessarily work for the next child. The parents reported that they have asked for suggestions on Facebook forums as well as from their child's teachers and therapists. I heard several parents emphasize that the child has to learn the skills to complete tasks they are being asked to do. The parents also stated that some tasks are obviously easier than others.

Ultimately, a lot of the individualized approaches came out of learning from trial and error. Some of the techniques are parent-guided, and others are child-directed. Megan described how listening to a 2-minute podcast called *Chompers* has helped her daughter focus while brushing her teeth. Baysan shared that her teenage daughter carries small toys/objects with her to calm herself as she moves through her day. The parents reported that they try techniques that are suggested, work with what their children naturally do, and then develop approaches that they can support within their family. Most of the parents reported that, even with individualization, their child needs a lot of verbal prompting to execute routine tasks throughout the day.

Many of the parents described how their home environment is individualized to meet their child's personal needs. The parents stated that the children thrived when they had their own individual space. The families organize their homes in a manner that the children can find things like their cups, plates, toothbrushes, pants, and shirts. Also, the children's bedrooms are individualized to be a space of comfort and peace. Several of the parents shared that the children enjoyed their bedrooms and spending time alone in their rooms. Thus, the need for individualization encompasses approaches to structuring how the families spend their time as well as how they organize their spatial environment.

Consistency

If something isn't working within their home life, the families reported that they shift and try a different approach. Once they find an approach that works, they stick with it. The parents expressed how their children with ONH thrive on consistency, schedules, and routines. Maintaining a rigid schedule with high expectations can be challenging for the families. Over and again, I heard about how important it is for the families to maintain consistent scheduling, even when they want to break from their routines.

Alexa shared that "the psychologist told us 'get yourself a routine, whatever that routine is. It doesn't matter.'" So, the family instituted and maintained a consistent evening routine of dinner, shower, and then a bedtime story before sleeping. Alexa recalled how one night when she gave her son a shower and strayed from the routine of eating first, he said, “But, Mama, but, I’m hungry.” At that point, she knew that the routine was solidified for him.

Each of the participants emphasized things such as checklists, routines, and schedules. These types of tactics provide the children with a level of comfort that they need in order to thrive and transition through activities in their day. The parents remarked that transitions are particularly hard for their children. Baysan described her daughter’s rigidity, “ Ruby, she don’t shift easily.” Marie articulated, “He is a very black and white guy. We have always done checklists and . . . the routines help with anxiety.” Matt attributed a lot of his daughter’s growth with the structures their family maintains in their home lives: “We do a lot of routines, and that has been especially important part of our success.” Another participant described how they have to consistently embed sensory activities into her daughter’s playtime routines because those sensory activities help with regulating her daughter’s behavior.

Meeting Sensory Needs

Many of the parents reported that preferred sensory-based activities make their children happy. Several parents described how their children are happy in the summer when they can spend a lot of time at the pool. Playing in water and playing with music were the two traditional activities that a majority of the parents reported their children enjoying. In addition to these conventional types of activities, most of the parents reported that their child engages in sensory stimulation behaviors such as playing with fidget toys, spinning in circles, rocking, cutting paper, and kicking.

Sometimes the results of sensory stimming can cause problems for kids with ONH. Alexa described how her son has engaged in some stimulatory behaviors that have required redirection and training.

> He has some pretty significant stimming issues. It used to be on the mouth, hand on the mouth. He would smack himself on the mouth. It's gone to more head down, hand on the forehead. He had started picking on his left hand, his thumb, middle knuckle, and pinky knuckle.

Alexa stressed that he always has some kind of repetitive stimulatory behavior. Another mother described how her daughter kicks with her feet against the bed frame and other surfaces. She wondered if the preschool program her daughter attended had ingrained this habit because they spent so much time encouraging the children to explore materials with their feet.

Several of the parents reported that redirecting or moving the children away from self-stimulatory behaviors is difficult. Most of the parents reported that shifting activities, in general, is difficult for the children. As Erin put it, "There is no waiting her out because it doesn't work. She will always win that game." Megan stated, "I find that trying to convince her in the moment to change, or that things aren't that big of a deal, is mostly impossible. . . . Talking through things helps her a lot." Sarah shared that she can see her daughter's body language and that when her daughter is physically tense, Sarah can tell it's going to be a hard day.

The parents suggested that they can read their children's moods and body language, and they have found ways to support them at home. Most of the participants who have elementary-aged children reported that even with the structures and supports they provide, their child still relies heavily on verbal prompting to move through their daily routines and schedules at home. The participants who have older children remarked that their daily home routines have gotten easier. However, they also shared that it has taken consistency and a lot of work over the years to get their child to a higher level of independence at home. The parents emphasized that their children with ONH also need support, opportunities for involvement, and connections from people and organizations outside of the home.

Connections that Support Families of Children with Optic Nerve Hypoplasia

The families in this study have experienced various degrees of support from their connections with people and organizations in their communities. The parents have networked within their communities to find supports that have helped them meet their children's needs. In most cases, the immediate family provides the majority of the care and support for the children. The additional supports that participants mentioned provide things like childcare, education, therapy, and recreation. Some of the supports the families mentioned came from seeking help from people in their communities. Other connections were forged through work with organizations that are structured to provide support for the parents and children. In the following section, I discuss the supports that the families described. These support structures fall under the two main themes of (a) personal supports and (b) organizational supports.

Personal Supports

The parents described personal connections such as family, friends, faith, and networking that they have experienced. A few of the parents did not indicate having personal supports, or only mentioned the supports that are provided through organizations such as school or their private therapists. While none of the participants specifically indicated their marriage/spouse as a support, many who were married did make references to decisions and actions that they had made as a couple, suggesting that marriage may be a supportive structure. Megan recalled frustration with seeking connections to other families who were dealing with the same challenges, saying "There's nothing, there's no way to connect people. And when I would try to Google and search, there just wasn't a way for me to find people who were dealing with the same thing." Overall, the details of personal supports the families described (or didn't describe) speak to both resiliency and isolation.

Family Connections

A few of the participants stressed that their parents provide a lot of assistance and support with childcare. However, most of the participants reported that receiving support from their extended family has been difficult. I heard about stress, more than support, related to other members of the family helping with the child with ONH. Marie shared:

> He gets sick and overheated . . . so, like, my mom would never keep him. He makes her nervous. My husband's parents are not very supportive. So it is really like, because our own family doesn't really do much . . . it's harder for me to reach out past that.

Rachel described how she and her husband have had to adjust their work schedules to accommodate for their daughter's needs:

> We do not have any support. We have worked hard to keep our schedules. He would work during the day, and I would work at night, so we would never have a daycare situation for her. So it was always either him or I at home.

Molly explained how having family and friends help with care can disrupt the systems they have in place for their daughter:

> Because she requires such a strict schedule, that when you try to have family and friends get involved in her current schedule, schedules kind of fall apart, and then everything kind of falls apart. So, as much as you want to have the support . . . that can also complicate what you are working towards in your home. . . . So, if you have one, two,

> and three that you follow each day, Nana comes over and wants to do three, two, one, it makes things very complicated.

Babysitters

Even though many of the families qualified for respite care, none of the families reported using respite care services. However, several participants mentioned using babysitters from their community. Elizabeth described in detail how she found a nanny for her children and how this nanny has helped her family, saying “We met a lady on Craigslist for babysitting . . . my kids consider her to be their second mom . . . they even call her Mama Jane. . . . I don’t know how other families make it without a Mama Jane. I mean, seriously.” This nanny and her children have become like members of Elizabeth’s family. Mama Jane provides comfort, care, and stability for Elizabeth and her family as both she and her husband work and they have two children with ASD, including the son with ONH.

Several other participants specifically remarked at how difficult it is for them to find babysitters and when they did find babysitters, many quit. Sarah lamented, “We’ve never found anyone else that can handle her and be okay with it, and not just be terrified with every single step of the way.” One of the participants indicated that she has a few friends who help her, but that she initially had a hard time accepting the help of her friends.

Friendships

A few parents mentioned supports they receive from their friends. Baysan shared that she didn’t want to ask for help, but her friends helped her accept help:

> I didn’t even want to ask anybody to help . . . because, again, I thought, “Okay, what if they don’t understand why she’s acting like this, or obsessing over this?” And so, finally, I had a really good friend to say, “Get over yourself. We’re coming to get this baby. And

> we're going to go to the park and play" . . . and as she got older, I saw the relevance in saying "Okay, you all, I do need some help. I'm overwhelmed." And people that love her . . . they love her for her, just like I do. And I had to let them in my space.

Another mother described how she talks with other moms at her workplace to find out what's working for their families. A couple of the parents shared that they are friends with their child's TVI. While not all of the parents discussed their own friendships, many expressed concerns about their child's friendships.

Several of the parents described worries that they have about their children having friends and how they feel that friendships are important supports for children. Several of the participants acknowledged that their child prefers to spend time alone. Elizabeth stated,

> He doesn't really like to play with others. He would much rather be by himself. . . . So, we haven't really pushed a lot of exposure to social exposure just because he doesn't like it. And we should probably do that more.

Megan shared that she was planning to move her daughter to a state school for the blind for her middle school years, and friendships were one of the primary reasons for the move:

> You need commonalities with your friends. And when it's difficult to find those because of certain barriers, it makes it difficult to find friendships, and so taking that barrier away and being able to place her in a place, in the situation where she's surrounded by people in that one aspect, it takes away that one barrier, and will allow her to just flourish a lot more.

Sarah observed that other children don't know how to interact with her daughter, saying "A lot of kids who don't know her or don't understand her, they think she's a baby. 'She's such a baby.' That's what we would hear all the time." A few of the participants shared that their child benefits from opportunities to be around other children who are blind. Additionally, some of the participants mentioned that having connections with adults who are blind is helpful.

Connections with Adults Who are Blind

Several of the participants remarked on how they have learned from networking and talking with adults who are blind. Tate stated, “They offer a different perspective than even doctors can. Doctors go very much by the book, and adults who have been dealing with it themselves for 30 years have solutions that aren’t in a textbook.” Megan shared how she polled a group of blind adults for suggestions to help her find techniques to support her daughter with applying toothpaste to her toothbrush:

> I was like, “Guys, what do you do? Because I’m so tired of cleaning up toothpaste everywhere.” One of the ladies suggested, she said, “I just had my own tube of toothpaste, and I open it, and put it on my tongue and squeeze a little bit on my tongue and then put the lid back up. And it’s never a mess because it’s only in my mouth”. . . . And, I was like, “That is genius.” So, now, she has her own tube of toothpaste. And she knows exactly which one it is. We’ve got one that’s little bit different shaped from the other one, so that she knows which one is hers.

Other parents indicated that they would like opportunities to talk with more adults who are blind. Two of the parents have been working with an adult with ONH who has similar characteristics as their child. These parents shared that having connections with adults who are blind is invaluable and that they will continue to seek out opportunities to network and learn from adults who are blind.

Faith Life

Some of the participants shared that their personal faith life offers them both an outlet and support for managing the challenges of parenting. Sally stated:

> Our family, we're a family of faith, so we spend a lot of time praying and just trying to figure out the next best thing or how to solve a problem. That's how our family handles it, and I mean, that's kind of been how we've done this whole journey.

Several parents mentioned that their church is very welcoming, and one shared that someone in the church found books in braille for her child. However, a couple of the participants also shared that the church volunteers often don't understand their child's needs and that the volunteers are timid about having the child with ONH participate without an assistant. During member checking, Elizabeth shared,

> I went to church for the first time since the pandemic hit, and a lady approached me and asked me if I would want to start a Bible study with her for special needs mommas. How she even knew I was a special needs mom?? But I am so excited!!!!!!!!! I need friends so much, if I could do a cartwheel, I would.

Other participants also expressed how that their faith life has provided them and their child with friendships and support.

Organizational Supports

The parents indicated that they receive a variety of support from different organizations. The participants described activities and support their child receives from public and private organizations as well as the therapists who work through agencies. Several of the families mentioned valuing the connections that they have received through the National Federation of the Blind and the programs such as camps that the National Federation of the Blind offers. This study was conducted during the COVID-19 pandemic, and many of the supports that the participants typically receive have changed as a result of the pandemic. Additionally, the supports from organizations varied by state and regions within the states.

Community Organizations

In addition to the church communities that were discussed under the theme of *faith* in personal supports, the participants mentioned Special Olympics, community recreation clubs, Girl Scouts, and parent support groups. Overall, the participants have had varied experiences with inclusion in their communities. Elizabeth stated, “We were basically quarantined prior to the quarantine.” Other participants shared how they have encouraged their children to explore things like Girl Scouts and various church groups so that they could be exposed to different groups and people. Through her networking, Mabel found an after-school program for her son that provides him with both recreation and educational support.

Home-Based Therapies

Parents indicated that a variety of in-home therapies have helped them with meeting their child’s needs. Several of the families indicated that they access private therapies through Medicaid waivers to receive services**.** Sarah said, “Our pediatrician introduced us to early childhood intervention that was local right here in our town, and they came into our home and truly became our support system.” Many of the families reported having phenomenal experiences with their early intervention providers and that these providers were their support networks when their child was young.

Erin appreciated the resources from her daughter’s therapists, but described that participating in private therapies felt like more work. So, they discontinued private therapy when it felt overwhelming:

> It became we're at the clinic on these days, and we're doing this these days, and it just got to the point where it was like, "Yes, we're making some progress." Is it faster? Is it faster than just getting to have some free time and to enjoy our evening together and to be together? And, to me, the answer was no, it's not. . . . And we're blessed to be able to ask them questions, and they've been super supportive about how to make home life just as great.

A few parents mentioned that their child receives private occupational and music therapies and that their child enjoys these therapies, but they did not elaborate in further detail. Three families mentioned that their child receives private psychological counseling to work on obsessions, anxieties, and emotional regulation.

Speech-Language Therapy. Several of the families specifically mentioned that they have had negative experiences with their child's home-based speech-language pathologists. These families stressed that their child has decent receptive language skills, but that the private speech-language pathologists relied heavily on visual cues and visual prompting and did not adapt their instruction to meet the child's needs. The participants shared that these experiences were frustrating because their children struggle with expressive communication and the parents believe that problems with expressive communication is a barrier to making friends.

Applied Behavior Analysis Therapy. Three families shared that their child receives applied behavior analysis (ABA) therapy, and these parents spoke very highly of their experiences working with the board certified behavior analyst (BCBA) who comes to their homes. The participants reported that the BCBAs have worked on addressing a variety of behaviors, including screaming and self-injurious stimming. One of parents mentioned that their child has received ABA therapy since they were two years old.

Applied behavior analysis therapy was the one private therapy that the parents cited has continued, without interruption, during the pandemic. One mother shared that they have increased her son's sessions with the BCBA during the pandemic. The parents stated that the ABA therapy occurs in their homes as well as the surrounding public community. Elizabeth shared her frustration with the regulations around her son's BCBA therapist working in her son's school:

> We did a ABA program . . . it was really helpful because he struggles with empathy and transitions. . . . We were going to bring our ABA therapists with us to transition him into school and it turns out insurance won't let us do that.

Alternatively, another participant was very opposed to her child having a formal behavior assessment and has withheld her child's ASD diagnosis from the school team because she feels that the school will use the diagnosis as an excuse to lower expectations for her daughter.

Services Vary by Region

Several of the families have relocated while raising their child with ONH; these parents remarked on the differences in services from place to place. Marie said, "We were in between Utah and Nevada, and the resources are so different between the two states." Another mother reported having to fight for services before they moved to Colorado. Even within states, the availability and access to services vary.

In Sarah's state, there is a funded program to provide in-home support to kids. She described the frustration with lack of consistency with her child's case manager:

> We just got assigned a new case worker. We get assigned a new case worker anywhere from every 6 months to every 18 months, and we hear from them when they first get our

> case, and we never hear from them again, and the next time we hear from someone is when we get a new case worker again.

Another participant shared that the community programs in her region seem to depend on who is leading the efforts and that when the leaders move away, there have been collapses in programming.

The caliber and availability of TVIs and O&M specialists also came up in some of the interviews. One mother remarked how her son has had TVIs who couldn’t pass exams for their certification. Another participant shared that services in their region used to be amazing, but the lead O&M instructor left, and things seem to be falling apart without his leadership. Yet, another parent commented on the differences in service structure and delivery between neighboring school districts in a metropolitan area.

School

The families’ experiences with navigating school programming ranged from very positive to consistent difficulty. The main challenges the families cited were associated with the educational setting and low expectations that members of the school team set for the child. Several participants shared that accommodations are very important for their child and that when necessary accommodations were not provided, the child struggled with behavior; this causes conflict between the school team and the family. Sarah shared her frustration with fighting the school wanting to write a behavior plan for her daughter. She reported telling them, “You give me justification on why you need this. If you’re following her accommodations and you’re giving her what she needs, why do you need this other stuff?” Another mother recalled how her daughter advocated about her schedule with the school and the O&M instructor because she didn’t want to miss classes in order to attend her O&M lessons. One participant shared that her son is traumatized because the school has failed to differentiate for his learning disability in math.

For families who have had challenges with placements and supports at school, the main concerns expressed were around the school trying to place the child into a severe needs program. The participants expressed concerns that placing the child into a severe needs program both isolates their child and lowers the expectations for their child. However, several of the families indicated that their child benefits from having a 1:1 paraprofessional educator supporting them at school. Consequently, without authentic interactions with their peers, the social concerns the parents have are exacerbated. Rachel commented on the outcome of social isolation at school: “She has had more interaction with adults in her entire 13 years of life than she has ever had with children her age.”

Some of the participants reported that their child moves back and forth from the general education setting to the severe needs classroom throughout the day and week. While the participants shared concerns about setting and expectations, those concerns were directed at the school, in general. Most of the participants referred to their child’s TVI as a separate entity from the rest of the school providers.

Many of the participants spoke highly of the educational vision services their child receives. Most of the parents remarked that their child’s TVI provides immense support to their child and family. Tate said, “Thank God for TVIs. If there wasn’t vision teachers in the world, we would all be screwed.” The parents emphasized that having a TVI who can think outside the box and maintain high expectations is important for children with ONH.

Parents' Experiences Supporting their Child During the COVID-19 Pandemic

The first interviews for this study occurred three months into the pandemic. At this stage, the parents were reflecting on the changes during the end of the school year. Later interviews and follow-up communication with the participants yielded many rich details about their experiences with their child's educational services during the pandemic. Nine out of the 12 participants remarked that their child's special education services have changed dramatically. The participants who have children who have attended in-person learning commented that they felt very fortunate that their child was able to attend school. Only one participant, Elizabeth, commented that remote learning has been very positive for her family. She shared that the therapists and teachers "see me more as a person and not some crazy demanding mom wanting as much services as possible. My child is not as stressed and seems more happy overall."

The other families stated that remote learning has been very challenging for their children. "No calling. No computer. No teacher," were the words of one of the children represented in this study. The participants said that their children need in-person supports and that the children required a lot of assistance accessing their remote lessons. The participants described many additional demands and burdens that have been placed on them as parents. Alexa stated:

> Any type of tech issues could cause an overwhelming amount of frustration and shutdown. There were daily and weekly situations where he would not have been able to participate without someone, myself, with him to assist. By assist, I mean collecting supplies and setting up activities with the OT as well as cooking activities he did prior to winter break. It was also necessary for me to assist with tech issues on an almost daily basis. I did lunch walks with the kids and provided sensory breaks as needed.

Other parents reported needing support with their child’s technology and devices. The participants said that the pandemic has disrupted the structures and services that their child depends on for learning and behavioral regulation. One parent anticipated that when her daughter returns to in-person learning, post-pandemic, she will have an uphill battle to have the same (pre-pandemic) services put back in place for her child. Molly shared the struggles she has had with supporting her daughter’s education during the pandemic:

> Covid has been REALLY challenging and really took a lot of toll on parents and kids. Not only has society expected visually impaired kids to learn visually, our access to so many services has been delayed. Thank heavens we have an amazing independently owned place we receive OT and she has never had to close down and has continued to offer outside/covered area services. Vision support took almost 4 months to “get up to par level” and get a system that would actually allow Caylie to learn. Also, the constant change/unpredictability has been tricky . . . we have setup consistency at home to try and keep our systems in order, even when school/therapists were not able to support that.

Marie emphasized that her son stopped receiving special education services during the pandemic, saying “We lost all our SPED support . . . I was a one woman show, and I was not doing too great with all of it. . . . The lack of support was really hard for our family.” For most of the participants, the challenges associated with the pandemic were exacerbated by the demands of supporting remote education for their children with ONH. Consequently, many of the participants mentioned extreme fatigue and frustration related to parenting their child during the pandemic.

Conclusion

The goal of this study was to learn about the experiences that parents of children with ONH have with raising their children. I wanted to learn about the support structures and strategies that have helped families of children with ONH. The participants in this study shared their experiences through open-ended interviews. Three major categories emerged from the interview data: (a) resiliency of parents who have children with ONH, (b) strategies that families of children with ONH use to support their children, and (c) connections that support families of children with ONH. These categories and the themes they contain can illuminate approaches, interventions, and further pathways for research to support children and families with ONH.

CHAPTER V

DISCUSSION

Optic nerve hypoplasia is rising in prevalence and is a leading cause of childhood VI (Garcia-Filion et al., 2008; Ryabets-Lienhard et al., 2016). Medical research on ONH suggests that collaborative, multi-disciplinary care is needed to support the developmental needs of children with ONH (Ryabets-Lienhard et al., 2016). No research on educational interventions or researched-based models of educational programming for children with ONH exists. Moreover, intervention research is limited throughout the field of VIs (Ferrell, 2006; Sutter et al., 2020). My experiences working as a TVI and my work in educational research led me to pursue this study. I hope this study on parents' experiences will inform future research and practitioner efforts to develop interventions and programming to support children with ONH.

Children with ONH have varying degrees of VI and are at increased risk for concomitant hormonal dysregulation as well as behavioral and developmental problems (Ryabets-Lienhard et al., 2016). The complexities of having a VI with co-morbid conditions that impact health and learning suggest that children with ONH need specialized educational approaches to support their unique needs. Families are experts on the needs of their children. The methods that families use to support their children with ONH can inform researchers and practitioners. The expertise of parents of children with ONH can suggest new pathways to approach educational programming for children with ONH.

This study investigated families' experiences with support systems and the strategies that families use to raise their children with ONH. I expected to find that families' experiences with raising a child with ONH would include isolated and disjointed models of support from the medical and educational teams. However, most of the participants in the study remarked that they received referrals to early intervention from their medical providers. Furthermore, many participants indicated that their child's medical team connected them to ophthalmology services (or vice versa). The participants also stated that their child's educational teams are multi-disciplinary. I also expected to find that families employ individualized strategies to support their children through daily routines. A majority of the participants indicated that they use a trial-and-error method for problem-solving strategies to use with their children. I found that many of the families use similar and structured approaches (routines, repetition, consistency, and sensory-based approaches) to support their children. Finally, I expected to find that the comforts of the home environment would afford the children opportunities to practice their independent living skills. I thought that learning about the children in their home environment would illuminate environmental adaptations that could be used at school to support the teaching of ECC skills. However, my primary take-away was that the home environment affords necessary personal space to support the child's self-regulation needs. Many of the participants stated that their children thrived on having alone time in their rooms. This indicates that a defined, personal space in the school setting may be helpful for children with ONH. The findings of this study revealed that families employ resiliency, apply consistency in their strategies and daily routines, and use their limited personal and organizational connections to support the developmental needs of their children with ONH.

Restatement of the Research Problem

Optic nerve hypoplasia is a leading cause of childhood VI, and there are limited resources for families and practitioners who support children with ONH. As previously stated, the available research on ONH is medical or epidemiological, not educational. Even within the field of medicine, there are limited consensus and guidelines available for the medical providers who support children with ONH (Ryabets-Lienhard et al., 2016). Evidence suggests that educational providers are struggling to support the concomitant learning, sensory, and behavioral challenges associated with ONH (Bahar et al., 2003; Rundle Kahn, 2018; Rundle Kahn & Conroy, 2019; Sabine, 2019; Wooster, 2016). The prevalence of ONH juxtaposed with limited educational research on the topic, suggests that children with ONH, their families, and their practitioners need interventions and research to support them.

Parents are experts on their children. This phenomenological qualitative research study explored parents' experiences raising children with ONH. Parents' experiences and expertise can inform stakeholders of what areas are going well and what areas need improvement. Furthermore, the strategies that parents employ can illuminate directions for educational research and intervention development. Twelve parents of children with ONH were interviewed to explore the following research questions:

Q1 How are families of children with ONH experiencing support systems for raising their children with ONH?

Q2 What strategies are families using to support the developmental needs of their child with ONH?

Three major categories emerged from the interview data: (a) resiliency of parents of children who have ONH, (b) strategies used by families of children with ONH, and (c) connections that support families of children with ONH. In this chapter, these categories and their themes are discussed in detail as they pertain to the research questions. Some of the themes under the categories provide insights to both of the research questions. Where overlap between the categories and themes occur, an explanation is provided. This discussion of the study's findings is organized under the headings of the research questions.

Families' Experiences with Support Systems for Raising their Children with Optic Nerve Hypoplasia

The participants expressed that they receive support from a variety of organizations and individuals. The major categories of *resiliency of parents of children who have ONH* and *connections that support families of children with ONH* address how the parents experienced support systems. It is notable that school services, one of the major support systems for families of children with ONH, vary dramatically by region, even in neighboring communities. Overall, the families who live closer to a metropolitan area had stronger and more frequent connections to resources that provide support and services. Several participants indicated that a lack of qualified and knowledgeable personnel was a problem in their area. This finding is congruent with the literature on personnel shortages within the educational field of VIs (Howley et al., 2017).

The parents' resiliency started with their hope for their child's life. Resource gathering and advocacy work followed their child's diagnosis. The participants indicated that their child's medical providers are often learning alongside them and that the characteristics of ONH look different from one child to the next. Many of the participants indicated that they have had to continually advocate for their child's services and support systems. Consequently, the categories and themes around resiliency and connections are interrelated.

Organizational Supports

Many of the parents remarked that their child's early intervention services felt very supportive. A few of the families had to advocate for early intervention services or had trouble initiating early intervention services. Overall, early intervention seemed to provide the families with a level of support that met their needs. Several of the participants remarked on the discrepancies between the early intervention and school-based services. This is interesting because I wanted to understand the experiences of parents who have school-aged children. The parents reported that their early intervention services felt more supportive than their child's school-based services. Early intervention services are family-centered and routine-based. This suggests that services that work within the natural routines and rhythms of home life feel more supportive for children with ONH, and their families, than school-based services.

Several of the participants remarked on the structure and setting of services in the school systems. The parents recognized that the best education providers for their children are providers who can be creative problem-solvers; the term "thinking outside the box" came up in many of the interviews. Interestingly, creativity and innovation are not traits that are commonly measured in teacher performance reviews. However, these traits are highly valued by parents and are considered necessary for supporting children with ONH.

The parents stressed that each child with ONH is very different and what works for one child with ONH does not necessarily apply to their child. Individualization is a pillar of special education programming and the theme of individualization came up repeatedly in the interviews. Notably, several of the families cited specific problems with their child's IEPs, indicating that the school is not meeting their child's individualization needs. This suggests that IEP teams are failing to accommodate the individualized needs of children with ONH and that design and implementation of accommodations should be emphasized in the IEPs of students with ONH.

The parents cited that a lack of accommodations for the child's visual impairment was the major cause of problems with the child's educational setting or educational providers. In one case, the child's behavior escalated whenever the school insisted that she complete vision-based tasks. Many of the parents shared that they have had to advocate for their child's educational setting, or the least restrictive environment, within the child's IEP. These parents did not want their child to be placed in a self-contained classroom for children with severe needs because they felt that their child would not be appropriately challenged in that setting. Thus, while educational services and structures were noted as a primary source of support, these services also caused the parents to employ their advocacy skills. When parents have to continually advocate for appropriate services, they begin to anticipate problems and lose trust in their child's school team. This finding emphasizes that collaborative problem-and shared decision making are critical for determining the appropriate setting, accommodations, and supports for the child's IEP.

Supports for Education During the COVID-19 Pandemic

Parents serve as the primary teacher for their children throughout their development. The role that parents play as teachers has been exacerbated throughout the COVID-19 pandemic. While experiences with the COVID-19 pandemic were not the focus of this study, feedback from the participants captured their experiences during the unique circumstances of the pandemic. Initially, a few families referred to the support that they received during the late spring of 2020. Because the entire study was conducted during the pandemic, I decided to explicitly ask the participants if they would be willing to provide feedback on their experiences supporting their child during the pandemic.

A few of the families stated that their child had been fortunate to attend a school that has been in-person since the start of the 2020-2021 school year. One participant indicated that the remote learning environment was supportive for her child. Another family suggested that the pandemic has caused them to pull back on their advocacy efforts for their daughter. This same family reported that their shift in focus has resulted in their child's academic and personal growth; they intend to keep their focus on supporting their daughter at home. They have even ordered curricula and materials to support her at home.

However, most of the families reported that their child's access to an appropriate and rigorous education has suffered greatly during the pandemic. The participants cited learning platforms and websites that don't support assistive technologies for students with visual impairments, general technology problems, and their child's overall need for in-person interventions and therapies. Several participants mentioned that they have taken on extra duties with the children and that they are responsible for gathering supplies and facilitating therapies from home. Moreover, many participants cited the students' regression and the additional stresses placed on their families due to changes in school services during the pandemic. Several of the parents indicated that they could not work while supporting their child's remote learning needs. The families' resiliency during the pandemic has been tested; the parents expressed fatigue and isolation while supporting their child with ONH during this unprecedented time. Most of the limited supports that the families rely on have been removed during the pandemic.

Personal Support Systems

A majority of the participants indicated that support from their extended family was generally limited. The child's behavioral needs, including their need for structure and routine, were cited as barriers to receiving support and help with childcare. A few parents indicated that the child’s grandparents provide regular childcare to facilitate the parents’ work schedules. None of the families utilized professional respite care services, even though many of them indicated that they qualify for respite care support. This finding is interesting, considering that several of the families also cited challenges with finding and retaining quality private babysitters for their child with ONH. This suggests that even though the parents want and need respite, the parents don’t feel that they can release the care of their child to others because of the disruption to their child’s routine and the lack of follow-through by other care providers.

Many of the families shared that their relationships with their child’s early intervention team and their child’s TVIs were sources of support. A couple of the participants in the study mentioned that their child’s TVI is a friend of the family, sharing that they participate in recreational activities with the TVI outside of school hours. These relationships started as professional relationships and have been maintained, providing personal support for the families of children with ONH. Additionally, outside of school, some community organizations helped the families of children with ONH.

Community Connections

Most of the participants in this study indicated that their child has been involved with different community organizations. The two organizations most frequently mentioned were churches and the National Federation of the Blind. The parents who mentioned supports from churches indicated that their church provides them with valuable social connections. The participants appreciated their connections from camps and programs that were sponsored by the National Federation of the Blind. In particular, the parents reported that relationships with adults who are blind and have ONH have helped them strategize ways to support their child. Several of the families who did not have connections with adults who are blind indicated that they would like to know adults or older students with ONH.

While churches, the National Federation of the Blind, and a few other organizations were cited as providing support to the families, a tone of isolation was present through the interviews. One participant mentioned that the pandemic hasn’t changed much for her family because they were isolated before the pandemic. Typical community connections and activities that provide support to many families are absent for parents of children with ONH. Many of the parents expressed feeling isolated within their extended family. Furthermore, the participants shared that they were concerned about their child’s lack of friendships.

The children’s lack of friendships with same-aged peers was a concern of the participants. Many of the parents stated that their child doesn’t have any friends, and several indicated that their child relies on adults for prompting and interactions throughout the day. One participant articulated how her daughter has had more interactions with adults than she has ever had with her peers. Heavy reliance on adults for communication and prompting appears to help precipitate the social barrier for these children. School providers could facilitate social activities that incorporate the preferred activities of children ONH to foster friendships. However, none of the participants mentioned peer-mediated strategies or focused social skills instruction for their child.

Interestingly, several parents indicated that speech-language services have been problematic for their child. These participants shared that their child’s receptive language skills are strong, but their expressive language skills are lacking. The parents suggested that speech-language pathologists have relied on visual methods for teaching the child with ONH. In other words, these speech-language pathologists did not adapt their instructional strategies to meet the child's unique visual and sensory needs. I wondered if the problems the children have with expressive language are correlated with their problems making and maintaining friendships and social connections. Conversely, the participants who receive ABA therapies indicated that these therapies help with their child's challenging behaviors, leading me to wonder if BCBA therapists might be able to work with the children to help them develop social language skills and conversation starters.

Several of the parents mentioned that they have friends at church and work. These friendships provide the parents with emotional support and social opportunities that they value. Social media was only mentioned a few times in the interviews. I was surprised that the social media forums were not highlighted as a major source of social connections and, thus, support for the participants. This suggests that the families want personal connection and that their opportunities for personal connections are limited. Some of the participants mentioned that they would like to connect with other families from this study to share ideas and gain insights from other families who have had similar experiences. This led me to conclude that facilitated connections between families who are raising children with similar characteristics could be supportive and beneficial for families.

Resiliency of Parents who Have Children with Optic Nerve Hypoplasia

The resiliency of the parents informed each of the themes and subthemes related to supports for raising a child with ONH. First, the parents learned that each child with ONH is different. Next, they used applied problem-solving skills and sought connections and resources to find supports and strategies that would work within the dynamics of their family.

These families showed resiliency in the individual ways they made decisions that supported their child and home life. One participant mentioned that they decided to stop in-home therapies because they felt that having downtime in their schedule was beneficial. This parent reflected that having extra time in their evening schedule felt more supportive than continuing with additional intervention services after school. Several other families indicated that they have worked and advocated to have additional services and therapies added to their child's schedule.

Maintaining long-term goals for a child to live a happy and independent life can be challenging in the face of short-term goals that require substantial effort, structure, and repetition. This is one reason why resiliency is the cornerstone for both the supports and strategies that the families experienced and employed. The love and hope that these parents have for their children have carried them through some very hard times. Experts recommend a multi-disciplinary model of service for supporting children with ONH (Bahar et al., 2003; Ryabets-Lienhard et al., 2016). While the quality of services varied by region and throughout the transitions of the child's life, the parents demonstrated that their resiliency provided both strategies and support for their child.

Strategies that Families of Children with Optic Nerve Hypoplasia Use with their Children

The participants in this study stressed that they have individualized tactics to meet their child's developmental needs. Again, the resiliency of the parents was a major category that emerged from the interviews, and resiliency is directly related to the strategies that families use. I have already defined how the parents' resiliency provides the foundation for support and strategies. So, the focus of this section is on the strategies and tactics that the families have developed to support their child's developmental needs.

Many of the parents indicated that they have utilized trial-and-error methods to find ways to support their child. Overall, the participants reported that their children with ONH are rigid individuals and that the children need creative approaches that incorporate sensory activities and structure to accomplish tasks and learn. The main themes related to strategies that the families used include routines, consistency, and providing for their child's sensory needs.

Routines

The participants stressed that their child needs routines in order to be successful. Almost all of the parents described how their child depends on daily routines to navigate their days. A few of the parents discussed that they use checklists and written schedules in their homes. Other parents indicated that they use verbal prompts including phrases such as, "first we wash our hands, then we sit at the table." The families who had older children reported that the routines got easier over time and that their children became more independent throughout the day at home, as they got older. Many of the families stressed that their child needed repetition to master a task. When consistently implemented, routines provided repetition within the natural flow of home life.

Consistency

The families reported that their child needs consistency to mitigate anxieties and also to help them acquire and master skills. The generalization of skills to multiple environments was challenging for many of the children represented in this study. While it might take these children longer to learn specific skills, they eventually do make progress on their goals. However, this progress is only possible when the children have consistency in their routines and when clear expectations are established.

Several participants indicated that they have concerns about expectations for their child. These parents expressed concerns about their own expectations around the child’s behavior. Additionally, the participants stated that it is important for people who work with their child to have high expectations. These concerns are contrasted against the child’s significant reliance on adult prompting and support for task completion throughout the day. This confound suggests that the individuals who provide the prompting and support need to be vigilant about consistently holding students with ONH accountable for skills they have mastered. Furthermore, adults who support children with ONH need to ensure that the child has the skills they need in order to complete the tasks they are asked to do. These findings suggest that routine-based learning and interventions, such as those approaches that are used in early intervention, may be necessary to support some children with ONH through their school years.

Sensory Needs

Many of the participants shared that their child needs to engage in sensory activities throughout their day. A few parents described how they embed sensory breaks (swinging and music) throughout the day. The two main sensory activities that were mentioned were water play and playing with music. The children enjoy their bath times and swimming. One of the families reported that their child participates in formal music therapy sessions, and most of the other families shared that their child really enjoys listening to music or making music.

Meeting the child’s sensory needs is imperative to helping them work toward accomplishing their daily goals. One mother shared that she has scheduled sensory breaks for her son during his remote learning. Another parent described how they work on concepts while her daughter swings on a platform swing. Several participants shared that their child needs sensory stimulation and that sensory breaks are a part of their child’s educational accommodations.

Children with ONH need individualized structure, support, and sensory activities to help them develop and meet short- and long-term goals. Some of the parents' efforts are visible to their child's educational and medical teams. Other efforts of perseverance and creativity that the parents exert may be hidden to the practitioners and researchers who support and study the needs of children with ONH. These latter efforts are the strategies the parents employ to support their child's developmental needs at home and the connections that the parents make so that their child can be engaged within their communities.

Relations of Findings to Previous Research

Children with ONH have complex developmental needs, and this was evidenced in the experiences that the participants shared. Previous literature on ONH documents the concomitant learning and health problems that often accompany the diagnosis of ONH (Garcia-Filion et al., 2008; Ryabets-Lienhard et al., 2016). Ultimately, a diagnosis of ONH indicates a significant risk for the child's neurological functioning. Specifically, 60-80% of individuals with ONH have hypothalamic-pituitary dysfunction, and approximately 25% of children with ONH have a diagnosis of ASD (Ryabets-Lienhard et al., 2016).

Diagnosing ASD in children with ONH is challenging for several reasons. Assessing and diagnosing ASD in a child with a visual impairment requires a specialized understanding of the unique developmental and social challenges associated with visual impairments (Gense & Gense, 2005). Additionally, social communication barriers and behaviors such as rocking and hand-flapping, that many children with ONH exhibit, are behaviors that are commonly observed in children with ASD (Ek et al., 2005; Gal et al., 2010; Garcia-Filion et al., 2008). Children with ASD and visual impairments need unique and specialized interventions to support their development.

There is limited research focusing on interventions for children with visual impairments who also have ASD (de Verdier et al., 2019; Gense & Gense, 2011; Probst & Walker, 2017). Banda et al. (2014) conducted a systematic review of intervention studies on students with ASD and visual impairments. Their review yielded a total of eight studies; half of the studies addressed communication problems and the other four targeted behavior problems. Each of the studies utilized single case design, and the majority of the interventions began with a preference assessment prior to implementing an intervention (Banda et al., 2014). In addition to calling for replication research to help build an evidence base for this area of study, the authors concluded that future research efforts targeting the generalization of skills, including documentation of skill maintenance data, is needed (Banda et al., 2014).

Gense and Gense (2011) authored a practitioner report that provides suggestions for adapting learning environments for children with co-morbid ASD and visual impairments; the authors challenged professionals to apply knowledge from both fields to design programming for the unique population of learners. The foundation of the framework that Gense and Gense (2011) suggested includes the consideration of the unique sensory and biological needs of the child. In addition to using data and designing instructional strategies through task analysis procedures, the authors called upon educators to provide consistent reinforcements and opportunities for meaningful communication, and to offer support of concept development through concrete and tangible supports, when designing instruction (Gense & Gense, 2011). These recommendations are synonymous with the types of individualized, routine, and sensory-based strategies that the parents in this study utilized to support their children with ONH.

The findings of this study demonstrate that children with ONH need consistency, routines, and support for their unique sensory needs. Similar to children with ASD and visual impairment, or deafblindness, children with ONH can benefit from ABA therapy as well as relationship-based approaches to meet their developmental and behavioral needs (Clarke-Bischke & Crowley, 2011; Haakma et al., 2016). Consistency, routines, and the use of preferred and familiar activities help children with ONH regulate their emotions. These findings are congruent with recommendations for fostering the development of early self-regulation skills (Ayres, 2005; Cho & Palmer, 2008; Williams & Shellenberger, 1996).

As previously mentioned, problems with the hypothalamus and pituitary that frequently occur in children with ONH and ASD each elevate the risk for problems with self-regulation. The field of occupational therapy has a large body of research on sensory integration strategies that support children who have sensory processing disorders. Jane Ayres is widely recognized as the mother of sensory integration theory (Schoen et al., 2019). In the time since Ayres' introduced sensory integration theory, numerous research teams have investigated the efficacy of sensory-based interventions. There are a plethora of systematic reviews investigating the efficacy of sensory integration interventions for children with special needs (Barton et al., 2015; Bodison & Parham, 2018; Schaaf et al., 2017). The volume of reviews is, perhaps, a result of the competition to develop and identify evidence-based practices for students with special needs. In 2019, Schoen et al. published a systematic review of Ayres Sensory Integration interventions, using the *Council for Exceptional Children's Standards for Evidence-Based Practices* (2014)*;* the authors cited sufficient evidence for the establishment of sensory integration interventions based on Ayres' methods. Research on interventions that target self-regulation can inform practice and approaches for supporting children with ONH. Most of families in this study described that they apply sensory-based strategies to support their children through routines at home.

The parents of children with ONH have harnessed their own resiliency to meet and support their child's needs. The resiliency of parents of children with special needs and chronic illnesses has been studied. Experts recommend that the psychosocial demands on these families should be supported through an affirmation of their experiences and the provision of resources for healing and support (Koegel et al., 1992; Rolland & Walsh, 2006). Some of the stress experienced by families of children with special needs experience is immitigable; other stressors such as childcare, community, and educational supports can be alleviated through family-centered services such as respite and inclusive educational and recreational activities (de Verdier et al., 2019; Openden et al., 2006). Parents want to learn from adults who have experienced living with visual impairments. Consequently, connections with adults who have visual impairments and adult mentoring for students with visual impairments have been shown to increase self-efficacy in youth who with visual impairments (Bell, 2012).

The experiences of the participants suggest that many children with ONH struggle with expressive language and developing friendships. This finding is congruent with Heyl and Hintermair's 2015 study that found competent communication skills in children with visual impairments are positively correlated with social-emotional development. Furthermore, social skills are identified as an area in which students with visual impairments may need explicit support and instruction (Sacks, 2014). Friendships are an important part of childhood development and are commonly recognized as having a positive influence on adult and school life.

Meaning and Significance of the Study

The findings of this study provide a foundation for educational research on ONH. There are significant gaps in the literature on ONH, and this study reveals the experiences of parents who have navigated medical, educational, and home interventions while supporting their child's development. While ONH is a leading cause of childhood visual impairments, visual impairment is a low-incidence disability, and there is limited research available to address the functional and educational needs of children with visual impairments (Ferrell, 2006; Sutter et al., 2020).

Throughout my doctoral studies, I have received several requests to provide consultations to educational teams that support children with ONH. These requests tell me that the parents and educational providers of the children want support and suggestions to help their children. Many of the parents in this study said they were happy to be a part of a study that focused on ONH because resources on ONH were limited. The available literature on ONH is clear: there are multiple complications and associated challenges with ONH (Garcia-Filion & Borchert, 2013; Ryabets-Lienhard et al., 2016). However, beyond citing these characteristics and suggesting multi-disciplinary approaches to care, the literature is lacking tangible recommendations to support the developmental needs of children with ONH. The developmental implications gleaned from medical research on ONH and the substantial body of evidence supporting consistent approaches and sensory integration strategies for children with sensory processing challenges translates into the functional challenges that the families experienced in this study. The specific themes identified in this study provide insights into what is working for families and children with ONH.

The participants in this study identified that support, connections, consistency, routines, and sensory-based approaches to learning are critical to their child's success. In fact, the child's developmental outcomes are related to these themes. When any of these elements were lacking, their children demonstrated regression in their skills and had increased incidences of challenging behaviors. The parents in this study had extensive experience with navigating systems and educational approaches to support their children. These participants cited that early intervention services were the most supportive and helpful services they have received. Early intervention services are often family and routine-centered (Ely & Ostrosky, 2018).

There are discrepancies between family-centered early intervention services and the educational services for children with ONH in schools. The transition from early intervention services to school-aged services marks a significant change in routines and structure for children with ONH. Transitions and changes in routines are particularly challenging for children with ONH. School-home partnerships are critical and become strained when schools fail to accommodate the unique individual needs of the child with ONH. Expectations for student performance and progress are identified through the IEP process. Therefore, parents and providers must collaborate to determine appropriate expectations for children with ONH.

The parents in this study stressed that they have employed trial-and-error methods to support their children at home. School-based therapies and interventions for children with ONH should take into account the individualized methods that families and early intervention providers have developed to support children with ONH. These methods, routines, and sensory strategies should be integrated across both the school and home environments to maximize consistency in expectations. Children with ONH need repeated opportunities to practice new skills to achieve mastery. Consistency in expectations and methods across environments is critical for children with ONH.

This study revealed parents’ concerns about their child’s lack of friendships. While social skills are a component of the ECC for children with visual impairments, evidence suggests that TVIs are failing to utilize parent relationships to facilitate growth in non-academic ECC skills (Yarbrough et al., 2019). Families of children with ONH emphasized that their relationship with their child's TVI is crucial. This need implies that TVIs need adequate time and to build and maintain relationships with their students' families.

Families of children with ONH are often isolated within their communities and even within their extended families. This isolation leads to parents taking on many roles for coordinating support for their child. None of the families identified that they receive support from a social worker to coordinate their child's care and services. The most supportive connections for parents of children with ONH are personal and relationship-based: friends and family, church, and local community organizations. Additionally, parents of children with ONH value the expertise of adults with ONH and learning from other families of children who have similar characteristics as their child. There is a lack of infrastructure for identifying and forging these types of connections for families of children with ONH.

The findings of this study are significant because they highlight the collective expertise of parents of children with ONH. These findings can contribute to families', educators', administrators', health care providers', and researchers' understandings of approaches that work to meet the unique needs of children with ONH. Furthermore, these findings indicate that families of children with ONH need support educating their loved ones and community members on ONH and how the needs of their child with ONH translate across environments.

Participants in this study consistently shared that their children have very individualized preferences and needs. While not surprising, this finding suggests that the parent interview component of the children's educational assessments should explore the individual characteristics of each child, as these characteristics relate specifically to the areas of the ECC for children with visual impairments. By focusing on the child's characteristics and learning preferences, educational assessments and interventions for children with ONH can become strengths and preferences-based.

Implications for Practice

The findings of this study suggest that families of children with ONH have expertise to share, yet the parents and their children are often isolated in their communities and educational teams. The organizational supports for children with ONH are limited outside of early intervention and school, suggesting that organic social opportunities for children with ONH and their parents are somewhat limited.

Practitioners should network with members of the community to help provide comprehensive services, supports, and connections for families of children with ONH. Providing educational services to the student in their greater community may help children with ONH and their families bridge the gaps between school, home, and community involvement. Services such as O&M instruction and social skills practice, outside of school grounds, can increase the students' visibility in the community. This visibility can offer opportunities for providers to educate members of the community. Additionally, families want a connection with adults who are blind. Teachers of the visually impaired should have resources to connect families with adults who are blind. Agencies such as the National Federation of the Blind and the American Foundation for the Blind should work with teachers and families to provide connections and mentoring throughout the country. Families who live in rural areas may benefit from social connections with adult mentors that can be maintained via remote communication platforms.

Practitioners who teach and support children with ONH can also benefit from the expertise of adults with visual impairments. Chris Sabine is an adult who has ONH, and Mr. Sabine has published numerous blogs and videos that provide an inside perspective on his unique experiences living with ONH (ONH Consulting.com, n.d.). These resources may be particularly helpful for practitioners who wish to deepen their understanding of how challenges associated with ONH impact learning, employability, and quality of life.

Educational service providers should consider that routines and consistency are fundamental to supporting the child with ONH. Maintaining routines and consistency with expectations are important considerations for the IEPs of children with ONH. Therefore, a consensus around expectations for the child's independence and learning throughout the school day should be collaboratively determined. Several families indicated that their child receives support from special education para-educators. The adequacy of training for para-educators raises concerns related to student outcomes (Conroy, 2007; Lewis & McKenzie, 2010). When para-educators support educational programming for children with ONH, it is imperative that they receive training specific to the unique characteristics of the child. The parents of children with ONH can provide valuable insights into the needs of their child.

A diagnosis of ONH implies that the child will have unique needs beyond their visual impairment. Practitioners should apply creative methods to support and increase social skills and self-regulation in children because children with ONH are at significant risk for problems in these areas. The families in this study suggested that their children enjoy music and playing in water. Several participants also suggested that expressive language skills and speech-language pathology services have been challenging for their children. Practitioners who support children with ONH should explore the use sensory breaks throughout the child's day. Novice speech-language pathologists should seek the expertise of other providers who have experience working with students with visual impairments. The *Playing with Words* microsite on the Paths to

Literacy website may help providers initiate relationships, establish rapport, and develop meaningful instructional strategies for working with students who have ONH.

Finally, the participants in this study stated that networking with other families of children with ONH would be helpful. Practitioners can help connect families by reaching out to other providers in their region to find connections for the families. Offering social gatherings or virtual meetings for families of students with ONH is one simple way that practitioners can help families of students with ONH network with each other.

Limitations and Implications for Future Research

Research and educational resources specific to ONH are limited. This qualitative study captures and synthesizes the experiences that 12 parents of children with ONH have with navigating support systems and meeting their child's developmental needs. This study was conducted during a global pandemic, and the parents who participated in this study chose to participate. Therefore, only parents who were interested in the study and those who felt that they could dedicate the time to participation were included. Other families, perhaps those with even less support than the participants, may have felt that they could not dedicate the time needed to participate in the study. Additionally, families who felt that they had adequate support and services may have felt that they did not have anything to offer to the study.

While this study was open to participants from across the United States, no families on the east coast participated. The majority of participants were from Colorado and other western states; a total of seven states were represented in this study. However, discrepancies in services and supports were evident, even with limitations in the geographical distribution of the participants.

Only 1 of the interviews was conducted with both parents of the child. The other 11 interview participants were mothers. While I did not intentionally recruit couples for this study, it is possible that the partners of these mothers would have shared different experiences, thus representing a potential limitation to conclusions about families' experiences. An additional limitation is that my first-level member checking had a poor response rate. However, this limitation is mitigated by the response rate during the final and second-level member checks.

Finally, while I made deliberate attempts to bridle my own biases throughout the research process, there are many elements of subjectivity in research. For example, I had to make decisions about what data and quotes to include, and what to exclude. I attempted to minimize the interjection of my own opinions in the results section by working with a peer reviewer, member checking, and triangulation with existing literature. Future feedback from my participants, my dissertation committee, practitioners, and individuals with ONH will be the ultimate test of the dependability of this study.

Several different pathways for future research can be derived from the findings of this study. Investigation of child-centered, routine-based educational programming for children with ONH is one suggestion. The families identified that early intervention services felt more supportive than school-based services. Because of the differences between early intervention and school-based services, research focused on the transition to school is warranted.

An investigation of the strategies and experiences of BCBA therapists who support children with ONH could provide insights for educational providers, as well as for families who resist ABA therapy. Exploratory research that investigates sensory integration techniques throughout the school day is another suggestion. Since listening to and playing with music is commonly defined as a favorable activity for children with ONH, an intervention study focused on music therapy or the use of music throughout the school day may help innovate and define an evidence-based practice for children with ONH.

The participants stated they would like to network with each other to share ideas. Research on adult mentoring and parent-to-parent support within the community of families who have a child with ONH would be interesting and could inform future interventions. Research on positive collaborations between families, medical providers, adults with ONH, and practitioners can illuminate new strategies and approaches for supporting the developmental needs of children with ONH.

Conclusion

Children with ONH have complex individualized needs. Nevertheless, there are commonalities among individuals with ONH that we can address. Past research has focused on the characteristics and prevalence of ONH. This study explored the phenomenon of parents' experiences raising their children with ONH. Three major categories emerged from the data: (a) resiliency of parents who have children with ONH, (b) strategies used by families of children with ONH, and (c) connections that support families of children with ONH.

These three categories of data show that resources for families and practitioners of children with ONH are needed. During member checking, I shared that I would like to create a simple pamphlet with resources for grandparents and extended family members of children with ONH. The participants responded favorably and suggested that simple and updated resources would be helpful for their families. As a result of the findings of this study, I am also developing a matrix that lists the characteristics of ONH and cites both practitioners and research-based strategies for interventions that align with the characteristics. This matrix will be hosted for families and practitioners through the Paths to Literacy website. I hope that families and practitioners will be able to use this matrix to find resources specific to meet their child’s individual needs.

Practitioners and researchers can learn from listening to, and working with, parents of children with ONH. Family involvement and children’s individual needs are pillars of the IEP process. Administrators who supervise TVIs need to recognize that effective school-home consultation and collaboration requires time and the availability of resources. The parents in this study emphasized that a positive relationship with their child’s educational providers, and in particular, the TVI, is imperative for their child’s success. Raising and educating a child with ONH requires a tremendous amount of effort and energy. It was my intention that this study would respectfully and accurately represent the experiences of the families who participated. I am optimistic that these families’ stories of dedication and hope for their children will inspire future efforts to meet the needs of children with ONH.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

UNIVERSITY OF
NORTHERN COLORADO
Institutional Review Board

Date: 05/01/2020

Principal Investigator: Amber Rundle Kahn

Committee Action: **IRB EXEMPT DETERMINATION – New Protocol**
Action Date: 05/01/2020

Protocol Number: 2004000854
Protocol Title: Exploring Families' Experiences with Supportive Structurse While Raising a Child with Optic Nerve Hypoplasia

Expiration Date:

The University of Northern Colorado Institutional Review Board has reviewed your protocol and determined your project to be exempt under 45 CFR 46.104(d)(702) for research involving

Category 2 (2018): EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS OF PUBLIC BEHAVIOR. Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

You may begin conducting your research as outlined in your protocol. Your study does not require further review from the IRB, unless changes need to be made to your approved protocol.

As the Principal Investigator (PI), you are still responsible for contacting the UNC IRB office if and when:

- You wish to deviate from the described protocol and would like to formally submit a modification request. Prior IRB approval must be obtained before any changes can be implemented (except to eliminate an immediate hazard to research participants).
- You make changes to the research personnel working on this study (add or drop research staff on this protocol).
- At the end of the study or before you leave The University of Northern Colorado and are no longer a student or employee, to request your protocol be closed. *You cannot continue to reference UNC on any documents (including the informed consent form) or conduct the study under the auspices of UNC if you are no longer a student/employee of this university.
- You have received or have been made aware of any complaints, problems, or adverse events that are related or possibly related to participation in the research.

If you have any questions, please contact the Research Compliance Manager, Nicole Morse, at 970-351-1910 or via e-mail at nicole.morse@unco.edu. Additional information concerning the requirements for the protection of human subjects may be found at the Office of Human Research Protection website - http://hhs.gov/ohrp/ and https://www.unco.edu/research/research-integrity-and-compliance/institutional-review-board/.

Sincerely,

Nicole Morse
Research Compliance Manager

University of Northern Colorado: FWA00000784

APPENDIX B

RECRUITMENT POST

Recruitment Post

UNIVERSITY OF
NORTHERN
COLORADO

Hello parents/primary caregivers,
I am a teacher for students with visual impairments and I am a doctoral student in special education. Are you a parent of a child (ages 5-18) who has optic nerve hypoplasia and additional behavioral challenges and/or developmental delays? If so, I would appreciate the opportunity to talk with you about your experiences navigating support systems for your child and I want to learn about strategies you are using to support your child through daily routines and long-term goals.

If you are interested in participating, please complete this brief google form to identify whether you meet the inclusion criteria and so that I have a way to contact you:
https://docs.google.com/forms/d/1jdaSkCr7RJVpGE9WQec_hkKREoHKt9DYiESa03Fh4uk/edit
After you complete this form and provide your email address, I will contact you with the procedural safeguards and information about providing consent for participation. Your participation will be voluntary and your participation will serve as indication of your consent. You will be asked to complete a survey that will collect your demographic information and we will schedule a time for your interview. The interview should take no longer than an hour and it will be completely confidential.

Thank you! I look forward to hearing from you.

Amber Rundle Kahn
rund8143@bears.unco.edu

Doctoral Student
School of Special Education
University of Northern Colorado

APPENDIX C

PARTICIPANT SAFEGUARDS AND ELECTRONIC CONSENT

Participant Safeguards and Electronic Consent

UNIVERSITY OF NORTHERN COLORADO

CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH
UNIVERSITY OF NORTHERN COLORADO

Project Title: Exploring Families' Experiences with Supportive Structures While Raising a Child with Optic Nerve Hypoplasia.

Researcher:
Amber Rundle Kahn, M.S.Ed., COMS, Ph.D. Student in Special Education: Blindness and Visual Impairments
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Research Advisor: Dr. Paula Conroy, Professor, Special Education
Email: paula.conroy@unco.edu

Purpose and Description: This qualitative study seeks to understand people's experiences with raising a child who has Optic Nerve Hypoplasia (ONH). Through interviews and personal reflections, this study will collect and analyze the individual experiences of parents of children with ONH. Through participating in this phone interview, you will have a chance to share your experiences and perceptions of the impacts of ONH on your life or practice. This study aims to contribute to the body of literature on the relevant topic of ONH.

The interview will take approximately one hour and will be recorded and further analyzed for coding of themes presented by yourself, and other participants in the study. Demographic information will also be recorded. However, your personal information will not be disclosed (e.g. name, contact information, location, etc.). All data collected from this study will be saved onto a password protected hard-drive that will only be accessible to the primary researcher and advisor for the purposes of this study. You will select a pseudonym to provide confidentiality to your responses.

The only cost in volunteering for this study will be your time. Other than helping to improve the understanding of supportive structures and strategies for supporting children with ONH, there will be no compensation for this study. There are no more foreseeable risks associated with this study greater than those encountered in a typical professional setting.

Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Please take your time to read and thoroughly review this document and decide whether you would like to participate in this research study. If you decide to participate, your completion of the research procedures indicates your consent. Your participation is considered to be a waiver of your written consent. Please keep or print this form for your records. Additional copies of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact IRB Administrator, Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910

APPENDIX D

DEMOGRAPHIC INFORMATION SURVEY

Demographic Information Survey

(Collected by Google Form prior to interview)

Thank you for the interest in my study. The information collected in this form will provide me with demographic information that I will use when analyzing and reporting the data from your interviews and reflections. All personal information that you provide will be de-identified in the final reporting process to protect your confidentiality.

Contact Information:

Your name

Your contact information (email and phone)

1. Tell me about your child

a. Please provide 5 words that you would use to describe your child

b. All medical diagnoses (including but not limited to: optic nerve hypoplasia, septo-optic dysplasia, hypopituitarism, autism spectrum disorder, hydrocephaly, ay other visual impairments such as cerebral visual impairment, etc…)

c. Age of your child

d. Gender of your child

e. How severe is your child's visual acuity? Can they see to read print or pictures in books?

f. What is your child's primary learning media/how does your child access educational materials? (braille, print, auditory)

g. How many years has your child has received special education services?

h. Did your child receive early intervention services?

i. Did your child attend preschool?

j. Where does your child spend most of their school day? (check: general education classroom, special education classroom, combination of general education/special education, a specialized school for children with visual impairments?

k. What are the titles of service providers on your child's IEP team? Check all that apply: (special education teacher, teacher for students with visual impairments, teacher of the deaf/hard of hearing, occupational therapist, physical therapist, speech language pathologist, mental health professional, nurse, type of service providers are on are the roles of people on your roles?

l. Does your child receive any therapeutic services outside of the school day? If so, please check: (occupational, physical, or mental health therapy)

2. Tell me about your family structure

a. Who lives in your home with you and your child who has ONH?

b. Do you have extended family or friends who help provide childcare and support?

c. Who from your family typically attends IEP meetings? Have you ever brought anyone else to meetings?

d. Do you help other families who have similar experiences to yours?

APPENDIX E

INTERVIEW PROTOCOL

Interview Protocol

These questions are designed to be open ended

How are families of children with ONH experiencing support systems for raising their children with ONH?

1. What were you told about ONH during the initial diagnosis?

2. Does your child's medical team provide you with connections for community supports? *Please explain.*

3. What types of adult support does your child receive at school?

4. Tell me about the relationships that help you support your child.

5. Tell me about ways that you feel you and your child are included in your community.

6. Do you receive any help with in-home care or respite care?

What strategies are families using to support the developmental needs of their child with ONH?

1. Please tell me about some of your typical daily routines such as getting ready for school in the morning, or spending the evening together as a family…*Considering these routines:* How do you support your child through these daily routines?

2. Prompting is when you verbally or physically remind your child to do something. Tell me about prompting your child and how your child responds to directives.

3. What types of prompting are you providing your child when they do daily activities?

4. What kind of resources do you consult, including books or websites that help you with parenting and raising your child?