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This mixed-methods study sought to examine the perceptions of family stress and resilience in parents with young children who are deaf or hard of hearing. A theoretical model based in family stress theory was used to guide the study. Quantitative data was obtained from the Parenting Stress Index version 4 short form and the Family Resilience Assessment Scale. Qualitative data was obtained through semi-structured interviews with parents who attended *The Care Project* retreat hosted in Wrightsville Beach, North Carolina, in November 2019. Quantitative results indicated parents experience an average level of stress and a high level of resilience. Qualitative results revealed that parents experience challenges with frustration, feelings of isolation, and stress. However, they found strength in meeting parents in similar situations, thinking of their progress with the diagnosis as a journey, and the idea of persevering through with the challenge with which their family is faced. Implications of the findings support further investigations of the lived experiences of families with children who are deaf or hard of hearing, their stress, and their resilience.

FAMILY STRESS AND RESILIENCE IN FAMILIES WITH YOUNG CHILDREN
WHO ARE DEAF OR HARD OF HEARING

by

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APPROVAL PAGE

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TERMINOLOGY

Stressor: events that can provoke crisis or trigger situations (Malia, 2006).

Family Stress: the process of family change over a period of time and is comprised of a complex combination of variables that interact over time (Malia, 2006).

Family Resilience: the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of the diagnosis of a chronic health condition in a child (Patterson, 2002).

Deaf: used to refer to a group of deaf individuals who share/use ASL as their primary language and hold certain beliefs about their level of hearing. These beliefs include their level of hearing as a central part of their identity (National Association of the Deaf, 2020).

Hard of Hearing: used to denote a person with some degree of hearing loss who does not identify as Deaf (National Association for the Deaf, 2020).

Family Centered Care: healthcare that provides a partnership in decision making between the healthcare professional and the family of the child (American Academy of Pediatrics [AAP], 2012).

Support Services: used to denote any service the parent may have received which they feel has been supportive for them and their family.

CHAPTER I

INTRODUCTION

Hearing loss is one of the most prevalent disabilities present at birth in the United States with the Center for Disease Control (CDC) estimating one to two out of every 1,000 babies screened will be diagnosed with some degree of hearing loss (CDC, 2019a). Hearing loss in childhood can affect language acquisition, psychosocial behavior, emotional development, the child's academic performance, and future employment opportunities (Garg & Gupta, 2015; Seewald & Tharpe, 2011; Smith, Bale, & White, 2005). Children who are deaf or hard of hearing are more likely to report lower quality of life (QoL) and wellbeing (Keilmann, Limberger, & Mann, 2007; Wake, Hughes, Collins, & Poulakis, 2005).

Of the children born deaf or hard of hearing, 90% are born into families with little to no experience with childhood hearing loss (Mitchell & Karchmer, 2004). This diagnosis may impact how family members interact with one another (Erbasi, Scarinci, Hickson, & Ching, 2018). Families with children who are deaf or hard of hearing report experiencing differing levels of stress, grief, and feelings of being overwhelmed (Kurtzer-White & Luterman, 2003). These feelings and experiences can lead to reported low levels of psychological well-being (Lederberg & Golbach, 2002) and high rates of stress (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). It has been seen that families with

children who are deaf or hard of hearing who are able to receive appropriate support services and resources tend to fare better than those who do not (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). After the diagnosis of hearing loss, it is critical that the families be provided with appropriate resources because families with resources show lower levels of stress (Hintermair, 2006). Parent-to-parent support is a key resource for families with children who are deaf or hard of hearing (Henderson, Johnson, & Moodie, 2014). Parent-to-parent support systems are described as a group in which parents with lived experience share and support other parents (Friedman Narr & Kemmerly, 2015). Oftentimes parents with older children or more experience with childhood hearing loss become mentors to newer parents. This relationship between parents offers a unique benefit to both the mentor and the mentee as they are both able to find empowerment, which can often lead to a decrease in parent stress levels (Hintermair, 2006).

A. Family Stress Theory

Stress is comprised of a complex combination of variables that interact over time. All families experience stress and stressors, but some families show a higher ability to manage these events or times (Malia, 2006). Family stress theories attempt to explain why some families show a better ability to cope with stress than others (Malia, 2006; McCubbin & Patterson, 1983).

The diagnosis of childhood hearing loss can lead to many sources of stress for families. These sources may include strained family relationships, increased tasks and time commitments, increased financial burden, and social isolation (Patterson &

McCubbin, 1983). This study explored the perceived stress and resilience of families of young children who are deaf or hard of hearing. The study viewed stress as defined by the Double ABCX model (see figure 1). This model describes how families react to stress and how they respond to the changes that an event or situation makes to family rules, roles, rituals, and adaptation (McCubbin & Patterson, 1983).

B. Resilience

The concept of resilience has emerged from the desire of researchers to take a “strengths-based” as opposed to a “deficit-based” perspective when investigating the experiences and perceptions of families. For the purpose of this study, resilience is defined as the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the diagnosis of a childhood hearing loss (Patterson, 2002). Families who are able to respond to the diagnosis with resilience are more likely to cope with the diagnosis at a level of functioning that is either similar to or stronger than they were before (Herrman et al., 2011). Although this change may be evident in all families, it is particularly relevant to families with children who are deaf or hard of hearing because of their high reported levels of stress (Pipp-Siegel et al., 2002). In these families, even normative stressors, such as the child starting school, may be magnified due to the diagnosis (McCubbin, McCubbin, Thompson, Sae-Young, & Allen, 1997).

C. The Care Project

The Care Project is a nonprofit organization based in North Carolina that was founded in 2009. It provides support for families with children who are deaf or hard of

hearing and assists families through the grieving process to a place of hope that they can effectively parent a child who has a hearing loss. The overarching goal of *The Care Project* is to bring hope to families who have children who are deaf or hard of hearing so that they can more effectively manage their child's hearing loss and the effect of the child's hearing loss on family functioning (The Care Project, 2020).

The development of *The Care Project* began when Dr. Johnnie Sexton, Au.D., was working with families with children who are deaf or hard of hearing and he became aware of the limited availability of emotional support for them. He developed *The Care Project* as a resource for these families. He started filming parents and their stories (J. Sexton, personal communication, August 16, 2019). Video journaling is a method of reflective practice and has been shown to help participants make meanings from their experiences (Parikh, Janson, & Singleton, 2012). In this case, it allowed these parents to sit in that moment, and share their emotional journey. Dr. Sexton stated, "it's amazing to see how proud [the families] are when they look back over time and see where they started and see how far they've come," (J. Sexton, personal communication, August 16, 2019). Through the process of video journaling with families, several themes emerged. The first notable theme was the concept of resilience. It was a term used by the first father of a child who is deaf or hard of hearing to be videoed. Other themes that have emerged include grief, and the emotional journey of the family. *The Care Project* has used these themes on which to build their vision and mission. After founding *The Care Project*, Dr. Sexton partnered with the North Carolina Early Hearing Detection and Intervention (EHDI) program. *The Care Project* met with families of newly diagnosed

children, and trained staff on how to work with families with children who are deaf or hard of hearing at Town Hall meetings. It was during this time that they began offering *The Care Project* retreats for these families. *The Care Project* grew with the reauthorization of the National EHDI program along with a change requiring state EHDI programs to allocate 25% of funds to family support and engagement (Early detection, diagnosis, and treatment regarding deaf and hard-of-hearing newborns, infants, and young children, 2017). This allowed *The Care Project* to partner with more states and allowed *The Care Project* to broaden the type of retreats they offer. In February of 2019 they held the first Parent-Professional Collaborative retreat.

D. The Purpose of the Study

The purpose of the study was to document the perceived levels of stress and family resilience in families of young children who are deaf or hard of hearing who attend a retreat hosted by *The Care Project*. Few studies have explored the concept of family resilience in this population. Of the studies that have used the term resilience, they do not actually use resilience as an outcome measure or process (Olecká, & Ivanová, 2012). Since family resilience is a rich and valuable topic when discussing the experiences of families with children who are deaf or hard of hearing, the field of early intervention and deafness, of which pediatric audiology is an integral component, would benefit from studies investigating how families adapt to the life changing event of the diagnosis of hearing loss in their children.

Chapter II outlines the theoretical framework for the study and provides an overview of the literature concerning children with chronic health conditions, their families, the support they receive, family stress theory, and family resilience. This lens is then applied to children who are deaf or hard of hearing and their families. Chapter II also introduces a theoretical model which guides the study. Chapter III presents an introduction to qualitative research methods, phenomenology, and mixed methods designs for research. The specific research methods for the study are detailed in Chapter III. Chapter IV reports the results from the questionnaires and the semi-structured interviews. Chapter V provides a discussion of the results in relation to the current literature. It also presents the limitations of the study as well as directions for future research.

CHAPTER II

REVIEW OF THE LITERATURE

Children who are deaf or hard of hearing and their families are faced with a unique set of challenges (Calderon & Greenberg, 1999). These challenges impact all family members and can mar the parents' early relationship with their child who is deaf or hard of hearing (Gilliver, Ching, & Sjahalam-King, 2013). Parent-to-parent support has been found to be beneficial in both the general literature about children with chronic health conditions as well as literature specific to children who are deaf or hard of hearing. In this chapter, the literature about children with chronic health conditions, how these chronic health conditions effect families, and the support for families is reviewed. A review of the literature regarding children who are deaf or hard of hearing and their families and the support these families receive is presented. The theoretical framework for the literature review focuses on family stress theory and family resilience (Malia, 2006; McCubbin & Patterson, 1983). A predictive model of family resilience is introduced to provide a construct for describing how families with children who are deaf or hard of hearing perceive family centered emotional support.

A. Children with Chronic Health Conditions

A chronic health condition is any condition that lasts one or more years, requires consistent medical attention, and causes limitations on a person's activities of daily living

(CDC, 2019b). An increase in the number of children living with chronic health conditions has been documented. A longitudinal study conducted in 2010 revealed that 12.8% of children and adolescents in the United States in 1994 had chronic health conditions; this number had increased to approximately 25% of children by 2000 (Van Cleave, Gortmaker, & Perrin, 2010). It is also estimated that up to 5% of these children have multiple chronic conditions (Gerteis et al., 2014).

These conditions can affect the children's lives in many ways including academic performance (Forrest, Bevans, Riley, Crespo, & Louis, 2011; Taras & Potts-Datema, 2009), well-being (Barlow & Ellard, 2006; Cadman, Boyle, Szatmari, & Offord, 1987; Erickson, Patterson, Wall, & Neumark-Sztainer, 2005), and future socioeconomic status (Lowry, Kann, Collins, & Kolbe, 1996) depending on the health condition. Children with chronic health conditions often show lower self-concept and self-esteem with children diagnosed with sensory and neurological disorders at the greatest risk (Lavigne & Faier-Routman, 1992). This indicates that children with chronic health conditions are faced with multiple challenges to their QoL from various areas.

The CDC describes well-being as a combination of factors including mental health and physical health. In essence, a person with a positive well-being feels their life is going well, and they feel optimistic (CDC, 2018a). It has been seen that children with chronic health conditions are more likely to judge their well-being as poorer than their peers. They were more likely to report depressive symptoms and lower self-esteem than children without chronic health conditions (Erickson et al., 2005). This indicates that a

chronic health condition may affect a child's well-being by changing the child's outlook on their life.

The World Health Organization (WHO) defines QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHO, 2014). A person's health-related quality of life (HRQOL) is a concept that includes a person's mental and physical health as well as their social, emotional, and social functioning (Office of Disease Prevention and Health Promotion [ODPHP], 2014). Both QoL and HRQOL are impacted in families with children with chronic health conditions (Goldbeck, 2006). Varni, Limbers, and Burwinkle (2007) investigated the HRQOL of over 2,500 children with various chronic health conditions such as end-stage renal disease, cancer, gastrointestinal conditions, and asthma. They found an overall decrease in HRQOL in children with chronic health conditions than in age-matched peers. This indicates that HRQOL is affected no matter which chronic health condition is diagnosed.

B. The Effect of Children with Chronic Health Conditions on Families

Children with chronic health conditions are likely to have a lower HRQOL than children without chronic health conditions. This decrease in HRQOL is also seen in the parents and siblings of these children (Bai, Herten, Landgraf, Korfage, & Raat, 2017). Barlow and Ellard (2006) performed a meta-analysis to investigate the trends within the theme of psychological effects on children with chronic health conditions and their families. They found that although there was some variation between studies as to whether strong psychological effects were seen for these children, their parents, and

siblings the trends between all the investigations show it likely that the effects of chronic health conditions are present in families.

Families with children with chronic health conditions are faced with many challenges; both the typical challenges faced by parents as well as challenges specific to the child's condition, and challenges caused by negative social stigma (McConnell, Savage, & Breitzkreuz, 2014; Paster, Brandwein, & Walsh 2009). Studies have shown higher levels of stress and decreased marital quality (Abbot & Meredith, 1986; Felizardo, Ribeiro, & Amante 2016) in families with children with chronic health conditions. Parents have also reported a loss of friendships, feelings of isolation, anger, resentment, shock, and sadness which can lead to anxiety, tension, and stress (Paster et al., 2009). There is often a profound sense of loss and unfairness after the diagnosis which makes it a distressing time for family members (Rolland & Walsh, 2006).

Difficulties in coping with issues surrounding parenting a child with a chronic health condition as reported by parents have been described as a source of anxiety, as well as a feeling of overprotection and rigidity within the family (Paster et al., 2009). Parents of children with functional limitations to their chronic condition, such as hearing loss, vision loss, and others that affect communication, have shown higher levels of stress than parents of children with other chronic health conditions (Silver, Westbrook, & Stein, 1998). Thus, although the specific chronic conditions experienced by families may differ, the parents of children with any chronic health condition appear to experience similar occurrences as they care for and parent their children.

Effects of the presence of a child with a chronic health condition are also seen in siblings of these children. These siblings are two to three times more likely than their peers to experience psychological adjustment problems (Cadman, Boyle, & Offord, 1988; Sahler et al., 1994). Within their families, siblings may experience extra caregiver burden, differential treatment, and a disparity of family resources (McHale & Gamble, 1989; Quittner & Oipari, 1994). Within their communities, siblings may experience limited knowledge about the child's condition, negative peer reactions, and disruptions in social activities (Bluebond-Langner, 1996). However, siblings of children with chronic health conditions are often seen to be more caring than their peers, but this can be used by the siblings to mask the negative effects of having a sibling with a chronic health condition by using denial as a coping mechanism (Houtzager, Grootenhuis, & Last, 1999). Siblings have been found to demonstrate an increased risk of behavioral problems and may be absent from school regularly (Houtzager et al., 1999). Moreover, psychological wellbeing and cognitive development were lower for siblings of children with chronic health conditions (Sharpe & Rossiter, 2002). However, this relationship may not be as clear cut as once believed. Although families with children with chronic health conditions do consistently report increased feelings of stress, there is evidence that they achieve cohesion through the use of effective coping skills. The family's adjustment to the presence of a child with a chronic health condition does not indicate the absence of stress but that the family effectively uses their resources to manage the stress (Felizardo et al., 2016).

Abbot and Meredith (1984) investigated the strengths of families with a child with a chronic health condition. They compared the marital and family strengths of families with and without a child with a chronic health condition and found no significant differences between the groups. They also investigated whether families with children with chronic health conditions develop additional strengths to cope with the additional stress and responsibilities. They found that the majority of parents questioned reported that having a child with a chronic health condition has made their family grow stronger, closer, and more unified. Lastly, they examined the coping skills used by these parents; they determined that they were able to successfully adapt to the family change once they defined their situation as an overall positive one.

When a child is diagnosed with a chronic health condition, parents can still experience a loss of the image of their ideal child. This loss often initiates a grieving process (Dyson & Fewell, 1986; Phillips, 1991). The typical grieving process is thought to progress through distinct phases of denial, anger, bargaining, depression, and finally acceptance (Kubler-Ross & Kessler, n.d.). However, losses such as a child being diagnosed with a chronic health condition are more ambiguous. An ambiguous loss is one that is not as concrete as a death and therefore families do not always progress through the same stages (Betz & Thorngren, 2006). These parents experience many stressful situations with the four most commonly reported being the time of diagnosis; the ongoing health care needs of their child; developmental transitions; and illness exacerbations and hospitalization experienced by the child (Melynk, Feinstein, Moldenhouer, & Small, 2001). For many parents, the uncertainty associated with chronic health conditions

creates a situation in which they cannot see an end to their current circumstances and therefore have no hope of resolution for their grief (Titelman & Psyk 1991; Atkinson 1994).

Despite the grief faced by these families, many families are able to move through the grieving process and restore their functioning. Family resilience after the diagnosis of a childhood chronic health condition is the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor (Patterson, 2002). Families show resiliency in many ways such as balancing the needs of the diagnosis with the other needs of family members, maintaining family flexibility, and attributing positive meaning to their situation (Patterson, 1991). Some families are more resilient than others from the initial diagnosis. However, resilience is something that can be gained through communication and support (Black & Lobo, 2008).

C. Family Stress Theory

Family stress is the process of family change over a period of time and is comprised of a complex combination of variables that interact over time (Malia, 2006). This change may be due to external or internal forces which cause the family to divert from their normal level of functioning (Boss, Bryant, Mancini, 2016). All families experience stress and stressors, but some families show a higher ability to manage these events or times. The diagnosis of a chronic health condition, such as childhood hearing loss, can lead to many sources of stress for families. These sources include strained family relationships, increased tasks and time commitments, increased financial burden, and social isolation (Patterson & McCubbin, 1983). Family stress theories attempt to

examine why some families show a better ability to cope with stressors experienced in their lives than others (Malia, 2006; McCubbin & Patterson, 1983).

Family stress theory is particularly relevant to families with children with chronic health conditions because of the reported increased feelings of stresses experienced by families with children with chronic health conditions (Felizardo et al., 2016). These families experience many sources of stress that can impact their wellbeing and quality of life. These sources of stress may include strained family relationships, modifications in family activities and goals, a burden of additional tasks and responsibilities, financial burdens, and social isolation (Figley, 1983). These stresses may impact how these families view themselves and their relations to other families as well as their own identities and roles within the family (Patterson & Garwick, 1994). This can lead to a period of dysregulation within the family and additional stress (Figley, 1983).

D. The Double ABCX Model

The Double ABCX model (Figure 1), developed by McCubbin and Patterson, describes how families react to stressors and how they respond to the changes that the original stressor, along with the pileup of other life events, make to family rules, roles, rituals, and adaptation (McCubbin & Patterson, 1983). This model includes the initial event leading to an imbalance of families after a stressor as well as the rebalancing of demands and resources over time to account for the ongoing stress of caring for a child with a chronic health condition (Patterson & McCubbin, 1983).

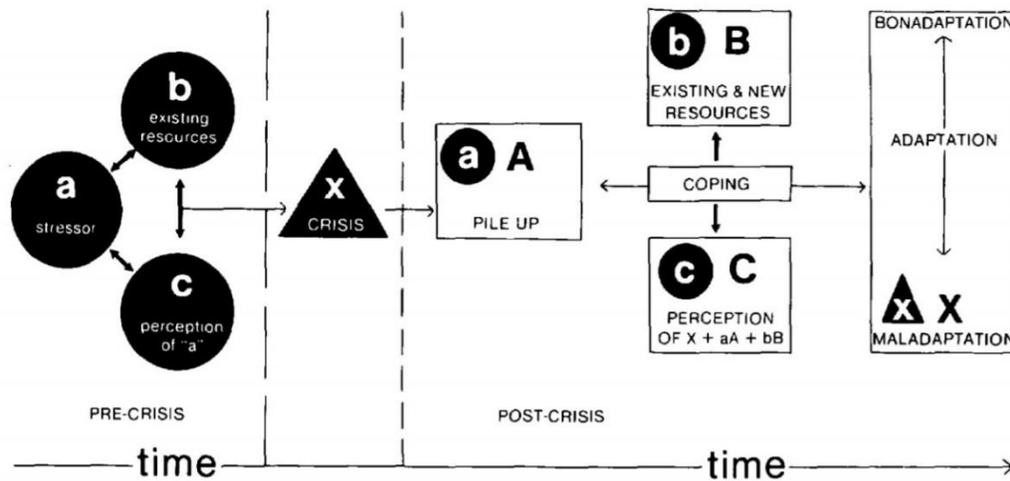


Figure 1. Double ABCX Model

The Double ABCX model describes how families may perceive a period of stress. It includes the initial stressor (A) which is combined with the family's resources for responding to the stressor (B) and the family's perception of the stressor (C). Those combined lead to the X factor of the family crisis. The stressor (A) is defined as a life event that has enough significance to the family to affect change (Boss, 1988). The family resources (B) are how the family manages the change from the stressor (McCubbin & Patterson, 1983). The C factor is the family's perception of the stressor and available resources; how seriously do they feel this event is and do they have sufficient resources to manage the situation (McCubbin & Patterson, 1983). The X factor, crisis, is conceptualized as the amount of disorder in the family system after the stressor (McCubbin & Patterson, 1983). The Double ABCX model then moves to the post-crisis phase. Families may experience pileup (aA) which is the additional life events that

happen after the crisis. These events may include normative transitions such as a child starting school, additional stressors, or consequences from the family's efforts to cope with the crisis. This may lead to the family utilizing their existing resources and seeking out new resources (bB). These resources may include personal resources, social support, and family system resources. Families combine the pileup (aA) as well as the existing and new resources (bB) in their definition of the new situation (cC). As families cope with the initial crisis phase as well as the post-crisis phase, they adapt (xX) (McCubbin & Patterson, 1983).

Family adaptation (xX) is the central construct in the Double ABCX model. Family adaptation is the balance between the needs and resources of the different levels of families and their communities. This balance is achieved through relationships between family members, and between families and the community in order to balance the demands of the stressor and the resources available to the family (McCubbin & Patterson, 1983). In families with children with chronic health conditions, family adaptation involves many stressors, strains, and hardships occurring simultaneously that the family must address. Family adaptation implies that families who show higher levels of adaptation are better able to offset the demands they face in a stressful situation with their existing and new-found resources.

E. Family Resilience in Families with Children with Chronic Health Conditions

From the family stress literature, the concept of resilience emerges. Families that demonstrate resilience are those with the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of

the diagnosis of a chronic health condition in a child (Patterson, 2002). This impacts family functioning because all people and families experience times of stress. Those families who are able to react to these times in such a way that shows resilience are more likely to come through the experienced stressor at a level of functioning that is either similar to or stronger than they were before (Herrman et al., 2011). This is apparent in all families, but families with children with chronic health conditions are likely to experience additional stressors that families with children without chronic health conditions do not face.

Families with children with chronic health conditions face a different set of stressors. These stressors included those that are experienced by all families as a part of daily living, as well as stressors unique to the child's diagnosis, and possibly other stressors unique to the family (McCubbin, Balling, Possin, Friedrich, & Bryne, 2002). Resilience is an especially important concept to these families because even the stressors experienced as a part of the family's daily life may be magnified due to the child's health condition (McCubbin, McCubbin, Thompson, Sae-Young, & Allen, 1997). Family resilience has been conceptually measured using the Family Resilience Assessment Scale (Sixbey, 2005). Plumb (2011) investigated the impact of social support and family resilience on parental stress in families with a child diagnosed with autism spectrum disorder. The parents in this study reported a mean total resilience score of 138.3 with a standard deviation of 17.5.

F. Support for Families with Children with Chronic Health Conditions

When families with children with chronic health conditions are provided with care that is both comprehensive and well-coordinated, a positive impact is seen on child and family wellbeing, satisfaction with care, adherence to care plans, and pain management (Anderson, Loughlin, Goldberg, & Laffel, 2001; Drotar, 2001; Kazak, 2001). This care must include support for both the children and the families (Garwick, Kohrman, Wolman, & Blum, 1998). Parents of a child with a chronic health condition are at a higher risk for emotional hardship if they do not receive the needed support for their family (Farmer, Marien, Clark, Sherman, & Selva, 2004). These data suggest the strong need for support systems for families with children with chronic health conditions.

Paster et al. (2009) investigated whether coping strategies differed for parents of children with chronic health conditions than for parents of children without chronic health conditions. They found a significant difference between the groups. When parents of children with chronic health conditions have access to social support; they report less stress and fewer depressive symptoms. It was also seen that when parents have access to appropriate coping strategies, such as social support or planful problem-solving their stress decreased. This study highlights that having a child with a chronic health condition can also be a source of strength for these families. Paster et al. stated:

Parents of children with disabilities identified their children as reasons for strengthened family ties, strengthened religious faith, and an expanded social network. Other sources of family strength included greater pride and sense of accomplishment, greater knowledge about disabilities, less likelihood to take things for granted, and greater tolerance, sensitivity, and patience. (p. 1338)

Parents of children with chronic health conditions are especially qualified to provide support for other parents (Kerr & McIntosh, 2001). Such parent-to-parent support provides families with a mutual exchange of information, thoughts, and resources, and affirmational support (Henderson et al., 2014). These aspects provide families with an increased sense of power, a sense of belonging, and a feeling of manageability for the child's care (Law, King, Stewart, & King, 2002).

Parents reported that parent-to-parent support groups help families move from feeling lost to getting to a healthier, more sustainable place for their family (Bray, Carter, Sanders, Blake, & Keegan, 2017). Such parent-to-parent social support groups were beneficial to their families, and parents report that they are very satisfied with the support provided by such groups (Solomon, Pistrang, & Barker, 2001). These support groups provide parents of children with chronic health conditions with validation, connectedness, and a sense of empowerment (Nicholson, Martin, & Sexton, 2018). This then allows the parents to move through their grief and to a place of strength for the family (Kerr & McIntosh, 2001).

Although the majority of the parent-to-parent support groups studies focus on the parents or the child with a chronic health condition, siblings are also affected by the stress of having a child with a chronic health condition in the family (Houtzager et al., 1999). Lobato and Kao (2002) investigated the integration of siblings into these support groups for families with children with chronic health conditions. They found that when siblings are involved in the support, their knowledge about the condition increases, they feel more

connected to the family, and behavioral problems decreased. This provides strong evidence for the inclusion of siblings in support groups.

G. Prevalence and Attributes of Children who are Deaf or Hard of Hearing

As stated previously, a chronic health condition is any condition that lasts one or more years, requires consistent medical attention, and causes limitations on a person's activities of daily living (ADLs) (CDC, 2019b) Childhood hearing loss fits this definition and therefore can be considered a chronic health condition. Hearing loss is one of the most common disabilities present at birth. The CDC (2019a) estimates that 0.005% of children born in the United States are born with some measurable degree of hearing loss. The prevalence varies from one to three babies per 1,000 births in the well-baby nursery up to two to four per 1,000 births in the neonatal intensive care unit (NICU) (Seewald, & Tharpe, 2011). Half of all babies with congenital hearing loss have no known risk factors (CDC, 2019a). In addition, 14.9% of children ages 6 – 19 years have some measurable degree of hearing loss in at least one ear (CDC, 2019a). Of these children who are deaf or hard of hearing, 90% will belong to families with little to no experience with childhood hearing loss (Mitchell & Karchmer, 2004).

Hearing loss can impact language acquisition, psychosocial behavior, emotional development, the child's academic performance, and future employment opportunities (Garg & Gupta, 2015; Seewald & Tharpe, 2011; Smith et al., 2005). It also causes children to expend more listening effort throughout the day causing children who are deaf or hard of hearing to experience more fatigue during and after the school day (Hicks & Tharpe, 2002). Academically, the percentage of children who are deaf or hard of hearing

who fail at least one grade increases from 29.2% in third grade to almost half (47.4%) by 9th grade (Bess, Dodd-Murphy, & Parker, 1998). Children who are deaf or hard of hearing are also significantly more likely to not finish high school (Emmet & Francis, 2015). Even a mild or unilateral hearing loss increases the risk of the child repeating a grade (Anderson & Matkin, 2007). Research has shown that early identification of hearing loss accompanied with appropriate intervention can have a mitigating factor on these effects for children who are deaf or hard of hearing (Downs, Yoshinaga-Itano, 1999; Moeller, 1996; Robinshaw, 1995).

Children who are deaf or hard of hearing have been shown to experience more problems with self-esteem and stress when compared to children with normal hearing (Bess, Dodd-Murphy, & Parker, 1998). Additionally, children who are deaf or hard of hearing are at a greater risk for challenges with their psychological wellbeing and have a lower HRQOL as reported by their parents (Wake et al., 2005). Research shows that children who are deaf or hard of hearing consistently rate their own HRQOL significantly lower than that of peers without hearing loss (Keilmann et al., 2007). Children who are deaf or hard of hearing also report a higher incidence of depressive symptoms than children with normal hearing (Theunissen, Rieffe, Kouwenberg, Soede, Briaire, & Frijns, 2011). This could impact the children's well-being because if children who are deaf or hard of hearing and their parents are consistently rating QoL as poorer than other children, they are not as likely to have the optimistic outlook needed to have a positive feeling about life which leads to good wellbeing (CDC, 2018a).

H. The Effect of a Child who is Deaf or Hard of Hearing on Families

When a child is diagnosed with a hearing loss, all members of the family are affected (Calderon & Greenberg, 1999). Childhood hearing loss effects family quality of life, family interaction, and family resources (Jackson & Turnbull, 2004). This diagnosis can impact the way family members interact with each other and their community (Erbasi et al., 2018). Parents are often expected to develop and enact new roles in their position as parent of a child who is deaf or hard of hearing. These new roles may include those such as language therapist and hearing aid specialist (Gilliver, Ching, & Sjahalam-King, 2013).

Parents with children who are deaf or hard of hearing often report feelings of being overwhelmed and inadequate to the task of managing their child's hearing loss (Kurtzer-White & Luterman, 2003). These feelings are often present at the time of the initial diagnosis and can reappear at times of transition, such as starting school (Gilliver et al., 2013). Parental guilt is often present and pervasive (Kurtzer-White & Luterman, 2003). When asked what their initial reaction was to the diagnosis of hearing loss in their child, most parents recalled being shocked or stunned (Gilliver et al., 2013). Parents of children who are deaf or hard of hearing report higher levels of context-specific stress, including communicating with their child and child behavior problems (Quittner et al., 2010).

Families with children with newly diagnosed hearing loss are faced with a unique set of challenges (Zaidman-Zait, Most, Tarrasch, Haddad-eid, Brand, 2015). The Joint Committee on Infant Hearing's (JCIH) 2019 position statement stated that all babies

should be screened for hearing loss by one month of age and the babies who do not pass the screening should have a comprehensive audiologic evaluation by two months, with babies who have a confirmed hearing loss at this point to receive appropriate intervention by three months. The goal of Early Hearing Detection and Intervention (EHDI) programs is to improve and expand the care received by infants and parents during this process (National Center for Hearing Assessment and Management [NCHAM], 2019). This means that parents are required to make several decisions about treatment (Matthijs et al., 2012), communication modality (Crowe, Fordham, McLeod, & Ching, 2014) and intervention (Decker, Vallotton, & Johnson, 2012) quickly and these decisions are often emotional and challenging (Kurtzer-White & Luterman, 2003). In one study, many parents reported a belief that hearing loss could be easily managed merely by the fitting of hearing aids and that this would return their child's hearing to normal levels. However, the belief that early treatment and intervention for a child who is deaf or hard of hearing will lead to normal development may serve to place unnecessary guilt or pressure on families when early intervention did not happen or was not possible, or when the chosen intervention does not provide the desired outcomes (Gilliver et al., 2013).

Much of the research of the effects of hearing loss on family dynamics has focused on the mothers of children who are deaf or hard of hearing. Several studies indicate that they show lower levels of psychological well-being than mothers of children with normal hearing (Lederberg & Golbach, 2002). There are also distinct differences in mother-child communicative interactions. Hearing mothers of a child who is deaf or hard of hearing are often more directive and use less rich language than they would with a

child with normal hearing (Kurtzer-White & Luterman, 2003). Mothers of children with lesser degrees of hearing loss tend to report more stress than when a child has a more severe hearing loss (Pipp-Siegel, et al., 2002). This may be due to the ambiguity of the child's hearing level and the possible delay in diagnosis (Kurtzer-White & Luterman, 2003).

Fathers of children who are deaf or hard of hearing have not received much attention in the literature. Fathers report that their child's diagnosis of hearing loss did not have a negative effect on their relationship with the child and they felt included in the process overall (Houston, Fenton, Holt, Munoz, & Nelson, 2012). Additionally, when surveyed, both mothers and fathers of children who are deaf or hard of hearing state a high level of parental involvement however the nature of this involvement is different than that of the mothers (McNeil & Chabassol, 1984). Ingber and Most (2012) found that fathers of children who are deaf or hard of hearing report higher levels of parental involvement and show higher levels of self-efficacy. In contrast, it has also been reported that there is no significant difference between levels of stress reported for mothers and fathers of children who are deaf or hard of hearing (Zaidman-Zait et al., 2015).

Siblings of children who are deaf or hard of hearing have been found to be at higher risk for developing stress and poor adaptation skills and often report a feeling of isolation within the family (Atkins, 1987). They may also face issues such as perceived parental partiality toward the child with the hearing loss or inadequate communication with parents. (Raghuraman, 2008). Siblings of children who are deaf or hard of hearing may resent the attention received by the child who is deaf or hard of hearing from their

parents or may feel that the parents have different, higher, expectations for them (Atkins, 1987). It has also been suggested that siblings of children who are deaf or hard of hearing develop enhanced communication skills (Raghuraman, 2008).

However, a more positive temperament has been noted in older siblings of children who are deaf or hard of hearing than those with normal hearing siblings, and they display fewer behavior problems as a sibling's severity of hearing loss worsened (Raghuraman, 2008). Additionally, no significant differences have been seen in the quality of sibling relationships, and parent perceptions greatly match sibling report of the relationships (Raghuraman, 2008; Verté, Hebbrecht, & Roeyers, 2006). Yet, many families with children who are deaf or hard of hearing are able to meet the challenges they face and thrive. It is possible that these families show a higher level of resilience than families who do not obtain their desired outcomes (Luckner, 2011).

I. Family Stress in Families with Children who are Deaf or Hard of Hearing

Families with children who are deaf or hard of hearing experience stress related to the diagnosis of hearing loss. This can be due to financial concerns, e.g. concerns about paying for the hearing aid and follow up care (Limb, McManus, Fox, White, & Forsman, 2010), or stress related to the child's development (Quittner et al., 2010). Studies have shown that parents of children who are deaf or hard of hearing report higher levels of stress, including communicating with their child and child behavior problems than parents of children with normal hearing (Dirks, Uilenburg, & Rieffe, 2016; Quittner et al., 2010). Topol, Girard, St. Pierre, Tucker, and Vohr (2011) measured the effects of maternal stress on child language and behavioral outcomes in children with hearing loss

using the Parenting Stress Index 3rd edition. The mothers of children with hearing loss in their survey reported a mean total stress score of 67 with a standard deviation of 9.9, a mean Parental Distress score of 24.6 with a standard deviation of 5.6, and a mean Parent Child Dysfunctional Interaction score of 18.0 with a standard deviation of 4.2.

Possible predictors of stress in mothers of children who are deaf or hard of hearing have been investigated. It was found that mothers who reported a higher number of daily hassles, less access to social support, and annual family income had a significant impact of the mother's level of reported stress. Other factors included any additional chronic health conditions or disabilities, and more severely delayed language in the child who is deaf or hard of hearing (Pipp-Siegel et al., 2002). However, the level of reported stress changes over time. Parents of children with recently diagnosed hearing loss report high levels of stress related to health care and family well-being whereas families with children who have more experience with hearing loss report higher levels of stress related to education and support systems (Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008). These studies demonstrate that families with children who are deaf or hard of hearing experience high and differing levels of stress depending on the time, their experience, and level of resources.

Recalling the double ABCX model (McCubbin & Patterson, 1983) of family stress (see figure 1), families with a child who is deaf or hard of hearing could experience the initial diagnosis as the stressor (A). Then the families' available resources (B), e.g., financial resources, and the family member's perception (C) of the balance between the stress of the diagnosis and the resources would lead to them either experiencing the

dysregulation of a crisis (X) or not. After this dysregulation, the pileup (aA) could consist of other children in the family going through a transition, or illness of a family member. This new level of family functioning along with any existing and new resources (bB), such as support groups, are then combined into the family's new perception of their situation (cC). All this leading to the level of adaptation (xX) experienced by these families.

J. Family Resilience in Families with Children who are Deaf or Hard of Hearing

As previously stated, family resilience is a concept that emanates from the family stress literature and is defined in this study as the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of the diagnosis of a chronic health condition in a child, in this case hearing loss (Patterson, 2002). This impacts families with children who are deaf or hard of hearing because the level of family resilience demonstrated will influence how these families react to and move forward with the diagnosis of childhood hearing loss.

Family resilience is also closely tied with family well-being and QoL. Families who demonstrate higher levels of resilience tend to also score higher on measures of well-being and quality of life (Walsh, 2004). This indicates that high levels of resilience lead to a person or family feeling more satisfied with their lives. Families with children who are deaf or hard of hearing show high levels of satisfaction with their family life, but struggle with child outcomes and communication skills (Jackson, Wegner, & Turnbull 2010).

However, research in the area of family resilience in families with children who are deaf or hard of hearing is in its infancy. Many studies performed evaluate QoL, and stress, but resilience has not been conceptually defined in the hearing loss literature and therefore the few studies that have been performed do not actually measure resilience as an outcome or process in their results (Olecká, & Ivanová, 2012). Thus, this area of research offers potential for improving family centered care with families with children who are deaf or hard of hearing.

Of the studies of children who are deaf or hard of hearing and their families that use “resilience” as a concept, outcomes are primarily measured via questionnaires and/or interviews. Jackson et al. (2010) evaluated family QoL via questionnaire and qualitative analysis of open-ended responses. They suggested a focus on balancing of resilience sources and requirements to support the emotional needs of the family. Minchom, Shepherd, White, Hill, and Lund (2003) distributed a survey aimed at identifying stress and anxiety reduction techniques used by parents of children who are deaf or hard of hearing. They found parents benefitted when they had access to educational support services (e.g. sign language classes for families who chose this mode of communication), and support from other parents of children who are deaf or hard of hearing. Ahlert and Greeff (2012) investigated the resilience qualities present in families that helped support them through the challenges of having a child who is deaf or hard of hearing. They found the protective factors of family routine, social support, affirming communication, family hardiness, problem-solving skills, religion, a search for meaning, and acceptance of the child’s hearing status. When families showed higher levels of these factors, they were

more likely to show higher levels of resiliency and were able to meet the challenges present in raising a child who is deaf or hard of hearing. These studies demonstrate how resilience as a concept has been used broadly in the area of children who are deaf or hard of hearing. Therefore, research aimed specifically at investigating the resilience of these children and their families would contribute to how hearing healthcare and early intervention professionals can facilitate such families' resilience and reduce their stress.

K. Support for Families with Children who are Deaf or Hard of Hearing

After the diagnosis of hearing loss, parents need information about childhood hearing loss, its consequences, and about the support the child will need (Eleweke, Gilbert, Bays, & Austin, 2008). Parents who are provided with resources show lower levels of stress (Hintermair, 2006). There is evidence to support the importance of support groups in the literature for families with children with chronic health conditions (Shilling et al., 2013) as well as for families with children who are deaf or hard of hearing (Calderon & Greenberg, 1999; Eleweke et al., 2008; Erbas et al., 2018; Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). However, many medical professionals do not provide families with information about support options because the focus is on the medical needs of the child instead of providing true family-centered care (Eleweke et al., 2008). Families with children who are deaf or hard of hearing have stated a desire for education that is comprehensive, individualized, and high quality (Bernstein & Barta, 1988). To achieve this level of education, practitioners should take a family-centered approach to the care provided to families with children who are deaf or hard of hearing.

K.1. Family-Centered Care

Family-centered care (FCC) is healthcare that provides a partnership in decision making between the healthcare professional and the family of the child (American Academy of Pediatrics [AAP], 2012). Benefits of FCC include improved clinical decision making, a greater understanding of the child's and family's strengths and needs, better follow-through with the agreed treatment plan, more effective communication, and better outcomes and greater satisfaction with services (AAP, 2012). Utilizing a family-centered model requires that health care professionals are capable of providing information to families that is timely, accurate and at a level the families are able to understand, possess active listening skills, can help identify and attend to the family's unique problems or needs, are able to foster confidence in family members as well as competence and independence in parents, and provide strategic guidance to parents (Brown, Abu Bakar, Rickards, & Griffin, 2006).

Although FCC has been widely accepted by the healthcare field, there have been issues with its implementation. There appear to be misunderstandings about what FCC is, how to implement it, and how to determine if practitioners are utilizing FCC (Kuo et al., 2012). In audiology, parents of children with newly identified hearing loss are often simply observers during testing and although they are included in case history and counseling, it is often assumed by the audiologist that the parent will follow through on their own with the stated recommendations (Gravel & McCaughey, 2004). For audiologists to truly adopt FCC they need to have an open conversation about the different recommendations and options available to families at the time. This

conversation not only gives families a heightened sense of self-efficacy, but also builds trust between parents and the audiologist (Sass-Lehrer, 2004).

K.2. Organizations that Support Families with Children who are Deaf or Hard of Hearing

Many organizations offer professional support services for parents of children who are deaf or hard of hearing as a component or adjunct to of family centered care resources for families. Some of these organizations include The John Tracy Center, Alexander Graham Bell Association, Hands and Voices, Beginnings for Parents of Children Who are Deaf or Hard of Hearing, and *The Care Project*. Each organization has a unique viewpoint from which they approach their services. The John Tracy Center provides speech-language and audiology services as well as support for the families of the children served at their clinic and through online events (John Tracy Center, 2019). The Alexander Graham Bell Association provides support for families who want their child who is deaf or hard of hearing to learn to listen and speak. There are local chapters of A.G. Bell which sponsor their own events for parents and families (A. G. Bell, 2019). Hands and Voices is a parent driven organization for parents of children who are deaf or hard of hearing (Hands and Voices, 2012). Beginnings was established in North Carolina in 1987 to provide emotional support and access to information as a central resource for families with deaf or hard of hearing children (Beginnings, 2019). *The Care Project* is a nonprofit organization based in North Carolina that provides support for families with children who are deaf or hard of hearing and attempts to help families through the grieving process and to a place of hope (The Care Project, 2020).

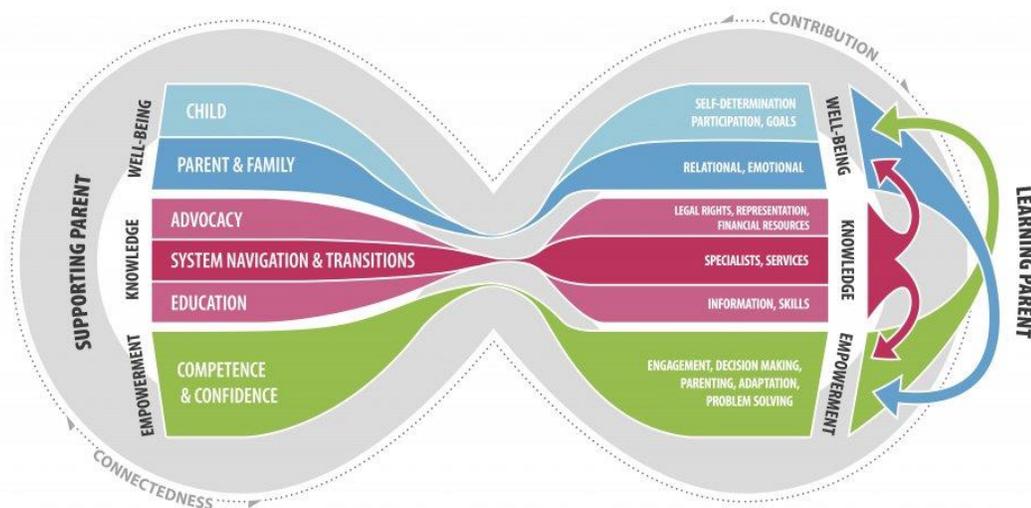
Parent-to-parent support is a key tenet in family-centered care for families with children who are deaf or hard of hearing (Henderson et al., 2014). Parent-to-parent support systems were established in 1971 and are described as a group in which parents with lived experience share and support other parents (Friedman Narr & Kemmery, 2015). Parent-to-parent support groups offer families empowerment and often lead to a decrease in parent stress levels (Hintermair, 2006). Parents who receive information about support services available are best equipped to deal with the needs and challenges this diagnosis brings (Eleweke et al., 2008). These support groups as components of the professional organizations listed above provide families resources that highlight an empowerment and resource orientation (Hintermair, 2006) and build understanding among other educators and professionals (Friedman Narr & Kemmery, 2014).

K.3. Parent-to-Parent Support for Parents of Children who are Deaf or Hard of Hearing

Henderson et al. (2014) discuss the importance of parent-to-parent support groups for families with children who are deaf or hard of hearing. These support groups provide parents with resources that are different from those obtained from health care professionals. Thus, parents of children who are deaf or hard of hearing benefit from parent-to-parent support. As Henderson et al. stated:

Relevant and timely support and intervention are important for families of children identified with hearing loss because the majority of these children will be born to parents with normal hearing who were not expecting the diagnosis. (p. 437).

A conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing as designed by Henderson et al., (2014) is shown in Figure 2. The key components described in the framework are: 1. family wellbeing; 2. child wellbeing; 3. knowledge, and 4. empowerment. These components are joined through the concepts of mutuality and connectedness.



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Figure 2. A Conceptual Framework of Parent-to-Parent Support for Parents with Children Who are Deaf or Hard of Hearing (Henderson, Johnson, & Moodie, 2014)

K.3.a. Family Wellbeing

The component of family wellbeing includes emotional support, adaptational support, and relational support. These components combine to help the parents feel more

capable of managing the care for their child and psychologically healthy. Emotional support acknowledges and addresses the grief and other negative emotions felt by parents after the initial diagnosis of hearing loss in a child or during times of transition. This support helps parents gain the tools to deal with these emotions and move through to a place of strength (Henderson et al., 2014). Adaptational support helps parents develop their own tools and strategies for dealing with the negative emotions they have about the diagnosis of hearing loss. These tools may include changing routines for the family to create an optimal environment for all family members (Henderson et al., 2014). Relational support refers to the parents' relationship with their family, both immediate and extended. This type of support is aimed at helping parents and family members gain an understanding of the child's hearing loss so they can all have positive interactions and relationships (Henderson et al., 2014).

K.3.b. Child Wellbeing

Child wellbeing includes participation, autonomy, and goals. Participation was described in this model as child participation in the hearing and Deaf communities or the child being able to partake fully in typical school and extracurricular activities. Parent-to-parent support groups may be able to assist in this participation as other more experienced parents may have suggestions for how the children can fully partake in such activities. Parents also wish for their child to gain autonomy, or a sense of self. While having a child with a chronic health condition can make it difficult for parents to allow the child to explore and interact as a typically developing child would, it is still important for this development to take place. Parent support groups can help parents see what other

parents in their situation are trying or have tried and allow them to support their child in the development of their autonomous nature (Henderson et al., 2014). Parent-to-parent support groups can also give parents reassurance about both the short- and long-term goals they have set for their children. It can be difficult for parents to see past their current situations; Parent-to-parent support allows for other parents in different circumstances with different experiences to share and discuss the goals they have chosen for their child. This allows the parents to have more perspective (Henderson et al., 2014).

K.3.c. Knowledge

The concept of knowledge is also included in implementing parent support according to the Henderson et al model. In this part of the support system families gain accurate, unbiased information about childhood hearing loss. This is important to include in a support system because parents may not receive this information anywhere else (Henderson et al., 2014). This concept also includes advocacy and navigation of systems. Advocacy includes gaining information about the legal rights, representation, and funding available to both the child and families. Navigation of systems includes information about the services available for families and children who are deaf or hard of hearing and how to best obtain these services (Henderson et al., 2014).

K.3.d. Empowerment

Empowerment is a critical concept to include in a support system for parents of children who are deaf or hard of hearing. By families gaining information and skills in decision-making, self-awareness, problem solving, and engagement via support system,

their competence and confidence in handling the challenges they will face in parenting a child with a hearing loss will be increased as described by Henderson et al. (2014).

K.3.e. Mutuality and Connectedness

Mutuality and connectedness tie all the components of family support together. Mutuality is the process of the shared exchange of information between participants. This exchange allows parents with more experience in a certain area to mentor parents with less experience. Henderson et al. (2014) state that providing support is important and beneficial to both the parents receiving the support as well as the parents providing the support. Connectedness refers to the atmosphere of the affiliation among members of the support group. The group should provide a place where parents can experience social affiliation with others. This affiliation allows for a more open and honest sharing of experiences and feelings (Henderson et al., 2014).

Although the components of the Henderson et al. (2014) model are important to consider when developing a support group for families with children who are deaf or hard of hearing, this model does not acknowledge parents' experiences with support groups. As previously discussed, parents of children who are deaf or hard of hearing consistently report high levels of stress (Kurtzer-White & Luterman, 2003) and have stated a desire for support groups (Eleweke et al., 2008; Hintermair, 2006). Thus, in order to improve the implementation and delivery of support for parents of children who are deaf or hard of hearing it is necessary to obtain parents' perceptions of what elements of a support group are most helpful for them as they navigate their family's adaptation to a potentially stressful situation.

L. Proposed Theoretical Model for the Study

The theoretical model (see Figures 3 and 4) developed for this study incorporates concepts from Family Stress theory and applies them to the process of how families adapt to the diagnosis of their child's hearing loss. The Double ABCX model (McCubbin & Patterson, 1983) and the conceptual framework developed by Henderson et al. (2014) combine in the proposed model to show how families can evolve and show resilience following the diagnosis of their child's hearing loss. Because families with children who are deaf or hard of hearing have been found to experience higher levels of stress than families with children with normal hearing and that there are many factors that lead to the level of adaptation experienced by these families (Dirks et al., 2016; Meizen-Derr et al., 2008; Pipp-Siegel et al., 2002; Quittner et al., 2010) the proposed theoretical model was developed.

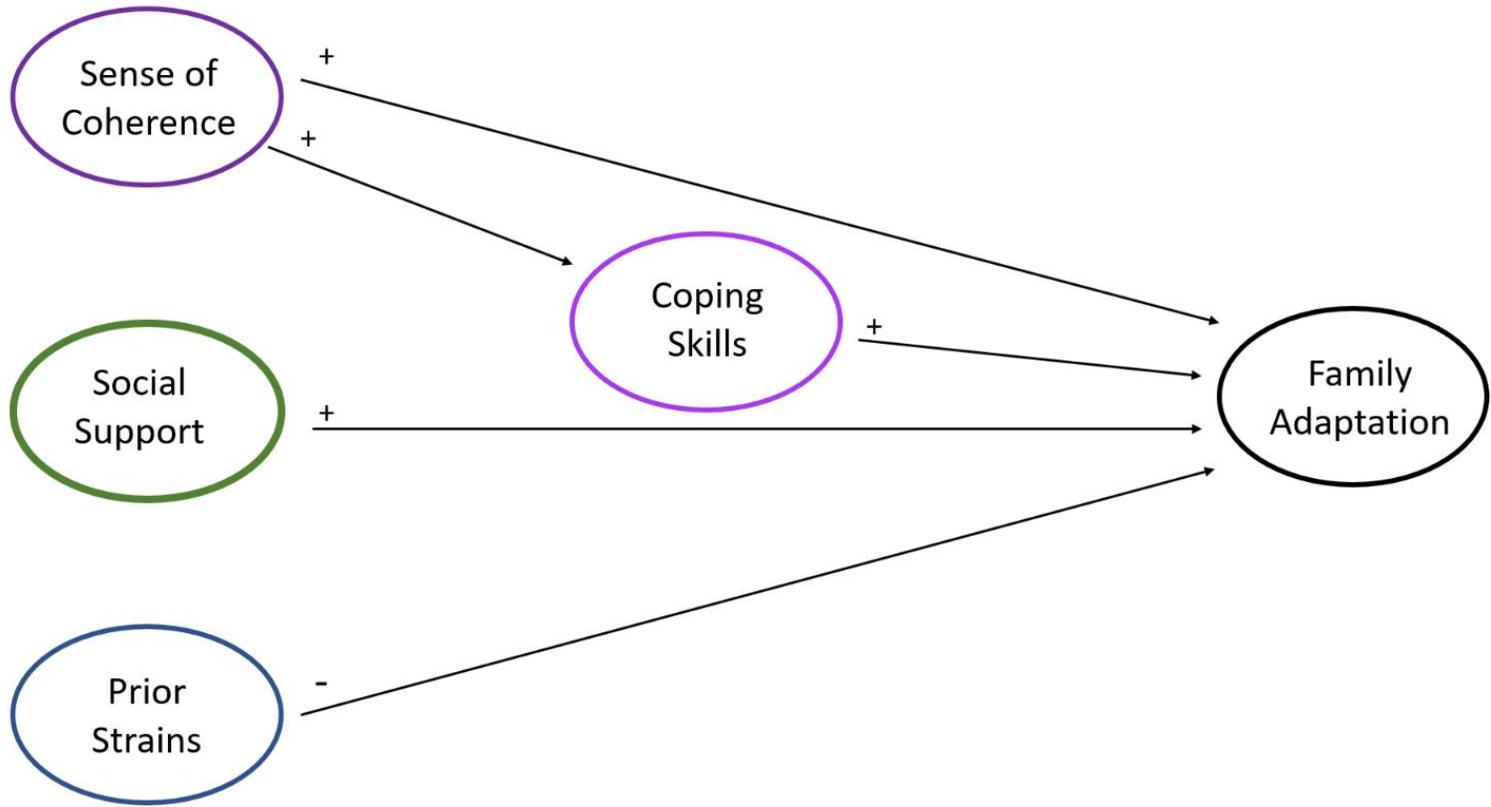


Figure 3. Using Theoretical Terms from Family Stress Theory to Predict Family Adaptation

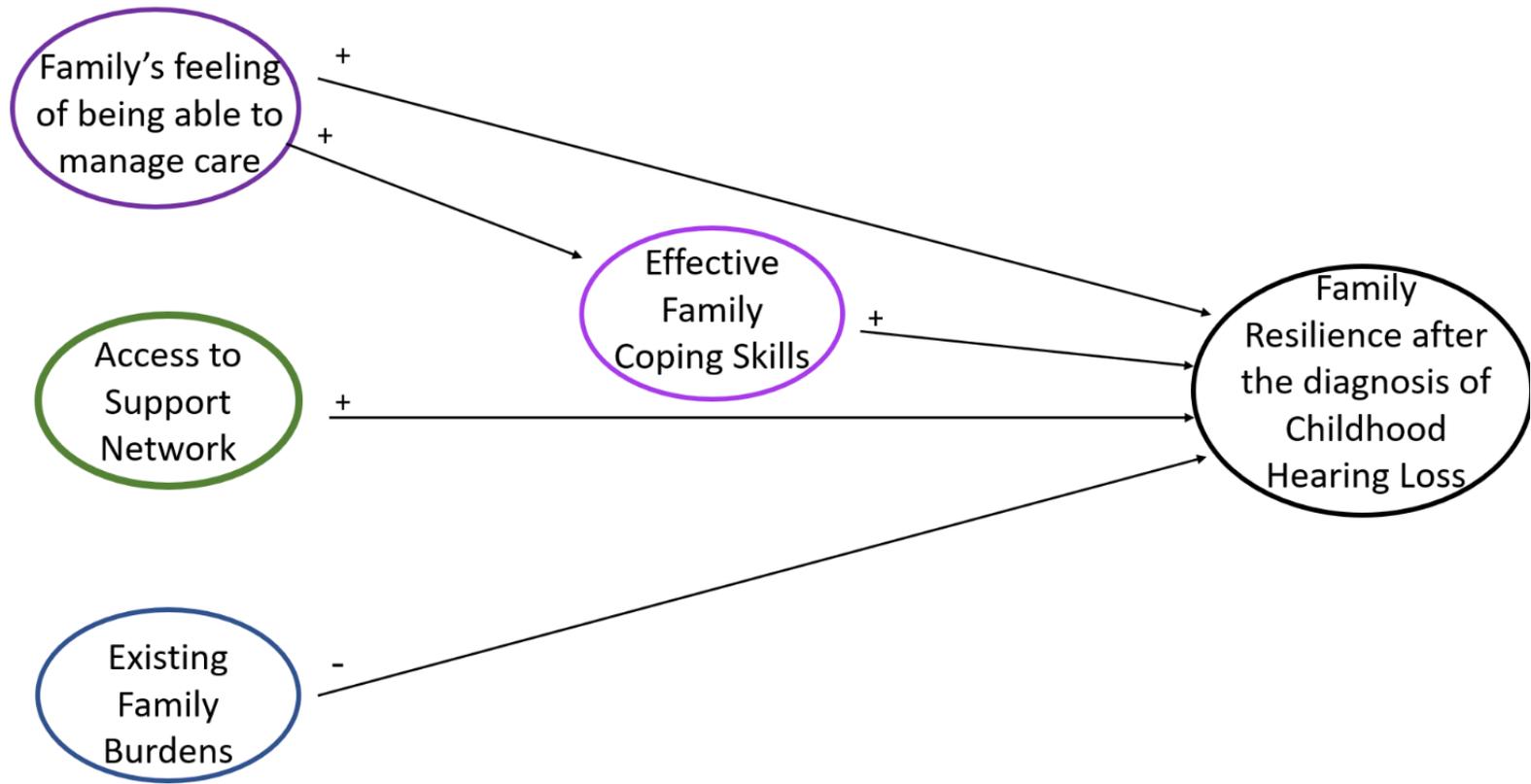


Figure 4. Application of Theoretical Terms from Family Stress Theory to Predict Family Resilience After the Diagnosis of Childhood Hearing Loss

The theoretical concepts presented in Figure 3 are then described in more applicable terms in Figure 4, so that Figure 3 constitutes a bird's eye view of Figure 4. In Figure 3, concepts from Family Stress theory are used to predict the theoretical outcome of family adaptation with regard to constructs of sense of coherence, coping skills, social support, and prior strains. In Figure 4, the substantive constructs of a family's feeling of being able to manage their child's care, effective family coping skills, access to parent-to-parent support groups, and existing family burdens are used to predict the outcome of family resilience after the diagnosis of childhood hearing loss.

This study posits that families of young children who are deaf or hard of hearing will show higher levels of resilience when they have access to social support, feel the situation of their child's hearing loss is manageable, and do not have an imbalance of resources due to other previous existing burdens on the family.

The following sections detail the predictors used in the proposed theoretical model, the relationships between the predictors and family resilience after the diagnosis of childhood hearing loss and provides examples of what has been found in the literature about the relationship between these concepts. The stated predictive constructs demonstrate why some families will demonstrate higher levels of resilience after receiving this diagnosis than others.

Family adaptation (xX) is the balance between the needs and resources of the different levels of families and their communities. Family adaptation is achieved through relationships between family members, and between families and the community in order to balance the demands of the stressor and the resources available to the family

(McCubbin & Patterson, 1983). This definition implies that families who show higher levels of adaptation are better able to offset the demands they face in a stressful situation with their existing and new-found resources. Thus, family resilience is deduced from the theoretical construct of family adaptation.

L.1. Deducing Families' Feeling of Being Able to Manage the Care from Sense of Coherence

Sense of coherence is defined as the extent to which the world is viewed as manageable, intelligible, and meaningful (Antonovsky & Sourani, 1988). A higher level of coherence gives families an impression of control over their lives. This feeling of control leads these family members to believe that they are capable of managing the care needed by a child with a chronic health condition such as hearing loss. There is a positive association between the family's feeling of being able to manage the child's care and family resilience. This association is deduced from proposition 1.3 in Burr (1973) "the definition a family makes of the severity of changes in the family social system influences the family's vulnerability to stress, and this is a positive, monotonic relationship." This positive association is proposed because when families feel they are in control; they are better able to handle situations that come their way. This feeling of control helps these families better balance the demands of managing the care of a child with a chronic health condition such as hearing loss. Antonovsky and Sourani (1988) investigated the relationship between sense of coherence and family adaptation in a sample of 60 married Israeli males disabled by illness or injury, and their wives. They found a strong relationship between the two constructs for both the husbands and the

wives. This provides support for the proposed proposition because of the strength of the relationship which suggests that a higher sense of coherence and family adaptation are present in the same couples. Olsson, Larsman, and Hwang (2008) examined the relationship between risk, sense of coherence, and well-being in parents of children with intellectual disabilities and children without intellectual disabilities. They found that both risk and well-being were positively related to the parents' sense of coherence. This provides support for the positive association between the family's feeling of being able to manage the child's care and family resilience because in this study well-being was defined as part of family resilience.

L.2. Deducing Family Coping Skills from Coping Skills

Coping skills are how a group manages within a stressful time or situation (Malia, 2006). These skills can be at the individual, dyad, group, or community level. Family coping skills are the skills specifically used by a family to successfully manage a stressful time or event such as the diagnosis of childhood hearing loss. Family resilience develops not through the evasion of stressors, but through a family's successful use of protective factors to cope with these events and become stronger (O'Leary 1998). The positive association between family's feeling of being able to manage the care and family resilience is partially mediated by family coping skills. This mediation leads to a higher level of adaptation because when families have more or are better able to use their coping skills, they are more likely to feel their situation is manageable, and this leads to a higher level of family adaptation. For example, Jones and Passey (2005) examined the relationship of family adaptation and coping skills of parents of children with

developmental disabilities and behavior problems using the Double ABCX model. They found that parents were better able to manage the stress of managing the care of a child with a developmental disability when the families had effective coping skills. This supports the second leg of the mediation path proposed in this model because it states a positive relationship between effective coping skills and family resilience. Additional support for the mediational hypothesis in the model is grounded in the findings of Koen, van Eeden, and Wissing, (2011) who investigated the resilience in a group of nurses. They were interested in discovering what personal aspects lead nurses to be less likely to experience burn out. They found that there was a significant relationship between the nurses' level resilience, sense of coherence, and their use of effective coping skills.

L.3. Deducing Access to Support Networks From Social Support

Social support encompasses the resources received from social relationships, belonging to groups, and other networks (Malia, 2006). Social support can come from extended family members, friends, within the community, or other aspects of society such as a support group. Families with children who are deaf or hard of hearing benefit from social support as it provides emotional support, encouragement, advice, companionship, and tangible aids such as transportation (Figley, 1983). In this model, parent-to-parent support groups are specifically outlined. Henderson, Johnson, and Moodie (2014) discuss the importance of parent-to-parent support groups for families with children who are deaf or hard of hearing. These support groups provide parents with resources that are different from those obtained from health care professionals. Parent-to-parent support groups offer families empowerment and often lead to a decrease in parent

stress levels (Hintermair, 2006). There is a positive association between access to support networks and family resilience after the diagnosis of childhood hearing loss. In the Double ABCX model, Families who have access to social support are able to obtain more resources. The availability of new resources changes the level of family adaptation. An increase in resources availability and diversification of resources leads to higher levels of adaptation in these families (McCubbin & Patterson, 1983). Tak and McCubbin (2002) investigated the relationship of social systems on the resiliency of families with a child diagnosed with congenital heart disease. They found that having an appropriate social system provided a resiliency factor for these families. This study provides support for the hypothesis because the proposed model states that high levels of family resiliency will be found when families have access to parent-to-parent support groups. Kazack and Marvin (1984) explored the relationship between the social support of families with children with chronic health conditions and the stress the families experienced. They found that, although families with superior social networks continued to show high levels of stress, they also had high levels of family strengths. This report provides support for the positive association between social support and family adaptation because of the positive relationship found between strength and social networks.

L.4. Deducing Existing Family Burdens from Prior Strains

Within the family stress literature, strains are defined as a mismatch between the accrual of demands and the available resources (Malia, 2006). This mismatch can be due to financial burdens, relationship problems, an existing illness in another family member, or any number of other hardships that families may already be experiencing at the time of

the diagnosis of childhood hearing loss. There is a negative association between existing family burdens and family resilience. Proposition 1.2 stated by Burr (1973), “When a stressor event occurs, the vulnerability to stress influences the amount of influence the stressor has on the relationship.” Although this particular proposition provides a positive relationship, a negative association between the constructs of prior strains and family adaptation is proposed in the proposed model. This negative association is proposed because the more strain experienced by these families, the less they will be able to balance the demands of the chronic health condition with their resources. Support for the proposed negative relationship between these constructs in this hypothesis was found in the literature as demonstrated in the findings of McCubbin (1989) and Leske (2000). McCubbin (1989) examined the relationship between prior strains and family adaptation in single-parent versus two-parent households of children with a chronic health condition. No significant difference was found between the groups for the amount of stress, accumulation of stressors, demands, and resource strains. However, prior strains were seen to be a factor affecting the level of family adaptation in both groups. This finding supports the negative relationship proposed in the model. Leske (2000) investigated the stress felt by families after the critical injury family member. This critical injury could be a motor vehicle accident, gunshot wound, or other injury that caused major health and financial problems but not the death of the family member. The relationship between prior strains and adaptation was seen to be negative because families reported a lessened ability to manage the new stress of the injury. This provides support for the proposed relationship in the model of existing family burdens and family resilience. The concepts

used in the described model show how some families may demonstrate a higher level of family resilience after the diagnosis of childhood hearing loss than other families.

M. Purpose of the Study and Research Questions

The purpose of the investigation is to evaluate the perceived level of stress and resilience experienced by families with young children who are deaf or hard of hearing. In order to assess the effect of emotional support groups on families with children who are deaf or hard of hearing, a theoretical model was developed. The concepts of perceived stress and Family Resilience will be examined. The previous chapters outlined the purpose of the study, the underpinnings of the study in the literature, and the theoretical orientation and research methods which guide the present study.

Research Question One: What level of stress is experienced by parents of young children who are deaf or hard of hearing?

Research Question Two: What level of resilience is experienced by parents of young children who are deaf or hard of hearing?

Research Question Three: What are parents of young children who are deaf or hard of hearing perceptions of their family's stress and family resilience?

Research Question Four: What are parents of young children who are deaf or hard of hearing perceptions of how their attending *The Care Project* Family retreat has benefitted their management of their child's hearing loss and family adjustment to the diagnosis of their child's hearing loss?

CHAPTER III

METHODS AND MATERIALS

A. Introduction

The purpose of the investigation was to evaluate the perceived level of stress and resilience experienced by families of young children who are deaf or hard of hearing. The previous chapters outlined the purpose of the study and the underpinnings of the study in the literature. The following chapter will detail the theoretical orientation and research methods which guide the present study. This study is a mixed-methods triangulation design which incorporated the integration of results from both qualitative data from semi-structured interviews and quantitative data from questionnaires. Through the chosen methodology, the researcher obtained a more complete perspective of the experiences of the families raising a child who is deaf or hard of hearing.

B. Introduction to Qualitative Methods

Qualitative research has gained in popularity since the 1980s and continues to grow in acceptance (Huberman & Miles, 2002). Qualitative research involves the accumulation of data represented through words, pictures, or symbols and is often tied to an assumption of relativism (O'Leary, 2017). It may include descriptions of individuals, situations, experiences, attitudes, and beliefs (Patton, 1982). Qualitative research allows researchers to probe deeper into questions of meaning, assess social processes, identify barriers to change, and find reasons for the success or failure of different interventions

(Starks & Brown Trinidad, 2007). When qualitative data is analyzed, it provides a rich understanding of the people or situations being investigated (O’Leary, 2017).

Lofland and Lofland (1971) outline four main elements of qualitative research. Primarily, the qualitative researcher must be close enough to the people, event, and/or situation being studied in order to gain a thorough understanding of what is happening. Then the researcher must have the goal of encapsulating what is truly happening instead of merely what is being said. The data constitutes uncontaminated descriptions of the people, event, and/or situation being studied. Finally, the data consists of direct quotations from subjects which can be both spoken and written.

Qualitative research has been criticized as being small scale and impossible to generalize; however, qualitative methodology provides the researcher with many benefits. These include the depth provided by the data that allows qualitative studies to capture the complexities of the people, event, and/or situation being studied. In addition to the depth provided by qualitative studies, data based on human experience is powerful and compelling. Furthermore, although data are typically unable to be generalized, they can often be transferable to similar settings (Anderson, 2010). Although the analysis of qualitative data can be quite time consuming and the quality of the data can be influenced by biases, when qualitative studies are designed appropriately, the researcher can manage these challenges to attain relevant and cogent conclusions (Anderson, 2010).

The qualitative research methods used in this study include specifically the use of phenomenological methods to guide semi-structured interviews. The use of these specific research methodologies will facilitate the goal to reveal the lived experiences of the parents of young children who are deaf or hard of hearing.

B.1. Introduction to Phenomenology

This study seeks to understand the lived experiences of families with a young child who is deaf or hard of hearing. Although families with children who are deaf or hard of hearing have been examined regarding their stress, little is known about the resilience of these families. Previous studies have typically examined mothers' perspectives via questionnaires. Jackson et al. (2010) found that families would benefit from a focus on balancing of resilience sources and requirements to support the emotional needs of the family. Minchom et al., (2003) found parents benefitted when they had access to educational support services (e.g. sign language classes for families who chose this mode of communication), and support from other parents of children who are deaf or hard of hearing. These two studies demonstrate how resilience as a concept has been used broadly in the area of children who are deaf or hard of hearing; however, there is much left to learn in this area. Qualitative research methodologies offer an appropriate means to gain insight regarding how families with children who are deaf or hard of hearing manage their everyday lives and attain positive family adaptation to their child's hearing loss.

Given the goal of this research study, phenomenology was selected as the appropriate qualitative methodology. The purpose of phenomenology is to explore the perceived, lived experiences of individuals and the meanings they distinguish from these experiences (Moustakas, 1994). O’Leary (2017) describes phenomenology as “The study of phenomena as they present themselves in individuals’ direct awareness and experience. Perception, rather than socio-historic context or even the supposed “reality” of an object, is the focus of investigation (p. 192).”

One may ask why it is important to gain an understanding of someone’s perception of something? The truth of a situation in question is subjective and only obtainable through the examination of a person’s embodied perspective (Starks & Brown Trinidad, 2007). Therefore, the reality of these situations is examined through lived experience (Starks & Brown Trinidad, 2007). Phenomenology is a way to attempt to understand why people may behave illogically because it examines how people are feeling rather than what they are thinking (O’Leary, 2017). Moustakas (1994) describes phenomenological research as research which seeks to encapsulate the wholeness of a phenomenon that one may uncover the essences of the experiences in question. He states that “the empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience” (Moustakas, 1994, p 13). It is through the examination of lived experiences of subjects that researchers are able to represent the knowledge found in these events and situations. Since families with children who are deaf or hard of hearing often report feelings of stress and being

overwhelmed (Kurtzer-White & Luterman, 2003) it is imperative that researchers delve into these experiences so that practitioners can design and implement strategies and resources to assist such families. What are the predictive factors that lead some families to report higher levels of stress than others? This study posits that the availability of emotional support groups, such as *The Care Project* retreats, allow families to experience higher levels of resilience after the diagnosis of hearing loss in a child.

B.2. Subjectivity Statement

It is appropriate to include a subjectivity statement in qualitative phenomenology research designs so the researcher can confront his/her personal experiences that have the potential to influence the outcome of the study (Moustakas, 1994). Through developing a subjectivity statement, the researcher engages in *Epoch* as defined by Moustakas, (1994), as a process that requires the researcher suspend prejudices, biases, and preconceived ideas in order to gain a fresh perspective on the people, events, and situations being examined. This process requires the researcher to take a period of time with full concentration on what appears in their consciousness and then recognize and reflect on what comes to mind in that period (Moustakas, 1994).

The following section will detail my background in areas related to family resilience and children who are deaf or hard of hearing as central to *Epoch* and my Subjectivity Statement for the research. As I have clinical experience working with children and their families as a pediatric audiologist, it is necessary for me to acknowledge my attitudes and opinions. Through this statement, I will address and bracket my own experiences so I can approach this study from an unbiased perspective.

My interest in the lived experiences of families with children who are deaf or hard of hearing developed through my clinical work as a pediatric audiologist. I worked at one of the top ranked pediatric hospitals in the nation for two years. During this time, I worked with many families who had children who are deaf or hard of hearing. I had families on my case-load who were experienced with the diagnosis as their children were older and they were several years past the initial diagnosis as well as parents of newborn babies who had failed their newborn hearing screening and I was the person to diagnose their infant with hearing loss, and families at all points in-between. While this work was rewarding as I was able to follow these families through their progress, it also made me aware of several limitations both I and the families faced.

I felt that even though I was following best practice guidelines I was not providing my patients or their families with the truly comprehensive care they needed and deserved. I was limited in the time I had to spend with each family, with my availability of appointments, and with my knowledge of the full services required by a family of a child who is deaf or hard of hearing. My knowledge was primarily limited to the audiologic needs with some information on the grief process families typically proceed through after receiving the diagnosis of hearing loss in a child.

My experiences are not unique in this aspect. Many of the audiologists I know and have worked with, while they care deeply for their work and their patients, simply do not have the benefit of having a complete picture of everything involved with the care of children who are deaf or hard of hearing. I was lucky enough to work with an Auditory Verbal Therapist, Allison Haggerty MS, CCC-SLP, LSLS Cert. AVT, and together we

educated each other on our different aspects of caring for a child who is deaf or hard of hearing and their families. Through our partnership we were able to extend the care we were able to provide to the children we served at our clinic. However, we were both still frustrated by the fact that we were unable to provide truly comprehensive care for these families.

I have always felt strongly about family-centered care (FCC) as it is practiced in pediatric audiology. As a pediatric audiologist, it is not only my job to diagnose and treat hearing loss, but to help families learn about hearing loss, Deaf culture, and help them navigate the world to the best of my abilities and when we reach the limit of my abilities, to help them find additional resources. I believe pediatric audiologists do not just treat the child but the family as well. I believe that this style of health care provides the best outcomes for all involved. My work as a clinician will help me build rapport with participants during the interviews.

C. Mixed Methods Research Design

The study used methodology that incorporated the collection and analysis of both quantitative and qualitative data (O'Leary, 2017). Mixed methods designs can overcome some of the shortcomings of a purely quantitative or qualitative approach in that a researcher can develop a broader understanding of the question by adding depth and insights to numbers through inclusion of dialogue, narratives, and pictures. This also allows for the study to encapsulate varied perspectives (O'Leary, 2017). Mixed methods designs offer researchers the ability to engage in a thorough social explanation of the process being examined (Almalki, 2016).

One form of mixed methods study design is the triangulation design. This design seeks to gather complementary yet distinctly different data on the same topic which can then be integrated for analysis and interpretation (Almalki, 2016). Collection of each set of data is not dependent on the other, but instead are separate processes. Triangulation attempts to obtain confirmation of one data source through validating it with a different data source (O'Leary, 2017). These data sources are distinct from one another in both the collection and analysis of data (Almalki, 2016). The goal of a triangulation design is to look for corroboration between the different data sources (O'Leary, 2017). When done correctly, this is an efficient study design (Almalki, 2016).

In this study, the triangulation design was utilized by blending together the results of surveys and analysis of the themes found in the interviews. This design is appropriate for the research study because the overarching research question “How is the level of family resilience and family stress in families with children who are deaf or hard of hearing served by access to emotional support, specifically *The Care Project* retreats” is best addressed with a combination of both quantitative and qualitative data. This combination allowed the researcher to investigate the high levels of stress reported by families with children who are deaf or hard of hearing (Gilliver et al., 2013; Jackson & Turnbull, 2004) and probe into the perceived level of family resilience

D. Institutional Review Board

Approval from the University of North Carolina Greensboro Institutional Review board (IRB) was obtained on November 1, 2019. It was determined that this study qualified for an exemption. A copy of the IRB notice is attached in Appendix A.

E. Subjects

Participants were recruited from the families attending *The Care Project* Retreat in Wilmington, NC, in November 2019. Parents of children who are deaf or hard of hearing were selected as the focus of this study. Dr. Sexton stated that the retreats aim to have at least 10 parent partnerships present (J. Sexton, personal communication, August 16, 2019). For this study, nine parent partnerships were recruited for participation in the questionnaires and interview process. Exclusion criteria for the study include parents who do not have a child who is deaf or hard of hearing, parents of children who are deaf and hard of hearing who do not attend *The Care Project* Retreat.

E.1. Recruitment Procedure

A list of Care Project retreat dates and locations was obtained from *The Care Project* website (<http://www.thecareproject.com/retreats/>). Dr. Johnnie Sexton, founder of *The Care Project* who is a pediatric audiologist with over forty years of audiology experience was consulted about dates. It was decided that the annual retreat for families with children aged birth to 5 years would be the appropriate site for data collection (personal communication, August 16, 2019). This retreat was held at the Holiday Inn in Wrightsville Beach, NC, from November 22nd to the 24th 2019.

The Care Project retreat offers families informational seminars, bonding time with other families, social activities, and special sessions for moms, dads, siblings, and children who are deaf or hard of hearing. The goal of *The Care Project* retreat is for these families to increase their resilience, community-building and ability to advocate for themselves, their family, or their family member as they experience and adapt to their

child's hearing loss and the impact it has on their family functioning (The Care Project, 2020). A permission letter for the use of *The Care Project* family retreat as a recruitment site was obtained from Dr. Johnnie Sexton, Au.D.

E.1.a. Distribution of Questionnaires

Parents received the informed consent, selected questionnaires, family information sheet, and an instruction sheet with a link to a video of the researcher explain the study and the documents in the packet in the mail before *The Care Project* Family Retreat. The instruction sheet and video inform the parents that the questionnaires are intended to be completed separately and returned to the researcher at their scheduled interview time. Parents who did not complete the questionnaires were provided with an addressed stamped envelope to mail the questionnaires to the researcher.

E.1.b. Interview Process

Interviews were conducted in a private room within the Holiday Inn. Parents were scheduled a time to be interviewed however the researcher was available at other times during the retreat in case parents need to reschedule their time. Any parent who did not wish to participate was not be required to complete the interview. Interviews were video recorded utilizing Video Recorder App on an Acer CB3-532-C47C Chromebook with a table mic connected.

F. Instrumentation

F.1. Quantitative Data

The quantitative data obtained for this study consists of parent's individual responses to two questionnaires which were mailed to the families two weeks before the

retreat: The Parenting Stress Index 4th edition short form (PSI- 4 SF) (Abidin, 2012); and the Family Resilience Assessment Scale (FRAS) (Sixbey, 2005). The completion of these questionnaires allowed the researcher to assess the families' perceived level of stress and family resilience. Family resilience has been linked to stress (Herrman et al., 2011; McCubbin et al., 2002; McCubbin et al., 1997; Walsh, 2004) and therefore the combination of responses of the selected questionnaires will provide a more complete view of the parent's perception.

F.1.a. Parenting Stress Index

The PSI- 4 SF is a validated and often used instrument to study this population, it is a logical and verifiable tool which will give the researchers an insight into the lived experiences of these parents. The PSI in its current and previous iterations have been used in numerous studies of families with children with chronic health conditions (Carey, Nicholson, & Fox, 2002; Cushner-Weinstein, Dassoulas, Salpekar, Henderson, Pearl, Gaillard, & Weinstein, 2008; Potterton, Stewart, & Cooper, 2007). The PSI- 4 SF contains 36 statements in three domains: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and difficulty of child (DC) which combine to form the Total Stress scale. Possible scores range from 36 to 180, indicating the overall amount of stress experienced in the parenting role as a function of the three subscales. The PSI- 4 SF is intended for use with parents of children age one month to twelve years. Revisions from previous editions include: improvement in cultural sensitivity of language; increased internal consistency of scales; age-based norms for sub-scale levels; fathers included in standardization; and the addition of T scores (Abidin, 2012). It is estimated

that the average completion time for the PSI- 4 SF is approximately 20 minutes (Abidin, 2012).

The PSI- 4 SF was rated on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). To determine the subscale (PD, P-CDI, or DC) and total stress scores, all subscales were summed, with the overall score indicating the total level of stress. In the analysis, the higher the total score, the higher the level of stress; the lower the total score, the lower the amount of stress.

On the PSI- 4 SF, stress levels considered normal are between the 16th and 84th percentile. Scores within the 85th to 89th percentile are considered high. Scores in the 90th percentile indicate that the individual experiences clinically significant levels of stress. It is important to note that the total score on the PSI- 4 SF only indicates the overall level of stress perceived by the parent in their role as a parent and does not consider life stressors outside that role. It is also important to note that the total score on the PSI- 4 SF reflects the stress associated with parenting, the parent-child interaction, and the child. According to Abidin (2012), the internal reliability alpha coefficients are 0.98 for total stress, with 0.96 for Parent Domain, and 0.96 for Child Domain.

F.1.b. Family Resilience Assessment Scale

The Family Resilience Assessment Scale was developed to conceptually measure family resilience (Sixbey, 2005). This questionnaire includes three primary constructs from which a six-factor scale to assess family resilience was developed. These factors are: Family Communication and Problem Solving; Utilizing Social and Economic

Resources; Maintaining a Positive Outlook; Family Connectedness; Family Spirituality; and Ability to Make Meaning of Adversity.

The measure uses a 4-point Likert Scale that ranges from strongly disagree to strongly agree. The FRAS contains six subscales. A higher score on the FRAS indicates a high level of family resilience, and a low score indicates a low level of resilience. The FRAS consists of sixty-six questions and one open ended question. The total score of the FRAS can range from 66 to 264. The FRAS uses a Likert scale with strongly disagree = 1 to strongly agree = 4. Items 42, 48, 57, and 62 are reversed scored, therefore for those questions, strongly disagree was coded as a four and strongly agree is converted to one. The overall internal consistency of the FRAS is $\alpha = 0.96$. Three well known and widely utilized instruments were tested and found to have good concurrent criterion validity with and reliability with the FRAS. These were the Family Assessment Device 1 ($\alpha = 0.91$), Family Assessment Device 2 ($\alpha = 0.85$), and the Personal Meaning Index ($\alpha = 0.85$) (Sixbey, 2005). This scale has not been validated on families with children who are deaf or hard of hearing. To ensure it was an appropriate tool to use for this population, two parents of children who are deaf or hard of hearing, a practicing pediatric audiologist, and two speech-language pathologists reviewed the questions to ensure that they applied to families with children who are deaf or hard of hearing. This review also established that 30 minutes was the approximate amount of time required to complete the surveys.

Internal consistency for this questionnaire was computed using Cronbach's Alpha. Cronbach's Alpha is calculated from the pairwise correlation between items and can be thought of as the average correlation between all possible split-halves reliability estimates

(University of California Los Angeles Statistical Consulting Group, 2019). A reliability coefficient of .70 or higher is acceptable; the FRAS shows an acceptable level of internal consistency in all subscales except Family Connectedness (FC) (.61) and Ability to Make Meaning of Adversity (AMMA) (.65) (Sixbey, 2005). The low-reliability coefficient for the FC subscale may be attributed to the four reverse coded questions which are part of this subscale.

F.2. Qualitative Data

The qualitative data obtained for the study was from semi-structured interviews with the parents. An interview is a method of data collection in which the researcher asks participants open-ended questions around a central theme or topic (O’Leary, 2017). Interviewing is the most frequently used data collection strategy in qualitative studies (Burnard, 2005; Nunkoosing, 2005; Sandelowski, 2002). Interviews can be conducted as structured, semi-structured, or unstructured (Baumbusch, 2010). A structured interview has a set script from which the interviewer cannot vary. A semi-structured interview is more flexible than the structured interview. In this format the interviewer has a set question plan but can vary from this in order to achieve a more natural feel or to pursue an interesting topic the interviewee introduced. An unstructured interview attempts to obtain information from the interviewee about their beliefs and opinions about the topic in question without the use of a script (O’Leary, 2017). This study will utilize the semi-structured format. Semi-structured interviews are utilized extensively as an interview format (Jamshed, 2014).

The interview protocol for the present study was peer-reviewed by two parents of children who are deaf or hard of hearing, an Auditory-verbal therapist, and a practicing pediatric audiologist. The interview protocol is provided in Appendix C. Questions were developed in order to obtain the opinions, perceptions, and attitudes of participants about their family's level of resilience and stress. The interviews were conducted as individual or parent pairs depending on the preference of the parents. Parents were scheduled for their interviews. However, the researcher was available during other times during the retreat in order to be accommodating to family needs if the scheduled time is not ideal for them. If the parent was unavailable during the retreat, the researcher was available via Skype in the weeks following the retreat.

G. Data Analysis

Data analysis was performed separately on the quantitative data collected from the PSI- 4 SF and FRAS and on the qualitative data collected from the semi-structured interviews.

G.1. Data Management

All information obtained from participants was kept confidential. The qualitative data collected through the semi-structured interviews does not include identifying information. Subjects were assigned numeric values based on the interview schedule. A list of the interview schedule was kept on a password-protected computer. All paper data collected (questionnaires: PSI- 4 SF and FRAS) were stored in a locked cabinet in a locked room on the third floor of the UNCG Ferguson building. Electronic data (recordings of interviews, research data extracted from paper data and inputted into an

electronic data sheet) were de-identified. Electronic data were stored on Sarah Allen's computer in her office. The de-identified data were also be stored online on Sarah Allen's secure UNCG Box account. UNCG Information Technology has Box accounts set up at the top level of security and is used by UNCG to house online research data. Data will be destroyed ten years after the study has closed.

G.2. Analysis of Quantitative Data

The information obtained from the individual surveys were inputted into an SPSS spreadsheet and coded for several variables. Quantitative data was analyzed based on parent gender. This information provided insight into the possible differences which may lead some families to perceive a higher level of stress or resilience than others. The information utilized for coding the surveys was obtained from the Family Information Sheet which parents received in their packet (Appendix G).

G.3. Analysis of Qualitative Data

Interviews with three families were conducted at *The Care Project* Retreat in Wrightsville Beach, North Carolina, on November 23, 2019. One family's interview was conducted via Skype on December 5, 2019. All interviews were video recorded and transcribed verbatim through the use of the transcription software provided by UNCG. The process involved uploading the video recordings of the semi-structured interviews to Studio, generating captions, and then downloading them to review. To ensure the accuracy of the transcriptions the researcher listened to each recording while reading the transcribed version. Participants were offered a chance to review their transcripts in an

effort to ensure they agree with their responses and there were no additional comments they wish to have added (O’Leary, 2017).

The qualitative data obtained were analyzed utilizing the multi-step process described by Creswell (2014). In this process, the researcher begins with a thorough review of all transcripts. After the review of all the transcripts, each transcript will be thoroughly examined for emergent themes (O’Leary, 2017). After the completion of the initial examination data will be reviewed a second time. The purpose of the second review is to determine whether any additional information could be included in the established themes or if a new theme emerges (Creswell, 2014). Data were then summarized and linked back to the overarching research question of the effect of emotional support groups, specifically *The Care Project* retreat, on family resilience in families with children who are deaf or hard of hearing.

G.4. Trustworthiness

With the analysis of the qualitative data collected from the semi-structured interviews in this study, it is important to remember that the purpose of a phenomenological study is to encapsulate the first-hand lived experiences and perceptions of the subjects (Moustakas, 1994). Within qualitative research, validity refers to the depth and rigor of the information obtained (Creswell, 2007). The purpose of the qualitative research is not to produce generalizable results but to fully examine the situation in question (Creswell, 2014). To ensure that the data collected was credible several measures were taken: 1) employment of a theoretically consistent design; 2) engaging in researcher reflexivity; 3) member checks; 4) debriefing with peers.

G.4.a. Theoretically Consistent Design

The design of the study is theoretically consistent with the goal of the study, to assess the effect of emotional support, specifically, *The Care Project* retreats, on the family resilience in families of young children who are deaf or hard of hearing. The PSI-4 SF and FRAS provided information about the perceived level of stress and resilience in these families. This information is valuable because of the reported high levels of stress in families with children who are deaf or hard of hearing (Dirks et al., 2016; Meinzen-Derr et al., 2008; Quittner et al., 2010) and the limited availability of research studies which use family resilience as a measure

G.4.b. Reflexivity

The researcher's *reflexivity* will be engaged throughout the study as is required by phenomenological research. The researcher engaged in *epoch* which was described in the subjectivity statement. Epoch was used to keep the researcher's views of the phenomenon in question separate from the subject's so that the subjects' perceptions can be regarded clearly (Moustakas, 1994). This process was revisited continually to ensure that the researcher's own ideas, values, prejudices, and experiences did not override those of the participants.

G.4.c. Member Checking

Member Checking involves sharing the transcribed interviews with the subjects. This allows them to review their own material and address any concerns about their statements, the correctness of the transcription, or additional comments they may have (O'Leary, 2017). Engaging in the member check process helps ensure the correctness and

trustworthiness of the data obtained and therefore analysis and the research study as a whole (Seidman, 2013).

G.4.d. Peer Debriefing

Since three of the four interviews were conducted in one weekend, *peer debriefing* during data collection was not be possible between all interviews. However, during data analysis, the researcher had several debriefing sessions with peers who were familiar with the needs of children who are deaf or hard of hearing, their families, and with qualitative research methodologies. These sessions were tracked and reviewed as necessary.

CHAPTER IV

RESULTS

The purpose of this study was to examine the family resilience and stress of parents with young children who are deaf or hard of hearing. This mixed-methods research study had two parts. First, the quantitative portion, questionnaires were given to parents of children who are deaf or hard of hearing who attended *The Care Project* Retreat in Wrightsville Beach, NC, in November 2019. The two questionnaires were: 1) The Parenting Stress Index version 4, short form (PSI-4 SF); and 2) The Family Resilience Assessment Scale (FRAS). Second, the qualitative portion, parents were given an opportunity to participate in a semi-structured interview either at the retreat or via Skype after the retreat. In this chapter, results from the responses to the PSI-4 SF and FRAS questionnaires and the semi-structured interviews are presented. The return rate for the surveys was 75%, and all surveys returned were 100% complete. Interviews were conducted either in person at *The Care Project* retreat or via Skype in the two weeks following the retreat based on the participant's availability. Interviews were conducted with 44% of the families who attended *The Care Project* retreat. Video recordings of the in-person or Skype interviews were transcribed, and emergent themes were identified for each interview according to procedures outlined by Creswell (2014). This chapter provides the results of the quantitative and qualitative data analyses conducted.

A. Demographic Information

Seven families participated in the study. Table 1 displays the demographic information about the parents, as obtained from the Family Information Questionnaire (Appendix E). Participant ages ranged from 32 to 45 years, with a mean age of 36.8 ($SD = 4.26$). Half of the parents reported having finished a bachelor's degree, with 16% reporting having completed a high school diploma or equivalent, 16% a graduate degree, or a professional degree. All participants were married with none reporting a prior marriage. They reported being the child's mother or father, respectively. The majority of the parents reported their race as White (66%) with two parents reporting their race as Black and two as Hispanic.

Table 1. Parent Demographic Information for Each Family

Family ID		Parent Age	Parent Gender	Highest Level of Ed	Marital Status	Race/Ethnicity
Family One	Parent A	33	F	Bachelor's Degree	Married	White
	Parent B	The parent did not participate in this study				
Family Two	Parent A	45	F	Professional Degree	Married	Black
	Parent B	42	M	Professional Degree	Married	Black
Family Three	Parent A	39	F	Graduate Degree	Married	White
	Parent B	The parent did not participate in this study				
Family Four	Parent A	38	F	Bachelor's Degree	Married	White
	Parent B	32	M	High School Diploma	Married	White
Family Five	Parent A	33	F	Bachelor's Degree	Married	White
	Parent B	37	M	High School Diploma	Married	White
Family Six	Parent A	33	F	Bachelor's Degree	Married	White
	Parent B	32	M	Bachelor's Degree	Married	White
Family Seven	Parent A	39	F	Bachelor's Degree	Married	Hispanic
	Parent B	39	M	Graduate Degree	Married	Hispanic

Table 2 reports the birth history of each child who is deaf or hard of hearing for each family. The majority of children were the result of a full-term pregnancy (71%), with the two premature births also being reported as twin births. Forty-three percent of the children had neonatal intensive care unit (NICU) stays and received some form of Oxygen while in NICU. Two of the children (29%) developed jaundice, and four (57%) received antibiotics while in the hospital after birth. All of the children (100%) reportedly received a newborn hearing screening (NBHS). One hundred percent of the children failed this screening and were referred for further testing by an audiologist.

Table 2. Birth History of Each Child who is Deaf or Hard of Hearing for Each Family

Family ID	Full Term Pregnancy	NICU Stay	Child Received Oxygen	Jaundice	Antibiotics delivered in the hospital	Child received NBHS	Results of NBHS
Family One	Full Term	Yes (31 Days)	Yes	Yes	Yes	Yes	Failed
Family Two	Full Term	No	No	No	No	Yes	Failed
Family Three	Premature (27 weeks)	Yes (146 Days)	Yes	Yes	Yes	Yes	Failed
Family Four	Premature (35 weeks)	No	No	No	Yes	Yes	Failed
Family Five	Full Term	Yes (2 Days)	Yes	No	No	Yes	Failed
Family Six	Full Term	No	No	No	Yes	Yes	Failed
Family Seven	Full Term	No	No	No	No	Yes	Failed

Table 3 displays the hearing loss information of the child who is deaf or hard of hearing in each family. The majority of children (57.1%) were identified as deaf or hard of hearing at birth, with one child identified by age three months and two children identified by age six months. The majority of children (85%) were diagnosed with a bilateral hearing loss with only one child diagnosed with a unilateral hearing loss. The majority (57.1%) of children were diagnosed with a bilateral profound hearing loss and use bilateral cochlear implants. The other children were not identified with symmetrical hearing loss and use either hearing aids or cochlear implants. Two families (28.5%) reported their child's hearing loss as having progressed since the initial diagnosis with four families (57.1%) reporting that their child's hearing loss has remained stable since the diagnosis with one family reporting they are unsure whether their child's hearing loss has changed since the initial diagnosis.

Table 3. Hearing Loss and Listening Technology for Each Child

Family ID	Age of Child at ID	Unilateral or Bilateral Loss	Degree of Loss Left Ear	Degree of Loss Right Ear	Listening Technology Used Left Ear	Listening Technology Used Right Ear
Family One	At Birth	Bilateral	Profound	Profound	Cochlear Implant	Cochlear Implant
Family Two	At Birth	Unilateral	Severe	Normal Hearing	Hearing Aid	No Devices Used
Family Three	4-6 Months	Bilateral	Profound	Profound	Cochlear Implant	Cochlear Implant
Family Four	At Birth	Bilateral	Profound	Profound	Cochlear Implant	Cochlear Implant
Family Five	1-3 Months	Bilateral	Profound	Moderate to Severe	Cochlear Implant	No Devices Used
Family Six	4-6 Months	Bilateral	Profound	Profound	Cochlear Implant	Cochlear Implant
Family Seven	At Birth	Bilateral	Severe	Severe	Hearing Aid	Hearing Aid

Table 4 presents the reported early intervention and support services received by the families. All families reported receiving both support services as well as early childhood intervention (ECI) services. All families reported receiving support services from NCBeginnings, with the majority (85.7%) reporting having received this support at least by three months after receiving the diagnosis of hearing loss. The majority of families specifically reported receiving ECI speech therapy services (57.1%), with 85.7% reporting these services were initiated at least three months following the diagnosis of their children’s hearing loss.

The only support services listed as being received by the families was NCBeginnings. This program was established in North Carolina in 1987 to provide

emotional support and access to information as a central resource for families with deaf or hard of hearing children. Through NCBeginnings, families are provided with informational and resource support to assist them in making informed decisions about their child’s care that helps empower them to advocate for their child (Beginnings, 2019).

Table 4. Early Intervention and Support Services Received by Each Family

Family ID	ECI Services Received	Length Receiving ECI Services	Support Services Received	Length Receiving Support Services
Family One	Speech and Play therapy	Since receiving the diagnosis	NCBeginnings	Since receiving the diagnosis
Family Two	Speech Therapy	Over 1 year since receiving the diagnosis	NCBeginnings	Over 1 year since receiving the diagnosis
Family Three	0-3 signing and speech services	Within 3 months of receiving diagnosis	NCBeginnings	Within 3 months of receiving diagnosis
Family Four	DPI, DHHS	Within 3 months of receiving diagnosis	NCBeginnings	Within 3 months of receiving diagnosis
Family Five	Speech Therapy	Within 3 months of receiving diagnosis	NCBeginnings	Within 3 months of receiving diagnosis
Family Six	Itinerant Teacher, Case Worker	Within 3 months of receiving diagnosis	NCBeginnings	Within 3 months of receiving diagnosis
Family Seven	Teacher of the Deaf	Since receiving the diagnosis	NCBeginnings	Since receiving the diagnosis

B. Quantitative Results

Complete questionnaires were obtained from both parents for five families and only from the mother for two families. Responses from the PSI-4 SF and the FRAS questionnaires were inputted into a de-identified SPSS spreadsheet. Descriptive analysis was conducted for all completed questionnaires. This analysis shows individual differences within families and across different variables. This was done due to the small number of participants in the study because there were too few participants in this study to make inferential statistics meaningful. Parents' raw scores for the PSI-4 SF are presented in Figure 5. The PSI-4 SF has three subscales: Parental Distress (PD); Parent-Child Dysfunctional Interaction (P-CDI); and Difficult Child (DC). The scores for the subscales are presented in figures 6, 7, and 8. The parents' total scores for the FRAS are presented in figure 9. The FRAS is comprised of six subscales: Family Communication and Problem-Solving; Utilizing Social and Economic Resources; Maintaining a Positive Outlook; Family Connectedness; Family Spirituality; and Ability to Make Meaning from Adversity. The scores for these subscales are presented in figures, 10 through 15.

B.1. PSI-4 SF

The PSI-4 SF is a measure of perceived stress related to parenting (Abdin, 2012). Scores on the PSI-4 SF can range from 36 to 180 with higher scores indicating higher levels of perceived stress in the participant. For the PSI-4 SF, parents reported an average total score of 63.67 ($SD = 16.16$) with a range of 44 to 104. Overall, the scores were in the normal range with one parent, the mother from Family One, displaying a much higher level of stress than the other parents in the study. Her total score of 104 was in the

clinically significant range. This mother reported that her husband is in the military and was currently deployed at the time of the retreat. It is possible that this circumstance is a corroborating factor with her substantially higher level of stress when compared with other parents in this study. Figure 5 shows the total scores for the parents for the PSI-4 SF for all participants.

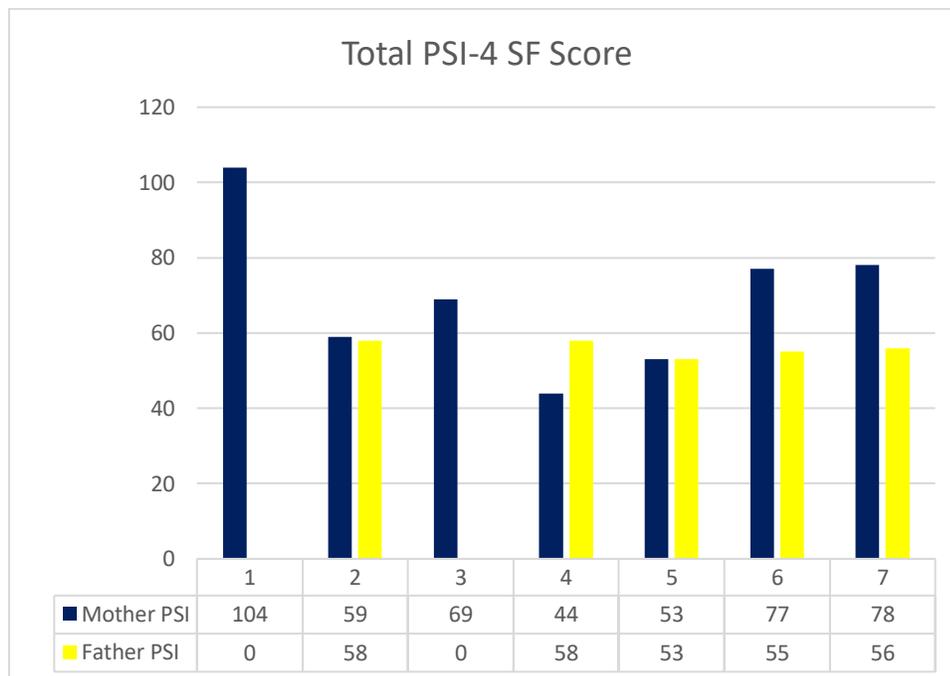


Figure 5. Total PSI- 4 SF Scores

B.1.a. Parental Distress

The PD subscale is a measure of the level of distress the parent experiences in their role as a parent directly related to the personal factors of parenting (Abdin, 2012). High scores in this subscale indicate high levels of distress experienced by the parent. Scores for this subscale can range from 12 to 60. The parents reported an average of

25.33 ($SD = 6.17$) for this subscale. Since the average of 25.33 is in the middle range of the possible scores, this finding indicates that the parents in this study feel an average level of distress when parenting their child who is deaf or hard of hearing. Figure 6 displays the individual scores for each participant.

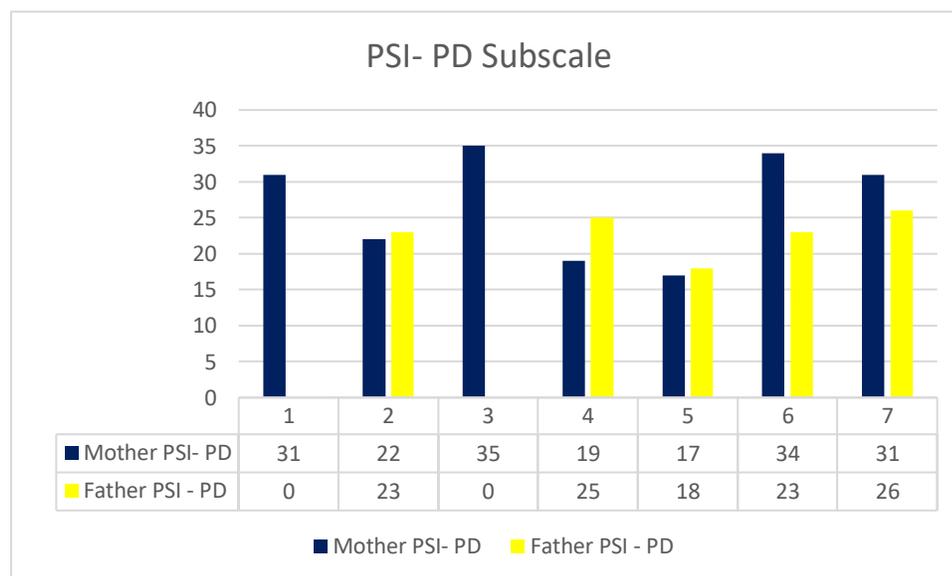


Figure 6. Parental Distress Subscale Scores

B.1.b. Parent-Child Dysfunctional Interaction

The P-CDI subscale measures the perception of the parent that their child meets their expectations of having a child (Abdin, 2012). High scores in this subscale indicate that the parent is not being reinforced in their role by the child. It is also possible that high scores indicate that the parent-child bond has not been adequately established (Abdin, 2012). Scores for this subscale can range from 12 to 60 with a median score of 36. The average score study parents attained was 17.58 ($SD = 7.24$) for the P-CDI subscale. Since this average score is relatively low in the possible range of scores, it

indicates that the parents, overall, feel they are being reinforced in their role of parent by their child who is deaf or hard of hearing. Figure 7 displays the parents individual scores for the P-CDI subscale for the PSI-4 SF.

The score for the mother in Family One is considerably higher than the scores for the other parents. In fact, she scored in the 94th percentile in this subscale which indicates she has experienced clinically significant stress in this area. Some factors that may be contributing to this high level of perceived stress are that her son was the most medically complex child in the study and her husband is active duty military. He was deployed at the time of *The Care Project* retreat.

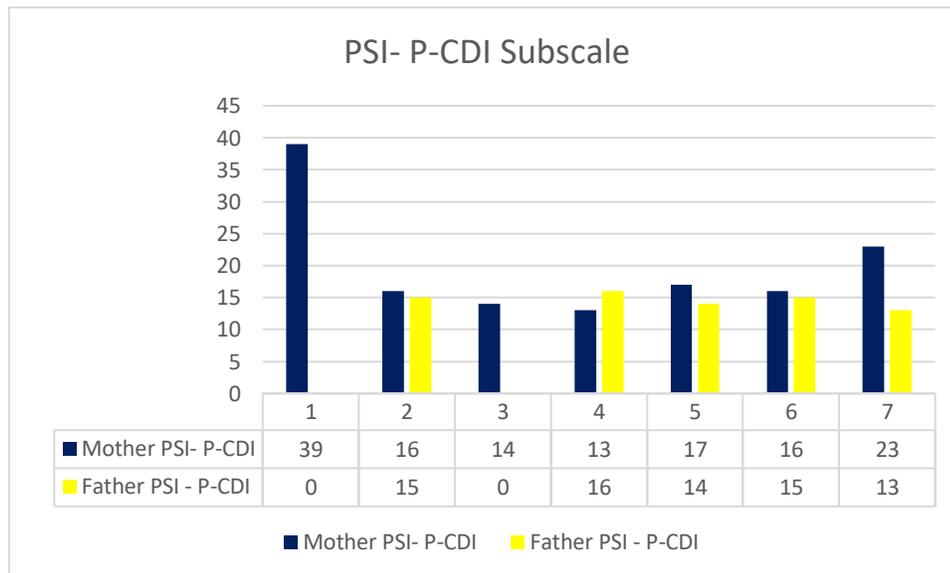


Figure 7. Parent-Child Dysfunctional Interaction Subscale Scores

B.1.c. Difficult Child

The DC subscale measures the parents’ perceptions of their child’s behavioral characteristics as either easy or difficult to manage. High scores in this subscale indicate

behavior of the child with which the parent may be struggling to manage (Abdin, 2012). Scores for this subscale can range from 12 to 60 with a median score of 36. The parents in this study reported a mean score of 20.75 ($SD = 5.63$) for the DC subscale. Since the average reported score is in the middle range of the possible scores, the parents in this study feel their child who is deaf or hard of hearing is average behaviorally.

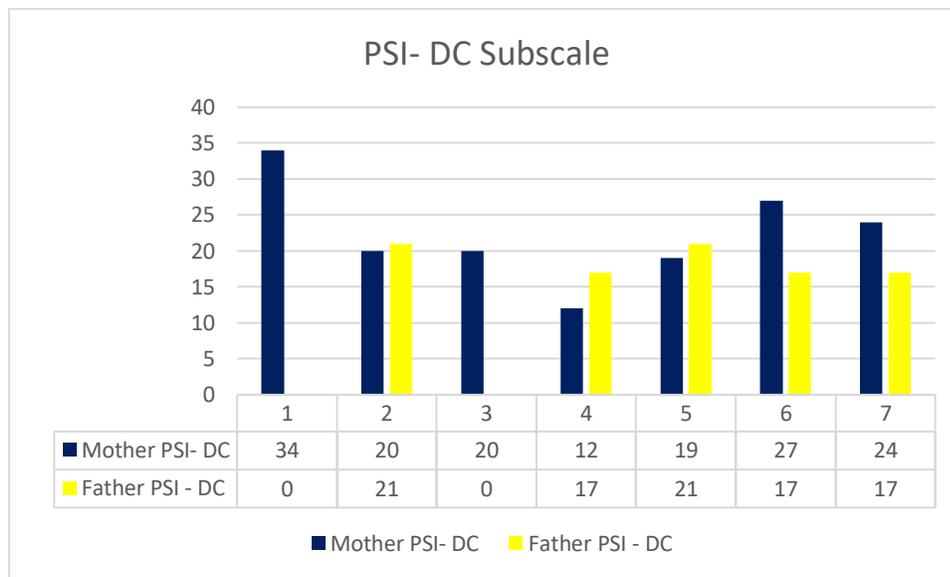


Figure 8. Difficult Child Subscale Scores

B.2. Family Resilience Assessment Scale

The Family Resilience Assessment Scale (FRAS) was developed as a conceptual measure of family resilience (Sixbey, 2005). Possible scores for the FRAS can range from 66 to 264 with higher scores indicating higher levels of perceived family resilience. Parents reported an average total score of 206.83 ($SD = 16.94$) with a range of 190 - 242 for the FRAS. Figure 9 shows the total scores for the FRAS reported for each participant. Overall, the scores were high for all parents that completed the FRAS. The range of

scores reported for the parents in this study is on the high end of possible scores. This indicates that parents in this study feel a substantial level of resilience.

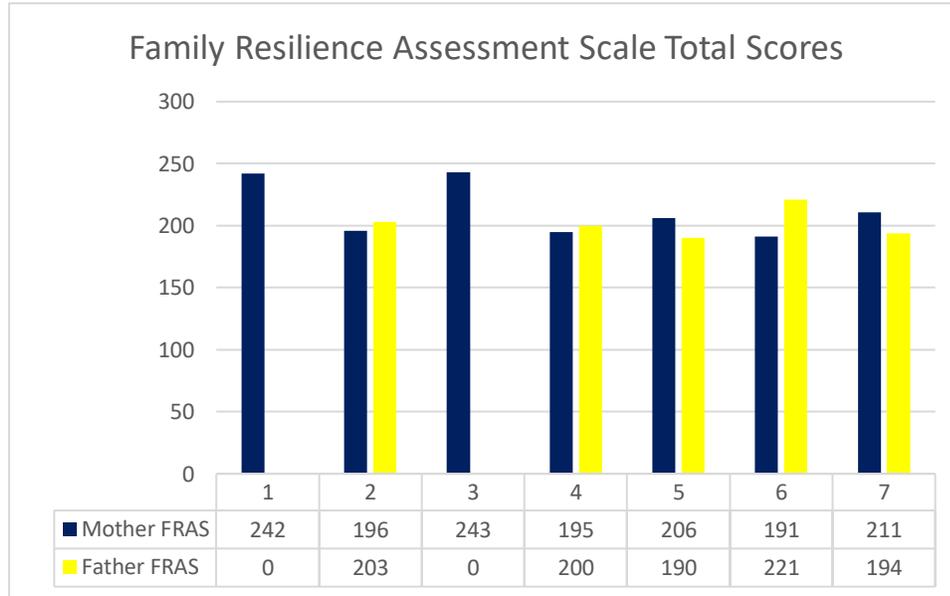


Figure 9. Total FRAS Scores

B.2.a. Family Communication and Problem-Solving

The Family Communication and Problem-Solving Subscale is a measure of the family’s ability to convey their feelings, information, and facts clearly and openly when discussing problems and solutions (Sixbey, 2005). Possible scores range from 7 to 28 with higher scores indicating higher levels of clarity in communication. The average score for the for the parents in this study was 20.25 ($SD = 2.22$). This indicated that the families in this study feel they are communicating clearly about their feelings, issues, and solutions. Figure 10 shows the scores for this subscale for each participant.

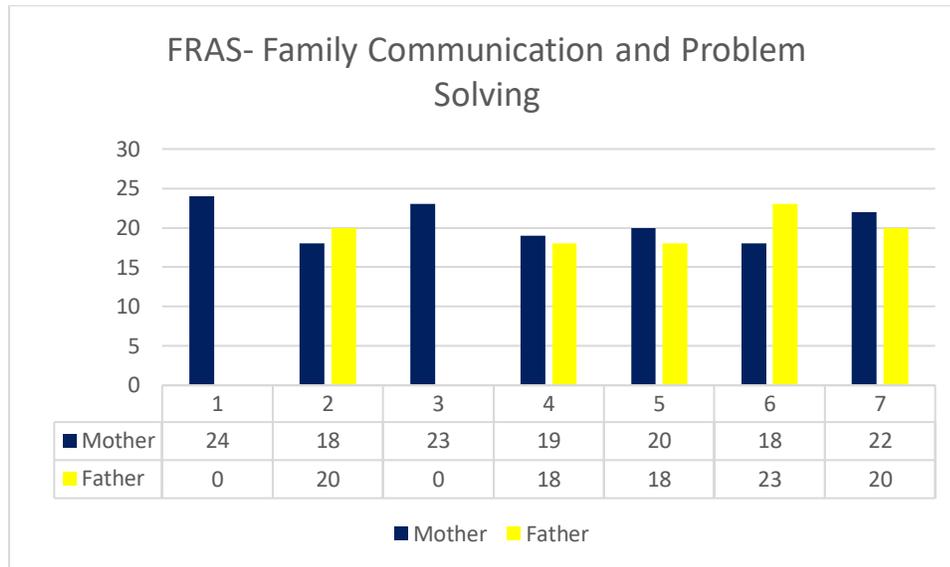


Figure 10. Family Communication and Problem-Solving Subscale Scores

B.2.b. Utilizing Social and Economic Resources

The Utilizing Social and Economic Resources (USER) subscale is a measure of the family’s ability to carry out their typical tasks and identify and use resources. Higher scores in this subscale indicate a high level of ability to identify resources available to the family (Sixbey, 2005). Possible scores for the USER subscale range from 16 to 64. The average score for the for the parents in this study was 46.75 ($SD = 6.06$). Overall, these scores are fairly high which indicates that the families in this study are aware of the resources available to them as defined by the FRAS. Figure 11 shows the scores for this subscale for each participant.

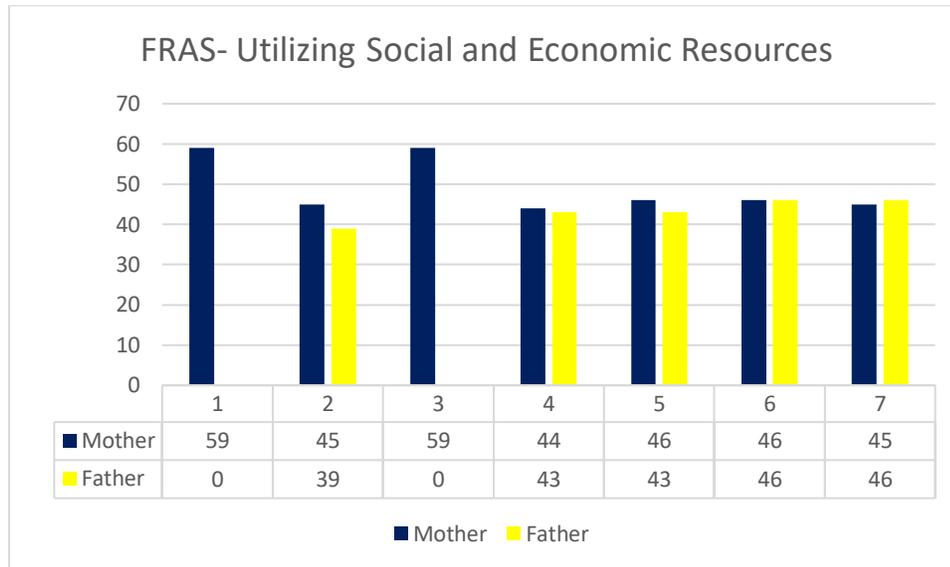


Figure 11. Utilizing Social and Economic Resources Subscale Scores

B.2.c. Maintaining a Positive Outlook

The Maintaining a Positive Outlook (MPO) subscale is defined as the family’s ability to maintain that there is hope for the future. Possible scores for this subscale range from 7 to 28 with higher scores indicating a more positive outlook for the family (Sixbey, 2005). The average score for the for the parents in this study was 23.58 ($SD = 2.71$).

These high scores indicate that the families have a positive outlook for the future for their family. Figure 12 shows the scores for this subscale for each participant.

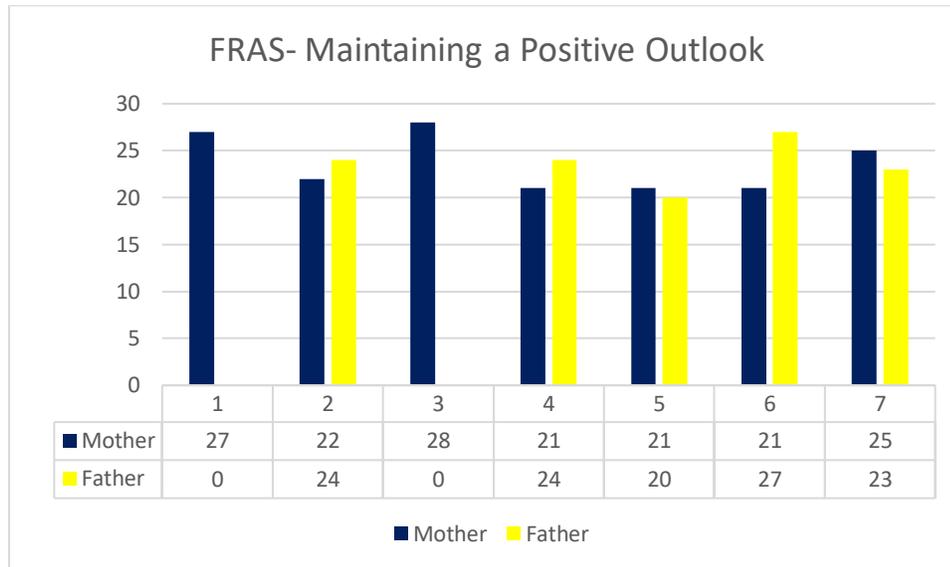


Figure 12. Maintaining a Positive Outlook Subscale Scores

B.2.d. Family Connectedness

The Family Connectedness subscale is defined as the family’s ability to bond together in times of trouble. The possible scores for the family connectedness subscale range from 6 to 24 with higher scores indicating a higher level of bonding perceived within the family (Sixbey, 2005). The average score for the for the parents in this study was 20.33 ($SD = 2.15$). The high scores in this subscale for the participants in this study indicate that they perceive high levels of bonding within their family. Figure 13 shows the scores for this subscale for each participant.

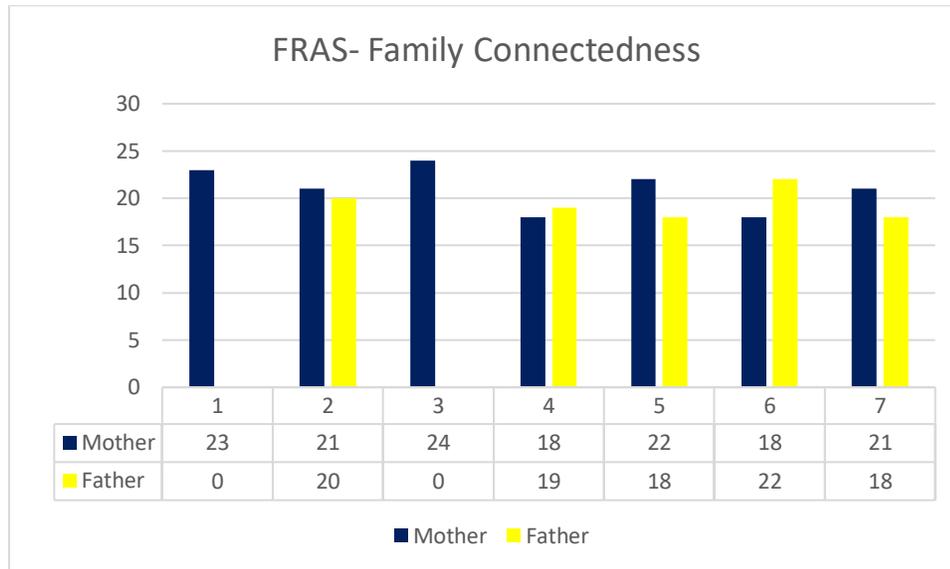


Figure 13. Family Connectedness Subscale Scores

B.2.e. Family Spirituality

The Family Spirituality subscale is a measure of the family’s ability to use a larger belief system to provide them with guidance and meaning. The possible scores range from 4 to 16 with higher scores indicating a higher perceived ability to use their personal belief system (Sixbey, 2005). The average score for the for the parents in this study was 10.83 ($SD = 3.51$). This high average score indicates that the families in this study are able to pull on their family’s belief system when needed in difficult times for guidance or structure. Figure 14 shows the scores for this subscale for each participant.

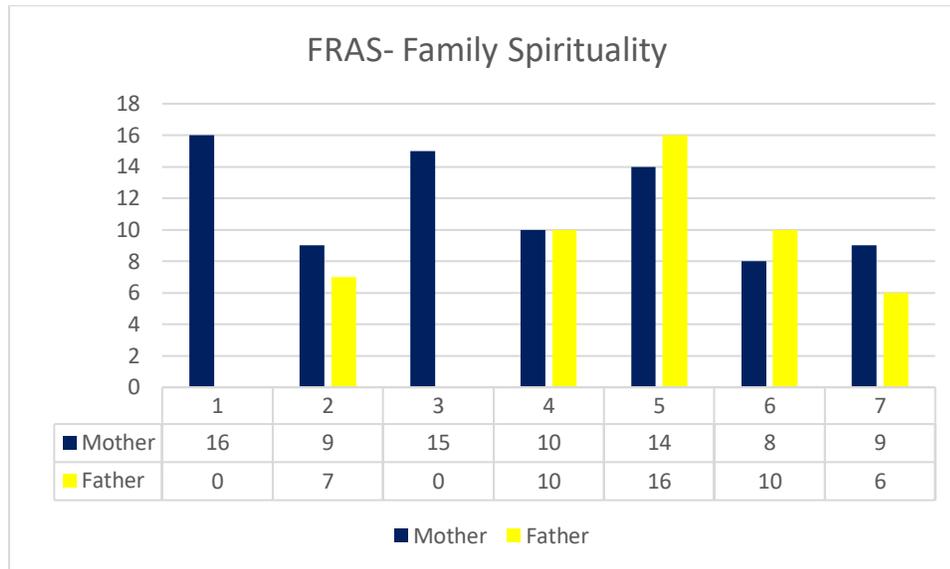


Figure 14. Family Spirituality Subscale Scores

B.2.f. Ability to Make Meaning of Adversity

The final subscale in the FRAS is the Ability to Make Meaning of Adversity (AMMA) subscale. The AMMA subscale is defined as the family’s ability to incorporate adverse events into their lives while understanding their reactions in relation to the adverse event. The possible scores for the AMMA subscale range from 7 to 28 with higher scores indicating higher levels of perceived ability to understand the family’s reaction related to an adverse event. The average score for the for the parents in this study was 23.33 ($SD = 2.53$). These high scores indicate that the parents in this study were able to reframe their thoughts surrounding the diagnosis of hearing loss in their child and have moved to a more resilient mindset. Figure 15 shows the scores for this subscale for each participant.

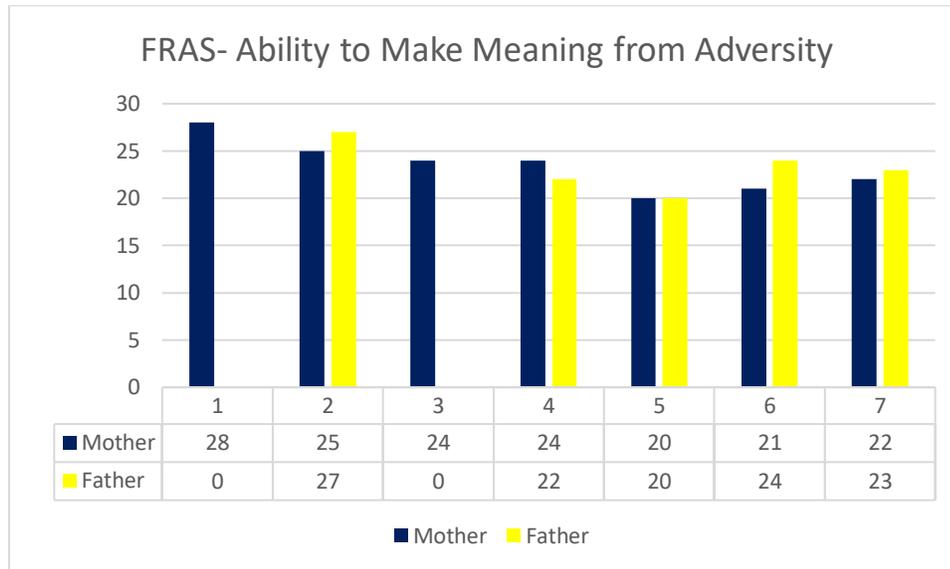


Figure 15. Ability to Make Meaning from Adversity Subscale Scores

C. Qualitative Results

Following the transcription and de-identification process for the video recordings of each of the interviews with each family, the qualitative analysis was conducted via ATLAS ti software to code data. Through the process of phenomenological reduction as described by Moustakas (1994), the full nature of the phenomenon of family resilience and stress in families with young children who are deaf or hard of hearing emerged as it appeared in the four semi-structured interviews. A bracketing process (epoche) as described by Moustakas (1994) was used to separate the views of the researcher from the perspectives of participants. All statements were examined as equally relevant and related to the research questions under investigation (Moustakas, 1994).

The semi-structured interviews progressed through four question blocks. These blocks included background information about the family and the child who is deaf or

hard of hearing, the family's interactions with and feelings about *The Care Project*, questions related to family stress, and finally questions about family resilience. In the final block the parents were asked to provide their personal definition of the word resilience and were then presented with the definition used for the study, the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of the diagnosis of a chronic health condition in a child (Patterson, 2002). During the interview, each parent was asked to express their personal definition of the term resilience before they were presented with the definition of resilience for the study. They were then asked how they felt the definitions were similar or different and if there was anything that they would change in either definition. They were also asked how the concept of resilience is important to families with children who are deaf or hard of hearing. Following the interviews, the video recordings were transcribed, and those transcriptions were sent to the individual participants to review and provide feedback they felt was necessary in the member checking process as described by Creswell (2014).

In presenting the qualitative results, each family's profile is presented along with the results of the analysis of textural and structural descriptions for those who were interviewed. The names of participants have been changed to ensure confidentiality. Family profiles provide demographic and descriptive information about participant families in this study. The textural descriptions encompass the details of the participants' experiences raising a child who is deaf or hard of hearing. Structural descriptions comprise the participants' emotions about their experience raising a child who is deaf or

hard of hearing (figure 16). Table five operationalizes the relevant terms, experience, and context used in the textural and structural analysis. The textural and structural descriptions are organized with the six sections: The Diagnosis, Their Support Network, Goals, *The Care Project*, Family Stress, and Family Resilience. The composite textural and structural descriptions of all participants' experiences are then presented. The chapter concludes with a description of the Essence of the experiences of raising a child who is deaf or hard of hearing from the perspectives of all participants in the study.

Peer debriefing was completed during the analysis. In conducting the qualitative analysis, the researcher took time to have debriefing sessions with qualitative methodologies, and the analysis was reviewed by a speech-language pathologist who has experience working with children who are deaf or hard of hearing and is also familiar with qualitative methodologies. An audit trail was kept throughout the research study and was reviewed as necessary.

Phenomenological Research Organization



Figure 16. Organization of Phenomenological Reduction

Table 5. Relevant Terms, Experience and Context Used in the Textural and Structural Analysis

Type of Coding	Definition	How Researcher Identified It
Epoche/Bracketing	Researcher's personal viewpoint	Reflecting on personal experiences and memories
Textural	Phrases related to their experience raising a child who is deaf or hard of hearing	Transcribed data containing: 1) A personal pronoun with a verb 2) Phrases indicating the parent's experience
Structural	Phrases related to how the parent feels about raising a child who is deaf or hard of hearing	Transcribed data containing: 1) Reference to a setting or situation or specific context that influenced the parents experience 2) Any emotional situation described
Synthesis of Meaning and Essence	Significant statements; data which describe both experience and context	Reviewed all statements with similar themes, evaluated and validated as the core themes or the experience

C.1. Family One: The Miller Family

C.1.a. The Miller Family Profile

Jessica and her family live in Eastern North Carolina. Jessica's husband is in the military and was deployed at the time of the retreat. She reported that she does not have much family support in this geographic area because they are a military family and have moved quite a bit. Jessica's questionnaire responses were reported as Family One in the quantitative section of this chapter.

Jessica has three children, a daughter, Parker, and two sons, Billy and David. Her youngest son, David, was born with bilateral cochlear malformations along with other mobility and visual disabilities. He has been fitted with bilateral cochlear implants. He received his first cochlear implant at 18 months of age and the second side two months before the interview. He also wears glasses and utilizes a walker. Jessica's family primarily uses Cued Speech to communicate with David. They have also used ASL and do use spoken language as well. Jessica was interviewed at *The Care Project* Retreat with Olivia Davis who is reported as the final family in the qualitative section. Olivia Davis did not provide responses to the questionnaires as reported in the quantitative section of this chapter.

C.1.b. The Miller Family Textural Description

C.1.b.1. The Diagnosis

Jessica Miller had no previous experience with children who are deaf or hard of hearing before her son David was born. He was born with bilateral cochlear malformations, and his doctors were unsure whether or not he had functioning auditory

nerves. She stated that, “I’m from a hearing family and everybody supports hearing. I’ve never even met another deaf person before my son.” She struggled with the diagnosis at first and even sought counseling. At present, it is still unclear how much David hears, but she knows that “he doesn’t hear like what a child with normal anatomy would hear.”

David does have bilateral cochlear implants and appears to be responding with them. She shared, “So he does hear in the speech banana. He knows if I call his name he will look at me and come to me.”

Jessica and her family have tried a few different communication modalities with David. They have tried American Sign Language (ASL), listening and spoken language, and are currently primarily using Cued Speech. She stated that her husband cues more than she does she explained about [Cued Speech], “but it’s just it’s been really difficult for me to learn.”

C.1.b.2. Support Network

Jessica does not have an expansive support network. She stated that she does not think her parents or her husband’s parents truly understand the impact or the severity of David’s hearing loss. She stated that her mother even said, “Oh, now he’s fixed” after David received his first cochlear implant. She had to explain to her mother, “First of all, mom, he wasn’t broken... and it doesn’t work like that like it’s going to take a lot of time of work and I don’t know what you know what this implant means for him.”

Being a military family, they do move quite a bit. Therefore, they do not have the extensive friend group that others may have who have lived in the same town for years on end. She stated, “I mean the support I have like I’ve found.” She and her husband have

been active in searching out groups and organizations, which they believe will help them manage David's hearing loss.

C.1.b.3. Goals

Jessica's goal for David is that he be successful, happy, and know that he is loved. Her goals for her family include that they continue learning the best way to communicate with David and that all her children grow to be successful and know how to advocate for themselves. She also hopes that her children will remember "to not exclude people something that's one thing that's been hard for me to watch people exclude [David]. When they shouldn't, they should just include everybody."

C.1.b.4. The Care Project

The Care Project has become a substantial part of Jessica's family's support network. She and her husband first learned about *The Care Project* at a Cued Speech camp where they met Lara Pike. Lara is the office coordinator for *The Care Project* and organizes the retreats. Lara shared her experience raising her son, who has a hearing loss, and Jessica and her husband began looking into *The Care Project*. This retreat was their second retreat and Jessica mentioned she tried to take her kids to every event *The Care Project* sponsors.

Jessica's main goal for participating with *The Care Project* is to meet other parents in similar situations. She wants a community for herself and her children. She emphasized that "I like to have the kids around other deaf kids because they just get so excited. They're like mom there's a deaf kid. And you know where we live the deaf kid is [David]." When asked what keeps her coming back to *The Care Project* she said "I just

really like being around everybody. I think that Johnnie Sexton really cares about the kids. He's wonderful Lara too. I mean, they're awesome awesome people, awesome resource. We have a good time while we're here too.”

C.1.b.5. Family Stress

The majority of Jessica's stress comes from her lack of family support. She revealed that it does not appear that her parents nor her husband's parents really care to learn what they need to in order to be an active part of David's life, “I've showed them you know the sign for nana, and papa, and food, and more, you know just the basic stuff and they won't use it. They don't want to use it.” This puts a strain on Jessica's relationship with her parents and in-laws. It is also interesting to note, Jessica is the mother in Family One who had the highest score on the PSI-4 SF. It is possible that other factors contributing to her considerably higher score when compared to the other parents in the study are due to from the lack of support she feels from her family.

Another source of stress for Jessica is how people react to David when they are out in public. She stated that many people tend to walk up to her and ask her outright what is wrong with her son, “then you know just taking him out. I mean he's got the implants and the pilot cap and people they just have the stupidest questions ever, and it just drives me insane.” Not only does she find this incredibly rude, but it also hurts. She has started being rude in return when people ask her that, especially if they ask in front of her other children. She does not want her other children to feel that there is something wrong with David. She is stressed about how David will have to respond to these types of

questions throughout his life. According to Jessica, “I don't want the other two kids or [David] to feel like he's that there's something wrong with.”

C.1.b.6. Family Resilience

Jessica’s personal definition of the word resilience was “getting beat down and then getting up again, and you just have to keep on getting up.” She was presented with the definition of resilience for the study and she did not wish to add to change anything. She believes that resilience is important to families with children who are deaf or hard of hearing, “because they have to advocate for their kids. I mean you can't just stop. We can't just go on home and hide somewhere. Like you have to keep on doing it.”

C.1.c. The Miller Family Structural Description

C.1.c.1. The Diagnosis

The diagnosis of hearing loss was challenging for Jessica. At the time of the diagnosis, she was unsure of what steps to take. She explained, “I just didn't know what to do, you know?” Even as she progressed with getting David listening technology, she still faced challenges, “Well, I mean you know when he was first born and he had the hearing aids on and everybody was staring at him and stuff you know whenever we went out and you know it was hard. I didn't know what to do and I cried a lot.”

She wishes that people were more understanding of others' differences and didn't jump to conclusions about their family so quickly. She voiced that “Since having [David] the human race has let me down. I just really thought that people were more understanding and not as harsh. But, in reality, they are. And I'm really worried about that for him.” Since she did not have any experience with children who are deaf or hard of

hearing before having David, she really had to adjust and learn quite a bit stating, “I mean, I’m from a hearing family and everybody supports hearing. I've never even met another deaf person before my son. I was pretty... I just I just didn't know what to do.”.

During the interview, while Jessica shared her journey with the diagnosis and communication modality. She disclosed some concerns about David ever learning to communicate. Oliva Davis, who is another mother with a child who is deaf or hard of hearing who attended the retreat and was also interviewed at the same time as Jessica Miller, shared her experience with her oldest son, Jackson.

I wouldn't worry. My oldest son Jayden he signs and then he likes to speak for himself as well. So I find that as he grows he's able to be able to use both languages. So you're doing good. Jayden started to learn to speak I think it was more about around five. Around there so you he's more aware and older and more aware of language.

Hearing these comments from Olivia gave Jessica a feeling of validation for her son's progress and she added that hearing that affirmation “feels very good.” She thanked Olivia for sharing and said that she felt better after hearing her experience.

C.1.c.2. Support Network

Jessica does not feel that she has a reliable support network. She does not feel that her parents nor her in-laws are accepting of David's hearing loss and they do not appear to be willing to take the steps needed to be able to communicate with him. Although this makes her sad, she has had to come to terms with it. She emphasized, “So I mean if they don't want to be part of life then they don't want to be part of it. I feel really sorry for them cause they're going to miss out on a great kid.” This lack of support from her family

is very frustrating for Jessica. However, Jessica does feel that her husband is as supportive as he can be while he is deployed. She noted that when he Skypes with their children, he makes sure to spend time with David and to cue to him.

Jessica has been active in finding her own support network as she expressed, “the support I have like I’ve found” and she feels that *The Care Project* has added enormously to her support network. She also feels supported by her Early Childhood Intervention specialists. However, she also noted that the support that she has received from these organizations has made her feel the lack of support from her family more acutely. She commented “they don't get it and they don't want to get it. That's the way I feel.”

C.1.c.3. Goals

Jessica had difficulty verbalizing the goals for David and her family. She felt that her goals sounded “stupid.” However, once she stated her goal that “I just want him to be successful,” she felt that it was important not only for her family but for those who come into contact with her family as well. Her goal of people being more inclusive comes from her feeling of isolation as well as seeing David left out of some activities. This experience has made her more aware of the need for inclusivity in all events and activities.

C.1.c.4. The Care Project

The Care Project has become a substantive part of Jessica’s support network. She feels that the community provided by *The Care Project* has helped her family feel less isolated. She also feels that the information provided by *The Care Project* has helped her learn more about what is available for David. Her children enjoy going to events sponsored by *The Care Project* because they get to see other children like their little

brother so it makes them feel part of the community as well. As Jessica stated, “We have a good time while we’re here too. You know the kids the kids love coming they are constantly like they ask you know like whenever I told them that we were going to do another retreat.”

Jessica feels that the benefits provided, meeting other parents, hearing other perspectives, getting to talk with others who understand what she is going through have really helped her understand the process of raising a child who is deaf or hard of hearing, “just the support and like all classes and then I’m know later where we’re going to break off with the females and the males separate. I think it helped last year.” She added that she also enjoys being around people who she feels truly care about her and David.

C.1.c.5. Family Stress

Jessica feels her stress is not only about their current situation, but about how David will progress in his development. She experiences stress in keeping up with his equipment, “he wears glasses too so he’ll take his glasses off he’ll throw them... that’s probably been the most stressful is when he’s done hearing for the day, and apparently done seeing for the day too. He takes everything off.” She is also aware that he is two-years old and that two-year old’s can be difficult, “you know he’s 2 [years old] he doesn’t want to do anything.”

Although she feels that their stress level at home is manageable, taking David out in public brings a new level of stress. She is constantly on alert for someone to make a rude comment to her about David and added that the only thing that makes her feel better is to be rude in return, “They’re are so rude about it too. I just have to start being rude

back you know.” It makes her sad to think that these comments could impact the way that her other children think about David, “it's just so frustrating because it's just like you know why would you say that in front of his brother and sister and me who think he's perfect.” She is also frustrated that people do not seem to think about what they are saying and the impact that it will have on her and her family. She stated, “One time [her daughter, Parker] was like ‘Why did they say what's wrong with him?’ And I said, ‘[Parker], they’re an idiot.’ You know. And [Parker] was like ‘Can I say that word?’”

C.1.c.6. Family Resilience

Jessica feels that resilience is very important for her and her family. She understands that her ability to keep going even when she experiences the stressful events comes from her resilience she declared, “I mean you can't just stop. We can't just go in a hole and hide somewhere; you have to keep on doing it.” Her experience with the diagnosis was challenging and she stated that “I mean I just really had to get thicker skin since he's been born.”. She also understands that she has to keep advocating for her children and learning more about deafness. She stated “There's a lot of people going to beat you down and tell you that you know what you're doing is wrong. You have to just keep on going.” This statement shows how she may feel disheartened at times, but that she will continue to keep doing what she believes is best for her family.

C.2. Family Two: The James Family

C.2.a. The James Family Profile

William and Emily James have been married for fourteen years. They both have graduate and professional degrees. William has a master’s degree in Biology. Emily has a

master's degree in Public Administration. Both have completed a Law degree. They live in Eastern North Carolina. William reported having been diagnosed with dyslexia and poor working memory. At the time of the interview, Emily had lost her voice due to a cold, so William did the majority of the talking. They were interviewed on site at *The Care Project Retreat*. William and Emily's questionnaires were reported as Family Two in the quantitative section of this chapter.

They have two children, their oldest son, Anthony, and their daughter Ava. William and Emily are older parents, being in their late 30s when their son was born and early 40s when their daughter was born. Ava has unilateral auditory neuropathy spectrum disorder (ANSD) and utilizes a hearing aid. Anthony has normal hearing, but he has severe nut allergies. The James family is pursuing listening and spoken language as their communication modality for Ava and their family.

C.2.b. The James Family Textural Description

C.2.b.1. The Diagnosis

The James family had a long journey with the diagnosis of unilateral ANSD with their daughter. Ava failed her newborn hearing screening in one ear and was referred to an audiologist for further testing. At that time, her parents decided to continue her care at the University of North Carolina Chapel Hill (UNC) due to family connections with that center. They reported not having a clear diagnosis of Ava's hearing loss for over a year, "because it took almost a year, over a year to get that diagnosis because they're saying 'oh everything's normal. We don't know why. Maybe it's you know nerve damage or maybe but everything structurally is fine.'" (William). When they finally did receive the

diagnosis of unilateral ANSD it was concerning to them because after a year of inconclusive test results, they were scheduled for Ava to be seen by a different audiologist and were immediately told about this diagnosis before she had evaluated Ava. According to William, “they were inconclusive. One [ear] was fine and the other inconclusive. And then she, that audiologist left. So we got another audiologist. So she immediately, her first day it was ‘Nice to meet you. She has...,’” (William).

At this point, they are working with their audiologist to determine the best course of treatment for Ava. William reported that Ava’s audiologist mentioned the option of Ava receiving a cochlear implant, “She’s like ‘Oh we just finished a study two months ago I think she’d be a great candidate.’” William added, “It’s like wait a minute where’s the data.” He also expressed concerns that Ava is not showing any difficulties related to her hearing and they do not want to pursue a surgery that would “destroy what hearing she has in that ear which she’s actually saying is her good ear.” They have sought opinions from Ava’s speech-language pathologist and teacher of the deaf and they have obtained conflicting differing responses.

C.2.b.2. Their Support Network

The James’s support network is primarily composed of their family. William has a family connection with the UNC audiology department and his father is a physician. When they are confronted with challenges following an appointment, they explained that they tend to do their own research and reach out to their family members for advice. “We do our research you know ... then, of course, we ask [family member who works at UNC]. She’s been a great resource. And then my father being a physician, we get his side

of the medical. So those are the kind of things that we use.” Currently, they feel that this level of support has worked fairly well for them. However, they would like to meet other parents with children who are deaf or hard of hearing to learn from their experiences.

C.2.b.3. Goals

William and Emily’s primary goal for both of their children is that they grow to have the lives that Anthony and Ava want to have. They hope that their children become “functional, capable adults with rewarding lives,” (William). They hope that they are giving their children “the tools that they need to be successful and independent,” (William).

C.2.b.4. The Care Project

William and Emily first heard about *The Care Project* from Ava’s speech language pathologist. This was their first retreat and first interaction with *The Care Project*. Their expectations coming into this retreat weekend were to meet other parents with children who are deaf or hard of hearing and to learn from their experiences. Until the retreat, they had not met any other parents with children who are deaf or hard of hearing, William explained, “We haven’t met any other parents going through the same thing in the community. So that’s what’s so beneficial which is hearing their stories and their experiences.” They hope to be able to build a community with these families and compare experiences even after the retreat is over, especially with the families who live in close proximity to them.

C.2.b.5. Family Stress

When asked if they could relay any stress-related events related to raising a child who is deaf or hard of hearing William and Emily focused on the medical aspects of their experience. They are stressed when they have to go to their audiology appointments because they are not sure what the audiologist is going to say and whether or not they will be presented with yet another new option for Ava. “Stress-related, not knowing what they’re going to say from appointment to appointment. You know, getting bombs dropped on you,” (Emily). William mentioned that it is sometimes stressful not knowing whether Ava is having difficulty hearing or if she is being stubborn and misbehaving “it’s stressful just knowing ok, when do I need to step in and help my hearing-impaired child versus when do I need to put on dad mode and you know and do the whole discipline thing.” Otherwise, they expressed that raising Ava is not any more stressful because of her hearing loss, “In [Ava’s] day to day, she’s just a normal child ... Because it’s the most stressful things with her are the typical raising a child things, and not her hearing loss at this point,” (William).

C.2.b.6. Family Resilience

When asked to give a personal definition of the word resilience, Emily described resilience as, “the will to thrive.” William stated that the word was “almost synonymous or so with perseverance. Resilience is having strength but also flexibility.” When asked to relate the word resilience to their family, William highlighted resilience as “being able to have your overall ideal, having an overall goal that we have set for a family again raising children that are going to have the lives that they want to lead.” After reading the

definition of resilience for the study, they both felt that it was similar to how they think of resilience and did not wish to make any changes to the definition. However, William did stress that the concept must be thought of as individual and that a person's own perspective and experiences will shape how they feel about their current circumstances. Related to families with children who are deaf or hard of hearing, William and Emily stressed the idea of flexibility concerning resilience.

It changes with respect to each individual's experience. Something that could be stressful to me, could be you know could be a relief to someone else they could have been projecting something larger like it could be hearing loss [and] they thought it was an inoperable brain tumor (William).

C.2.c. The James Family Structural Description

C.2.c.1. The Diagnosis

The primary emotion that surfaces when the James family talks about the progress of going through receiving the diagnosis of Ava's unilateral ANSD is frustration. They expressed frustration that the diagnosis took so long, over a year. Moreover, they are frustrated that the person who finally gave them the diagnosis did so without examining their daughter, and they are frustrated with the lack of specificity the diagnosis provides. "So now it's like what is this? Well, then you have this whole range of things that sounds like a catch-all that it sounds like you all don't know specifically the cause." William further stated that he was not "necessarily like devastated or heartbroken," (William) by the diagnosis. William added

You do go through all these emotions. You want to fix something. But hearing about the issues... The most I guess the most frustrating thing. Overall, we were not necessarily like devastated or heartbroken or anything it was just like 'what did she need?' You know. Let's go from there (William).

He and Emily also feel that having a son with severe nut allergies has given them some perspective for Ava's diagnosis. With Ava, although her auditory neuropathy spectrum disorder is something she will have to cope with her entire life, it is not something that will keep her from obtaining her goals in life as he stated, "with her even though she had this I know that there are means that she could be functioning." In contrast he describes Anthony's nut allergy: "all these different environmental factors that some people don't like looking at the news the media failure to recognize it as being a true illness, but that can actually kill him you know." He also discussed that, "So even though she was diagnosed with this I know that there are means for her. Whereas with the food allergies that sort of thing is completely, you have no real control so it's just that." which shows the parallels he has drawn between the different diagnoses for his two children.

C.2.c.2. Their Support Network

When speaking about their support network Emily and William feel that they are well served overall. However, when talking about school and their Individualized Education Program (IEP) meetings they wish that the professionals were not so focused on Ava's hearing loss and would view at her more as a whole person. "'She's going to have this issue because she has hearing loss and that's why she, you know, she's has a speech delay.' And it's like wait a minute. Can't she just have a speech delay for having a

speech delay?” (William). They do feel supported by their current speech language pathologist. They believe that she knows Ava well and does not think of her only as a child who is deaf or hard of hearing, “So I think that's the most helpful. Those people actually spend time with her and are able to assess what she needs based on who she is and her personality versus just the clinical,” (William).

C.2.c.3. Goals

The goals William and Emily have set for their children do not differ based on their individual diagnoses. William stated that the “overall goal that we have set for a family of raising children is that they are going to have the lives that they want to lead.” The James family feels that even though both of their children have certain medical diagnoses which may make their children growing into a functioning, independent adults more challenging for them, that they are fully capable of meeting these goals in the end.

C.2.c.4. The Care Project

When the James family talks about *The Care Project*, their main desire is an overarching one of community building. This desire does align with the mission statement of *The Care Project*, so their goal could be achieved through partnership with *The Care Project*. Emily disclosed that their expectations coming into the retreat included “Meeting other people in similar situations, and hearing other people's experiences, making connections with other families.” William and Emily’s desire to meet other parents also reflects their uncertainty of what is the next best step for Ava. They feel that it beneficial for them to hear from other parents who had children who had received cochlear implants since that has been presented as an option for Ava. However, they are

still uncertain how well their story aligns with the experiences of other parents. William described, “It was really good hearing some of the people talk about the change before and after the children get the cochlear implants and how it did make an impact. I'm still not sure how that applies to our child because we don't know...”

C.2.c.5 Family Stress

The James family does not feel that they are more stressed than the average family raising children. They understand they have unique challenges, but they feel that every family has unique challenges. It is up to each family to understand their circumstances and figure out what will work best for them to overcome those challenges. William related this with his own experience, “I guess just relating it to my personal experience you know ... What's stressful is that she may be so intelligent and that different behavior that we think are behavior related is actually her compensating for something, a problem that's been identified.”

They do feel that the majority of the stress related to Ava's hearing loss is due to the fact that they are unsure about how it will affect her moving forward. William revealed, “it's the uncertainty of it. Like if she's profoundly deaf then we would know OK this is the box she's in, but right now she doesn't have a box.” Since her a diagnosis of unilateral ANSD, it is unknown exactly what Ava can hear in that ear day to day. William reported that with his science background he wants to be able to quantify everything, but with Ava's hearing loss, he is unsure how to do that, “So with [Ava], we know she has hearing loss from her testing but as far as behaviorally and developmentally we haven't necessarily seen any I want to say like acute concrete examples of how her hearing loss

has affected her,” (William). This uncertainty has led to feelings of stress in certain aspects, mostly related to how to move forward with her audiologic care.

C.2.c.6. Family Resilience

The main concept that William wanted to stress when he talked about resilience was flexibility. He expressed that it was very important to state that each family’s unique circumstances will impact their perspective and, therefore how they feel about any given situation, he specified, “The only thing I would not necessarily disagree with is, I would assume from the family to family was it was acceptable would be quantified differently”. He even included the word in his personal definition of the word resilience “having strength, but also flexibility.” Both Emily and William feel that their own family has come through this diagnosis well; they do not feel that the diagnosis of unilateral ANSD has severely impacted their lives. However, they also acknowledge that the same diagnosis may be more impactful for a different family. As William stated, “Resilience comes with being able to accept and meet any of those challenges that may come in come towards us on that, on the road to that journey to raising the you know functional capable adults that have rewarding lives.”

C.3. Family Three: The Brown Family

C.3.a. The Brown Family Profile

Charlotte Brown and her husband, Tim, live in Central North Carolina. They both have graduate degrees and are employed by a university. They live in the town Charlotte grew up in therefore they have many members of Charlotte’s family living nearby. There is also an active Deaf community in their area, and they are doing their best to ensure

their daughter has exposure to that culture as well. Charlotte's questionnaires were reported as Family Three in the quantitative section of this chapter.

Charlotte and Tim have twin two-and-a-half-year-old daughters Amy and Ella. Their daughters were born prematurely and spent nearly five months in the NICU. Ella was diagnosed with a heart condition, necrotizing enterocolitis, and hearing loss. She had two heart procedures while still in the NICU. Charlotte and Tim were reportedly very reclusive the two years after their daughters were born. They are now exploring more options and learning more about how they will have to advocate for Ella in school and beyond. Charlotte was interviewed via Skype.

C.3.b. The Brown Family Textural Description

C.3.b.1. The Diagnosis

Charlotte and Tim Brown received the diagnosis of bilateral ANSD for their daughter, Ella, after she had spent five months in the NICU and had two heart procedures. Charlotte stated that at the time of the NBHS, they were told that the reason she did not pass could be because Ella had "fluid [in her ears] she was on the vent for a long time...". The determination of Ella's hearing level took several months because Ella had "outsmarted" the behavioral tests. She was finally diagnosed with a profound hearing loss and fast-tracked for a cochlear implant. The Brown family primarily utilizes listening and spoken language with Ella. However, they did use ASL with her before she received her implants and have been purposely using ASL still with Ella while her spoken vocabulary develops.

C.3.b.2. Their Support Network

The Brown family has a firm support network among their family and friends. They live in the town in which Charlotte grew up, and therefore much of her family and friends still live close by. Charlotte's parents live a couple of minutes' drive away and have been available to help with the girls as needed. Tim's parents live in Orlando Florida, so they are not as interactive with the girls, but Charlotte said, "but they are they're very very supportive too." They also draw support from the Deaf community associated with their university and Charlotte is in two Facebook groups, one for moms with kids with cochlear implants and she also follows the Med-EL cochlear implant group.

Charlotte's mother "had a friend one of her best friends from high school adopted a daughter from China. And when she was nine months old, they discovered she was deaf and she was one of the early recipients of an infant cochlear implant." Charlotte's mother and the friend are still close, and this is another resource for Charlotte. When she has a question, her mother will call her friend and ask when or if her daughter went through a similar stage of behavior or development. This provides some validation for Charlotte knowing that Ella is progressing along the same trajectory that the other child did. However, even though she stated that they do have a good support network, she does feel isolated at times. As she shared, "We really do kind of feel isolated here just because we don't know a lot of other families especially families of toddlers who have hearing issues." She also explained that they drive to a bigger city that is roughly an hour away in

order to take advantage of some of the events going on for children who are deaf or hard of hearing.

C.3.b.3. Goals

At this point, Charlotte's main goal for Ella is for her to learn to speak English and continue with her Auditory Verbal Therapy. As Ella progresses in this goal, future goals include for her to be able to go to a mainstream school, and to be able to do anything that her sister does. Charlotte's goals for their family are the same as her goals for Ella. She wants her daughters to feel like they are "equal in that they can do whatever they want to together." As a family, she hopes that they can continue to learn ASL. She added that her goal is "to learn [ASL] for her sake to be able to communicate with her how we need to communicate with her. And if it helps her in the future be a part of a community, she wants to be a part of, then that's fine too."

C.3.b.4. The Care Project

Charlotte's first interaction with *The Care Project* was the Parent-Professional Collaborative hosted in Greensboro, NC, in February 2019. She stated that it was her first time being away from Amy and Ella. They were almost a year old at the time but had been born so prematurely that Charlotte and Tim imposed some self-isolation. She explained that the Parent-Professional Collaborative

The girls were just turning two and we had we really had been on lockdown as a family because of having such premature babies... But it was a really good experience because the first time I met some other families with young kids and older kids who were implanted in this decade really and so it just kind of felt more of a support community there.

The retreat in Wrightsville Beach was the first retreat that the Brown Family attended. Charlotte stated that they were unsure whether the drive from Western North Carolina to the beach with twin two-year-olds would be worth it, but they had decided to go mainly because they do feel isolated where they are in their small town. After the retreat, they were glad they had gone. Charlotte revealed that, “[the retreat] definitely gave us perspective, it gave us hope.” They especially enjoyed the teen panel where they heard from older children who are deaf or hard of hearing share their experiences. She stated that it was “a unique opportunity.”

C.3.b.5. Family Stress

The stress-related events Charlotte described were primarily related to Ella’s speech development. Ella’s speech is not progressing as quickly as Charlotte would prefer. According to Charlotte, “Sometimes I just I get frustrated that progressing as fast as I want her to or sometimes she's not in the mood to pay attention when I'm trying to work with her.” However, she does realize that the severity of Ella’s loss, as well as her hearing age, are factors that will influence how quickly she progresses with her speech development. Charlotte reported that there are times when Ella is not willing to work on her therapy goals, and that “she’s also two and a half and that's her job is to not want to sometimes.”

Other stress-related events for Charlotte surface in her reading posts in the Moms of Kids with Cochlear Implants Facebook group. She mentioned that there are times when a mom will post that their child is already talking, and the child is younger than Ella. However, Charlotte reminds herself that the child may not have as complex of a

medical history as Ella, may have some residual hearing, or the multitude of other factors that may be involved as she expressed, “The mom group is hard because it’s just so many people on different levels and in different experiences. And I risk comparing myself too much with people,” she then added “I just I have to like put myself back into reality and remember that she's two and a half and she's only been hearing for a little over a year and I know and she's doing the right things.”

Since Ella does have other medical conditions, there is stress related to her health in general. Ella had a dental procedure in January 2020 and she has been scheduled for another heart procedure in the Summer of 2020. Charlotte disclosed that when she lets herself think about everything they have been through as well as everything left to go through it can become overwhelming. She stated she will have, “a little pity party I guess but then put things in perspective and then realize that they’re doing fine.”

To manage her stress, Charlotte talks, “with my husband, talk with my mom and... we thankfully don't have those all at the same time because then... But just you know remind each other where we are and what we're doing.” If she has a question Charlotte’s mom will reach out to their friend who has the adopted child with a cochlear implant.

C.3.b.6. Family Resilience

Charlotte’s personal definition of the word resilience was “being able to keep going even when things are hard. Just being able to not let like the little things get down get you down or keep you from doing what you need to do.” She was presented with the definition of resilience for the study and stated that she agreed with it. There was not

anything she wished to add or remove from the study definition of resilience. She discussed that the concept of resilience is important to families with children who are deaf or hard of hearing because “It doesn't rule your life completely. It definitely changes some of your decisions but, you definitely can still be a complete functioning family even with a child who has hearing loss and allow them to reach the same goals that anybody else can.” She stressed that the concept of resilience helps parents with children who are deaf or hard of hearing “be the same parent you would no matter what circumstances.”

C.3.c. The Brown Family Structural Description

C.3.c.1. The Diagnosis

The diagnosis of hearing loss was challenging for Charlotte and Tim. However, it was not as challenging as the other medical conditions Ella had. Ella was in the NICU for almost five months and they were “just happy to be bringing her home.” The diagnosis of hearing loss was viewed as just another hurdle that they would have to overcome. According to Charlotte, “We were just glad that she was healthy and we were like if losing her hearing is what we have to walk away with from this experience, that's a much better deal than anything else we could ever have ever had before with everything she went through.”

C.3.c.2. Their Support Network

Charlotte shared that she feels very supported by her parents, in-laws, and community. She feels that when she is having a rough day where she loses her perspective, she is able to call on someone and they will help her. One important part of Charlotte's support network is her mother's friend who has a child with a cochlear

implant. Although the child is now in her early 20s, Charlotte is able to speak with the mother and gain a sense of whether what Ella is going through is developmentally normal, “I think that sometimes just hearing that ‘that’s normal, that’s OK’ is all I need to hear.”

C.3.c.3. Goals

Charlotte feels that the goals she has for Ella and their family are achievable. She feels that these goals will make Ella able “to excel in whatever she wants to do.” However, she still wants Ella to have access to the Deaf community if she prefers to in the future. She feels that this access may help “her in the future be a part of a community she wants to be a part of.”

C.3.c.4. The Care Project

Charlotte is glad that she has found *The Care Project*. She feels that the information she and her husband learned at the retreat was very beneficial. She also voiced that they appreciated the teen panel where they were able to hear from older children and teenagers who are deaf or hard of hearing. Hearing their perspective provided some insight on what path they may want to choose for Ella in the future. They had struggled with some of the decisions because they realize that they are having to make life altering decisions for a different person as she shared, “you know we want to respect her individuality as much as we can but try to make the best decisions for her”. Charlotte and her husband have tried to take what they think Ella would want into account as much as possible, but they are unsure if they have done exactly what she would have wanted if she were old enough to verbalize her desires. The access provided

by *The Care Project* helped allay some of their concerns in that area. Charlotte conveyed, “being able to hear things that these almost young adults are saying kind of will help us make better decisions for [Ella] in the future.” They also appreciated *The Care Project* enabling them to meet so many other parents with children who are deaf or hard of hearing. Charlotte was very excited to meet another twin mom as well. She described that they bonded quite well and hopes that she and the other mom will keep in touch as their children get older. She stated, “it just kind of felt more of a support community there [at *The Care Project* retreat].”

C.3.c.5. Family Stress

Charlotte expresses the most issue with stress when she lets herself lose her perspective, as she stated, “I feel like it kind of ebbs and flows with stress.” She feels that Ella isn’t progressing as quickly or easily with her speech development as she would like, or as some other children who are deaf or hard of hearing. Some of these feelings of stress come from comparing Ella’s development to stories that other moms post in the Moms of Kids with Cochlear Implants Facebook page. According to Charlotte, “people who maybe lost their hearing and had hearing before or had some residual hearing and in they’re a little bit further along in their speech and then that’s where I don’t do too well.” She also realizes that this is an issue stating, “comparison is the root of evil.”

C.3.c.6. Family Resilience

Charlotte feels that her family’s level of resilience has helped them cope with all the medical diagnoses and procedures that they have had to go through in their daughter’s first two years of life. She feels that “the closeness of our family. And then I would say

our faith gives us strength when we when we need something other, bigger than ourselves to pull upon” have contributed to their level of resilience. The concept of resilience is important to Charlotte because she wants to make sure that she and her husband have healthy relationships with their daughters. She stated, “I know some people who have might have issues and not relate to their child in the same way because they're afraid that they can't communicate with them or that they might be different.”

C.4. Family Four: The Davis Family

C.4.a. The Davis Family Profile

Olivia Davis is Deaf. Deaf is used to refer to a group of deaf individuals who share/use ASL as their primary language and hold certain beliefs about their level of hearing. These beliefs include their level of hearing as a central part of their identity (National Association of the Deaf, 2020). A licensed ASL interpreter was utilized during this interview. Olivia is from New York State and reported that she grew up in the hearing world. She was exposed to the Deaf community in college and felt that she found where she belonged at that time. She now uses ASL as her communication modality. She reported that her parents have become more involved in the Deaf community as she has had Deaf children. Olivia did not complete the questionnaires for the quantitative portion of this study.

Olivia has four children, a daughter, Jenna, and three sons. All three of her sons were also born deaf. Her oldest son, Jackson, chose to have a cochlear implant when he was four years old. Her middle son, Greg, was diagnosed with Autism spectrum disorder along with hearing loss and he does not use any listening technology. Her youngest son,

Liam, has bilateral ANSD and has no perception of sound. All members of her family communicate with ASL and also utilize some spoken language in different situations. Oliva was interviewed onsite at *The Care Project* Retreat with Jessica Miller who was reported as Family One in both the quantitative and qualitative sections of this chapter.

C.4.b. The Davis Family Textural Description

C.4.b.1. The Diagnosis

Oliva Davis had a different reaction to her children being born deaf than the other parents interviewed for this study. Because she is Deaf and participates in Deaf culture, having children who are also Deaf is a positive attribute. Olivia shared that when her oldest son was born, she was “really excited.” She viewed this as “something they could share.” She explained that when her oldest son, Jackson, was born, they were living in a different state. When he did not pass his NBHS, the hospital staff simply understood that he was part of a Deaf family and she shared, “So when he did fail the hearing screening, he was a day old and they came over it's like congratulations he's Deaf. They gave me referrals to Rochester School for the Deaf and they referred me to an audiologist to get the process rolling.” However, with her other two Deaf sons, who were born in North Carolina. It appeared to her that the hospital staff was unwilling to accept the fact that her children were deaf. They kept rescreening her children until she refused further testing. She stated “I already know that he is deaf. We don't need to do screening again.”

C.4.b.2. Their Support Network

Olivia reported she did not have much support for her hearing loss growing up. She was “made to” participate fully in the hearing world until college when she learned

of the Deaf community. For her children, life has been different. She has given them the option to have access to both worlds. She emphasized, “in the Deaf community I get a lot of support.” This support helps Oliva and her family advocate within the school system. Olivia’s parents have also become more accepting of the Deaf community, “they have three Deaf grandchildren and they want to be involved.” They have learned more and more ASL as their grandchildren grow older, so they are all able to communicate.

C.4.b.3. Goals

Olivia’s goals for her children are, “for them to know how to advocate for themselves and know what they're going to be faced with. Most important that they be happy and you know are educated and they're able to spread awareness of different things that do occur.” She also acknowledges that all three of her Deaf children are very different and have different needs. Olivia expressed, “for the three children that are Deaf they're all different. They have different interests and so each of them have different goals... Whatever they think is best for them and what they want to do we'll support it.”

C.4.b.4. The Care Project

Oliva was the only Deaf parent at the retreat and this experience was Olivia’s first retreat with *The Care Project*. She shared that she had met Johnnie Sexton at a North Carolina Early Hearing Loss Detection and Intervention (EHDI) meeting about two years ago. She described that this retreat was different than she had expected; she had hoped for more interactions between the parents. She shared, “I had different expectations, not many but different. I think I'm not trying to be negative at all because I don't see this the negative, but it’s a little different. The vibe is different than I expected.”

C.4.b.5. Family Stress

Olivia stated that their family's stress level at home is not high. She stated, "at home our stress level really I wouldn't say is high. We're really open at home. We all sign. We have captions on the TV, we have a video phone that comes up so we're able to make phone calls." But outside of the home is where the stress begins. She experiences stress related to, "how do I advocate, how to find the right services, how do I help with IEP how that's decided and who's the right audiologist, right doctor all the right people who consider the children." The most stressful situation for Olivia is the education system. Olivia expressed:

I always have to make sure the proper education and that he's not just disregarded, or you know they try to say that he needs this or that. I want him to have the same and equal experience that other kids do. And then my son who is Deaf plus, he goes to the school for the Deaf. And then he has totally different experiences I know he's different, so I have to make sure that he's also getting appropriate education. He's not isolated. And with him (gestures to youngest child) again it's another type of service that he. So I think education is stressful.

C.4.b.6 Family Resilience

Olivia took several minutes to reflect on her personal definition of resilience. However, she did state that the concept of resilience "is not new." She remarked, "Life keeps going, so don't no matter what, we just have to keep on going." When presented with the definition of resilience for the study she wanted to add that the concept was open-ended. When asked to apply the term to families with children who are deaf or hard of hearing, she stated that the concept of resilience is about realizing how similar things are for their families, "It's important for them to know there is a Deaf world, a Deaf

community and that they can be involved and learn about the culture and learn about different types of resources available.”

C.4.c. The Davis Family Structural Description

C.4.c.1. The Diagnosis

Olivia had different experiences with her three sons diagnoses. With her first son’s diagnosis she felt happy that he was deaf and had an easy experience with the hospital staff getting referrals. The diagnoses of her other two sons made her frustrated with the hospital staff when they wanted to continue screening and did not appear to accept the fact that her children were deaf as herself. So, by the time her youngest son, Liam, was born she told the staff “I have had enough. I’m like, Hang on one second. I already know that he is Deaf. We don't need to do screening again.” Although Olivia was happy and excited to be able to share Deaf culture with her sons, she did admit that she was conflicted. She understood that this would be something that could bring them closer together but was also something that would make life challenging for both of them. According to Olivia “I thought that there are a lot of challenges he would face. And I was excited at the same time, but I was like oh no. So, there was this conflict inside me.”

C.4.c.2. Their Support Network

Olivia feels very supported within her community. With the Deaf community, Olivia receives support, “they know of the kind of resources there are and what kind of services that we’re able to use.” She also feels that her family has become more accepting of Deaf culture as she has had children. When she was a child, she was not aware that the Deaf community existed she described:

Well to be honest with you I grew up with my family who all could hear. And I was only Deaf one in the family so there wasn't a lot of support as I grew up. I grew up having to speak and I didn't learn sign language until later on. Actually, I learned signing really when I was younger, but it was more of an English. So, American Sign Language, I learned that in college. And that's where I found my identity and who I am that yeah I am Deaf. And there's nothing to shy about with that or be ashamed of that is who I am and my identity. Once I learned that, I was able to get immersed in Deaf culture. And that's where I've been since.

With her children, she feels it is important that they have “an awareness of both worlds”.

C.4.c.3. Goals

Olivia's goals for her children and her family include advocacy, education, and awareness. She was able to verbalize these goals easily and has thought about them extensively about them. She feels these goals are not only important for her family, but for the Deaf community as a whole, “we are able to be successful and we are able to learn and perhaps can learn both speech and sign language at the same time so we are able to learn anything.” She is also aware that her three Deaf children may have differing goals and is accepting of their individual wants and needs. She feels that since her children are all unique individuals it only makes sense that they have their own unique goals as she stated, “they're all different. They have different interests and so each of them have different goals. And whatever, basically they want. Whatever they think is best for them and what they want to do we'll support it.”

C.4.c.4. The Care Project

Olivia was slightly disappointed with the retreat at the time she was interviewed. She wished that the activities would include interactions among the parents. She did not feel that the other parents were very comfortable around her yet but realized that some of

this would come with time, as she explained, “hopefully they will be more comfortable with me later on.”. However, she viewed this retreat as a growth experience “for all of us.” She wishes that hearing parents of children who are deaf or hard of hearing would reach out to the Deaf community because “we have the same struggles.” Olivia shared:

I would love to have parents who come here [to The Care Project retreat] to learn from other Deaf parents we have the same struggles. We’re in the same shoes so it's okay to interact and get different perspectives and I want the other parents to see me as not you know I'm not broke and you're their child's not broke. And we are not and it's something we have to be fixed. We are Deaf and we're able to do everything. But hear. The children are accepted.

C.4.c.5. Family Stress

Olivia seemed to accept the stress of being a Deaf person in a hearing world as part of life, as she conveyed, “It's always interesting I find daily I find some kind of how it really affects the person who can hear and you know we gesture and things but it’s interesting.” She has dealt with the stress of being a deaf person her entire life and has learned how to work around the communication barriers she experiences. She does wish there was more awareness and education about the Deaf community and the services needed. She shared some frustrations about how difficult it can be for her to even order food at a restaurant; that hearing people always seem to be taken aback when they see her signing, she stated “People who hear they stand there and they’re in a little bit paralyzed in a way like they're shocked and like they never see a Deaf person in person.” Being at home with her children she does not feel they have any communication barriers. They are able to communicate with each other and they have the assistive devices needed to make

sure they are comfortable and safe. However, she knows that her children will face barriers outside of the home, as she shared, “Well [we] face it every day. You know every time I go to a restaurant or it’s a struggle. We have a lot of barriers.” To help manage this, she feels she must advocate and educate as much as possible. She feels that the more she does now, the easier it will be for her children later down the road.

C.4.c.6. Family Resilience

The concept of resilience was more challenging for Oliva to describe. With her experience being a Deaf individual, she has dealt with barriers and challenges her whole life. She has had to learn to overcome them and move through to the next one. She emphasized “Life keeps going. So, no matter what, we just have to keep on going. And look at how we can advocate for ourselves. Stand up and stand for what we believe in.” This feeling of having to keep pushing through the challenges is Olivia’s feeling of resilience. She is not going to let the challenges define her or her children, she is going to meet them and work her best to find a solution to them.

D. Composite Textural Description (All Participants)

D.1. The Diagnosis

All the children failed their NBHS and were referred for further testing with an audiologist. While only one family, the Davis family, had any substantial experience with children who are deaf or hard of hearing before having a child of their own who was diagnosed with hearing loss, none of the families felt that the diagnosis was unduly upsetting. One family, the Miller family, did appear to struggle with the diagnosis more than the other families. However, the child in this family has more medical challenges

than the other children of parents in this study. All of the families expressed some interest in learning about Deaf culture and use ASL as either a primary or secondary mode of communication or have considered incorporating it with their child's speech language development. For example, the Miller Family has incorporated both Cued Speech and ASL in their communication with David.

D.2. Their Support Network

Although all families have at least part of a support network for assistance, three of the families (The James, Brown, and Davis Families) feel they have a more stable network on which to rely than the other family interviewed, the Miller Family. However, all families expressed interest in learning about more ways to support their child who is deaf or hard of hearing as well as the rest of their family. This desire for more support reflects their feeling of a lack of support in certain areas. For example, Jessica Miller mentioning that she feels her parents "still think that they think some sort of miracle is going to happen if that makes any sense." This desire is also apparent as mentioned by the James family when they discussed their desire for more knowledge about what they can do to support their child:

I guess at this point it is really more so just hearing other people like us and the families' emotional response to everything because medically it's still kind of up in the air with what she needs or it appears that way to us because every time we go with something different.

D.3. Goals

All families were able to verbalize goals for their child who is deaf or hard of hearing. The goals the parents have set for their child who is deaf or hard of hearing included their speech and language development and learning to advocate for themselves. All the parents hope that their children grow to be happy and independent adults. The goals that the parents have set for their families included growing together as a family to be the best they can and continual learning of the best methods for communication with each other. For example, Jessica Miller expressed, “we’re just doing the best we can. I mean I think we're doing OK. I mean I don’t know, I guess we’ll see.”

D.4. The Care Project

Only one of the families interviewed, the Miller family, had previously attended a retreat hosted by *The Care Project* before the one in November 2019. The families’ primary expectations for the retreat included meeting other parents with children who are deaf or hard of hearing and gaining more knowledge about how to best serve their child audiologically, medically, and in their education. As Charlotte Brown shared, “I think that it made a big difference. My husband and I really appreciated it.”

D.5. Family Stress

The parents reported that the most stressful aspects of raising their child who is deaf or hard of hearing are either normal child rearing stressful events or dealing with how people outside of their family react to them and their child. Thus, not only do these parents have to deal with the typical two or three-year old developmental demands in their child, they are also managing their child’s hearing loss. This can lead to internal

struggles described by Charlotte Brown when she discussed comparing her daughter's speech-language development to other children's' development in the *Moms of Cochlear Implant Kids Facebook* group. It can also lead to conflict between the parent and other people as Jessica Miller described when she disclosed that there are times when people ask her about her son in a rude manner and the only thing that makes her feel better is to be rude in return.

D.6. Family Resilience

All the families recognized the importance of the concept of resilience. Their definitions highlighted persevering and keeping going even when the going gets tough. The parents all agreed with the definition of resilience for the study, as the definition was thought of in an individual manner. This means that resilience for one family may look different than that of a different family. As described by the James family, "it depends on the individual whether with some people may be a relief" and the Brown family described:

I think that for some families it does come with... It could maybe lead to emotional distress in a lot more ways that might be lingering. But I think making sure that you have the right resources to still have a healthy, even a healthy relationship with your child is important.

E. Composite Structural Description (All Participants)

E.1. The Diagnosis

Feelings about the diagnosis of hearing loss in a child varied among the parents. Based on their backgrounds and their circumstances parents were either excited about the

diagnosis or somewhat saddened. No parent reported the overwhelming feeling of grief that has been reported in other studies (i.e. Kurtzer-White & Luterman, 2003). The parents reported that they felt they wanted to know what the next best step to take for their child. Jessica Miller was the parent who appeared to struggle the most with the diagnosis. She did seek counseling after David was born. However, her son is the most medically complex child of the parents who were interviewed, and it is likely that these feelings were complicated by his other diagnoses.

E.2. Their Support Network

Every family has a different level of support, but each family has built their own network based upon what they feel will best serve their child who is deaf or hard of hearing as well as the other members of their family. For example, Jessica Miller did not feel she had a very expansive support network, whereas Olivia Davis felt quite supported by both her family and the Deaf community. Their support networks provide them with information and emotional support when needed. These family members, friends, and other groups are a source of strength for these families. As William James explained:

We ask my [family member]. She's been a great resource. And then my father being a physician, then we get his side of the medical. So those are the kind of things that we use. Those techniques are still very clinical in preparing. The Care Project allows us to see how other people to prepare emotionally.

E.3. Goals

All families expressed that the goals they have set for their families and their children who are deaf or hard of hearing will help them in their overall goals of raising

happy, independent adults. The parents feel that their goals are achievable, and that what they are doing now with and for their children will help them in attaining their long-term goals. This can be seen in the quote shared by Jessica Miller, “I guess for my family I like for our goals, it sounds stupid, but like for us all to continue... You know how we I think we've been doing okay.”

E.4. The Care Project

The families differed in how they felt about *The Care Project*, however, their experience levels with *The Care Project* at the time of the interviews were different. Two of the four families, the Miller and Brown family, expressed that *The Care Project* has been very beneficial in helping them manage their child’s diagnosis of hearing loss. The James family was still unsure exactly how *The Care Project* would fit in with their existing support network. Olivia Davis shared that she wished there was more interaction between the parents. She explained, “The vibe is different than I expected. I'm the only Deaf individual here, Deaf parent. So, it was different. So hopefully they will be more comfortable with me later on.” For the James and Davis families, the interviews were performed before the end of their first retreat, so it is not surprising that their opinions about how *The Care Project* could assist them were still being formed.

E.5. Family Stress

All of the parents experienced stress about their current situation: whether it be the stress of raising a two to three-year old child, the stress of the diagnostic and intervention appointments, the stress of meeting the communication needs of their child, the inherent stress in family daily life, or of being in a culture that doesn’t fully recognize

your own the parents shared that they experience stress daily. These stressors can lead them to feel frustrated with their situation at times. For example, Olivia Davis emphasized that she constantly has to educate people, “If [I] want to go to a drive through I have to park, go in, and then I'd say you know can we wright back and forth I need paper and pen. ... So, you know just having to get a paper and pen they're in the back.” However, most of the parents have a sufficiently supportive network that when they do experience those strong feelings of stress and frustration, they can access someone to help alleviate those feelings. For example, Charlotte Brown disclosed that will either call on her husband or other members of her support network and “remind each other where we are and what we're doing.”

E.6. Family Resilience

The parents felt the concept of resilience was important to consider when discussing families with children who are deaf or hard of hearing. They expressed that they are resilient and have been able to meet and manage the challenges they have been faced with in their lives. As Jessica Miller explained, “Well you just keep on pushing through and like just does nothing going to get us down”. The William James spoke of resilience in terms of perspective, “What's the expression the grass always looks greener? So, depending on your perspective you're depending on your experience you may see something a maybe debilitating to you but then another person may disagree.”

F. Essence

The final step in Moustakas's (1994) phenomenological analysis requires the reduction of the phenomenon to its essence. Essences provide information about the

central experiences of participants after the data from transcripts of interviews were reduced into themes that provide information about what was experienced and themes that provide insight into the influences that affect how participants' perspectives and perceptions. In this step, the composite textural description and composite structural description were combined to reveal the essences of the parents' experiences raising a child who is deaf or hard of hearing (Moustakas, 1994). Creswell (1998) describes essences as the final step in data analysis in order to describe the meaning of the experience for participants. Information from textural and structural themes were used in order to describe the essence of the experiences for participants in this study. In this research study, the phenomenon being studied is the lived experience of parents with children who are deaf or hard of hearing. The themes that emerged as measures of the research helped to capture the true essence of the phenomenon of raising a child who is deaf or hard of hearing. The composite textural and structural or essence, has three domains which integrate the experience and the context of the experience. Figure 17 displays the three major essences with nine sub-essences deduced from the semi-structured interviews.

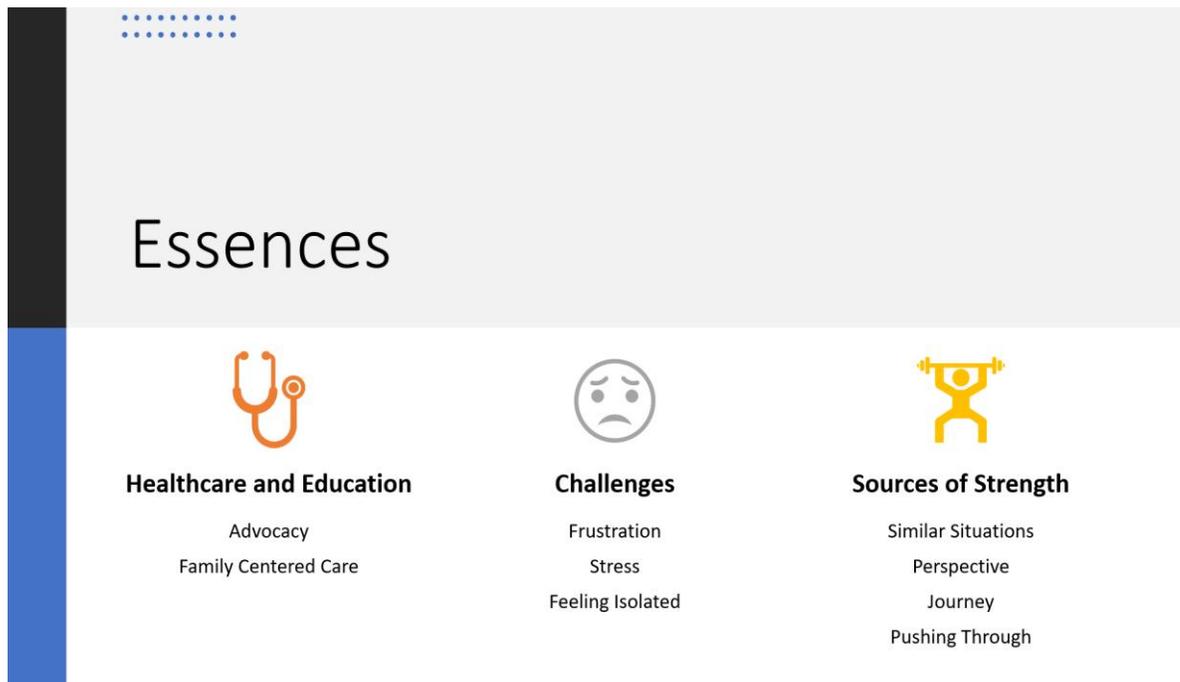


Figure 17. Essences Deduced from Parent Interviews

F.1. Essence One: Healthcare and Education

F.1.a. Advocacy

Not all of the parents used the term advocacy, but they were all concerned with how to best advocate for their child. The families all stated in some form or another that as soon as they heard that their child was deaf or hard of hearing their reaction was to figure out how to ensure that they received the best services and care possible. As stated by the James family, “We weren’t necessarily like devastated or heartbroken or anything it was just like ‘what did she need?’ You know. Let’s go from there.” Although the oldest child in the study was three-years old, all the parents were already concerned about how they would advocate for their children when they attend school. Olivia Davis had the most experience in this area. As a Deaf individual raising three Deaf sons, she is already

aware of many of the challenges they face. She described her main concern in this area as, “How do I advocate, how to find the right services, how do I help with IEP how that’s decided and who’s the right audiologist, right doctor all the right people who consider the children.” This sentiment is shared by Charlotte Brown when she discusses that she is already in the process of planning for her first IEP meeting “we’re about to have our first IEP meeting... I don’t even know how many kids with cochlear implants they’ve worked so I don’t feel like really good right now about that support. So I might look for some secondary support.”

F.1.b. Family Centered Care

The tenets of Family Centered Care (FCC) are shared decision making, respect, open communication, and strength-based approaches (Johnson, Abraham, & Shelton, 2009). These tenets appeared as important to the parents in this study. They want people working with their children who understand their unique situation and are willing to have discussions about what is the best course of care for their family. As William James stated, “The people that come to your home and work with your child. I think that’s more beneficial. I should say work with you and your child. But that’s been more beneficial and impactful.”

F.2. Essence Two: Challenges

F.2.a. Frustration

The level of frustration varied across the participants, but frustration was consistently present among all parents. Although they were not all frustrated about the same events or circumstances, they all had experiences related to their child who is deaf

or hard of hearing which caused them to feel frustration. It is important to note that they did not report feelings of frustration with their child who is deaf or hard of hearing, but with circumstances surrounding their child. They were frustrated with how the world reacted to their child, as Jessica Miller stated about people talking to her about her son, “You know whenever somebody walks up to him and they're like what's on his head Why's he wearing that. What's wrong with him. You know it's just so frustrating because it's just like you know why would you say that.” They also expressed frustration with the medical establishment, as Olivia Davis described:

They continued to screen him I felt like maybe three or four times in one day they screened him again in a week or three weeks old and month old and then again we repeated it at three months old to make sure there was no fluid in his ears. So it made me feel like ugh! you know. I already know he's Deaf.

Frustration with the school system was evident as William James commented:

You make all these IEP determinations when she could have other issues beyond that. She could be you know dyslexic maybe she can't repeat those word words back then you give me that list at three because she can't remember the picture because she has poor memory.

Thus, the feeling of frustration appears to be related to the parents feeling not heard or understood by those with whom they were interacting.

F.2.b. Stress

Although all the parents were able to discuss stressful experiences related to their child who is deaf or hard of hearing, different circumstances created these stressful experiences. Some parents were more concerned about their child's speech-language

development, some were more concerned about finding the best audiologic treatment, while others were concerned about how their child will grow up in a hearing world. These circumstances are unique to raising a child who is deaf or hard of hearing (Pipp-Siegel et al., 2002) but are not unique to each family with a child who is deaf or hard of hearing. For example, William James disclosed, “In [Ava]’s day to day- She's just a normal child you know. So the stress comes into- okay we're going to see this next appointment and not actually in not the stress of raising her”

F.2.c. Feeling Isolated

The diagnosis of hearing loss in a child can make the family feel that they are alone, especially if they do not know any other families with children who are deaf or hard of hearing (Paster et al., 2009). It can be challenging to find families who relate to what their family has experienced if the other family does not have a child who is deaf or hard of hearing. As Charlotte Brown revealed, “We really do kind of feel isolated just because we don't know a lot of other families especially families of toddlers who have hearing issues,” this statement emphasizes the desire of parents to meet families with children who are deaf or hard of hearing. Even Olivia Davis, who is very involved in Deaf Culture has experienced this feeling, she stated “I grew up with my family who all could hear. And I was only deaf one in the family so there wasn't a lot of support as I grew up.”

F.3. Essence Three: Sources of Strength

F.3.a. Similar Situations

Although each family has their own unique set of circumstances there are some aspects of raising a child who is deaf or hard of hearing to which all the families interviewed can all relate. Each parent mentioned that one of their objectives in attending The Care Project retreat was to meet other parents with children who are deaf or hard of hearing. They felt that these parents would understand their circumstances and they would be better able to relate to each other and feel less isolated. Charlotte Brown stated “But it was a really good experience because the first time I met some other families with young kids and older kids who were implanted in this decade really and so it just kind of felt more of a support community there,” and as William James stated “Just for being here, and hearing from some the families like this were two families here in [the city they live in]. I think that we but we haven't met any before this.”

F.3.b. Perspective

Every parent interviewed stated that although they may have been at least somewhat upset when they received the diagnosis of hearing loss for their child, they were not overcome with grief as previous literature as proposed (Kurtzer-White & Luterman, 2003). The parents credit this with their ability to keep their child's diagnosis of hearing loss in perspective. They realize that although this diagnosis will likely make aspects of their life and their child's life more challenging, it is not the worst diagnosis they could have received, as can be seen when William James said, “we heard some of the stories of things that wasn't so it was disheartening but it wasn't to me, me, it wasn't

devastating. It was just OK. What does she need? Let's give her that.” Although two of the families have children who are more medically complex, and one family has two older children who are Deaf, the diagnosis of hearing loss can still provide challenges for individual children. However, even the James family was able to find some perspective with this diagnosis since their older son has severe nut allergies and they feel this is a more severe diagnosis than their daughter’s unilateral auditory neuropathy spectrum disorder. Charlotte Brown stated that seeing other children who are deaf or hard of hearing helps her maintain her perspective, “I know every kid is different but it's also good to just kind of see where other people are and see if they are all doing the same thing you know and they're making the same steps.”

F.3.c. Journey

The concept of these parents’ progression in understanding their feelings about parenting a child who is deaf or hard of hearing and their child’s progression with their development as a journey was present in all the interviews. The parents viewed their pre- and post-diagnosis perceptions of raising a child who is deaf or hard of hearing with compassion, knowing that they were trying their best with the knowledge they had at the time. All the parents acknowledge that there is still much to learn about the world, their child, and what their child will need to be the best they can be in the world. As Jessica Miller stated “But you know we’re just doing the best we can. I mean I think we're doing OK. I mean I don’t know, I guess we’ll see,” this quote illustrates the collective mindset of these parents. They are working to do the best they can for their children and intend to

learn as much as they can about children who are deaf or hard of hearing to be able to help their children reach their potential.

F.3.d. Pushing Through

Pushing through refers to the way the families define of the concept of resilience. They all agreed that the concept of resilience was important to families with children who are deaf or hard of hearing, and even if they were unable to state a personal definition of resilience, they agreed in principle without any major changes with the definition of resilience for the study when it was presented. The parents emphasized that the concept of resilience is important because as a parent with a child who is deaf or hard of hearing they have to “keep going”. They have to continue to learn what the best way to serve their child is and how to achieve that. As Jessica Miller expressed “You have to keep on learning sign language you have to keep on doing whatever you set out to do. There's a lot of people who will beat you down and tell you that you know what you're doing is wrong. You have to just keep on going.” This mindset is also displayed by a quote from Olivia Davis, “Life keeps going. So, no matter what, we just have to keep on going and look at how we can advocate for ourselves [and our children], and stand up for what we believe in.”

CHAPTER V

DISCUSSION

This mixed-methods design study explored the lived experiences of parents with young children who are deaf or hard of hearing. The overarching research question for this study was: How do parents with young children who are deaf or hard of hearing perceive their level of family stress and resilience? Parents included in this study were parents with children who are deaf or hard of hearing who attended *The Care Project* retreat hosted at Wrightsville Beach, North Carolina, November 22 – 24, 2019. To obtain quantitative measures, the parents in this study were asked to complete two questionnaires, the Parenting Stress Index version four short form (PSI-4 SF) and the Family Resilience Assessment Scale (FRAS). To obtain qualitative data, a subset of the parents also participated in semi-structured interviews about their experiences raising a child who is deaf or hard of hearing and their experiences with *The Care Project*.

This chapter reviews the results from the questionnaires and the semi-structured interviews and connects the data obtained in the current study to the findings to the current literature described in Chapter Two. The discussion of the results is structured in the four sections and their subsections outlined in the Literature Review. The first section, the effect of having a child who is deaf or hard of hearing on families, discusses the qualitative results obtained concerning how the parents felt when they learned their

child had been identified as deaf or hard of hearing. It also addresses their reported feeling of isolation. The second section in this chapter discusses the results related to family stress. This section is related to the research questions “What level of stress is experienced by parents of young children who are deaf or hard of hearing?” and “What are parents of young children who are deaf or hard of hearing perceptions of their family's resilience and family stress?”. The third section, family resilience in families with children who are deaf or hard of hearing, also addresses the research question “What are parents of young children who are deaf or hard of hearing perceptions of their family's resilience and family stress?” and focuses on the separate research question of “What level of resilience is experienced by parents of young children who are deaf or hard of hearing?”. The fourth section within this chapter, support for families with children who are deaf or hard of hearing, addresses the research question, “What are parents of young children who are deaf or hard of hearing perceptions of how their attending *The Care Project* Family retreat has benefitted their management of their child's hearing loss and family adjustment to the diagnosis of their child's hearing loss?”. After the findings are discussed, the limitations of the study and directions for future research are noted. The chapter culminates with the researcher's conclusions for the present study.

A. The Effect of Having a Child who is Deaf or Hard of Hearing on Families

A.1. Receiving the Diagnosis

The diagnosis of hearing loss in a child impacts all members of the family (Calderon & Greenberg, 1999). This diagnosis has been shown to affect the family's

quality of life, family interaction, and family resources (Jackson & Turnbull, 2004) and can also affect the way family members interact with each other as well as their interactions with their community (Erbasi et al., 2018). The current study found that the parents do feel that their lives have changed since having a child who is deaf or hard of hearing. However, they do not feel that the diagnosis was as impactful as previous literature suggests (e.g. Lederberg & Golbach, 2002), this feeling is highlighted in the semi-structured interviews, as Charlotte shared, “it wasn't the worst thing that ever happened to us. You know we were just like, ‘well, OK we'll do it. We'll deal with it,’ you know we'll make the best of it.” This shows that although these specific parents in this study do not feel that the diagnosis of hearing loss was the most dreadful news that they could have received, they do realize that it has made a difference in both their lives as well as in the lives of their children.

When asked what their initial reaction was to the diagnosis of hearing loss in their child, most parents recalled being shocked or stunned (Gilliver et al., 2013). In contrast, while the parents in this study primarily reported feelings of frustration, and sadness, they also reported having a feeling of determination when they learned their child had been identified as deaf or hard of hearing. One parent who is Deaf reported feelings of excitement but also expressed being conflicted about those feelings. Overall, no parent stated that they experienced the overwhelming levels of grief that have been previously reported (Kurtzer-White & Luterman, 2003), instead they viewed this diagnosis as a challenge but one they would persevere through and overcome. As William stated, “[The diagnosis] was disheartening but it wasn't to me, it wasn't devastating. It was just OK,

what does she need, let's give her that.” William also shared his acknowledgement of the parallels for each of his children’s diagnoses, “So even though she was diagnosed with this I know that there are means for her. Whereas with the food allergies that sort of thing is completely, you have no real control so it's just that.” He feels that the diagnosis of unilateral ANSD is more easily manageable, and he is not as concerned about his daughter’s diagnosis as he is regarding his son’s allergies. Therefore, he feels that his son’s diagnosis of severe nut allergies has had more of an effect on his family than has his daughter’s hearing loss.

Olivia had a different reaction to discovering her children were born deaf. Because she identifies as being culturally Deaf, she did not perceive her children being born deaf or hard of hearing as disappointing. In fact, she described her first reaction as “really excited.” However, she did explain that her feelings became more mixed about the news as, “I realized how much I would have to advocate for him ... you realize that there are a lot of challenges.” As her children have grown, she has made sure that she keeps their unique personalities in mind when advocating for them as she explained:

For the three children that are deaf they're all different. They have different interests and so each of them have different goals. ... How do I advocate, how to find the right services, how do I help with IEP how that’s decided and who's the right audiologist, right doctor all the right people who consider the children.

Thus, one can perceive that although Olivia’s initial reaction to her sons being born deaf was different than the other parents in this study, they all have similar concerns for their children.

A.2. The Feeling of Isolation

The majority of parents in this study reported a feeling of isolation regarding being a parent with a child who is deaf or hard of hearing. This finding has been seen in families with children who are deaf and hard of hearing (Kurtzer-White & Luterman, 2003). Parents of children with chronic health conditions have also reported a loss of friendships, feelings of isolation, anger, resentment, shock, and sadness which can lead to anxiety, tension, and stress (Paster et al., 2009). This is exemplified in Charlotte's expressing, "We really do kind of feel isolated here just because we don't know a lot of other families especially families of toddlers who have hearing issues.". This feeling was a common thread among the qualitative interviews. Thus, there is a need for parents to meet other parents with children who are deaf or hard of hearing.

Because their children do face unique challenges and develop in a slightly different way than children with normal hearing (Seewald & Tharpe, 2011) it is not surprising that parents with children who are deaf or hard of hearing seek out other parents with children who are deaf or hard of hearing to see if their journey is congruent with that of other parents. This is supported by Jessica Miller revealing that *The Care Project* has allowed her "to meet people in similar situations" which she feels has added to her family's ability to manage her son's hearing loss because "where we live there's nothing," so she does not feel she has been able to find other parents with children who are deaf or hard of hearing outside of *The Care Project* retreats. When parents with children who are deaf or hard of hearing meet parents in similar situations the feeling of isolation becomes less pronounced. This desire is at least in part what led these parents to

participate in *The Care Project* retreat, which Charlotte felt, “was a really good experience because the first time I met some other families with young kids and older kids who were implanted in this decade really and so it just kind of felt more of a support community there.”. Oliva had a different perspective of her desire to meet other parents with children who are deaf or hard of hearing. Because she is Deaf and a member of the Deaf culture community, she would like hearing parents of deaf or hard of hearing children to have more knowledge about Deaf culture. She feels that this knowledge will help parents understand what their child is experiencing as well as what they may be faced with in the future. She shared, “I would love to have parents who come here to learn from other Deaf parents we have the same struggles. We’re in the same shoes so it's okay to interact and get different perspectives.”

B. Family Stress in Families with Children who are Deaf or Hard of Hearing

This study employed a Family Stress Theory lens to examine parent perceptions of their stress related to raising a child who is deaf or hard of hearing. Family stress theories attempt to examine the complex combination of variables which interact overtime that impact a family’s level of functioning (Boss, Bryant, Mancini, 2016). Specifically, family stress theories attempt to explain why some families appear to cope better with certain situations and stressors than do other families (Malia, 2006). The identification of a child as deaf or hard of hearing can lead to many sources of stress for families. These sources may include strained family relationships, increased tasks and time commitments, increased financial burden, and social isolation (Patterson & McCubbin, 1983).

B.1. What Level of Stress is Experienced by Parents of Young Children Who are Deaf or Hard of Hearing?

The parents in the present study were asked to complete the PSI-4 SF. This selected questionnaire is a validated and often used tool that measures the participant's perceived level of stress related to their parenting. The parents in this study reported total scores similar to those reported by Topol et al. (2011) in their study of mothers with children who are deaf or hard of hearing. Topol et al. (2011) reported a mean total stress level of 67 ($SD = 9.9$) which is in the average range. Likewise, the results of the present study found that parents with children who are deaf or hard of hearing experience average levels of parenting stress. The present study's result of low stress levels in these parents is different than what has been seen in the previous literature (e.g. Quittner et al., 2010). Quittner et al. (2010) discussed that parents with children who are deaf or hard of hearing report higher levels of parenting stress related to context-specific measures such as language delays and child behavior problems.

It is important to note that the mother in Family One, Jessica, had a considerably higher total score on the PSI-4 SF than all the other parents surveyed. In fact, her total score was in the clinically significant range. It is plausible that there are other factors contributing to her noticeably higher score when compared with the scores of the other parents in the study. For example, factors in Jessica's life that may contribute to her stress include the lack of support she feels from her family, the other diagnoses she is managing with her son, and the fact that her husband is active duty military and was deployed at the time of this study. She shared in her interview that the diagnosis of hearing loss was

challenging for her, stating, “I just didn't know what to do,” but she also feels that she and her family are managing the diagnosis well and “we’re just doing the best we can.”

Although there are many possible reasons for the overall lower levels of stress indicated by the parents in this study, the researcher posits that this is at least partly due to early identification of their child’s hearing loss through Universal Newborn Hearing Screening (NBHS). All the families in this study had children who were identified through the NBHS process, thus, they did not experience the prolonged period of uncertainty surrounding the diagnosis of their child’s hearing level and their speech and language development and waiting for serviced to facilitate their child’s speech and language development. This is in contrast with diagnostic practices of past decades during which the average age of diagnosis for childhood hearing loss was considerably older (National Center for Hearing Assessment and Management [NCHAM], 2019). Moreover, the parents in this study have benefitted from the Early Hearing Detection and Intervention (EHDI) programs whose goal is to improve and expand the care received by infants and parents during the diagnostic and early intervention process (NCHAM, 2019).

In addition to their children being identified through the NBHS process, all families reported receiving support through the North Carolina Infant-Toddler Program (NC ITP), which is North Carolina’s early intervention program, as well as from NCBeginnings from very early on in the post-diagnosis process. These parents are also participating in retreats hosted by *The Care Project*, which suggests that they are proactive in actively seeking ways to help and advocate for their children. Recalling the Double ABCX model (McCubbin & Patterson, 1983) (figure 1), the parents’ obtaining

such new support systems after learning of their child's diagnosis of hearing loss would be in the bB portion, existing and new resources, of the model as these parents have obtained several new resources since their child's diagnosis it is evident that their relationships with support systems have facilitated their level of family adaptation (xX) in the model. As described by the Double ABCX model, a higher level of family adaptation indicates that families are better able to offset the demands they face in a stressful situation with their existing and new-found resources (McCubbin & Patterson, 1983). For example in applying the Double ABCX model to one family in this study, William and Emily's journey might be described as the initial diagnosis of hearing loss as the stressor (a), with the family reaching out to their family members in the medical field, specifically William's father who is a physician and his aunt who has connections to UNC Chapel Hill Audiology as (b) their existing resources. This combined with their initial perception of the diagnosis of hearing loss that William described as "what did she need? You know. Let's go from there." However, it was not clear to them as to the best path for their daughter, which led them into the change in family functioning of the crisis (x). While they were attempting to discover the best path for Ava, life continued and there were other events that were also perceived as stressful. These events, such as when they were assigned to a new audiologist, would be described as the pile up (aA). During this time, they reached out and learned about new resources they can rely on, such as *The Care Project*, that is included in the bB portion of the model. All of these events now combined lead to William and Emily's new perception (cC) of Ava's diagnosis of

unilateral ANSD. This new perception along with other life events and their new and existing resources related to Ava's hearing loss lead to their level of adaptation (xX).

It has been noted that mothers of children with lesser degrees of hearing loss tend to report more stress than when a child has a more severe hearing loss (Pipp-Siegel, et al., 2002). All the children in the present study were diagnosed with at least a severe hearing loss, per parent report, therefore it is possible that these diagnoses may also play a role in their lower than expected levels of stress. These parents do not have the stress related to the uncertainty of the level of their child's hearing loss. They have made the decision about their treatment plans and have been able to progress through their Individualized Family Service Plans or adjust their Plans as needed to meet their family's unique circumstances.

Parents of children who are deaf or hard of hearing report higher levels of context-specific stress, including communicating with their child and child behavior problems (Quittner et al., 2010). The Difficult Child (DC) subscale on the PSI-4 SF measures the parents' perceptions of the child's behaviors as either easy or difficult to manage (Abdin, 2012). The parents in this study overall scored in the average range on both these subscales, this indicates that these parents do not perceive their child who is deaf or hard of hearing to have a large number of behaviors that are difficult to manage. However, the mother from Family One, Jessica, obtained the highest score for this subscale. Her score on the DC subscale of 34 was 7 points higher than the next highest score and 14 points higher than the average score for the parents in this study. This indicates that Jessica perceived her child's behaviors as more difficult to manage

compared to the parents of other children in this study. This is consistent with previous literature (e.g. Quittner et al., 2010) as Jessica and her family are still trying to determine which communication modality option will work best for their family, therefore they are unsure how to best communicate with David.

Sources of stress for families with children who are deaf or hard of hearing have previously been reported to include strained family relationships, modifications in family activities and goals, a burden of additional tasks and responsibilities, financial burdens, and social isolation (Figley, 1983). The parents interviewed for this study reported the medical aspect of their experiences as the most stressful situation surrounding their child who is deaf or hard of hearing. Within this essence they included the appointments, managing the equipment, and their child's speech-language development. However, the parents did not feel that their level of stress was substantially higher than that of other families with two- to three-year old children.

Family stresses as previously reported in the literature may also affect how the study families view themselves and their relations to other families as well as their own identities and roles within the family (Patterson & Garwick, 1994). This feeling was most prevalent with Jessica. She expressed feelings of sadness and disappointment when discussing her parents and her husband's parents. She stated, "if they don't want to be part of life then they don't want to be part of it,". This quote reveals that she is, at this point, resigned to not having her parents or her husband's parents as part of her support system. This is especially notable since Jessica's total PSI score was considerably higher

than the rest of the parents scores in the present study. Thus, it is plausible that her lack of support from her family contributes to her high stress score.

Although lack of family support is a factor to consider when discussing the stress experienced by families with children who are deaf or hard of hearing, there are many other possible factors as well. Possible predictors of stress in mothers of children who are deaf or hard of hearing have been investigated previously. It has been found that a higher number of daily hassles, less access to social support, additional chronic health conditions or disabilities, and more severely delayed language in the child who is deaf or hard of hearing have an impact on the mother's reported level of stress (Pipp-Siegel et al., 2002). The possible predictors of stress as revealed in the present study include lack of access to social support and the presence of additional chronic health conditions or disabilities in a child.

Although the parents in the current study did not report high scores on the PSI-4 SF it is possible this is due at least in part to the fact that all of these parents have access to support networks. They are all receiving services through NC ITP and have received services from NCBeginnings. All the parents were also participating in *The Care Project* retreat; therefore it is likely that these parents are being proactive in their search for support for their family and their child who is deaf or hard of hearing. Thus, the strength of this predictor of stress for this group is lessened.

Two families, Family One, Jessica, and Family Three, Charlotte, reported that their child who is deaf or hard of hearing has additional medical conditions they are managing. These mothers participated in the qualitative section of the study as well and it

does appear that the presence of additional diagnoses was a contributing factor to their level of stress. Charlotte stated, “if you do combine [the hearing loss] with everything else we went through it sometimes just becomes too much”. Although Charlotte did not have a high of a PSI score as did Jessica, Charlotte had a more expansive support network (e.g. her parents who live close by). Further research is needed to further document the levels of family stress in parents with a child with only hearing disorder versus parents of a child who has multiple disorders.

B.2. What are Parents of Young Children Who are Deaf or Hard of Hearing Perceptions of Their Family's Stress?

The results from the semi-structured interviews in the present study on regarding the parents’ perceptions of their stress from the semi-structured interviews was deduced. Additional factors were identified by the parents during the interviews as contributing to their stress in raising a child who is deaf or hard of hearing as described in the challenges section of the essences portion of the qualitative analysis. The families who were interviewed reported challenges with feelings of frustration, isolation, and stress. Moreover, the families described feelings of frustration when they discussed how the world has reacted to the fact that their child is deaf or hard of hearing or with their interactions with professionals in the medical community. This feeling has influenced the parents’ feelings of isolation, which in turn can lead to their experiencing more stress. As Jessica highlighted when she revealed:

Since this experience since having [David] the human race has let me down. I just really thought that people were more understanding and not as harsh. But in reality, they are. And I'm really worried about that for him. I'm just going to have to teach him to stick up for itself and move on.

Such feelings of stress are often present at the time of the initial diagnosis and can reappear at times of transition, such as when a child starts school (Gilliver et al., 2013). Parents of children with recently diagnosed hearing loss report high levels of stress related to health care and family well-being, whereas families with children who have more experience with hearing loss report higher levels of stress related to education and support systems (Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008). These studies demonstrate that families with children who are deaf or hard of hearing experience high and differing levels of stress depending on the time in their child's development, their experience with service delivery system agencies, level of resources available to support their child's growth, and the family's perception of their well-being.

The families in this study have had time to adjust to the diagnosis of their children's hearing loss, thus they are already thinking ahead. This is apparent in the concern the parents show in contemplating what they and their children will be faced with in the coming years. This mindset can be seen in the quote by Charlotte when discussing her preparation for her first IEP meeting for her daughter, "I don't even know how many kids with cochlear implants they've worked with so I don't feel like really good right now about that support. So I might look for some secondary support.". Thus, the parents are actively searching for ways to help their children. This is at least in part why they are attending *The Care Project* retreat, to learn about and obtain more resources

that will help them serve their child the best they can now and in the future. This mindset will serve the parents well as their children grow and they encounter more and new challenges as their children mature.

C. Family Resilience in Families with Children who are Deaf or Hard of Hearing

The concept of resilience has emerged from the family stress literature (Walsh, 2004). The definition of resilience used for this study was the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the diagnosis of a childhood hearing loss (Patterson, 2002). Resilience was quantitatively measured using the Family Resilience Assessment Scale (FRAS). In the qualitative semi-structured interviews participants were asked to provide their personal definitions of the concept of resilience, they were then provided with the definition of resilience for the study, and then asked how they thought the two definitions were similar or different and if there was anything they would change about either definition. Parents were also asked how the concept of resilience is important to families with children who are deaf or hard of hearing.

C.1. What Level of Resilience is Experienced by Parents of Young Children Who are Deaf or Hard of Hearing?

The parents in the present study were asked to complete the FRAS. This selected questionnaire was developed to conceptually measure a family's level of resilience. The parents' average total score on the FRAS was 206.83 ($SD = 16.94$). This finding is considerably higher than was seen in the Plumb (2011) study that investigated the impact of family resilience and social support on parental stress in families with a child

diagnosed with autism spectrum disorder which reported an average total score of 138.3 ($SD = 17.5$). The lowest total score reported by an individual parent in the present study is higher than the highest total score reported by a parent in the Plumb (2011) study, thus indicating that these parents of children who are deaf or hard of hearing demonstrate a higher level of family resilience than parents of children with autism spectrum disorder. This high level of resilience in parents of children who are deaf or hard of hearing has not been previously reported in the literature. Although there are likely a variety of reasons for this difference, it is possible that at least in part, the parents of children with autism spectrum disorder had children who are more severely involved medically or behaviorally than the children of parents in the present study. Further research is needed to confirm and assess this study's findings of a high level of resilience in parents of deaf and hard of hearing children.

C.1.a. Information from the FRAS Subscales

The FRAS is comprised of six subscales: Family Communication and Problem-Solving; Utilizing Social and Economic Resources; Maintaining a Positive Outlook; Family Connectedness; Family Spirituality; and Ability to Make Meaning from Adversity. Overall, there was little variability between parents on the individual subscales with most parents scoring high in each subscale and the parent partnerships scoring similarly. The Family Spirituality subscale indicated the most variability between parents. Although the average score for the parents of 10.83 ($SD = 3.51$) is on the high end of possible scores, the range of scores tells a different story. The possible range of scores for this subscale is 4 to 16. The parents in this study scored between 6 and 16. This indicates

that although the average score reveals that the parents in the present study have a high perceived ability to use their personal belief system to provide them with guidance and meaning, some parents in this study do not use this ability to the same degree. The variability on the Family Spirituality subscale is notable because of the protective factors found by Ahlert and Greeff (2012). They investigated the resilience factors present in families that helped support them through the challenges of having a child who is deaf or hard of hearing. The protective factors found included family routine, social support, affirming communication, religion, a search for meaning, and acceptance of the child's hearing status. It was seen that families who showed higher levels of these factors, were more likely to show higher levels of resiliency. The results of the present study indicate high levels of resilience irrespective of the level of family spirituality. Therefore, it is possible that although parents with a higher level of family spirituality do use this skill as a protective factor, parents with a lower level of family spirituality have other protective factors on which they are able to rely.

There are a variety of possible reasons why the parents in this study obtained such high scores on the FRAS. The researcher posits that these may include the fact that all the children in this study were diagnosed through NBHS, are currently receiving services from ECI, and have received other support services as well. It is also possible the families had the means and support necessary to be able to attend *The Care Project* retreat. Furthermore, the fact that the parents attended *The Care Project* retreat demonstrates that they have been active in searching for support for their family.

C.2. What are Parents of Young Children Who are Deaf or Hard of Hearing Perceptions of Their Family's Resilience?

Information was deduced from the semi-structured interviews to address the second portion of the third research question. Interestingly, all parents interviewed for the qualitative portion of the study incorporated similar themes in their personal definitions for the word resilience. Table six displays each parent’s personal definition of resilience they provided before they were given the definition of resilience for the study. Parents viewed resilience in terms of their individual circumstances, highlighting flexibility, strength, and perseverance. This is notable because those characteristics the parents indicated are all related to ways they have coped with the diagnosis of hearing loss in their children.

Table 6. Parent’s Personal Definitions of Resilience

Parent	Definition of Resilience
Jessica	Getting beat down and then getting up again, and you just have to keep on getting up
William	Synonymous or so with perseverance. Resilience is having strength but also flexibility.
Emily	The will to thrive
Charlotte	Being able to keep going even when things are hard. Just being able to not let like the little things get you down or keep you from doing what you need to do
Olivia	Life keeps going, so don't no matter what, we just have to keep on going

Families display resiliency in multiple ways such as balancing the needs of the diagnosis with the other needs of family members, maintaining family flexibility, and attributing positive meaning to their situation (Patterson, 1991). Some families are more

resilient than others from the time of the initial diagnosis, while others can gain a feeling of resilience through communication and support (Black & Lobo, 2008). The proposed model for family resilience introduced in chapter two (figures 3 and 4) theorizes a positive association between access to support groups and family resilience. The present study provides evidence supporting the proposition that access to a social support system has a positive association with family resilience after the diagnosis of hearing loss in a child. Thus, when parents with children who are deaf or hard of hearing have access to support groups, such as *The Care Project*, they will demonstrate higher levels of family resilience. More research is needed to explore how families of deaf and hard of hearing children define resilience and the levels of resilience experienced in these families.

D. Support for Families with Children who are Deaf or Hard of Hearing

After a child has been identified as deaf or hard of hearing, parents need information about childhood hearing loss, its consequences, and about the support the child will need (Eleweke et al, 2008). It has been shown that parents who are provided with resources show lower levels of stress (Hintermair, 2006). The importance of access to family support groups has been documented in many studies of the effects of informational and social support from support groups for specifically designed for families with children who are deaf or hard of hearing (Eleweke et al., 2008; Erbas et al., 2018; Moeller et al., 2013). Such support groups help parents feel an increased sense of power, a sense of belonging, and a positive feeling of their ability to manage their child's care and development (Law et al., 2002). They also provide parents with validation, connectedness, and a sense of empowerment (Nicholson et al., 2018).

Parent-to-parent support groups have been documented to be especially effective with families with children who are deaf or hard of hearing (Henderson et al., 2014). Such support groups have been shown to be beneficial to families, with parents reporting high levels of satisfaction with the support provided by these groups (Solomon et al., 2001). Parents with children who are deaf or hard of hearing are especially qualified to provide support for other parents (Kerr & McIntosh, 2001). This type of support provides families with a mutual exchange of information, thoughts, and resources, and affirmational support (Henderson et al., 2014). Thus, these aspects of support lead to families feeling an increased sense of power, a sense of belonging, and higher feeling of manageability for the child's care (Law et al, 2002).

The parents in this study found support from many external sources. The most prominent external sources of support were reported to be NC ITP, NCBeginnings, NBHS, and *The Care Project*. All parents reported that their child was identified through the NBHS process and had been identified as deaf or hard of hearing by six months of age. The 2019 position statement from the *Joint Committee on Infant Hearing (JCIH)* advised that states should strive to have all babies screened for hearing loss by one month of age and the babies who do not pass the screening should have a comprehensive audiologic evaluation by two months, with babies who have a confirmed hearing loss at this point to receive appropriate intervention by three months (JCIH, 2019). This is a shift from previous generations when many children were not identified until they were much older (NCHAM, 2019). Thus, early identification means that families are able to start receiving intervention services sooner. All families in this study reported receiving

services from NC ITP and NCBeginnings. These support services provided the families with information about hearing loss in childhood and the services the children may need moving forward in their development (Beginnings, 2019). In addition to information about children who are deaf or hard of hearing, early childhood intervention provides parents with ongoing support to assist the family with their child's development (CDC, 2019c). Specifically, the NC ITP provides services such as speech-language services and family support (NC ITP, 2019).

D.1. What are Parents of Young Children Who are Deaf or Hard of Hearing Perceptions of how Their Attending The Care Project Family Retreat has Benefitted Their Management of Their Child's Hearing Loss and Family Adjustment to the Diagnosis of Their Child's Hearing Loss?

This study was conducted at a retreat hosted by *The Care Project*; and the above question was presented to parents at *The Care Project* retreat. It was important for the present study to document the effect this state organization may have on these families: their abilities to understand their child's hearing loss; their abilities to foster their child's development; and their abilities to provide a supportive nurturing family life for their child. *The Care Project's* mission states that they are "dedicated to bringing hope to families who have children and/or adults with hearing challenges through counseling experiences aimed at the processing of the emotional stages of grief." (The Care Project, 2020). The parents in this study reported a higher level confidence regarding managing their child's care by attending these retreats as particularly voiced by William:

Just the goal of building a community knowing that there are resources and people available that if we have questions that we can reach out to with our specific situation. I guess at this point it is really more so just hearing other people like us and the families' emotional response to everything because medically it's still kind of up in the air with what [Ava], with what she needs or it appears that way to us because every time we go with something different.

D.1.a. The Role of Mentorship

A crucial theme of parent-to-parent support is the importance of mentorship provided by more experienced parents with children who are deaf or hard of hearing to newer parents. This mentorship contributes to a feeling of empowerment for both parents which can often lead to a decrease in parent stress levels (Hintermair, 2006). An example of this type of mentorship was seen when Olivia shared her experience with her oldest son's speech and language development with Jessica during their interview. Olivia was able to share her knowledge following which Jessica reported a feeling of validation after hearing Olivia's experience. Jessica also emphasized that she was looking forward to a portion of the retreat in which the mothers sit together and share their experiences, thus contributing to the mentorship aspect of *The Care Project*. The Henderson et al. (2014) conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing (figure 2) describes four key components: 1. family wellbeing; 2. child wellbeing; 3. knowledge, and 4. empowerment. According to the parents in this study *The Care Project* provides assistance in each area. Family well-being includes emotional support, which is support that acknowledges the grief these parents experienced. This support is at the core of *The Care Project's* mission as William explained "that's what's so beneficial which is hearing their stories and their experiences and hearing... It was

really good hearing some of the people talk about you know the change before after the children get the cochlear implants and how it did make an impact.” The concept of child well-being includes participation, autonomy, and goals. Although this is not included in the retreat agenda for this age group, Dr. Sexton mentioned that as the children grow older, other retreats begin to address this area (J. Sexton, personal communication, August 16, 2019). It is also apparent that the parents are currently concerned about this aspect as Charlotte explained:

My husband liked hearing the perspective of these teenagers and what they struggle with what they want because you know that's what we're having to make decisions for another human right now. And you know we want to respect her individuality as much as we can but try to make the best decisions for her. And so being able to hear things that these almost young adults are saying kind of will help us make better decisions for her in the future and so I think that was really strong and you just don't get the opportunity to be in front of a panel of high schoolers who all are implanted you know

D.1.b. The Role of Knowledge

Knowledge is important for such support groups to facilitate and emphasize because parents with children who are deaf or hard of hearing need accurate, unbiased information about childhood hearing loss (Eleweke, et al., 2008). *The Care Project* strives to provide this through the speakers at the retreat and Olivia hopes to

have parents come here to learn from other Deaf parents. We have the same struggles. We're in the same shoes so it's okay to interact and get different perspectives and I want the other parents to see me. I'm not broke and you're their child's not broke. It's something we have to be fixed. We are Deaf and we're able to do everything but hear. The children are accepted.

Another component of empowerment involves families gaining skills in decision-making, self-awareness, problem solving, and engagement. This concept is clearly expressed by Jessica when she was asked if *The Care Project* has added to her family's ability to manage her child's hearing loss and she shared "I do. I think it has. You know just the support and like all classes ... I think it helped last year." *The Care Project* embodies all four of the key components of the Henderson et al. (2014) conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing as listed above. Thus, *The Care Project* is part of an effective support system for parents with children who are deaf or hard of hearing.

E. Limitations of the Study

The current study was limited by several factors. Participants were included only if they were attending *The Care Project* retreat hosted at Wrightsville Beach, NC, in November 22 - 24 2019, so the perspectives of other parents with children who are deaf or hard of hearing were not included in this study. Consequently, this study investigated a small number of participants so inferential statistics were unable to be performed. Therefore, it is tenuous to make any statements generalizing these findings to the larger population of parents with children who are deaf or hard of hearing. Responses from the surveys were not obtained from every parent nor parent partnership who attended *The Care Project* retreat, and even fewer parents were interviewed. Although all surveys that were obtained from the parents were complete, it is possible that due to the length of the three questionnaires (demographic, PSI-4 SF, and FRAS) the parents did not place the same level of attention to the questions at the end of the last questionnaire leading to a

possible difference in reported scores. The subjects were selected from the group of parents who attended *The Care Project* retreat, therefore it should be considered a self-selected participant group which indicates a possible selection bias.

F. Directions for Future Research

Future research in the area of the lived experiences of family stress and resilience in families with children who are deaf or hard of hearing should include studies with larger samples and an investigation of the experiences and perceptions of parents of other age groups of children who are deaf or hard of hearing as the levels of family stress and resilience may differ based on the different life stages and transitions they experience. Additionally, surveys and interviews from parents from other states in the United States need to be obtained. A survey of extended family members should also be conducted to compare the perceptions of stress and resilience as expressed between the parents with children who are deaf or hard of hearing and other family members. When surveying parents of older children it will be appropriate to obtain responses from the child who is deaf or hard of hearing or any siblings to compare their perceptions to those of the parents. An investigation into the lasting effects of *The Care Project* retreat should be conducted with a longitudinal evaluation with the parents in this study to examine how families who attend a retreat hosted by *The Care Project* are functioning long-term. Investigations should also include researching factors leading to the high levels of resilience found in the study parents. It would also be appropriate to conduct similar studies with parents with children who are deaf or hard of hearing who have not attended a retreat hosted by *The Care Project* as they may experience differing levels of family

stress and resilience. It would be pertinent to compare *The Care Project* mission and support activities with those of other support groups for families with children who are deaf or hard of hearing. Further research can also be done to compare the families' perception how they received the diagnosis, as well as their level of stress and resilience, from the time their child is identified as deaf or hard of hearing as they progress through raising their child who is deaf or hard of hearing. Research can also be conducted comparing the perceptions of parents with children who pursue hearing aids, cochlear implants, as well as the perceptions of parents with children who are deaf or hard of hearing who pursue manual communication such as ASL or Cued Speech.

G. Conclusions

The current study sought to examine the perceived level of stress and resilience experienced by families with young children who are deaf or hard of hearing. The concepts of perceived stress and family resilience were examined. The results from the study found that the parents who attended *The Care Project* retreat in Wrightsville Beach, NC, on November 22 – 24, 2019 demonstrated average levels of stress as measured on the PSI-4 SF and considerably high levels of resilience as measured by the FRAS. The parents who participated in the semi-structured interviews reported core experiences related to healthcare and education, challenges of frustration, stress, and the feeling of isolation, and sources of strength with finding others in similar situations, maintaining their perspective, thinking of their progress as a journey, and persevering through whatever challenges with which they are faced. These reports reveal the perceptions of parents concerning their experiences raising their children who are deaf or hard of

hearing. This study serves as a foundation for further inquiry into the lived experiences of families with children who are deaf or hard of hearing, their stress, and their resilience so that the professionals who provide services for them can more fully understand the social-emotional context in which these families live.

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APPENDIX A

IRB NOTICE

From: UNCG IRB

Date: 11/01/2019

RE: Notice of IRB Exemption (modification)

Exemption Category: 2.Survey, interview, public observation

Study #: 19-0667

Study Title: Family Resilience and Stress in Families of Young Children who are Deaf or Hard of Hearing

This submission has been reviewed by the IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

Parents of young children who are deaf or hard of hearing who attend The Care Project Family Retreat will be asked to complete two questionnaires, a demographic questionnaire, and participate in a semi-structured interview about their experiences raising a child who is deaf or hard of hearing. The goal of this study is to investigate the level of perceived stress and family resilience in these families.

Modification Information:

Parents will receive an email in their account provided to The Care Project letting them know that the packet will be mailed to the address that they shared with The Care Project.

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. **Please utilize the the consent form/information sheet with the most recent version date when enrolling participants.** The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

Please be aware that valid human subjects training and signed statements of confidentiality for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/university-policies/research_data/.

APPENDIX B

INFORMED CONSENT

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: Family Resilience and Stress in Families with Young Children who are Deaf or Hard of Hearing

Principal Investigator and Faculty Advisor: Sarah Allen, Au.D., and Denise Tucker, Ph.D.

Participant's Name: _____

What are some general things you should know about research studies?

You are being asked to take part in a research study. Your participation in the study is voluntary. You may choose not to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. There may not be any direct benefit to you for being in the research study. There also may be risks to being in research studies. If you choose not to be in the study or leave the study before it is done, it will not affect your relationship with the researcher or the University of North Carolina at Greensboro.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

What is the study about?

This is a research project. Your participation is voluntary and will not impact your family's participation in this or future retreats hosted by The Care Project. The purpose of this study is to document the perceived level of family resilience and stress in families with young children who are deaf or hard of hearing.

Why are you asking me?

You are being asked to participate because you have a child with hearing loss in your family and are attending The Care Project Family Retreat.

What will you ask me to do if I agree to be in the study?

Participants in the study will be asked to complete two questionnaires about family resilience and stress, and a demographic sheet which they will receive and complete before they come to the retreat. It is estimated that the questionnaires will take approximately 1 hour to complete. Participants will be scheduled to participate in a semi-structured interview about their experiences raising a child who is deaf or hard of hearing which will be scheduled during the retreat. Interviews will take roughly 30 minutes. Participation in the interview portion of the study is optional. Participants can complete the survey portion of the study without participating in the interview.

Is there any audio/video recording?

If you agree to participate in the interview, your interview will be video recorded for transcription purposes. Quotes may be used from the interview; however, the recording will not be available to any except those on the research team. Because your voice and image will be potentially identifiable by anyone who sees the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the recording as described below.

Access to the videos will be controlled by the study's PI, Dr. Sarah Allen, and the only members of the research team will have access to the videos. You will be assigned a de-identified number before the interview begins and you will not be asked to provide identifiable information about you or your family.

What are the risks to me?

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants.”

If you have questions, want more information or have suggestions, please contact Sarah Allen, Au.D., and Denise Tucker, Ph.D. who may be reached at (336) 256-2004 or via email at sjallen2@uncg.edu.

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

Are there any benefits to society as a result of me taking part in this research?

Information gained from this study may provide a deeper understanding about the experiences of parents with young children who are deaf or hard of hearing.

Are there any benefits to *me* for taking part in this research study?

There are no direct benefits to participants in this study.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you, or payments made for participating in this study.

How will you keep my information confidential?

All information obtained in this study is strictly confidential unless disclosure is required by law. All paper data collected (i.e. questionnaires) will be stored in a locked cabinet in a locked room on the third floor of the UNCG Ferguson building. Electronic data (recordings of interviews, research data extracted from paper data, and inputted into an electronic data sheet) will be de-identified, meaning your data will be given a number. Your name will not appear in the electronic spreadsheet. When your data is shared, it will only be identified by the assigned subject number. Electronic data will be stored on Sarah Allen’s computer in her office. This de-identified data will also be stored online on Sarah Allen’s secure UNCG Box account. The UNCG Information Technology has Box accounts set up at the top level of security and is used by UNCG to house online research data. Data will be destroyed ten years after the study has closed

What if I want to leave the study?

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

What about new information/changes in the study?

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant:

By signing this consent form, you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate, in this study described to you by Sarah Allen, Au.D.

Signature: _____ Date: _____

APPENDIX C
PERMISSION LETTER

September 27, 2019

To: Institutional Review board (IRB) of The University of North Carolina at Greensboro

Re: Study # 19-0667

To Whom It May Concern:

As Founder and Executive Director of The Care Project, I consent to the use of the 2019 North Carolina Retreat as a data collection site toward the completion of research study # 19-0667.

This consent is contingent upon completion of the study as described. Any changes to the study are subject to my approval prior to implementation.

Sincerely,

Johnnie Sexton, Au.D.
Founder and Executive Director of The Care Project

APPENDIX D
INTERVIEW PROTOCOL

Hello and thank you for participating in this study. My name is Sarah Allen, I am a pediatric audiologist and a PhD student at UNCG. I am interviewing parents of children who are deaf or hard of hearing about their experiences and specifically about experiences with The Care Project retreats. These interviews will be recorded; however, only members of the research team will have access to the recording, and it will not be used without your permission. Do you agree to be recorded for the purposes of this study?

- Tell me about your family
- Tell me about how you felt when your child was diagnosed as having a hearing loss?
- Tell me about your journey with your child's hearing loss (the diagnosis, early intervention, etc.)
- How did you decide on the communication mode you use?
 - Is this the same communication mode you decided on initially?
- Describe your support network, please
- What are some of your goals for your child who is deaf or hard of hearing?
- What are some of your goals for your family?

Questions about TCP

- How did you hear about The Care Project?
- Describe your journey with The Care Project
- How do you feel The Care Project has added/will add to your family's ability to manage your child's hearing loss?
- Is this your first family retreat with The Care Project?
 - If yes- Do you feel this retreat has been or will be beneficial to your family? If so, please explain how. If not please explain why not

- If no- please describe what keeps you coming back?
- If this is your first retreat, what are your expectations of this retreat?

Family Stress

- Describe some stress related events about your experience raising a child who is deaf or hard of hearing?
 - How did you manage these events?
 - Is there something specific you do to manage the level of stress you experience?
- As you've encountered these events, has your level of stress remained the same throughout or has it changed with each event?
- Please describe why you feel this is the case

Family Resilience

- What do you think of when you think of resilience?
 - What does resilience mean to you and your family?
- So, for the purpose of this study we're defining family resilience as "the ability to cultivate strength and recover, gain strength, or bounce back to an acceptable level of family functioning after the stressor of the diagnosis of hearing loss in a child." How do you feel this definition of resilience may or may not be similar to how you think of resilience?
 - If so, is there anything you would add to your definition or mine?
 - If not, how do you feel they are different?
- How do you feel the concept of resilience is important to families with a child who is deaf or hard of hearing?
- What do you feel has helped your family go through the process of raising a child who is deaf or hard of hearing?

Prompts

- Why do you think that's so?
- Tell me a little more about what you mean

APPENDIX E

FAMILY INFORMATION SHEET



UNCG Family Stress and Resilience Study

Family Information Questionnaire

The Care Project Family Retreat 2019

Please answer the following questions so that we can know more about you and your child who is deaf or hard of hearing. You do not have to give your name or your child's name. For the study, a number will be assigned to you on this form.

Parent Study Number: _____

Information about your child:

Was your child born full-term or premature? Full-term Premature

If born premature, what was your child's gestational age at birth? _____ weeks

Was your child admitted to a Neonatal Intensive Care Unit (NICU)? Yes No

If yes, how long did your child stay in the NICU? _____ day/weeks (circle one)

If yes, was your child intubated/placed on oxygen? Yes No

Delivery: Vaginal C-Section

Did your child develop Jaundice? Yes No

Did your child receive antibiotics while in the hospital? Yes No

What was mother's age at delivery? _____ Years

Did your child have a hearing screening at birth? Yes No

If yes, did your child pass or fail the hearing screening? Pass Fail

Information about your family:

What is your age? _____ Gender: _____

As one of your child's primary caregivers, what is your relationship to the child?

- Mother
 Father
 Grandparent
 Aunt or Uncle
 Other (please specify: _____)

What is your highest level of education?

- Middle School (did not complete high school)
 High School or GED equivalent
 College: Bachelor's degree
 College: Master's/Graduate Degree
 Professional degree (e.g. Lawyer, Physician)
 Doctoral Degree

What is your current marital status?

- Single Cohabitation (living together) Divorced
 Married Separated Widowed

How would you describe your race/ethnic group?

- White
 Black
 Hispanic/Latino
 Other: _____

How many children are in the family? _____

How many children have been identified with a hearing loss? _____

Information about your child's Hearing History

How old was your child when he/she was identified with a hearing loss?

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> At birth | <input type="checkbox"/> 13-18 months |
| <input type="checkbox"/> 1-3 months | <input type="checkbox"/> 19-24 months |
| <input type="checkbox"/> 4-6 months | <input type="checkbox"/> 2-3 years |
| <input type="checkbox"/> 7-12 months | <input type="checkbox"/> After 3 years |

Describe your child's hearing loss:

- One ear has hearing loss
- Both ears have hearing loss

Degree of loss in left ear:

- Mild to Moderate
- Moderate to Severe
- Severe
- Profound

Degree of loss in right ear:

- Mild to Moderate
- Moderate to Severe
- Severe
- Profound

Has your child's hearing loss remained the same since the diagnosis?

- Yes
- No, it has changed
- I'm not sure

Listening Technology

Left Ear

- No device placed
- Hearing aid
- Cochlear Implant
- BAHA
- Other: _____

Right Ear

- No device placed
- Hearing aid
- Cochlear Implant
- BAHA
- Other: _____

At what age did your child begin using listening technology?

- Hearing Aids
- Cochlear implants

Support Services for your Child

Has your child received any support services prior to The Care Project Family Retreat (e.g. NCBeginnings for Parents of Children Who are Deaf or Hard of Hearing)?

Yes No

If yes, please list them below:

How long has your family received hearing support services?

- Since receiving the diagnosis
- Within 3 months of receiving the diagnosis of hearing loss
- Within 6 months of receiving the diagnosis of hearing loss
- Within 1 year of receiving the diagnosis of hearing loss
- Over 1 year since receiving the diagnosis of hearing loss
- I'm not sure

Has your child received any early intervention services?

Yes No

If yes, please list them below:

How long has your family received early intervention services?

- Since receiving the diagnosis
- Within 3 months of receiving the diagnosis of hearing loss
- Within 6 months of receiving the diagnosis of hearing loss
- Within 1 year of receiving the diagnosis of hearing loss
- Over 1 year since receiving the diagnosis of hearing loss
- I'm not sure

Is there any additional information that you would like to share about your child and your family related to your child's hearing loss?

APPENDIX F
INSTRUCTION SHEET

Hello Families of The Care Project,

Thank you for participating in this study. My name is Dr. Sarah Allen, Au.D., and I am a Pediatric Audiologist and a PhD candidate at the University of North Carolina Greensboro. My dissertation research is on exploring family resilience and stress in families with young children who are deaf or hard of hearing. For this project, we need each parent/caregiver to complete the included documents. Included in this packet you will find a copy of the UNCG approved consent form, a Family Information Sheet, and two different questionnaires (Parenting Stress Index-4 SF and Family Resilience Assessment Scale). Your responses to these questionnaires will help us explore the stress and resilience experienced by families of young children who are deaf or hard of hearing.

Please complete the questionnaires separate from your partner/spouse. The documents should take thirty to forty-five minutes to complete. You will need to bring the completed questionnaires and consent form to The Care Project Family Retreat. Your responses will be kept completely confidential. To see a video of me discussing the study and the questionnaires scan the QR code with your phone or visit

<https://sites.google.com/uncg.edu/sarah-allen-dissertation/>

Thank you for your time,

Sarah Allen, Au.D., CCC-A

