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Kimberly Wedner
Voices Being Heard: Experiences of
Adults with Congenital Hearing Loss
Being Raised in Hearing Families

ABSTRACT

This qualitative research was conducted to study how people with congenital hearing loss experienced the impact of being raised in families where all other members were hearing.

Literature pertaining specifically to people with congenital hearing loss was limited. Therefore this study reviewed previous written works mainly on families with a deaf member and linked them to the topic of people with congenital hearing loss in hearing families. The literature spoke to the importance of family members collectively contributing to the needs of a person with a disability on many levels. The theoretical framework of family therapy was used to study this topic.

The experiences of 12 adults who identified as having a congenital hearing loss and growing up in hearing families were explored through in-person, narrative interviews. People who participated were diagnosed with the condition of hearing loss from birth or early childhood. Questions were asked of participants about the general impact growing up with a hearing loss in addition to specific questions about parent-child relationships, sibling relationships, school experience, and services used.

Participants of this study were found to experience challenges and hurdles in their families whether it be in school, in social situations, or in communicating and getting their needs met by parents. Participants were also found to experience some sibling rivalry and be closest to a female family member. Despite challenges, participants were loved and accepted for who they were in their families regardless of having a hearing loss.

**VOICES BEING HEARD: EXPERIENCES OF ADULTS WITH CONGENITAL
HEARING LOSS BEING RAISED IN HEARING FAMILIES**

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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2011

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Chapter I

Introduction

Purpose Statement

Family dynamics are fragile. All families have intricate balances that can be upset by the slightest change, difference or complication. What happens when one member of a family is born with a hearing loss? When a daughter cannot hear her mother's voice from another room? When chronic ear infections or trips to the audiologist interrupt familial routines? When hearing loss impacts social and scholastic functioning? Both the child and the family can be impacted. Understanding the disability and the child's experience of the world can help the system function and help the child reach his or her highest potential.

The purpose of this exploratory research is to study how people with congenital hearing loss experienced the impacts of being raised in families where all other members were hearing. What were the challenges? How did the person with hearing loss deal with these challenges? How did their family deal with the challenges? What services existed and were utilized by the people with hearing loss throughout their formative school aged years and young adult lives? This research is being conducted mainly to gain insight into how people with a hearing disability feel impacted, if at all, being raised with those in the hearing community.

For the purposes of this study, congenital is defined as the condition being present at birth or early childhood (Brauer et al., 1998). Congenital hearing losses “can result from illnesses prior to birth on the part of either mother or fetus... or from hereditary (genetic) factors that are not yet fully understood” (Marschark, 2007, p. 35).

A great deal of research has been devoted to the study of deaf individuals and Deaf culture, however little has been written about people with congenital hearing loss. In the chapters that follow, definitions and contextualized explanations of any uncommon or potentially misunderstood terms will be provided for congenital, hearing loss, and Deaf culture (and why, for example, Deaf is capitalized).

In conducting the initial search for research on this topic, I found literature addressing other important areas surrounding hearing loss, such as the experience of deaf children with hearing parents (Brauer et al., 1998; Calderon & Greenberg, 2003; Feher-Prout, 1996; Jackson & Turnbull, 2004; Luckner & Velaski, 2007) and cochlear implant related writings (Jackson & Turnbull, 2004; Ross, 2007). However, few articles seemed to pertain specifically to people with congenital hearing loss. More studies and writings need to be done on this topic and a deeper understanding of the studies already conducted linking them to this topic is a place to start.

I used a broad theoretical base of family systems theory to understand what a person with hearing loss's experience was within the context of their hearing family. As was the case with the scarcity of literature specific to congenital hearing loss, I found a gap in the literature when I attempted to pinpoint a group of theoretical ideas that underlie the study of people with congenital hearing loss and their experience in their hearing families. Theories exist related to more of an activism or social justice piece of the disability movement in general (Burch, 2002; Hole, 2007; Jackson & Turnbull, 2004; Jankowski, 1997; Marschark, 2007). Within the literature where a social justice framework was used, these authors in the citation above mention that not enough study has been done on the topic of congenital hearing loss and family therapy to make sufficient generalizations. Nothing substantial turned up in the search for theories and ideas already published on studies of family therapy done specifically on a family affected by

congenital hearing loss thereby strengthening the argument to implement this study to provide perspective on people with congenital hearing loss raised in hearing families and the issues they face.

Research on congenital hearing loss is important for those who wish to gain more empirical knowledge about people with disabilities, specifically a person with hearing disabilities. Study on this topic may also provide useful treatment information for clinicians who encounter a client with a hearing disability. Last, this study may be beneficial for individuals with a disability themselves or parents and families of a person with a disability or hearing loss who are seeking information.

Chapter II

Literature Review

This chapter will review a survey of the literature as it relates to adults with hearing loss and their hearing families. A thorough review of findings from other experimental studies and writings will be examined. Definitions and terminology that are commonly used when reviewing readings on hearing loss will be explained. This chapter will include a discussion of the prevalence of hearing loss and the historical background of the Deaf movement. The concept of people with hearing loss being caught between two worlds, the world of the hearing and the world of the deaf, will be introduced in this chapter. A description of deaf and hard of hearing families and information about how communication impacts the hearing loss population will be addressed. The final section of this chapter will consider family theory as it applies to the study of the deaf and hearing loss community.

Definitions and Terminology

The purpose of this project is to study adults with congenital hearing loss. Several terms are necessary to explain and define before delving into a survey of the literature. To begin, different types and variations of the degrees of hearing loss exist. Some hearing losses are acquired later in life and other hearing losses are present at birth. Congenital means the condition is present at birth (Brauer et al., 1998). Congenital hearing losses “can result from illness prior to birth on the part of either mother or fetus... or from hereditary (genetic) factors that are not yet fully understood” (Marschark, 2007, p. 35). Due to medical advances, improvements have been

made in the ways we understand the causes of deafness and hearing loss. Eighty percent of the cases of childhood hearing loss have a genetic component (Arnos & Pandya, 2003).

The word *deaf* has different connotations when written with a capital D and with a lower case d. In the terminology used to describe Deaf culture, Deaf is an adjective and is capitalized to refer to the group of people who share American Sign Language (ASL) as their primary means of communication (Burch, 2002). The capitalization of Deaf depicts the need by the Deaf community to assert a sense of identity that was previously lacking. People use *deaf*, with a lower case d, to designate a medical condition. The distinctions among terms used to define hearing loss versus hearing impairment and the differences between being deaf and have a hearing loss are important. The World Federation of the Deaf (WFD) and the International Federation of the Hard of Hearing People (IFHOH) issued a joint statement in 1991 that adopted the term deaf and hard of hearing versus the term hearing impaired, which is used more widely in other countries (Marschark, 2007).

The term hearing impaired carries with it a negative connotation. The WFD and IFHOH joint statement on terminology also attempts to distinguish between a person with hearing loss and a deaf person. Hearing loss is a general term used to describe any degree of damage to a person's hearing, ranging from mild to profoundly deaf. Deafness is considered a complete lack of hearing, whereas hard of hearing connotes some hearing loss and some hearing present. Hearing loss can be categorized by which part of the auditory system that is damaged (conductive sensorineural, or mixed hearing loss), by the severity of the loss (measured in decibels), and by the configuration of the loss (high-frequency, bilateral, or sudden loss) (Type, degree, 1997-2010).

Prevalence of Congenital Hearing Loss

This section reports on the low incidence of congenital hearing loss diagnosis and scarcity of studies conducted on congenital hearing loss. The emotional impact of hearing loss and deafness are also discussed. Ammerman (2010) explained one possible factor for the lack of literature being that hearing loss was a low incidence disability that affects 1 to 6 per 1,000 births. It was not until recently that hearing loss was even looked for and diagnosed in children. In the late 1990s, a push began for the Universal Newborn Hearing Screening, which would ultimately make mandatory a test of every newborn's hearing before the baby's leaving the hospital (Ammerman, 2010; Moeller, Hoover, Peterson, & Stelmachowicz, 2009). The fact that congenital hearing loss affects such a small group furthers the need and importance for the study in this area. Especially for social work and the helping professions, study of such a group is important, as hard of hearing people are a vulnerable population whose needs may be often neglected.

Empirical Research on Hearing Loss

Friedman (2009) linked studying the experiences of people with hearing disability to depression in people with hearing loss. Much like the other literature, Friedman's article started out by saying that very few studies were done on the topic of people with hearing loss and that much of the literature reviewed leaves gaps to researchers being able to fully determine the experiences of people with hearing loss (Brauer et al., 1998, Friedman, 2009; Shapiro & Harris, 1976; Sloman et al., 1987). In Friedman's study, she hypothesized that by measuring loneliness and problem solving, she could assess for depressive symptoms in the deaf and hard of hearing. Her study used a series of self-report questionnaires of 126 women from Drexel University Department of Otolaryngology. While Friedman's study is limited in that she only administered

the questionnaire to women, her findings produced positive results that confirmed that loneliness and impaired problem solving were significant predictors of depressive symptoms for deaf and hard of hearing people. She found that “objective severity of one’s disability, speech discrimination, and the number of years one is deaf and hard of hearing” were all factors related to studying the depressive symptoms of people with hearing loss (Friedman, 2009, p. 7138).

Adjustment issues and emotional challenges cannot be generalized to represent all of those in the deaf and hearing loss population. The impact of deafness on overall development is related to various factors such as family environment, parental adaptation, family coping, school and community support, and the deaf person’s interaction with his or surroundings (Calderon & Greenberg, 2003; Friedman, 2009; Jackson & Turnbull, 2004; Moeller et al., 2009; Moores, Jatho, & Dunn, 2001).

It wasn’t until recently that writings about Deaf peoples’ own life experiences were published and that perhaps Deaf peoples’ experiences were even overlooked by preexisting research (Bruggermann, 2007). Bruggermann’s (2007) research on *Deaf lives leading deaf lives* delves into the ways in which previous studies have been limited in that the studies were conducted by “postlingually [meaning deafness which develops after the acquisition of speech], well-educated, literary-minded...white men”, which can be exclusionary and provide restrictions in the findings of the research (p. 112). Another limit to some writings is that the researchers sought to connect the life stories of the Deaf in comparison to “making it in the hearing world” instead of examining the Deaf culture as its own entity (Bruggermann, 2007, p. 112). Why it is necessary to examine Deaf culture will be clarified more in the next section.

Historical Background of the Deaf Movement

This section will provide information about the history of the Deaf movement. For the purposes of this study, the historical context of the Deaf population will be provided to better understand what Deaf people, and possibly people with congenital hearing loss, experience. To understand more of the background and movement of the Deaf, the research indicated that historically the Deaf community has fought to be recognized as its own culture, with its own language, identity, and to have others understand their struggle to make known what Deaf people have faced. One study of hearing children raised by deaf parents speaks to the struggle of the Deaf culture, Preston (1994) stated, "Hearing loss is a very real condition with very real consequences. Yet a long history of explanations and responses to deafness has reflected biases of the dominant hearing culture and continues to overshadow the understandings of deaf people themselves" (p. 9). Hole (2007) defined the Deaf movement by saying, "Deaf people do not want to be fixed [i.e. cured of deafness]; rather, they want to be respected as a linguistic, cultural minority and treated equally in relation to the hearing majority" (p. 263).

As is the case with many movements, the Deaf movement was prompted largely because Deaf Americans felt neglected by the society as a whole. The neglect was so much that "until the 1980's, there was virtually no scholarly study of deaf and hard of hearing people; information on the deaf came almost exclusively from 'outsiders': hearing educators, doctors, and policymakers" (Burch, 2002, p. 1). Inspiration for the Deaf movement began during the civil rights era. Some camps say the Deaf movement was prompted as a part of the disability movement, while others prefer the Deaf movement be kept separate from the broader disability movement.

Discussion around the nature of separateness of the Deaf community and culture remains a topic of debate among researchers and the general public. The dominant society's desire to mainstream and normalize the Deaf is one impetus that has informed the Deaf movement. In both early and current phases of the movement, society has created an ideology that posits that speaking and hearing are normal (Jankowski, 1997). Rebellion against the stigma of being different and not *normal* is what characterizes the Deaf participants' struggle.

Between Two Worlds

Where, then, does that leave the congenital hearing loss population? This section will discuss how people born with a hearing loss, by nature of being different from the majority of the population, experience the world from two perspectives, that of the hearing and that of the not hearing. Dual relationships are constructed by public discourse that leads to a "juxtaposition of discourses of normalcy and differences based on opposites"... such as, "hearing/not hearing, normal/disabled, oral deaf/signing deaf, and Deaf/deaf" (Hole, 2007, p. 268). Additionally, this section will look at the social construct of passing and how this causes complex identities to arise. Difficulties in finding professional services to help the family or person with hearing loss will be discussed.

Over 90% of deaf children have hearing parents (Gallaudet Research Institute, 2001). Therefore, the deaf and hard of hearing individuals will constantly be reminded of their differences. Calderon and Greenberg (2003) described "deaf children's acculturation [as] unusual in that they are minorities within their own families" (p. 180). Marschark (2007) noted, "as soon as a baby is identified as deaf, parents are likely to change their behavior" (p. 13). The deaf baby's "early understanding of the world will be somewhat different from [that of] hearing babies and different from [that of] other deaf babies who have deaf parents," thus showing the

complexity of the child's identity that may arise (Marshark, 2007, p. 14). While deaf children will experience themselves as a minority, just as in normal hearing families, each situation in a family is unique. The entire family is affected by having a deaf child, and having a deaf child in a family involves having the whole family work together with patience and understanding.

Within the hard of hearing population, the issue of passing as a person without a disability emerges because hearing loss and deafness is not a visible disability. Being a person with a disability may seem more socially acceptable or "easier for most people to recognize and accept the obstacles faced by someone in a wheelchair than someone with a learning disability" (Marschark, 2007, p. 17). The impulse for able-bodied people to minimize a hearing disability because the disability is not visible can essentially do harm in the long run.

The invisibility of people with hearing loss may, however, speak to some of the difficulties that exist within families and in finding ample information and/or services. In a review of hard of hearing people who received cochlear implants, a surgically implanted device that provides a source of sound to the profoundly hearing impaired, "most participants had little or no significant contact with social work services" (Ross, 2007, p. 361). Ross (2007) went further to say, "it would appear that patients were being presented with challenges that are not being addressed by the current service arrangements" (p. 358). This seemed to be the trend in the research despite the fact that this study made a generalization about people with cochlear implants.

The division between Deaf and hearing cultures make it complex for people with hearing loss to feel accepted by both the Deaf and hearing communities (Jackson & Turnbull, 2004). As notes earlier, this may cause deaf people to experience a greater sense of isolation or depression (Friedman, 2006; Jackson & Turnbull, 2004). Other people view their multiple identities as a

way to feel bonded by a unique language and community (Jackson & Turnbull, 2004; Luckner & Velaski, 2004).

Deaf and Hard of Hearing Families

All families are distinctive, however research shows that a family where one member is deaf or hard of hearing presents an additional layer of challenges (Feher-Prout, 1996; Jackson & Turnbull, 2004; Luckner & Veleski, 2004; Sloman et al., 1987). This section will speak to some of the similarities or strengths and some of the struggles that arise in hearing families with a deaf child. Potential ways of coping for families with a deaf member will also be discussed.

Some studies have shown that deaf families have more similarities to hearing families than differences (Fisiloglu & Fisiloglu, 1996; Moores et al., 2001). Fisiloglu and Fisiloglu (as cited in Moores et al., 2001) found that “families of deaf and hard of hearing children adjusted quite well to the stressor of raising a child with a hearing loss and that such families may be special but they are not necessarily dysfunctional” (p. 248). In another study where families with a deaf child were asked to reflect on factors they felt contributed to being a healthy family, respondents reported the value of family was held in high regard, ample support from extended family, friends, and members of the community were important, as well as support from the professionals at the child’s educational facility all contributed to the families strengths (Luckner & Velaski, 2004).

However, there are many struggles that accompany deafness or hearing loss. Learning of the diagnosis that one’s child is deaf or hard of hearing comes with many implications that many other families do not have to deal with and changes the family dynamic. Many hearing parents’ initial responses to the diagnosis of a disability were similar to the stages of mourning, where they experienced denial, anger, denial, bargaining, depression, and acceptance (Feher-Prout,

1996; Seligman & Darling, 2007). In addition, families had to immediately think about many new and complex pieces of information, such as amplification devices, sign language, educational interventions, and legal issues (Feher-Prout, 1996, Moeller et al., 2009).

Hearing loss was found to have “a detrimental effect on many aspects of daily living including the potential for loneliness and negative impacts on mental health” (Ross & Lyon, 2006, p. 357). Another study stated that “deaf people who embraced values of both the hearing world and the deaf culture appeared to have the highest self esteem” (Calderon & Greenberg, 2003, p. 179). Accessing community support around issues of deafness, finding adequate services, and being accepted by the Deaf culture may be problematic (Jackson & Turnbull, 2004). Last, deaf children and adolescents were found to be “delayed in language development, tend to show greater impulsivity and poorer emotional regulation, and often have an impoverished vocabulary of emotion language” (Calderon & Greenberg, 2003, p. 178).

Communication Barriers of the Deaf Within the Family

Communication is a key component to making most relationships work. This section will cover the ways communication is hindered and different in families with a deaf member compared to hearing families. Which mode of communication, whether it be sign language, spoken communication, or a combination of these, the family will choose to use with the deaf child will also be discussed.

As mentioned earlier, a high percentage of parents with deaf children are hearing (Gallaudet Research Institute, 2001). Research presented that deaf children needed additional support with involvement in family interactions (Jackson & Turnbull, 2004). A study conducted with deaf parents and their hearing child found that communication issues may hinder the

emotional relationships in the parent-child dyad, which in turn may disrupt healthy attachment of the parent-child or compromise the dyadic bond (Zarem, 2003).

Some research explains the various ways a deaf person learns how to communicate and how the communication style of a deaf person differs from everyday communication with a hearing person (Calderon & Greenberg, 2003; Guarinello et al., 2007; Moores et al., 2001). A comparative study was conducted to compare the ability of deaf versus hearing adult's ability to direct a deaf child's attention during play (Guarinello et al., 2007). This study found that the deaf child "cannot hear the language of their hearing mothers, and the fine-tuning that should happen does not. The result is a mismatch in language expectations, with deaf children acquiring language competence in a visual form while their families are more reliant on a spoken form. (Guarinello et al., 2007, p. 500). People who are deaf or hard of hearing rely on visual cues to communicate and interact with others (Calderon & Greenberg, 2003; Guarinello et al., 2007; Moores et al., 2001). Relying predominantly on visual cues for communication may cause many innuendos and larger content of conversations of those using spoken language to get lost in the processing ability of the deaf person. The need for the deaf person to have communication directed specifically to them was reported to be a tiring process for the deaf as well as others communicating with them because a lot of effort, time, and thought had to go into initiating and carrying out a conversation (Calderon & Greenberg, 2003).

Whether to use sign language, spoken communication, or a combination of these methods has been the debate among professionals and activists for quite some time. Throughout Deaf history and education, there were different schools of thought regarding the assumption that speech was the only natural form of communication. The oralists advocated for the use of speech and speechreading to replace sign language in belief that learning sign language reduced the

motivation for deaf children to learn to speak or read lips, thereby teaching the child to function in the hearing world. The manualists favored the use of American Sign Language (ASL) in an attempt to offer people who are deaf communication that is more easily adapted by the deaf child and to preserve a sense of community and their own language (Jankowski, 1997). In the United States, a method called total communication has been most popular. Total communication was introduced as a middle ground mode where several different language techniques such as, “child-devised gestures, ASL, speech, speechreading, fingerspelling, reading, and writing” were used (Ross, 2007; Sloman et al., 1987, p. 244). Issues often occurred when parents did not use sign language, which caused a greater chance for deaf children to be left out of conversations and those they were interacting with to be frustrated with the communication exchange (Calderon & Greenberg, 2003; Jackson & Turnbull, 2004; Luckner & Velaski, 2004; Moores et al., 2001). In a study conducted on families who identified as healthy, the family members used some form of sign to communicate (Luckner & Velaski, 2004).

Deaf families seeking services from helping professionals reported receiving skewed advice from professionals to push parents into using a specific communication method with their deaf child (Luckner & Velaski, 2004). The parents argued they knew what was best for their child and that professionals did not seem open to the parents’ perspective of which communication method they wanted to use. The Guarinello et al. (2007) study on hearing mothers versus deaf professionals to get the attention of a deaf child during play, found that the hearing mothers did a better job of retaining their child’s attention than the deaf professional. Issues in communication were also directly related to a family’s minority status and degree of hearing loss (Jackson & Turnbull, 2004). There is also an “issue of lack of communication skill and insecurity on the part of many adults... this often unconscious fear often leads many adults

to “talk down” to or reduce the linguistic and cognitive complexity of communications to deaf children” (Calderon & Greenberg, 2003, p. 179).

Family Theory and the Deaf

There are fundamental schools of family therapy along with theorists that conceptualized them. Quite a lot of literature on family theory exists, therefore for the purposes of this study, only a few names of the major theories that may help in understanding families impacted by a person with a disability will be mentioned. Studies that have been conducted using a family theory model will also be mentioned.

In the 1960’s, the most influential model of understanding how families worked was through systems theory. Murray Bowen was one of the main pioneers in systems theory. The basic tenet of family systems theory was derived from the notion of the whole being greater than the sum of its parts. Nichols (2009) described, “the power of family therapy [lies in] instead of isolating individuals from the emotional origins of their conflict, problems are addressed at their source” (p. 6). Systems theory “taught us to see how people’s lives are shaped by their interchanges with those around them” (Nichols, 2009, p. 66). Later, family theorists understood that cultural influences and subjective experience about family members’ beliefs also affect familial patterns of interaction. The combination of social forces that inform behavior became known as social constructionism, which taught ways to “look beyond behavior” (Nichols, 2009, p. 67); this has implications when studying families with disabilities who often times need to find alternative ways of relating to their child (Seligman & Darling, 2007).

Another important family therapy theory to mention is attachment theory, which lends itself to studying the inner lives of family members and infants bond to their primary caregiver. Attachment theory, which was mainly the work of John Bowlby and Mary Ainsworth, provided

an understanding of the way in which a deaf or hard of hearing child related to his or her caregiver in order for healthy social and emotional development to occur (Shilkret & Shilkret, 2008).

The literature surveyed lends itself to understanding family theory in relation to study of deaf children and their hearing families in many ways. In the general sense, “A disability in one family member affects the entire system and in turn affects the disabled person.” (Seligman & Darling, 2007). Family theory is a critical way to understand the experiences of an individual who may often times feel misunderstood within the context of their family. Theorists noted a susceptibility of the deaf child to become the focus for many conflicts within the family that do not pertain to the child (Rolland, 1994; Seligman & Darling, 2007; Shapiro & Harris, 1976). This is known in family theory as placing the deaf child as the scapegoat of the family.

Research on families with a deaf member reported the explanation for the scapegoating was due mainly to a communication breakdown in which hearing parents of deaf children often did not learn to use sign language or an appropriate form of communication with their children (Calderon & Greenberg, 2003; Jackson & Turbull, 2004; Luckner & Velaski, 2004; Moores et al., 2001). Sloman et al. (1987) noted “conflicts often occur between family members about which method of communication to employ” (p. 244). Family theorists hypothesized that the absence of an adequate communication system could be due to hearing parents’ negative or failed experience(s) with professional help during the early years of the deaf child’s life which led to feelings of failure as a parent and mistrust of professionals (Harvey, 2003; Seligman & Darling, 2007). There may also be an underlying difficulty in accepting their child’s deafness by their resistance to sign language and use of professional services. A lack of larger support from the community or larger systems may also be at play. Last, family theorists posited issues of

blaming the deaf child for acting out or being unresponsive may be a symptom of marital problems or untreated tension between other family members (Marschark, 2007; Rolland, 1994; Sloman et al., 1987).

Early family theorists proposed goals for working with deaf children to include the “facilitating of clear communication from the parents to the child, the introduction of early manual communication between parents and child, and the expression by the parents of consistent and reasonable expectations” (Shapiro & Harris, 1976, p. 87). Similar goals have been proposed by current family theory experts (Brueggermann, 2007; Calderon & Greenberg, 2003; Guarinello et al., 2007).

Family therapy, while its effectiveness has been studied, is still not as widely accepted a method of treatment as individual therapy. A recent study done in Israel concluded that with the increase in early intervention programs (EIPs) for children with hearing loss in educational programs, a greater shift toward family centered practices and services are being put into practice (Ingber & Dromi, 2009). Limitations exist in issues of diversity and cultural acceptance of family therapy. While the individual seeking counseling may welcome the help of a professional outside the family, in some social classes, age groups, and cultures, going outside the family unit is not accepted (Seligman & Darling, 2007; Sloman et al., 1987). In addition, researchers have reported finding skilled family therapists with the expertise in working with the scope of deaf or hard of hearing issues may be difficult to find (Luckner & Velaski, 2004; Sloman et al., 1987).

Summary

The literature surveyed showed that information presented on this topic of the study of how people with congenital hearing loss experience the hurdles they had in their families was sharply limited, which suggested that further study is needed. Scarcity of research may be

attributed to the low incidence of congenital hearing loss and the fairly recent mandate to screen newborns for hearing loss. Studies conducted in similar areas on the topic, such as those on deaf children and their experiences being raised with hearing parents are studied to link them to that of the congenital hearing loss population. The literature described the importance of historical context of the Deaf movement and culture as a whole to gain perspective to the position from which struggles have arisen and strides have been made in helping the general public learn about this unique group of people. The unique position of having been between two worlds, the hearing and not hearing worlds, which this population found itself due to the invisibility of hearing loss, was discussed. A comparison of deaf families and their communication struggles were analyzed.

The purpose of this study is to examine how people with congenital hearing loss experienced the impact of being raised in families where all other members were hearing. The theoretical framework of family therapy was used to study this topic. The literature spoke to the importance of family members collectively contributing to the needs of a person with a disability on many levels. The objective of this study is to examine how the person with congenital hearing loss feels they struggled by being raised in a hearing family.

Chapter III

Methodology

Introduction

This chapter will cover what I did in the data collection and data analysis when studying people with congenital hearing loss and how they felt impacted by being raised in a hearing family. The sections in this chapter will go over the research questions that I used, a description of my research strategy, and information about the sample used in my study. Ideally, after reading this section, the reader will have a better understanding of exactly how I studied the family experiences of people with congenital hearing loss and be able to replicate this study if desired.

Formulation

This section of the chapter will restate the purpose of the research and the questions that were asked to derive the answers that comprise the focus of my study. The purpose of this project was to study how adults with congenital hearing loss experienced the hurdles they had in their families. What were the challenges? How did the person with hearing loss deal with these challenges? How did their family deal with the challenges? In addition, I wished to examine what services existed and which were utilized by the people with hearing loss throughout their formative school-aged years and young adult lives. I was interested in how people with a hearing disability feel impacted by, if at all, by being raised with those in a hearing family.

Research Design

This section will go over an explanation of what I was measuring, the research design selected, the method used for my sample selection, and a description of my data collection instrument used.

The purpose of this study was to explore how people with congenital hearing loss felt impacted, if at all, by being raised in a hearing family. To study this population, I used a qualitative method and semi-structured interviews to collect narrative data. I used an exploratory/descriptive qualitative design because this is a little researched area and qualitative data will help to provide rich and nuanced findings, as opposed to the data that a quantitative approach would gather. An exploratory and descriptive design was appropriate to my questions because as mentioned there was not much information or previous study on my topic and further elaboration was necessary. Also, qualitative research design was suitable given that my data will vary greatly from person to person, which allows room for understanding more of what is going on instead of making generalizations about a group of people (Rubin & Babbie, 2010). As is the case with exploratory studies, participants' comments provided insight into and comprehension of their experiences without my being able to draw conclusions that fit the entire population of people with congenital hearing loss raised in hearing families.

The method used for the sample selection in my study was a nonprobability, convenience, snowball sampling. In order to gain access to conduct the 60-minute interviews with the hard of hearing participants, I recruited from an initial source, my local branch of a national hearing loss agency (refer to appendix A to see a letter from that agency), and then asked these first participants to suggest other potential participants. Snowball sampling method was used because people with hearing loss are not the most obvious within the community.

Rubin and Babbie (2010) discuss conflicting viewpoints in research that reliability and validity are not applicable in qualitative studies (Rubin & Babbie, 2010). The research conducted in my study was highly subjective. Participants were reporting on their own experiences of being hard of hearing persons in hearing families. The sample size was small, therefore making a generalization of the findings harder. All of these factors made the reliability and validity of the interviews conducted vary greatly. The point of qualitative studies, as stated in Rubin & Babbie (2010), “is to study and describe things in such depth and detail, and from such multiple perspectives and meanings, that there is less need to worry about whether one particular measure is really measuring what it’s intended to measure” (p. 89). Therefore, the reliability and validity of my study was not geared towards obtaining factual, quantifiable results, but rather learning and interpreting the stories of how a small group of the hearing loss population experienced the hurdles of being raised in a hearing family.

I used content theme analysis in my study for conclusion-drawing. Using content analysis provided a way of seeing patterns and understanding meanings from the qualitative interview material (Rubin & Babbie, 2010). To analyze my narrative data, I first reviewed all of the data that I gathered by listening to all of the recordings and reviewing the notes I took while interviewing. Next, I coded the data by looking for themes in the narrative data. The themes were a combination of repeated content and individual or unique responses. I made a list of themes to report on and then I generated exact quotations of what the person I interviewed said that fit under each theme. When I was finished coding, I reviewed my data for anything I might have left out.

I made one change in the research design during the course of conducting the study. I submitted an amendment to the Human Subjects Review Committee (HSRC) to update the

definition of the term congenital to include those who have been diagnosed with hearing loss from birth and early childhood. The rationale for this change was that a hearing loss often times was not screened during infancy as it is now. Also, 9 out of 12 of my participants reported that their hearing loss was not diagnosed until they entered school where a first grade teacher generally noticed that the child with hearing loss was not responding like other children. Modifying the definition of the term congenital to include people who were diagnosed with hearing loss both in infancy and early childhood was the only change made in the criteria for participation.

Sample: Who Participated?

My sample included 12 adults who identified as having a congenital hearing loss. Participants were diagnosed with the condition from birth or early childhood. I conducted 60-minute in-person interviews with my participants. The hearing loss included various levels of disability from mild, to moderate, to severe loss or deafness. I hoped to get a diverse a sample as possible with regards to race, age, gender, and, socioeconomic status, however this was not very feasible because I was recruiting all of my participants from the same agency and I did not ask any demographic screening questions beforehand. My sample was not representative of the entire population, and perhaps not even the hearing loss community, either, given its small size.

Sample: How Were Participants Recruited?

In order to gain access to the hearing loss population that I wished to participate in my study, I sent an email (see Appendix B) to the president of the Hearing Loss Association of Los Angeles (HLA-LA), a local chapter of a nationwide hearing loss agency, requesting to recruit participants. HLA-LA then sent a letter of approval (see Appendix A) to me, which I forwarded on to Smith College School for Social Work (SSW) stating that they granted me permission to

locate my participants with their agency and would abide by SSW Human Subject Review Committee. Next, I requested to announce my study and recruit participants in person during a monthly HLA-LA chapter meeting. I prepared a small speech about the purpose of my study, printed out a sign up sheet, and copies of my recruitment letter (see Appendix C) for those who perhaps knew someone else who may be interested or wanted to review the information and contact me later. Once a person agreed to participate in my research and met the requirements, I set up an interview session and obtained the informed consent form (see Appendix D). Following the interview, I emailed (see Appendix E) participants to thank them for their participation and to ask them to suggest other potential participants they may know, as this is a small group of people who are not the most obvious within the community, thus creating a snowball sample. I also posted my recruitment letter on the HLA-LA Yahoo! group site to gather participants. While much of my recruitment and initial communication took place online, I provided my phone number as an alternate method for those who prefer it or do not have computer access.

The participants allowed me to ask questions that pertained to their experience as a person with congenital hearing loss and to audotape record the interview session. I conducted all of the interviews in-person either at the participant's home or in a public place, such as my internship site or in one case, a deli. The participants responded to a series of open-ended interview questions about their challenges growing up as a person with hearing loss in a hearing family. For more detailed information, please see the interview guide (Appendix F). I broke up the questions into themes of basic, easy, information gathering questions in the beginning, to the more thought and feeling provoking questions at the end. I asked the participants to expand on certain responses and posed probing questions, such as "what was that like?" or "do you know why?" to ensure the most complete data was collected for each question.

I audiotaped the entire interview on my computer and on a digital voice recorder as backup, I also took notes about my thoughts, reactions, and observations during and after the interviews. Later, I transcribed and used content theme analysis of the data collected as described earlier. I integrated my field notes with the transcriptions, as possible and relevant.

Criteria for Selection

Participants were eligible for this study if they met the criteria of a) being an adult with congenital hearing loss that was diagnosed from infancy or early childhood, b) being raised by hearing parents, c) being able to communicate without using ASL, d) understanding the breadth and purpose of the study, and e) willing to share details about their life being raised with a hearing loss. If a person met these research requirements and agreed to participate, I set up a time to conduct a 60-minute in-person semi-structured interview.

Major Demographic Characteristics of the Sample

I asked demographic and background questions, such as age, gender, race, family information, and other information on the participants' hearing loss at the beginning of the interviews (see Appendix G). I asked demographic questions to be able to assess for the homogeneous and heterogeneous aspects of my sample. Also, I asked these questions in person (as opposed to via email beforehand), so that I could understand the breadth and specific demographic characteristics of my sample.

Other Information

This section will cover any miscellaneous facts about my study that were not answered in previous sections. When conducting interviews, I traveled near and far to collect the data. The farthest location was about one hour car ride away and the closest was a ten-minute drive. The longest interview was one hour long and the shortest interview was 28 minutes long. The average

interview took 40-50 minutes. I did not run into any problems getting my sample. I was lucky to have found the HLA-LA organization where people were willing to participate and met my study criterion.

Chapter IV

Findings

The purpose of this study was to explore how adults with hearing loss, who were raised in hearing families, felt about being raised in their hearing families.

This section contains findings that will be divided into three categories: in the home (describing experiences that took place within the home and family), out of the home (describing the world outside of the home and family, such as school and services used), and beyond the home (describing feeling-based content).

The major findings were as follows: Participants stated that parents did not listen to their needs, even when vocalized. Participants experienced sibling rivalry and jealousy with siblings. Most participants were closest to a female family member. Being in school and the workplace was more difficult. Social situations (especially adolescent years) were difficult. Resources were often used and seen as critical. Participants were loved and accepted for who they were.

Some other information that will be presented in this chapter will be a section giving demographic data about the study's participants and their hearing loss. This demographics section precedes an in-depth explanation of the findings.

Demographic and Background Information

This section will briefly go over demographic data, such as the total number of participants, their age, gender, and race. A discussion of the types of families that participated will be covered here, for instance how many had siblings, lived with both parents, etc. Lastly, the types of hearing loss, age at diagnosis, and devices used will be discussed in this section.

A total of 12 adults participated in the study. Seven were female and five male. Their ages ranged from 34-92 years old, with half of the participants falling in the 65-67 year old age category. Most people identified as White or Caucasian and two identified as Asian (one Chinese; one Filipino). All but one of my participants grew up in a home with both parents present. All 12 participants had at least one sibling. The participants were raised in various geographic areas and seemed to have come from many different cultural, religious, and socioeconomic backgrounds. For example, some participants grew up in large urban cities, while others were raised in more rural areas or smaller towns. A few of the participants disclosed their religious affiliations and class status, though these were not included in the demographic questions asked.

The severity of hearing loss, amplification devices used, and incidences of other disabilities varied greatly between participants. The severity of hearing loss varied from mild to deaf and one person was unsure. All participants said that their hearing loss was worse in one ear than the other. Most participants reported their hearing had worsened with age. Four participants used two hearing aids, one participant used one hearing aid, three participants wore two cochlear implants, two participants wore one cochlear implant, and one participant did not use any amplification device. With the exception of the one person who did not wear any device, all of the participants had worn hearing aids when they were younger or at one point in their lives. The incidences of additional disabilities within the family were also pretty diverse. Four participants reported another family member also had a disability. Two participants reported that another family member had hearing loss and two participants reported that another family member had the same genetic condition that they were born with. The remaining eight participants' said they

were the only ones they knew of who had a disability. Some participants identified the cause of their hearing loss as a genetic condition or their mother had complications during pregnancy that caused their hearing loss at birth, such as Rubella (German measles), Ushers syndrome, or Rh factor. Others said there was no known cause and their hearing loss was simply nerve damage or something they were born with.

In the Home

This section will discuss all of the findings that refer to dynamics in the home, relationships between the person with hearing loss and his or her parents, and the person with hearing loss and his or her sibling(s).

Parent-Child Communication

Participants with hearing loss found communication with parents regarding their hearing loss often difficult and ineffective. One of the participants said, “You have to hear to be able to communicate and if you can’t communicate, you’re lost.” Many other participants also felt that communication between family members was crucial. Participants felt that as children they were not being believed when they communicated to their parents about their needs surrounding their hearing loss.

One participant said she complained that her hearing aids were too loud, yet her parents neglected to pay attention to her dissatisfaction. She said:

I remember feeling really frustrated as a kid, not from hearing loss, but from [the] issue of wearing hearing aids... I said I didn’t like the sound and that they didn’t help. I don’t recall if they really helped or not. I know I didn’t like all the noise, it sounded like so much noise to me.

This participant said it was possible that her hearing aids were not properly fitted to her degree and type of hearing loss. She mentioned that she grew up in a very rural area, where an audiologist was not easily found or accessible. She got her hearing aids directly from a family friend, who was a dispenser who simply sold hearing aids, instead of from an audiologist trained to work with people with hearing loss. Later on in the interview, she continued by saying how

...frustrating it was that my parents did not listen to me about why I wouldn't wear them. Not listening to my reasoning, which was the background noise and me saying that it didn't help. And I remember me trying to explain it to them... and they said it's just like wearing eyeglasses. And I was like, no, it's not.

In this case, this participant was telling her parents exactly what the problem was and why she did not want to wear her hearing aids, but felt her parents were not listening to her or taking her seriously. She explained her frustration at her family's attempts to liken her situation to something they could understand, thereby downplaying it.

Similarly, another participant remembered that he

...complained to [his] parents about me not being able to hear. So they had me take a few tests and one of the audiologists said my hearing was fine. And they just needed that one test for my parents to say, ok fine, he hears just fine, rather than maybe face it.

This participant discussed that his parents had a language barrier and possibly some cultural components that may have impacted why his parents did not want to accept the news of his hearing loss. He mentioned that maybe if his parents were more "Americanized," they would have responded differently. He closed by saying his

biggest advice, let kids be really honest and when the kid says they think they have a problem with hearing, they have a problem with hearing. If they even think they do, they have a problem and they have to deal with it, right away. Don't put it under the rug.

Another participant said it was important to

...make sure you spend a lot of time with [the child with hearing loss] to help them to understand words... If child is completely deaf, make sure parents also learn sign language because sometimes they don't. Parents have to act like they have a disability to communicate with child.

Another participant in the study expressed the same idea, that parents have to act like they have a disability in order for the communication and needs of the child to be met most effectively.

Two people said one family member learned American Sign Language (ASL) and it would have been more helpful if other family members had learned ASL to communicate. One participant said his grandfather would turn his head to make sure he was looking at him so he could read his lips. Another participant recalled his frustration at not being able to communicate using sign language with his family. He said, "When I was 3, I learned sign language in preschool. Only my sister learned sign language... no one else in the family... it's hard, very frustrating." This respondent continued on to say that he wished his mother had been able to communicate with him this way.

Sibling-Child Communication

The person with hearing loss generally reported some level of jealousy or sibling rivalry with the hearing sibling in the home. Some negative feelings were reported, such as jealousy, which arose due to the person with hearing loss getting more attention within the family or the person with hearing loss feeling different and envious of the hearing sibling in some form. One

participant reflected on her relationship with her sister saying, “People feel competitive with me, I think. My sister was the beautiful one. I was the smart one... And I’ve always felt she was competitive with me. So I would say I wasn’t extremely close with any of [my siblings].”

Another participant mentions:

I did not get along with my sisters... There was always sibling rivalry and jealousy going on... they were very bossy and domineering. I had more confidence in myself... and that’s very typical too with the normal hearing siblings and one deaf sibling, there is a lot of turmoil that goes on between the siblings. I did not know it was typical until I heard some of my best friends tell me the same things.

Some mentioned a positive sibling bond, which was generally stronger with siblings who were closer in chronological age. It was gathered that a stronger sibling bond existed where a sibling acted as a protector figure to the person with hearing loss. This is type of close sibling bond was illustrated by this participant describing his relationship with his brother:

My brother was a year younger than I was... he was 14 months younger and we were like twins at an early age. So, we did everything together, so I had somebody there. In case there were problems with understanding or something, my brother was there. And he happens to be a bigger guy, so that helped.

Lastly, a participant spoke about his sibling experience:

As we were getting more into adulthood, there was always a little bit of an issue or a little bit of an awareness that it was becoming more of an issue... but it was one of those things that, like a lot of problems of this nature, you don’t really talk about it too much. Maybe avoid it. Each of us was coming into our own acceptance of dealing with our own conditions, which was rooted in a lot of denial, at least on my part. It was just easier not

to confront it or not talk about it and you just dealt with it. In that regard, there was a part of me that felt a little bit... sorry for them or a little bit of... embarrassment about it. It was a complex thing. It was kind of uncomfortable.

While the responses and stories varied from participant to participant, it did seem that the theme of sibling rivalry was a common thread among most of the participants. The participants did not seem able to separate out whether this was due to the hearing loss, personality differences, age differences, or several other potential factors. As one participant mentioned in the quote above, sibling relationships are complex in nature, which contributed to the richness of the responses given when asked about sibling relationships.

Relationships with Female Family Members

Participants reported they were closest to a female family member. It varied between being a sister, mother, or grandmother, but these were the main categories of female family members the participants were closest to. One participant emphasized that she and her grandmother were closest, by saying, "I was her favorite... she never put me down or made me feel stupid." Another participant reported, "My mother was my best friend... I don't think my mother saw me as having a hearing loss and if she did, she never showed it. I was just her daughter." Another participant recalls:

I was very close with both of my parents... my sister and I, she's 4 years older than me, so we weren't very close growing up, until I was probably 16 or so... but she's definitely my best friend now. My brother and I did a lot of things together as kids... we kinda butted heads a lot as kids and I wouldn't say we are close now.... [My sister is] just a more nurturing, empathic person.

This participant stated:

Growing up in large family, [the closeness] kinda shifted... [at] any given point in my life, I was a little closer to one sibling than the others, but I would say for sure that I was never closer to my brother... I remember feeling more of a connection with the females anyway. I liked being around my sisters. They were a little more doting. I was the baby brother.

Outside of the Home

This section refers to findings that pertain to the person with hearing loss's life outside of the home, more specifically, school, the workplace, social settings, and services obtained for hearing loss.

School and the Workplace

Participants struggled at school with certain teachers who were not sympathetic to their hearing loss and would cause embarrassment, mumble while speaking, or who would face the board while teaching, thereby leaving the hearing impaired person unable to lip read.

A participant recalls a story of feeling embarrassed by a teacher with great detail:

I do remember one incident in school, this was 5th grade. I had purposely forgotten to take [my hearing aids] to wear them to school and my mom brought them to me. She came to my classroom and she told the teacher that she needed to see me because I forgot my hearing aids, and they had this little conversation and I knew that my mom was there and I was just mortified. And so I went out in the hallway with my mother and she gives them to me and I put them on. Then as soon as I get back to class I take them out and I put them in my desk. Then my teacher comes around and she lifted up my pigtail and says where are your hearing aids. I said, oh I forgot them. And she says, no you didn't.

And she's loud now... saying, no you didn't, I just saw your mother bring them to you.

And I had to put them back on, and I remember being so humiliated.

Another participant remembered that she "did worse and worse in school because the classes got bigger and bigger. My name started with W, seated alphabetically, but if people said I was hard of hearing, sit in the front row, I wouldn't have had any trouble."

A couple participants stated the opposite, that "having a hearing loss helped me in school because I had pay attention to the teacher, had to overcompensate, had to focus extra hard."

Some participants described their hearing loss as cumbersome, while others were able to positively reframe their hearing loss and learned to work harder because of it.

Some participants responded that their school experience involved struggles about whether they were to use American Sign Language (ASL) or not. One person mentioned, "[My school] was oral. No sign language. It was strictly lip reading... learned sign language on the playground with other kids, but no sign language in the classroom... very strict about that."

Another participant mentioned deaf schools were all geared towards oral communication methods and lip reading. Another participant talked about this as well: "Back then, [schools] didn't rely on sign language. They were teaching you how to lip read. That was the main focus at that time. Now they do everything."

With regards to the workplace, one member of the study recalled having difficulties: "[I] got a job once I couldn't handle because of telephone, then later on got a better job that was all one-to-one communication." Later on in the interview she continued by saying:

In the old days you were careful about protecting your job... you didn't want to be named anything. Like if you were named a disability, then that ruined your job. I would say

there was no knowledge or interest or anything when I was growing up, because they weren't checking people in the schools.

Socialization

Many participants remembered grade school and early childhood years as more enjoyable and easier than their junior high and high school years. They attributed some of this to the changing of social dynamics as they developmentally got older, when they felt that their hearing loss set them apart from other kids. This participant said, “[School] changed dramatically when I went to junior high... [I] did ok academically, socially was very hard. [I] wanted to be accepted... took me a long time to find friends.” Several other participants shared the same experience of adolescent years being particularly difficult.

Another participant explained:

As a child, [hearing loss] probably contributed to me being very shy. I think that I realized that I didn't always hear correctly and I was nervous about saying things because I wasn't sure if I'd heard correctly. I know that when I got into high school definitely it was more obvious to me that I didn't always hear correctly, so I wouldn't say things sometimes in social settings because I wasn't sure, or especially if the conversation was going very fast, that I wasn't catching everything. So rather than saying something out of context, when people would say huh, so I just wouldn't say anything at all. So it definitely made me lose my voice a bit.

Another member of the study mentioned he struggled less in school, but recalled he struggled “more like in social settings or where I would really notice it, in like certain environments. I would say cars, like, especially if somebody speaks more quietly and they're driving in a car. I always notice it was hard for me to hear.”

Another participant described her social identity as this: “I was sort of isolated from the outside world...Sort of a loner growing up, I was more independent... I was moderately social but didn’t know what was going on.” She recalled pretending or faking that she knew what her friends were saying in certain social situations.

This section described how people with hearing loss viewed their teenage years as being particularly rough. Some other participants felt they definitely had to struggle more than their peers with normal hearing in social situations and described themselves as “isolated” and a “loner” with regards to social identity.

Resources, Services, Support

All of the participants mentioned that they either used some form of support or they would advise parents to get support for their children once the parents found out their child had a hearing loss. Most participants said they took lip reading classes, speech classes, or used some other form of services during childhood for their hearing loss. One participant said his “parents were smart enough to send me to professional lip reading classes when I was 9 years old... I am very grateful for that.” Later in the interview, he described more in detail the services and support he received:

My mother felt it was important for me to speak well. She wanted me to be able to perform as well as everybody else. I had both private lessons and in school. [I] had to go on Saturday where [I] had to read poetry books. So that helped... My mother would also get my hearing tested every year at the eye and ear clinic, one of the first in the United States... My mother would make me read speeches to her and she would comment to me whether I was getting taught correctly. So she pushed a little bit, which later on helped a

lot, immensely... I mentioned sometimes people picked on me because I was hard of hearing.

One of the participants described how quickly services and accommodations were put into place when her parents learned of her hearing loss:

When they found out... I was moved front and center in the classroom. They also had a traveling speech teacher and I would see her every week all through elementary school... remember doing lip reading... she would hold up the book with the pictures and cover up the word and speak them to me.

Whether participants reported they were or were not connected with services, they all said it was important to use whatever services one could find. Most people felt it was important to receive professional and social support outside the family in this situation. Some felt using mental health services was important. Other people felt the parents should also seek out services to find support in accepting and dealing with their child's hearing loss. Participants also stressed helping educate the parents as much as they could about what their child was going through, to help support the child.

A few of the participants said they had not been connected with services either because they were not aware they had a hearing loss until later or because services were not as readily available at the time they were growing up or in their geographic area. Despite not having been connected with services as a child, one participant spoke of the benefits of getting services later in life: "My whole social life and everything has bloomed in about the last 10 years, especially since [the HLA-LA] meeting... and this meeting started 5, 6, 7 years ago and it's just been wonderful since then."

Beyond the Home

This section will speak about the findings that pertain to issues that were more emotional and feeling-based in content, as well as consistent advice participants readily offered.

Acceptance and Love: That's Just How It Is

Most participants said they didn't realize how their hearing loss impacted them because their families loved and accepted them no matter what. Participants also discussed the fact that they did not know anything other than what they had, so they didn't experience their situation as particularly difficult or challenging.

One participant said she "felt family was very ordinary, always felt loved... to me, I didn't grow up thinking I had a hearing loss, I just thought I couldn't hear very well. I wasn't aware that I had a hearing disability until I was much older." Another person recalled, "My hearing loss wasn't a topic of conversation when I was growing up. It was just that [I had] a hearing problem and that was it. I grew up in a large family. I have lots of cousins and aunts and uncles and everyone accepted it." This participant remembered that she "never knew any better. In other words, I never felt I was any different as a child... my parents say I was perfect."

While more rarely discussed in the interviews, there was another side to the finding that family members were accepting and loving of the person's disability. This participant said that she was not close to her mother and recalls some not so fond memories. She said:

I guess my mother is the type of person, she wanted me to be hearing and I couldn't be. So if I mispronounced a word, she would correct me in front of other people, you know that kinda thing, so it made the relationship kinda difficult.

Another participant tells how her father was stricter with her than with her sister and always made her practice her speech. She recalls it seemed like her father felt guilty about her

hearing loss, so he tried to overcompensate by making her read aloud at home. Another member of the study recalled:

Looking back now, I kinda felt that that immediately branded me. I have a hearing loss. Danielle has a hearing loss. And also because I was put at the front of the classroom and having to sit with my back to my peers, and that went all the way through high school and college. I was already shy and I started to feel different because of that. It was a combination of shyness and this just added to it.

This section reported on the finding that most often participants felt accepted and loved by their families and people in their lives regardless of their hearing loss. This section also covered the few cases where participants felt their families were too harsh, not accepting, or they carried an internal stigma of being a person with hearing loss.

Chapter V

Discussion

My research was conducted to study how people with congenital hearing loss felt impacted by being raised in their hearing families. The experiences of 12 adults growing up with hearing loss in hearing families were explored through narrative interviews. Questions were asked of participants about the general impact growing up with a hearing loss.

This chapter will present the reader with a discussion of how each of my findings is consistent with the existing literature and examine aspects of my findings that add new ideas to the existing literature. I will also note areas where further research should be conducted to explore my findings. In this chapter, I also discuss what limitations or bias I brought to this study that may have distorted the conclusions. I will also discuss the influence I, as the interviewer, might have had on the data obtained from the participants. A brief discussion of how my findings could be put into practice in the field of social work will also be addressed.

Discussion of Findings

In this section I compare how my findings agreed with the literature or presented new ideas that added to the previous literature. I also point out how my findings substantiate the previous literature.

Finding Substantiated by Previous Literature

A significant portion of the findings of my research confirmed what the previous literature said about the challenges people with hearing loss and their hearing families face. This section will discuss how the following findings were supported by the literature that I reviewed: that certain situations were more difficult and challenging for a person with hearing loss such as

getting needs met and feeling they were listened to by parents and being in school and social situations. The finding that people with hearing loss were loved and accepted in their family despite their disability was also supported by the literature and will be discussed.

The literature discussed that 90% of parents with deaf children are hearing, therefore hearing parents will be able to empathize, but will not fully understand the complexities that come along with being deaf and will have vastly different experiences of learning to communicate and get by in the world (Gallaudet Research Institute, 2001). One of the participants explained that she told her mother several times that her hearing aids were too loud, they did not help her, and that wearing hearing aids was different than wearing eyeglasses. The participant must have felt very helpless in this situation because while she knew she needed the hearing aids, it seems she also needed someone to help her become more comfortable wearing them, either by getting them properly fitted or receiving emotional support around her dislike for the hearing aids. This participant may have felt that likening her hearing loss to wearing glasses made her feel as if her problem was not worthy of the attention she was asking for.

The literature also stated that deaf and hard of hearing children and their families need extra support with involvement in family interactions confirmed why participants viewed their parents as not listening to their needs (Jackson & Turnbull, 2004). Issues often occurred when parents did not use sign language, which caused a greater chance for deaf children to be left out of conversations and those they were interacting with to be frustrated with the communication exchange (Calderon & Greenberg, 2003; Jackson & Turnbull, 2004; Luckner & Velaski, 2004; Moores et al., 2001). One can imagine how hard it must be for a child to be unable to speak with their parent and for the parent to feel helpless, being unable to communicate most effectively with his or her child.

In addition, the finding that people with hearing loss do not feel listened to or understood by their parents and their peers is backed up by the concept found in the literature that deaf children feel like minorities in their own families (Marschark, 2007). Participants of my study spoke of their attempts to and frustrations with communicating with their parents about their needs either regarding their hearing aids or styles of communication. Perhaps the fact that most participants were the only child with hearing loss in their family and their parents could not understand what the child with hearing loss was going through first hand, may have contributed to the hearing impaired person not receiving the desired level of attunement.

The finding that parents did not listen to their child's needs is also substantiated in the literature. It is noted that many parents' responses to the diagnosis of their child having a disability was one similar to the stages of mourning (Feher-Prout, 1996; Seligman & Darling, 2007). Perhaps some parents were not yet ready to accept their child's hearing loss and the need to take in new information, such as that about amplification devices, sign language, educational interventions, and legal issues that the diagnosis comes with (Feher-Prout, 1996; Moeller et al., 2009). The complex addition of responsibilities that come with a diagnosis of hearing loss may cause the parent to disregard their child's needs as the participants explained in their interviews.

Participants also described situations where they felt lost in conversations during social interactions or in school settings with teachers. Most participants gave anecdotes of feeling lost in classes at school; for instance, if the teacher faced the chalkboard while teaching, the person with hearing loss missed information. Another participant said he remembered having trouble socially when riding in a car because it became harder to hear people's voices or read their lips. This finding echoes the literature that I surveyed that examines the fact that people who are deaf

or hard of hearing rely on visual cues to communicate and interact with others (Calderon & Greenberg, 2003; Guarinello et al., 2007; Moores et al., 2001).

The majority of participants also mentioned their adolescence years as being a particularly rough time emotionally and in terms of fitting in socially. This could be because adolescence is a time of transition and growth, with special attention on identity and individuation. Often times feelings of intense insecurity, depression, and hormones are experienced in teenage years which may explain why participants with hearing loss spoke about these years as being particularly difficult.

Despite the findings and examples from the literature above describing situations that were more challenging for people with hearing loss, the finding that most participants were loved and accepted for who they were in their families despite having a hearing loss was also supported in the literature. Fisiloglu and Fisiloglu (as cited in Moores et al., 2001) found that “families of deaf and hard of hearing children adjusted quite well to the stressor of raising a child with a hearing loss and that such families may be special but they are not necessarily dysfunctional” (p. 248). The majority of participants backed this up by explaining that they didn’t really realize they were different or weren’t treated any differently in their families—they were told by parents that they were “perfect.”

Findings That Added New Information to the Literature

I had two findings that I did not come across in my review of the literature and therefore they add new information to my topic of exploring people’s experience with congenital hearing loss being raised in a hearing family. These findings were that participants with hearing loss experienced sibling rivalry and jealousy with siblings and that the participants with hearing loss were closer to a female family member. Due to the fact that I came up with the findings that

participants experienced sibling rivalry and participants were closer to a female family member, yet these were areas that I did not come across in my literature review, perhaps more study needs to be done on these areas.

I did not come across anything substantiate in the literature I reviewed about the finding that participants experienced sibling rivalry and jealousy with siblings. I did not anticipate this finding. The finding that sibling rivalry exists among siblings with hearing loss and the non-hearing impaired sibling may also be one area that is less researched or talked about. I came across a source that said, “we actually know very little about how sibling relationships might be affected when one child is deaf” (Marschark, 2007, p. 174). Many of the participants in my study readily and consistently offered information about sibling relationships where they reported their normal hearing sibling was jealous of the attention they received from their parents as a result of their hearing loss. Participants also made reference to their normal hearing sibling sometimes being upset at being put in the position of caretaker if the person with hearing loss needed to be protected socially or within the family. In general, the dynamics between all siblings may present these same difficulties as those found with hearing loss-normal hearing siblings. However, it seemed to have been an important enough memory for most of the participants to report. To explore this finding further, I think conducting a search for research using key words such as sibling rivalry and deaf or hard of hearing should be used. Perhaps a study should be designed to interview people with hearing loss and their siblings to provide more empirical knowledge in this area.

I found that participants were closest to a female family member, another piece of information that adds to the existing literature. Most participants said that they felt a special bond to their grandmother, mother, sister, or in one case an aunt. Some participants stated they felt this

was because the female family member was more sensitive and empathic to their disability. Other participants said this was the person with whom they simply had the best relationship due to personality similarities. Participants may have been closer to a female family member because females generally tend to be more sensitive and nurturing. The females that the participants were closest to may have been more attuned to the participant's disability thereby forming a closer bond with the person with hearing loss. To explore this finding further, an investigation should be conducted on what qualities make participants feel more attached to female family members and why.

Summary

The literature that I reviewed supported a substantial amount of findings from my study. In addition, some of the findings presented new information that I had not come across in my literature review. People with hearing loss were found to experience challenges and hurdles in their families whether it be in school, in social situations, or in communicating and getting their needs met by parents. Despite these challenges, participants were loved and accepted for who they were in their families regardless of having a hearing loss.

Limitations, Bias, and More Ideas for Further Research

The limitations of this study were that the sample size was small (n=12), which limits the generalizability of the findings. The sample was mostly racially homogenous (10 of the participants identified as White or Caucasian and only two were people of color). The participants used a variety of devices (hearing aids and cochlear implants) and experienced various origins of their hearing losses, the participants predominantly had a higher degree and severity of hearing loss on the hearing loss spectrum (8 identified as severe or profound/deaf in at least one ear), but due to financial limitations I had to exclude anyone who used American

Sign Language (ASL) thereby missing out on the experiences of this part of the deaf and hearing loss community. When conducting further research it would be helpful to use a larger sample size to avoid some of the limitations in generalizability mentioned above and to avoid some of the biases discussed below. Also, conducting this study with those who use ASL to communicate rather than only using those who communicate using oral methods would be an interesting area to study to possibly produce different results.

The biases introduced into this study were as follows: Initially I believed that a person with congenital hearing loss raised in a hearing family changes the family dynamic, the person with hearing loss will have a different, perhaps more difficult experience than their hearing family members. However, upon examining the literature and interviewing participants I was able to see that the research and experiences varied; I was able to remain open to the experiences of the participants because like the other studies I read, I wanted the results of my study to come from the participants not my biases. Alternatively, because I have a hearing loss, I may have had an easier time getting people to participate because I knew where to recruit and participants seemed to trust me and open up because I was able to relate to them as they were telling their stories.

In spite of these possible biases, I made every effort to recognize my biases when analyzing and collecting the data and to maintain a neutral stance in terms of my perceptions and observations of the population with congenital hearing loss in this study.

Implications for Social Work Practice

The findings of my study, researching the challenges people with congenital hearing loss experience within their families, are important because they can help build empirical information regarding people with disabilities, more specifically people with hearing disabilities. My study

explores an often less researched area, therefore producing the findings of this study is especially important to look at the needs and experiences of a marginalized and overlooked group of people. The results of this study may be useful to clinicians in the social work and human service field for use with their treatment plans or work with individuals and their families who are affected by hearing loss. The findings of my study may also benefit the individuals themselves, as well as their parents and families who are seeking information.

During the interviews that I conducted I asked the participants if they had any advice they would give to parents who are raising a child with hearing loss and suggestions they would give to the person with hearing loss themselves in coping with the loss. Some of their suggestions were as follows: get children tested as early as possible and get set up right away with the proper amplification device (hearing aids, cochlear implants) and utilize services and support needed to cope with hearing loss. Attend support groups for people with hearing loss was advised and support groups for parents and families was seen as valuable as well. Parents of children with hearing loss and the children themselves should not be treated or viewed as being any less of a person because have hearing loss, keep expectations and self-esteem high.

I learned something new from each of my participants who shared their stories about what it was like growing up in hearing families with their hearing loss. It was both heartwarming and heartbreaking to hear my participant's experiences where there were struggles. Some people spoke of how they overcame these challenges and some people spoke of the ever-present hurdles they faced because of their hearing loss.

The overall theme that I walked away with after conducting this study is that more study and research needs to be conducted in the area of congenital hearing loss. The literature noted that little research on congenital hearing loss exists and the participants mentioned that learning

about people with congenital hearing loss is important for both the families and person with hearing loss themselves. More experiences need to be told and more empirical studies need to be done to get information about congenital hearing loss out into the world in an effort to continue to improve services and the way people with hearing loss live their lives.

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Appendix A
HLA-LA Approval Letter



January 20, 2011

Smith College
School for Social Work
Lilly Hall
Northampton, MA 01063

To Whom It May Concern:

Hearing Loss Association of Los Angeles (HLA-LA) gives permission for Kimberly Wedner to locate her research in this agency. We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by a Kimberly Wedner. HLA-LA will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

Sincerely,

Katherine Burns

President, HLA-LA

Hearing Loss Association of Los Angeles is a 501(c)(3) Nonprofit Organization. EIN and Tax ID number: 20-2044713.

Appendix B

Recruitment E-mail to HLA-LA

To Whom It May Concern:

I am a graduate student at Smith College School for Social Work. As part of my work towards my MSW, I am studying congenital hearing loss for my thesis. I am interested in interviewing people with congenital hearing loss who do not use ASL. Specifically, I want to find out about the challenges of growing up with a hearing loss in a hearing family (how the person felt challenged, the impact of the hearing loss, etc.). Would it be possible for me to post or send out a recruitment letter through your agency to request participants for my study?

Thank You In Advance,

Kimberly Wedner

APPENDIX C

RECRUITMENT FLYER/SCREENING EMAIL

Hello,

I am a graduate student at Smith College School for Social Work, and as part of my thesis, I am studying what it is like for a person with congenital hearing loss to grow up in a hearing family. I am interested in how people with a hearing disability feel challenged, if at all, by being raised in a hearing family. I am also interested in what services, if any, you used throughout your childhood. I hope you will allow me to interview you about your experiences.

Please read below to see if you meet the requirements.

- Are you at least 18 years of age with a congenital hearing loss? For the purposes of this study congenital is defined as being diagnosed with the condition from birth.
- Were you raised by hearing parents?
- Can you communicate during a one-hour in-person interview without using American Sign Language (ASL)?
- Are you willing to speak with me about your experiences growing up with a hearing loss in a hearing family?

By taking part in this study you will agree to participate in a 60 minute in-person interview session with me. I will ask you questions about your experiences as a person with congenital hearing loss and will audio tape record the interview.

If you meet these requirements and are interested in participating, please contact me by responding to this email or by calling me at [include phone number here].

I look forward to hearing from you and talking with you more about this important area of study.

Sincerely,
Kim Wedner

Appendix D

Informed Consent Letter

Dear Participant:

My name is Kimberly Wedner and I am a graduate student at the Smith College School for Social Work. I am currently working on my thesis research study. I am hoping to understand how people with congenital hearing loss feel impacted by the hurdles they experienced in their families. How did you and your family deal with the challenges your hearing loss presented? What services did you use throughout your childhood?

By taking part in this study you agree to participate in a 45-60 minute interview session with me. You will allow me to ask you questions that pertain to your experience as a person with congenital hearing loss and to audiotape record the interview session. You will be eligible for this study if you meet the criteria of a being at least 18 years of age with congenital hearing loss, who was raised by hearing parents, who can communicate without using American Sign Language (ASL) for an in-person interview, and who is willing to share these details about your life.

By taking part in this study you will have the opportunity to share your experience on a seldom-researched and seldom talked about topic. There is no financial compensation available for your involvement in this research, however it may benefit not only those in the helping profession working with persons with hearing loss and disability, but to others in the hard of hearing community and their families who may seek more information on this understudied and overlooked area. The possible risks that may be associated with your involvement in this research will be minimal. There may be some emotional discomfort elicited from the personal

nature of the questions asked during the interview. You will be provided with a list of referral resources in case additional counseling or support is needed due to such discomfort.

Your name and all other identifying information will be kept confidential. My Smith College assigned research advisor will have access to the data after all identifying information has been removed. Should a transcriber aside from me transcribe the interviews, the transcriber will sign a confidentiality pledge. In publications or presentations, the data will be presented as a whole and when brief illustrative quotes or vignettes used, they will be carefully disguised. All data (including notes, audio tapes, transcripts, questionnaires, etc.) will be kept in a secure location for a period of three years as required by Federal guidelines and any data stored electronically will be protected by the use of a password that limits access. Should I need the materials beyond the three year period, they will continue to be kept in a secure location and will be destroyed when no longer needed.

Participation in this study is voluntary and you may refuse to answer any question. It is possible to withdraw from the study by providing a written notice of withdrawal to me by April 15, 2011. All materials pertaining to you will be immediately destroyed should you choose to withdraw. If you have additional questions please do not hesitate to contact me anytime by emailing me at [include email address here]. If you have any concerns about your rights or about any aspect of the study, please email me at [include email address here] or contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND
THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO**

ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS
AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Participant signature

Date

Researcher signature

Date

Researcher contact information:

Kimberly Wedner

[include phone number and email address here]

Please keep a copy of this form for your records.

Thank you kindly for your participation.

Appendix E

E-mail for Snowball Sampling

Dear Participant:

Thank you for agreeing to participate in my research. Do you know anyone else that meets the requirements who might also be interested in participating? Like you, this person would have to be an adult with congenital hearing loss, who has hearing parents, who can communicate without ASL, and would be willing to respond to questions about their challenges growing up with a hearing loss in their family. Please forward the attached recruitment email if you know anyone who might appreciate participating.

Thank you kindly,

Kimberly Wedner

[include email address here]

Appendix F

Interview Guide

- To start, please tell me about your hearing loss?
- What was it like for you to be a child with your hearing loss?
- How, if at all, do you feel your hearing loss impacted you?
- What was your relationship like with your family growing up?
 - Describe the personalities of your family members?
 - In what ways were you close with your family?
 - What were recurring problems, conflicts, or themes in your family?
 - How did you and your family resolve problems?
- How do you feel your hearing loss has impacted how you related to your parents?
- How do you feel your hearing loss has impacted how your parents related to you?
- How do you feel your hearing loss has impacted how you related to your siblings (if applicable)?
- How do you feel your hearing loss has impacted how your siblings related to you (if applicable)?
- What particular family member – parent, sibling, etc. – if any, do you feel closest to?
- Why do you think you were closer to that particular family member?
- What was the tone and attitude around your hearing loss in your family?
- What were the norms or rules in the family around your hearing loss?
- What services, if any, did you use for your hearing disability growing up?
- How did you become connected with services?
- What was school like for you as a person with hearing loss

- What were your best/worst subjects?
- What areas, if any, did you notice you struggled in school?
- What areas, if any, did you notice you struggled at home?
- What advice would you give hearing parents who have a child with congenital hearing loss in relation to finding ways to best help their child overcome hurdles?

What advice in relation to coping mechanisms and overcoming hurdles would you give to the person with hearing loss?

Appendix G

Demographic and Background Questions

- How old are you?
- What is your gender?
- What is your race?
- What type of hearing loss do you have?
- What type of listening device do you use and how many – hearing aid(s), cochlear implant(s), etc.?
- Who was in your household while you were growing up?
- How many siblings do you have?
- What is the gender of your siblings?
- What are the ages of your siblings?
- Do any other family members have a congenital disability?

Appendix H

HSR Approval Letter



Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

February 24, 2011

Kimberly Wedner

Dear Kim,

Your amended materials have been reviewed and they are fine. I must say, however, as I reread your study, I realized that you have ignored the whole issue of ASL. If you have some participants who have severe hearing loss, this will have been an issue in their lives, I would think. If you have all people who have not gone the ASL route then that will definitely define your participants to a certain extent. I wonder if you are going to deal with this. For example, when a family has learned ASL and this is how they communicate, this is quite different than when a profoundly hearing impaired person had learned to speak. Of course, it has been a hot political topic. I am just wondering about you studying in this area without dealing with this at all. Do you think you should ask some questions about it? I'd be interested in your thinking on this.

In any event, we are happy to give final approval to your study.

Please note the following requirements:

Consent Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

A handwritten signature in cursive script that reads "Ann Hartman".

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Mary Beth Averill, Research Advisor