Obtaining hearing care services for children & adolescents with hearing loss: Patterns of access & experiences with care

by

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Obtaining hearing care services for children & adolescents with hearing loss: Patterns of access & experiences with care

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The purpose of this study was to describe patterns in utilization of care related to hearing loss and to understand patient experiences with treatment for hearing loss, among pediatric patients. We first conducted a preliminary analysis to explore patterns of hearing care utilization. Our analysis of 2017 Optum claims data showed that among 3,924 youth < 26 years of age with a hearing impairment diagnosis, only 1315 (36%) received hearing care services. Furthermore, those who received services had a significantly higher family income, were more likely to be white, and their parents were more likely to have completed college. Our qualitative study consisted of 6 interviews with patients under the age of 26 with diagnosed hearing loss and their guardian(s). The interviews explored patient experiences and satisfaction with hearing services and treatment received. Overarching themes were patients' positive relationships with their audiologist and the need for self-advocacy in many contexts. Participants described common threads in challenges to receiving insurance coverage as well as financial barriers associated with out-of-pocket costs. They also expressed fear of the unknown for what coverage looks like after their children outgrow qualifications for Medicaid. Participants living in rural areas described geographic barriers to care and to other resources. Future research is needed to identify the root causes of disparities in receipt of hearing care services to reduce barriers to accessing care.

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Preface

Many people helped make this research thesis possible, and I could not be more thankful for their support and mentorship. First, a big thank you to Dr. Hayley Germack for being my research mentor for 5 semesters. In addition to being a friend and mentor during the major life change that is college, you taught me the very basics of health services research and sparked a passion for more! To my thesis advisor, Dr. Jennifer Seaman, thank you for taking on my project even though you had little background in hearing loss. I appreciate your dedication and patience while coding and analyzing my interviews. This manuscript would not have been possible without our weekly calls and your constant support. I had fun navigating this process, and I hope you did too! Dr. Catherine Palmer, even though we just met this past summer, I thank you for welcoming me into your weekly lab meetings and for always providing honest, straight-forward feedback. Dr. Kathryn Wiseman and Dr. Tal Levin-Decanini, thank you both for taking the time out of your busy schedules to support my work and for bringing your professional perspectives to the team. Finally, I would like to thank the School or Nursing and the Undergraduate Research Mentorship Program for supporting my research these past four years and the Frederick D. Honors College for providing mentorship when I most needed it.

1.0 Background

Hearing loss affects roughly 48 million Americans today (Hearing Loss Association of America [HLAA], 2018). The World Health Organization (WHO) anticipates a major increase in hearing loss globally in the next several decades (World Health Organization [WHO], 2023). People with untreated hearing loss face challenges academically, socially, and economically; their quality of life is greatly affected by hearing loss, and many of those affected face depression due to those negative impacts (Allen, 2019; Ozminkowski et al., 2012). Untreated hearing loss is associated with increased cognitive decline, falls, depression, anxiety, and medically adverse events (Sarant et al., 2020). The WHO declared hearing loss to be one of the six leading contributors to burden of disease in industrialized countries; they also assert that those who experience untreated hearing loss have severely impaired quality of life (Zahnert, 2011). Hearing loss is a topic that demands attention.

1.1 A Brief Overview of the History of Hearing Loss

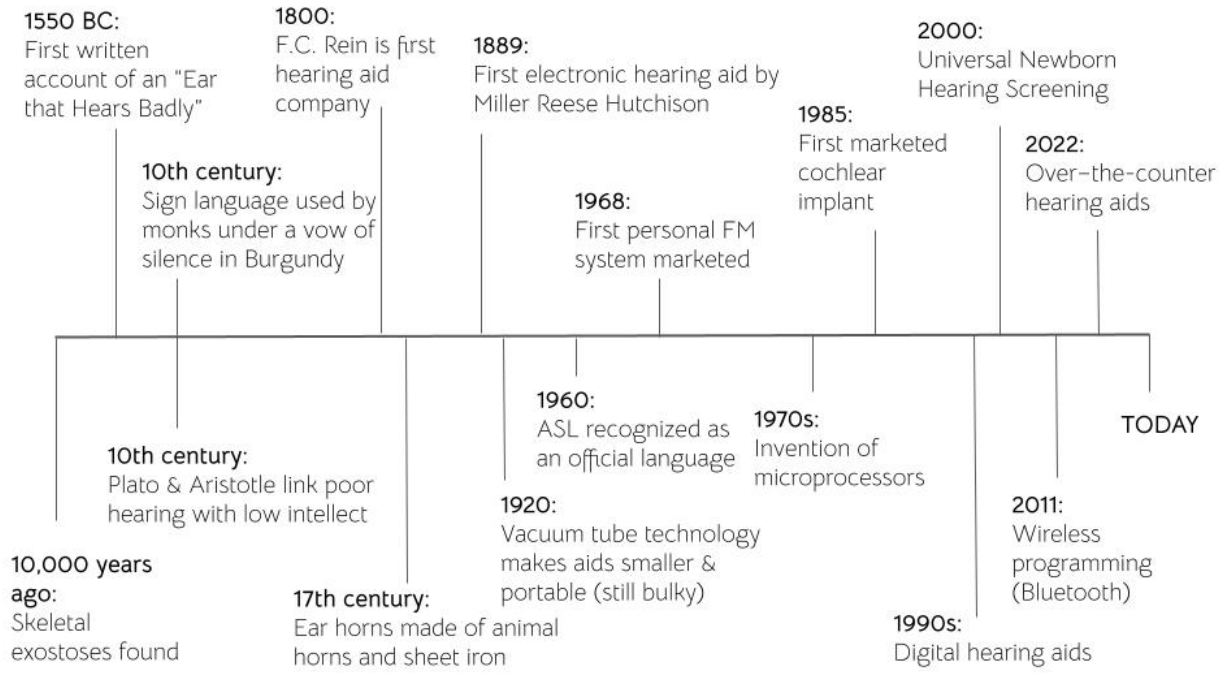

Figure 1: Timeline of hearing loss historical milestones

Hearing loss has been identified for tens of thousands of years since the beginning of mankind, as depicted in the much-simplified timeline above. It was first noted in severe exostoses, which are rare, bony growths large enough to induce hearing loss, that date back 10,000 years. The first written documentation of hearing loss dates back to 1550 BC and was given the name "Ear that Hears Badly." Even Plato and Aristotle spoke of poor hearing in their work and associated hearing loss with people of low intellectual ability because they could not voice their thoughts or converse well with others (Eleweke, 2011, p. 181). We know now that being Deaf or hard of hearing is not linked to intellectual ability without contributing outside factors. This thesis will explore the parallel medical and social histories of hearing loss, treatment, and the education of those who experience hearing loss and/or deafness.

1.2 Types of Hearing Loss

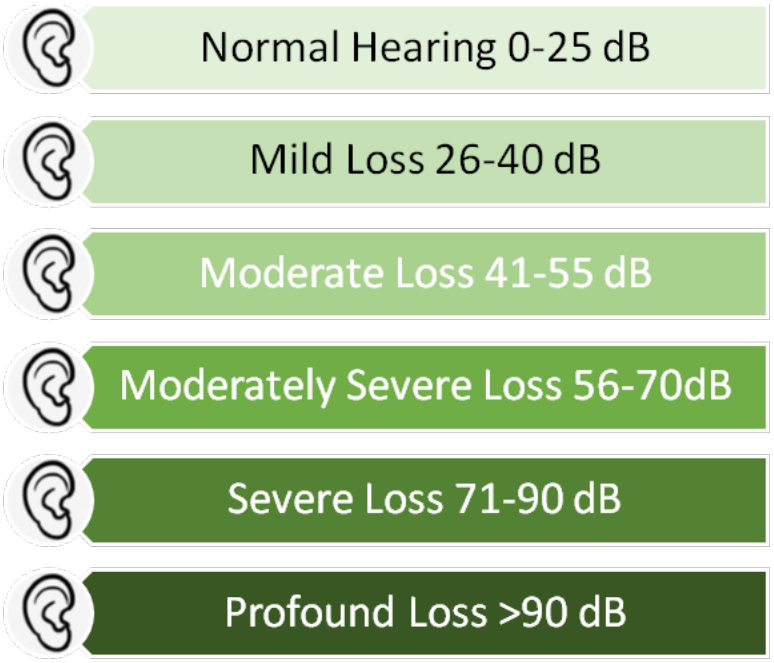

Figure 2: Degrees of hearing loss

Hearing loss is a complex health issue because there are different types and causes, most of which are relatively uncurable. Hearing loss diagnoses and individuals in the Deaf and Hard of Hearing (DHH) community itself are diverse. In clinical terms, there is a continuum of hearing loss with the vast majority of individuals experiencing mild to moderately severe sensorineural hearing loss (Steiger, 2015). The National Association of the Deaf (NAD) explains that one's identity in the DHH community often depends on age of onset, severity of hearing loss, and many cultural/community factors (NAD, 2023). Hard of hearing (HOH) describes someone with mild to severe hearing loss while "deaf" describes someone with profound hearing loss. Individuals in these categories may identify as "Deaf" depending on whether or not they utilize sign language or choose to function solely in the hearing world (NAD, 2023). Parents who desire for their children to identify with the Deaf community may seek out different services than parents who want their children to integrate into the hearing world. Some may prioritize acquisition of sign language while others may seek exclusively medical services with the goal of maximizing hearing and speech; some may choose a combination of both. "Deaf" describes a culture and community, which

consists of individuals who utilize visual language (ASL). These definitions are guidelines and do not necessarily bind an individual to a certain way of life.

There are 3 overarching types of hearing loss: conductive hearing loss, sensorineural hearing loss, and mixed hearing loss (Steiger, 2015). Conductive hearing loss is typically a physical issue, and causes can include damage to the outer or middle ear, ear drum injuries, or even a buildup of ear wax (Steiger, 2015). Surgical or medical treatment can often restore hearing in these cases. Sensorineural hearing loss is more complex, typically involving the inner ear, which is the sensory organ of hearing. This type of hearing loss can be sudden or develop over time from noise exposure and as a process of aging, among other reasons (Steiger, 2015). Though there are rarely curative treatments for sensorineural hearing loss, patients can benefit from auditory rehabilitation including amplification devices and related services. Mixed hearing loss is a combination of conductive and sensorineural hearing loss, and treatment includes resolution of the conductive component and then treatment of the sensorineural component through auditory rehabilitation. Degree of hearing loss ranges from mild to profound, as depicted in the hearing levels in Figure 2, and the severity dictates what type of treatment may be helpful to the individual (Clark, 1981). People with hearing loss may experience unilateral hearing loss (one ear) or bilateral hearing loss (both ears), and hearing ability can be symmetric or asymmetric between ears (ASHA, 2023). Hearing loss may be present at birth or may develop over time. Hearing loss may be stable or may worsen over time which is common in age-related hearing loss.

1.3 Medical and Technological Advances in Hearing Loss Treatment

For much of early history, ear trumpets were used to help one hear better by amplifying sound (Sammeth & Levitt, 2000, p. 213). Prior to this, home remedies including olive oil, goat's urine, bat wings, among other ingredients were thought to help an individual with this diagnosis to hear better (Bryan, 1931). It was not until after the telephone was invented that the first electronic hearing aid was created by Miller Reese Hutchinson. Initial hearing aids were very cumbersome and big, so when vacuum tube technology was created in 1920, aids became smaller and more portable, though they were nothing like the technology we see today. Prices have remained high over time, with a published average of $4,200 for two hearing aids and necessary services for a successful fitting, programming, and maintenance over a warranty period (Committee on Accessible and Affordable Hearing Health Care for Adults, 2016).

In 1968, wireless remote microphone systems were created for school children so they could better hear their teachers. These devices could send direct signals to a child's hearing aids or sound field speaker (ASHA, 2023). In the 1960s, microprocessors that had been invented during World War II led to another remodeling of hearing aids that decreased size once again and produced ear level devices, and then in the 1970s the first in-the-ear hearing aids were produced. In the mid-1980's surgically implanted cochlear implants were approved by the Federal Drug Administration (FDA) for use in adults with severe-to-profound hearing loss who could not benefit from hearing aids. This treatment was approved for children in 1990 (Zwolan, 2015). In 2000, the Joint Commission implemented Universal Newborn Hearing Screening, which requires infants to have their hearing tested before being discharged from the hospital. The past decade has seen continual improvements in cochlear implantation and signal processing leading to changes in eligibility to include individuals with less severe hearing loss and individuals with single-sided

deafness (Hainarosie, Zainea, & Hainarosie, 2014). Technology and clinical practice continue to improve creating personalized solutions for individuals, but there is still room for improvement in hearing care.

1.4 Hearing Loss in Children

According to a recent review, hearing loss affects 1 in 5 children in the United States by the age of 18 (Lieu, Kenna, Anne, & Davidson, 2020). On a positive note, with proper screening, children are being diagnosed earlier than ever before, which is essential in preventing the potential negative consequences of undiagnosed hearing loss (Lieu et al., 2020). Common hearing loss diagnoses that are present at birth result from genetic causes, trauma, congenital cytomegalovirus, and structural abnormalities and affect roughly 0.1% of the population; in the immediate post-natal period, hearing loss can occur as a result of prematurity or due to infections and medication exposures that are associated with a long stay in the neonatal intensive care unit (Lieu et al., 2020). In infants and young children, hearing loss is most commonly acquired from infection or trauma, and as kids grow, hearing loss causes are typically trauma-related (including noise-induced hearing loss), idiopathic, or genetic in nature. Since screening is an integral part of the immediate neonate-period, delayed-onset hearing loss can be considered a barrier to prompt treatment. Interestingly, the rate of noise-induced hearing loss is fastest-growing in adolescents in the U.S. population (National Institute on Deafness and Other Communication Disorders, 2022).

1.5 The Hearing Care Team

Since hearing loss tends to be variable and unique among cases, treatment often depends on patient-reported symptoms and referral guidelines. Traditionally, a patient may report hearing loss to their primary care provider, who will refer the patient to an otolaryngologist (an ear, nose, and throat [ENT] doctor) for a physical exam and an audiologist for the diagnostic testing that establishes the type, degree, and configuration of the hearing loss. Depending on severity and any structural abnormalities, or other concerns, more care team members may be consulted, like a neurologist, for example. Additional tests may be run such as vestibular testing and Magnetic Resonance Imaging (MRI) or Computerized Tomography (CT) scan to get the full picture. If the hearing loss is not medically treatable, the audiologist becomes the individual who partners with the patient to find the appropriate intervention for their hearing loss which typically will include amplification, communication strategies, and environmental manipulations. Once a patient has a diagnosis and a working treatment plan, the audiologist is typically the point of contact for all things hearing care: yearly check-up exams, new ear molds, hearing aid fittings and calibrations (ASHA, 2023). Specifically in school-aged youth, other health care professionals, such as a speech-language pathologist and specially trained teachers, may be necessary to support listening and speech-language skills (ASHA, 2004). Speech-language pathologists provide therapy services focused on speaking and articulation while specialized teachers may focus on language, ASL, and can tailor certain aspects of the curriculum for each student.

1.6 Social Implications of Hearing Loss

1.6.1 Emergence of Deaf Culture

In his novel, *Words Made Flesh: Nineteenth-century Deaf Education and the Growth of Deaf Culture,* R.A.R. Edwards writes extensively on the educational and cultural growth of a historically suppressed group. A majority of Deaf and Hard of Hearing (DHH) children are born to hearing parents; therefore, the lives of DHH individuals are intertwined with that of the hearing population (Edwards, 2012). Historically, the common perception of DHH persons is that they have a disability and are lacking a fundamental part of the sensory human experience. People experiencing deafness and hearing loss were isolated and pitied for much of history. Over time, a culture, language, and community formed, largely due to emergence of educational institutions, giving way to Deaf culture and Deaf identity, as denoted using an uppercase "D" (Edwards, 2012). Still, there is pushback; some believe in oralism and expecting deaf people to adapt to a hearing world while others believe our society and constructs should be rebuilt to be more accommodating to a diverse culture and people. This is exemplified with the emergence of new technology in the twentieth century, namely hearing aids and eventually cochlear implants, that aim to manage deafness in those with all ranges of hearing loss by providing an auditory signal (Edwards, 2012). This is an ongoing dilemma for DHH individuals, choosing between their Deaf culture and adapting to a hearing world.

In a recent Ted Talk, Rebecca Knill explains what it is like to be Deaf and how technology has changed her life (Knill, 2020). Knill was born with profound hearing loss that was the result of a virus in-utero; throughout her childhood, she wore powerful hearing aids, but eventually they were not powerful enough to compensate for her hearing loss. She explains that when she was young, there was no closed captioning for TV shows, and that she did not meet

another deaf person until she was 20 years old. Throughout her life, she felt she was missing a community, and she wanted to feel connected to others like her. Cochlear implant technology continued to advance, and Knill considered undergoing surgery that would allow her to hear. In the Ted Talk, she states that this was very controversial in Deaf culture, and she compares receiving cochlear implants to hear to changing the color of your skin. In the end, she decided to go through with the cochlear implant surgery, but the takeaway message is that there are many ways to look at any situation. Hearing loss and deafness exist on a spectrum, and DHH individuals may choose to identify any number of ways based on shared experiences and having a sense of community. Maybe there needs to be a change to the built environment that we have constructed to allow for simultaneous integration of deaf people and recognition of the distinct value of Deaf culture. The majority of individuals who have mild to moderately severe hearing loss identify with hearing culture. Consequently, they will pursue interventions to have access to spoken language. Therefore, it is important to acknowledge this when discussing access to treatment and public policy.

A setting that stands out as a mecca for Deaf culture and advancement is Gallaudet University (GU) in Washington, D.C. After decades of oralism-based education forced upon DHH populations, American Sign Language (ASL) was officially recognized as a language in 1960 after a Gallaudet University professor published evidence that ASL was a language with unique grammar structure. Additionally, in a 2018 article entitled, “A Charter and a Champion: The Meaning of Lincoln’s Legacy at Gallaudet,” the university president, Roberta J. Cordano, reflects on the university’s history, which dates back to 1864. Cordano (2018) shares that GU was revolutionary in providing education and empowerment to DHH communities. In 1988, students marched, demanding a Deaf President for the university, in a protest known as “Deaf

President Now." Cordano writes that "this seminal event was one of the most public and effective declarations of the political and civil rights of deaf people in this country." Today, DHH culture continues to emerge and evolve as an impressive, unique entity.

1.6.2 Education of the Deaf throughout History

This history of Deaf education is a long and tumultuous one. Schools that primarily taught using sign emerged during the eighteenth century in parts of Europe and eventually the United States; however, after the First World War, oralism (teaching in spoken language) became the recognized way of teaching with the aim to integrate DHH individuals into mainstream, hearing society (Edwards, 2012). American Sign Language (ASL) did not become a recognized language until 1960, and it was not used as a primary teaching method again until the 1970s. It was around this time that standardized testing became the norm and revealed that DHH students read at a much lower level than their normal-hearing counterparts (Edwards, 2012). It is also important to remember that ASL is not a direct translation of English, rather its own language entirely, indicating a need for targeted education. Prior to adequate education, DHH individuals had very limited communicative ability including gestures and basic vocalizations, which left DHH populations excluded from much of society. It is from this educational inequity that the offensive label, "deaf and dumb" was likely coined and in turn, painted DHH individuals in an inferior light for decades (Sacks, 1989). To integrate the Deaf into mainstream society while also conserving their culture, the bilingual-bicultural teaching method was adopted, which uses ASL as the primary form of communication while also using ASL to teach written English (Edwards, 2012). Today, there are advancements in technology that allow for this integration to be much more seamless with widespread availability of closed-captioning, automatic speech-to-text transcription in video conferencing, calls, voicemails, and even spoken communication (using apps like Google Live, Otter, etc.), and commonplace visual communication, like texting and social media. However, it remains essential to recognize and accept Deaf culture in our modernizing world.

1.7 Hearing Loss and School-aged Children

Hearing loss is a continuum and extremely individualized. Interventions and treatment depend on extent of hearing loss and personal preferences. While hearing loss is more common among older adults, 15% of school-aged children have some form of diagnosed hearing loss (Niskar et al., 1998). Overall, there is a research gap in recent literature pertaining to the treatment of children and adolescents facing hearing loss. In a PubMed search of 178 articles on hearing loss and access to care, only 22% focused on this target population. A vast majority of the existing literature focuses on older adult populations while younger populations with hearing loss may experience developmental effects of hearing loss that can result in long-term impacts. According to the Centers for Disease Control and Prevention (CDC), over 98% of newborns (3.5 million) underwent hearing screening in the United States in 2019, and among those screened, 9.7% were diagnosed with hearing loss. Specifically, in Pennsylvania, 131,440 newborns were screened in 2019 with 16% diagnosed with hearing loss (CDC*,* 2022). Along with the 9.7% diagnosed at birth, the CDC also reported 14.9% of children ages 6-19 incurred hearing loss later in life (CDC, 2022). While most children who develop hearing loss after infancy are identified via routine screening, there is still a fraction of children who slip through the cracks and do not get a proper diagnosis. In fact, a study looking at medical records from 2001 to 2011 at Children's Hospital of Pittsburgh of the University of Pittsburgh Medical Center, identified a false sense of security among parents and health care providers after a child passes the Newborn Hearing Screening which may contribute to subsequent underdiagnosing of hearing loss in youth (Dedhia, Kitsko, Sabo, & Chi, 2013). Children with untreated hearing loss are at high risk for academic, speech-language, and social-emotional difficulties compared to their normal-hearing

peers (McKay, Gravel, & Tharpe, 2008). Therefore, it is essential youth receive timely diagnosis and treatment.

In his novel, *Seeing Voices,* British author, scientist, and neurologist, Oliver Sacks, explores the power of language and communication in the Deaf population. Language and communication are essential in creating emotional connections, in being human. He states that rather than the extent of deafness, the time at which such hearing loss is acquired is key. While some acquire deafness later in life, it is those who develop it or experience congenital deafness prelingually who experience difficulties in connecting and learning; such individuals are at risk for severe emotional and social delay in addition to the obvious intellectual effects (Sacks, 1989). Throughout his written work, Sacks explains that language is not spontaneously learned but rather nurtured through contact with others, and when one is deprived of this connection, it can result in the previously mentioned deficits as well as extreme isolation.

1.8 The Hearing Screening Process

The Joint Committee on Infant Hearing (JCIH) releases position statements every few years, the most recent being 2019. In this executive summary, the JCIH explains the goals of Early Hearing Detection and Intervention (EHDI), which is essential to promote language and intellectual development (JCIH, 2019). The table below, courtesy of the JCIH 2019 report, provides guidelines for hearing screenings and diagnostic follow-up care based on common risk

factors.

Risk Factors for Early Childhood Hearing Loss: Guidelines for Infants who Pass the Newborn Hearing Screen

	Risk Factor Classification	Recommended Diagnostic Follow-up	Monitoring Frequency
	Perinatal		
1	Family history* of early, progressive, or delayed onset permanent childhood hearing loss	by 9 months	Based on etiology of family hearing loss and caregiver concern
2	Neonatal intensive care of more than 5 days	by 9 months	As per concerns of on-going surveillance of hearing skills and speech milestones
3	Hyperbilirubinemia with exchange transfusion regardless of length of stay	by 9 months	
4	Aminoglycoside administration for more than 5 days**	by 9 months	
5	Asphyxia or Hypoxic Ischemic Encephalopathy	by 9 months	
6	Extracorporeal membrane oxygenation (ECMO)*	No later than 3 months after occurrence	Every 12 months to school age or at shorter intervals based on concerns of parent or provider
7	In utero infections, such as herpes, rubella, syphilis, and toxoplasmosis	by 9 months	As per concerns of on-going surveillance
	In utero infection with cytomegalovirus (CMV)*	No later than 3 months after occurrence	Every 12 months to age 3 or at shorter intervals based on parent/provider concerns
	Mother + Zika and infant with no laboratory evidence & no clinical findings	standard	As per AAP (2017) Periodicity schedule
	Mother + Zika and infant with laboratory evidence of Zika + clinical findings Mother + Zika and infant with laboratory evidence of Zika - clinical findings	AABR by 1 month AABR by 1 month	ABR by 4-6 months or VRA by 9 months ABR by 4-6 months Monitor as per AAP (2017) Periodicity schedule (Adebanjo et al., 2017)
8	Certain birth conditions or findings: • Craniofacial malformations including microtia/atresia, ear dysplasia, oral facial clefting, white forelock, and microphthalmia • Congenital microcephaly, congenital or acquired hydrocephalus • Temporal bone abnormalities	by 9 months	As per concerns of on-going surveillance of hearing skills and speech milestones
9	Over 400 syndromes have been identified with atypical hearing thresholds***. For more information, visit the Hereditary Hearing Loss website (Van Camp & Smith, 2016)	by 9 months	According to natural history of syndrome or concerns
	Perinatal or Postnatal		
10	Culture-positive infections associated with sensorineural hearing loss***, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis or encephalitis	No later than 3 months after occurrence	Every 12 months to school age or at shorter intervals based on concerns of parent or provider
11	Events associated with hearing loss: • Significant head trauma especially basal skull/temporal bone fractures • Chemotherapy	No later than 3 months after occurrence	According to findings and or continued concerns
12	Caregiver concern**** regarding hearing, speech, language, developmental delay and or developmental regression	Immediate referral	According to findings and or continued concerns

Note. AAP = American Academy of Pediatrics; ABR = auditory brainstem response; AABR = automated auditory brainstem response.
* Infants at increased risk of delayed onset or progressive hearing loss
**Infants with toxic levels or with a known genetic susceptibility remain at risk
***Syndromes (Van Camp & Smith, 2016)
****Parental/caregiver concern should always prompt further evaluation.

Figure 3: JCIH's infant hearing screening guidelines

The JCIH recommends a 1-3-6 month timeline for all children: hearing screening within 1 month of life, diagnostic testing within 3 months, and intervention within 6 months (JCIH, 2019). In

exceptional cases, like the ones listed in Figure 3, additional testing is suggested. Even in cases where children pass the newborn hearing screening, it is recommended that individuals with risk factors undergo additional testing (JCIH, 2019). If a newborn fails the hearing screening, additional diagnostic testing occurs as soon as possible. Early detection and intervention are key prior to school in order for these kids to succeed academically, socially, and even emotionally. However, it is important to highlight the fact that "intervention" is a term used in the field of health care to capture next steps and resources that help an individual after receiving a diagnosis. It is important that interventions align with parent/guardian goals for their child and will vary depending on those goals; such interventions can include utilizing ASL as a primary mode of communication or obtaining an amplification device, among other options.

There are specific hearing screening requirements that vary state-to-state. Across states, babies born in-patient are required to be screened for hearing loss in the first 24-48 hours (prior to mother-baby discharge), and out-patient births should be screened within the first 30 days (Pennsylvania Department of Health, n.d.). In Pennsylvania, the Health Department requires students to have their hearing tested in kindergarten, first, second, third, seventh, and eleventh grade (Pennsylvania Department of Health, n.d.). Hearing screenings are also advised at all well-child visits, which are typically done annually in children up to 18 years old (American Academy of Pediatrics, 2007). The Centers for Disease Control and Prevention outlines protocol to follow if a child does not pass a hearing screening (CDC, 2022). Following a failed hearing screening, a full hearing test should be conducted by an audiologist. This typically requires a referral from a PCP or other health care provider. During the follow-up appointment, the audiologist will gather genetic and/or family health information to more fully understand the individual case (CDC,

2022). In some cases, depending on individualized symptoms, an ENT or neurology consult may be required (CDC, 2022).

While hearing loss is often detected in infancy or early childhood, individuals may develop hearing loss later in childhood or adolescence. Due to fewer opportunities for screening and additional unknown reasons, older children and teens with hearing loss slip through the cracks. Over time, prevalence of hearing loss, specifically among adolescents ages 12-19, has increased significantly for various reasons including genetics, noise exposure, trauma, perinatal issues, etc. A study also found that hearing loss was more common in families below the poverty threshold (Shargorodsky, Curhan, Curhan, & Eavey, 2010). Though the study did not determine a concrete answer as to why this is, they did find that participants who had a history of ≥3 ear infections at some point in their lives were more likely to have hearing loss, which may be contributable to barriers to a healthy lifestyle associated with living below the poverty threshold. Among teens, hearing loss is increasing for reasons that are not well-understood, and there appears to be a correlation with lower socioeconomic status and having a hearing loss diagnosis.

1.9 Coverage and Paying for Hearing Care

Even with proper screening, diagnosis, and initial treatment, youth with hearing loss still face significant barriers to accessing care, one such barrier being financial obstacles. Fortunately, there is insurance coverage for children in some cases. Specifically, in Pennsylvania, Medicaid covers the cost of hearing aids and services for children with hearing loss until they are 21 years of age (Yoder, 2020). Applying for this coverage requires extensive paperwork, access to the internet and a printer, and adequate health literacy. Additionally, programs like Pennsylvania's

Children's Health Insurance Program (CHIP) offer low-cost insurance coverage for children for families who do not qualify for Medicaid and cannot afford private insurance (Medicaid.gov, n.d.). Similar child-health insurance programs are required in every state in the U.S. While most insurance programs cover diagnostic hearing tests and audiology visits, they do not cover hearing aids, which can be a major out-of-pocket expense (ASHA, 2023). Coverage for traditional hearing aids is variable between commercial insurance plans. For adults, hearing aids are not covered by Medicare while cochlear implants are covered. For children, Medicaid coverage of hearing aids varies by state, and the availability of providers who accept Medicaid also varies. Cochlear implants are typically covered by either a commercial insurance plan or Medicare, the processor parts, and mapping of the device (AHSA, 2023). Overall, there is great variability among states concerning insurance coverage for hearing care.

1.10 Barriers in Accessing Care

In addition to financial barriers, geographical barriers remain a major hurdle for many patients. While hearing loss prevalence increases in the general population, mainly due to noise exposure and older populations living longer, the audiologist shortage in the United States is worsening and the number of audiologists remains inadequate to meet patient demand (Planey, 2019). One study found that parents of children with hearing loss in rural areas have trouble accessing specialized hearing services, were typically less knowledgeable about hearing loss than their urban counterparts, and also experienced challenges with insurance and funding for these services (Barr, Dally, & Duncan, 2019). In summary, the literature shows that there is a general

lack of audiologists, a lack of pediatric audiologists, and barriers associated with residing in a rural community.

1.11 Limitations to Hearing Care Technology

Current treatment for hearing loss typically includes screenings, visitations with audiologists, consultations with an ENT, hearing aids, remote microphone systems, and cochlear implants. However, hearing loss types and causes vary a lot from person-to-person, and it can be challenging finding the right fit, both financially and practically. In addition to experiencing barriers to accessing hearing services, limited research shows that existing treatment is not always sufficient or able to meet patient needs. A study assessing psychosocial development of 5-year-olds with cochlear implants (CIs) and hearing aids (HAs) concluded that even with timely diagnosis, proper interventions, and good language development, children with CIs and HAs still may exhibit psychosocial difficulties and experience troubles with daily communication (Wong et al., 2017). Another study interviewed patients ages 5-19 years with unilateral hearing loss of different degrees of severity and their family members. They found that although these children received HAs, including behind-the-ear HAs and wireless contralateral routine of signal (CROS) device, just under half (41%) of the population discontinued use of these devices for the twenty-two-month study due to discomfort and lack of benefit (Purcell, Jones-Goodrich, Wisneski, Edwards, & Sie, 2016). There is still room for improvement in the technology for hearing care, and patient preferences are an important factor in developing such technology.

2.0 Purpose of this Thesis

Early diagnosis and treatment for hearing loss in children is particularly important because untreated hearing loss can impact language acquisition and early education. During formative years, it is essential children learn how to communicate and connect with peers. Early intervention, that aligns with parental and patient goals, leads to educational, cognitive, and social benefits. Yet, current data shows that not all of these children receive hearing treatment. The literature reveals that geographical and financial barriers prevent all children from receiving treatment. To address this gap, it is important to understand who is receiving treatment, what barriers exist, and what hearing care looks like today, from a patient's point of view. This study aims to address these questions.

Although policies outline the recommended services, research suggests that not all children receive timely hearing services, and adherence to prescribed treatment is variable. The purpose of this study was to identify patterns in utilization of care related to hearing loss and describe patient experiences with obtaining hearing care services. To further understand large-scale demographic inequities among pediatric hearing loss patients while also learning about real-life experiences directly from the source, we selected a mixed-method approach.

3.0 Quantitative and Qualitative Studies

3.1 Quantitative Study

3.1.1.1 Quantitative Methods

This cross-sectional study used the Optum Integrated Claims-Electronic Health Record (EHR) database to identify 3,924 unique youth with hearing loss and continuous enrollment between January 1, 2017 and December 21, 2017. These are claims data from United Health Care containing information from 103 million patients in EHR data. We identified hearing loss using International Classification of Diseases 10th Revision (ICD-10) diagnosis codes and hearing services using the Healthcare Common Procedure Coding System (HCPCS) and Current Procedural Terminology (CPT) codes. Hearing services can include hearing tests and screenings, consultation with audiologists and ENTs, and prescription for and fitting of hearing devices such as hearing aids and cochlear implants, among others. We looked at gender, race, age, ethnicity, household income, percent of parents with a college education, and region. Chi-square tests and analysis of variance were used to examine differences between youth who received and did not receive services.

3.1.1.2 Quantitative Results

Sample. The sample contained 3,924 youth (<26 years old) with diagnosed hearing loss enrolled in large commercial insurance for the majority of 2017.

There were clear differences between patients with a hearing disorder diagnosis who received services and those with a diagnosis who did not receive services. Within this sample, there were no significant differences in treatment by gender. It is unknown if treatment provided during this year of coverage was initial or ongoing.

Results revealed that there were other significant, sociodemographic differences in receipt of care among youth with a hearing loss diagnosis. Chi-square tests and analysis of variance were used to examine differences between youth who received and did not receive services. Results can be seen in Table 1.

Table 1: Quantitative Results

TABLE 1	Received hearing service	Did not receive hearing service	P-Values
Total population	1415 (36.06%)	2509 (63.94%)	
Gender			p = 0.219
Female	672 (36.54%)	1167 (63.46%)	
Male	740 (35.56%)	1341 (64.66%)	
Age (mean, standard deviation)*	8.9 years (6.8)	11.4 years (7.4)	p = 0.001
Race*			p <0.001
African American	48 (22.12%)	169 (77.88%)	
Asian	42 (34.43%)	80 (65.57%)	
Caucasian	1206 (38.87%)	1897 (61.13%)	
Other/Unknown	119 (24.69%)	363 (75.31%)	
Ethnicity*			p = 0.009
Hispanic	60 (29.13%)	146 (70.87%)	
Not Hispanic	1208 (37.10%)	2048 (62.90%)	
Unknown	147 (31.82%)	315 (68.18%)	
Household income (mean, standard deviation)*	$46,802.18 ($14,735.52)	$45,208.44 ($11,910.90)	p < 0.001
Percent with college education (mean, standard deviation)*	27.1% (8.5%)	24.6% (7.5%)	p < 0.001
Region (frequency, percent)*			p < 0.001
Midwest	837 (59.15%)	1541 (61.42%)	
Northeast	277 (19.58%)	318 (12.67%)	
South	236 (16.68%)	360 (14.35%)	
West	28 (1.98%)	163 (6.50%)	
Other/Unknown	37 (2.61%)	127 (5.06%)	
*p-value <0.05			

On average, youth who received treatment were younger than those who did not receive treatment ($p = 0.001$). We identified significant racial disparities in receipt of treatment: 39% of Caucasian youth received care while only 22% of African American youth received care ($p<0.001$). There were also differences by ethnicity: 37% of Non-Hispanic youth received care compared to only 29% of Hispanic youth. The mean household income was just over $45,000, and analysis showed that youth receiving care had a higher median household income by roughly $1,600 ($p<0.001$). Finally, youth receiving care had a higher percent of college educated household members at 27.1% with a college educated household member ($p<0.001$). There were significant differences by region ($p<0.001$).

Of youth with a hearing loss diagnosis, the proportion receiving services is very low, and sociodemographic characteristics are strongly associated with receipt of services.

3.1.1.3 Quantitative Discussion

Just over one third of the population in this study with a hearing loss diagnosis actually received hearing care services, and of that fraction, there were clear disparities due to race, household income, and education level.

These results were not entirely surprising. Much of the current literature shows similar disparities in access to care among racial groups (Bush et al., 2017). Further research should address this disparity. Our data showed an existing inequity in accessing care depending on household income. A study by Smith, et al. (2019) parallels our findings; however, access to insurance does not explain this disparity. Depending upon the state, many economically disadvantaged families will have access to Medicaid or CHIP, which provides coverage for hearing care services that can be better than that provided through private insurance policies. There are two possible hypotheses that might explain a lack of access: families may not take advantage of programs for which they qualify, state variations exist, and there may be a lack of providers in their area that participate in Medicaid or CHIP. While our data did not differentiate urban residents from rural residents, current literature shows that in rural communities, children with hearing loss experience difficulty accessing care and funding care (Barr et al., 2019), which may be the result of having few providers.

A strength of this study includes the nationally inclusive database, which is representative of different regions, metropolitan areas, rural communities, and variable health systems throughout the country; with nearly 4,000 subjects, the data can be generalizable.

This study is not without its limitations. Though the data were nationally representative, it includes individuals who benefit from large, commercial insurance coverage. Additionally, children who have not received a hearing loss diagnosis are excluded from the data. The data

collection consists of children enrolled in care for one calendar year and does not specify when children received hearing loss diagnoses or by what means, whether it be through screening in a school setting, primary care setting, or others. Furthermore, this database accounts for insurance codes that were charged by a provider or healthcare center, so any out-of-pocket costs or care services that were not charged to the insurance company are excluded.

Future research is needed to understand if disparities in access to care are the result of system-level barriers (lack of local providers, providers that do not participate in Medicaid/CHIP); or child/family-level factors related to knowledge, attitudes, or beliefs about hearing loss treatment.

The second, qualitative portion of this study utilizes firsthand patient experiences to better understand hearing care services.

3.2 Qualitative Study

3.2.1.1 Qualitative Methods

Setting and Sample Selection. To better understand youths' experiences with hearing loss treatment, we conducted interviews with children with a hearing loss diagnosis (and their parents if the child was <18 years old) pertaining to patient experiences and treatment satisfaction. We recruited a convenience sample of participants from the hearing treatment centers of two large academic medical centers in Pennsylvania. Flyers were used to describe the goals of the study and included the primary investigator's contact information. Interested parties reached out via email. Over email, participants and the primary investigator (PI) set up a time to meet for a video conference and exchanged completed consent forms. The Institutional Review Board at the University of Pittsburgh reviewed and approved all steps of the study. All participants provided written consent after being informed of expectations for the study.

Study Design. A semi-structured interview guide was used to conduct 30-minute-long qualitative interviews over Zoom using the instant-captioning feature.

Data Collection and Analysis. This interview guide was developed with input from the research team, a 3-person team comprised of the PI and mentors with experience in qualitative research. We aimed to elicit unbiased, thoughtful responses about experiences with healthcare providers pertaining to hearing loss treatment. Demographic and clinical information were collected at the start of the interview. We collected basic demographic and clinical information including age, gender, race, hearing loss diagnosis and other medical diagnoses, education received, and rural versus Metropolitan residency. With a series of questions as a guide, the interviews probed on care received and experiences with hearing loss in school, at primary care practices, and in other life domains. We probed on participants' experiences receiving hearing care services including features of the experiences that they felt were barriers and facilitators to

receiving care, and satisfiers and dissatisfiers related to the care experience. We also probed on experiences in educational, social and emotional domains including school accommodations, social support, social interactions with peers, emotional experiences, and goals for treatment. Satisfaction with the results of treatment was explored through stories of being able to hear and satisfaction with hearing ability using the prescribed hearing devices (hearing aids, cochlear implants, remote microphone systems).

The audio recordings of the interviews were transcribed, redacted of any identifying information, and stored on a secure server at the University of Pittsburgh. The transcripts were subsequently coded using a constant comparative approach (Miles, et al. 1994). To develop the codebook, the primary investigator (MC) and co-investigator (JS) independently performed open, line-by-line coding of the first three transcripts to identify the emergent codes, categories, and themes, discussing the findings after each transcript was reviewed. Subsequently, we organized the codes into categories and themes. We then created a codebook which we subsequently used to code the remaining transcripts. All transcripts were coded by both the primary investigator (MC) and co-investigator (JS), who met routinely throughout the coding process. Any discrepancies were discussed and resolved by consensus, and the codebook was updated accordingly.

3.2.1.2 Qualitative Results

The sample consisted of 7 youths with hearing loss and five of their mothers. We conducted a total of 6 interviews (two participants were siblings). Participants under 18 years old were interviewed with a parent, all of which were hearing mothers; one 18-year-old participant was interviewed alone. Participants' ages ranged from four to 18 years old. Participants described having two types of hearing loss in this sample: 6 participants had bilateral sensorineural hearing loss; one subject had unilateral conductive hearing loss. Of the participants, 43% used hearing aids, and 57% used cochlear implants, all of whom used hearing aids prior to receiving their cochlear implants. Four subjects had a co-existing medical condition that was potentially associated with hearing loss (not confirmed). Three participants self-identified as rural-dwelling while the remaining three participants identified as urban-dwelling. Our analysis revealed multiple categories falling under two key domains: the care domain and the life domain. In addition, two overarching themes emerged: self-advocacy and the value of the audiology patient-provider relationship (Figure 4). Self-advocacy is defined as the "ability to communicate with others to acquire information and recruit help in meeting personal needs and goals" (Balcazar et al, 1991, p. 31). The role and importance of self-advocacy are seen in both the care and life domains. The value of the patient-audiologist relationship influences multiple aspects of the care domain. The following interpreted data can be viewed through these two lenses and connects our findings.

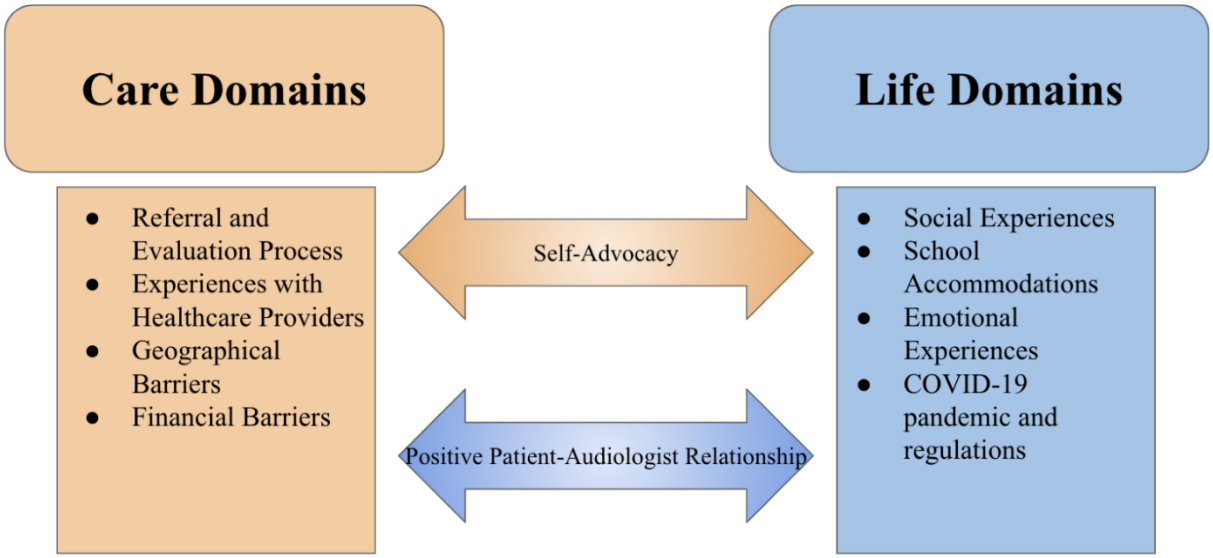

Figure 4: Qualitative results graphic

3.2.1.2.1 The Care Domain

3.2.2 The Referral and Evaluation Process

The majority of participants were referred for formal hearing evaluations by their primary care providers. For some the referral was made based on the results of a routine hearing screening; however, several sought a referral because they had concerns regarding their child's hearing.

> "C4 passed with flying colors for months, and then I actually know I was the one that noticed you know when C4 stopped hearing a lot of the stuff C4 had been hearing for the last five months. So at that point, I pretty much took matters in my own hands called down to [Large metropolitan hospital] and you know and got it, got in with the audiology department." (P3).

> "She [was] probably, maybe three or four months when we noticed that we live near there was a fire station down the house down the street from our house, and fire trucks go by all the time and like she wasn't very receptive to it like she'd kind of lay there. And she was our second child so we, we knew that like that was kind of unusual." (P5).

These examples demonstrate the role of self-advocacy in obtaining hearing care services. Despite passing newborn hearing screens and being dismissed by providers, parents eventually sought out care in several situations. Participants described how the initial hearing evaluation was lengthy and could involve multiple clinicians (ENT and Neurologist); however, they were ultimately connected with the audiologist, which was positive.

3.2.3 Experiences with Health Care Providers

Multiple participants reported that their primary care physician has very little knowledge of hearing loss and what the diagnosis requires. These participants tend to not depend on their primary care provider for information or guidance related to hearing. Rather, they rely primarily on their audiologist and sometimes the ENT. On the contrary, every participant described positive experiences surrounding their current audiologist.

> "Our audiologists have been great…they're very good at explaining you know if I don't understand something or if I have a question. They're very, you know, approachable…they're pretty quick to respond to me…We've made, you know, good decisions with good people" (P4).

> "I absolutely love C1's audiologist…I can tell that she really cares about C1, like a lot" (P1).

> "All the audiologists that we've ever worked with are really, really good, and they're very good at answering questions" (P5).

These healthy and trusting patient-provider relationships provide a solid foundation for parents and the patients so they may feel comfortable in seeking treatment.

One parent shared that she appreciates health care providers answering her questions and not rushing through procedures and exams as well as health care providers treating her kid like a

kid and going above and beyond with accommodations. Another parent explained that she appreciates when health care providers are up to date with the latest technology and willing to advocate for their patients to get that technology.

3.2.4 Geographical Barriers

There was a clear disparity between self-reported rural dwellers compared to self-reported urban dwellers regarding access to hearing services. Participants in rural areas reported long commutes and lack of care providers in their residential areas, which served as a barrier to care. Subjects in urban residences did not cite these issues.

> "They don't seem to understand that we live so far away...The resources and everything have always been so far away" (P2).

> "It's a good you know two-and-a-half-hour ride for us...So, we have a really hard time with a lot of people getting down there, because it's so far...There's no audiologists around here, pediatric or otherwise, that um you know will even see children up here" (P3).

> "I just feel that with a small rural district, we do not have a lot of experience with Deaf and Hard of Hearing community" (P5).

Self-advocacy becomes essential in these cases to ensure the children receive adequate support and care. As exemplified in the quotes by P3, distance was in fact a barrier because it requires time as well as gas and mileage expenses. P3 pointed out that it is best for them to cluster care when possible, to avoid the journey altogether. Due to geographical barriers, caregivers are forced to seek out specialized care to ensure their child has adequate resources.

3.2.5 Financial Barriers

Financial barriers included having to complete the tedious, time-consuming paperwork required to obtain the Medicaid coverage that is provided to all children in Pennsylvania (PA) with hearing loss, regardless of income. as well as needing to pay for out-of-pocket expenses, like batteries, when not given enough each month. One participant reported having no knowledge of the PA Medicaid coverage for the first year her child received hearing loss treatment. None of the parents knew what insurance coverage/payment would look like as their kids exceeded 21 years of age (without PA's extra Medicaid coverage) or 26 years of age (on their own for health insurance)

3.2.5.1.1 The Life Domain

3.2.6 Social Experiences

Nearly all parents reported improved interactions with devices while some youth reported that they did not notice a major difference with or without the aids. A major concern for participants was being able to hear friends in social situations, like the lunchroom at school. One participant shared that her cochlear implants failed, leaving her without any sound in one ear for an extended period. Every parent expressed satisfaction with hearing devices helping their child hear better compared to not utilizing a hearing device.

3.2.7 School Accommodations

Several factors contributed to dissatisfaction including a lack of accommodation in school and other activities.

> "One time at school, I think it was 9th grade, they made me take the hearing test and they literally – and I told them I cannot hear at all without them on – they literally told me to take off my implants and hope for a miracle" (C2).

Other subjects complained of schools lacking well-prepared instructors.

> "So they're supposed to be learning ASL through the teacher of the deaf,
> but unfortunately, she's not really well-versed in ASL, so we kind of have a teacher that doesn't really know what she's doing" (P4).

> "But I feel like they're, they're biggest problem for C4/C5, is their hearing and that those services that are kind of lacking the, you know, the lack of interpreters, the lack of, you know, teacher of the Deaf that actually signs, things like that is really is really what we're dealing with right not that I'm, I'm kind of fighting a hard battle with the district" (P4).

> "Only seeing somebody once a week for a half an hour. They're not really able to support the teacher and teach the teacher anything. C6 is on a learning support caseload, but they have limited knowledge and Deaf and Hard of Hearing supports" (P5).

Self-advocacy for proper education and training for educators is another battle these parents face.

3.2.8 Emotional Experiences

One of the biggest concerns across the board from this population is the necessity of being an advocate for their child related to care. Primarily, this issue revolves around timely diagnosis and school intervention. The majority of parents expressed worry towards their child being able to self-advocate in the future.

> "That would be a goal of mine as a parent, is seeing C2 being able to take that lead more" (P2).

Parents consistently showed worry about their child being able to advocate for themselves in future settings like in a massive college lecture or in the workforce. Parents showed concern about life transitions.

A majority of parents share the goal of academic success and increased individual advocacy for their child while the children hope to maintain their hearing and be able to experience day to day life with friends with minimal struggle. One mother expressed happiness at the fact that hearing aid visibility is increasing in pop culture, with a new American Girl doll who wears an aid and graphic novels like, *El Deafo.*

Another theme that became prevalent was the difficulties associated with COVID-19 regulations affecting children with hearing loss. For example, nearly every parent brought up the struggles of mask-wearing with lip-reading and understanding people. Parents reported feelings of guilt associated with asking someone to take down their mask to enhance understanding.

3.2.8.1 Qualitative Discussion

According to Miller (2014), with advancing technologies like cochlear implants, early interventions and diagnoses, among other factors, less and less students require full American Sign Language teaching, and most students that are considered Deaf or Hard of Hearing (DHH) can learn and be taught using an oralist approach through listening and spoken language (LSL) (Miller, 2014). This is interesting considering there has been a rise in Deaf culture. It also adds to an earlier point about how individual goals vary person-to-person, and not every DHH individual may want to use ASL or vice versa. Now, teachers of DHH students are not required by all schools to be ASL proficient, though it is preferred. The number of students requiring ASL teachers is decreasing over time, likely due to advancing technology. Our results support this finding and show that DHH students and their parents are not satisfied with this trend.

Our findings are consistent in that audiology care tends to be easier to access and more abundant in urban areas. Studies show that audiologists are needed across the country for adult populations and that they tend to be located in densely populated areas with higher median household income (Nagaraj, et al., 2019; Planey, 2019). In our study, participants located in more rural areas described having issues with consistent, competent resources, such as an ASL educator in the school setting or teachers who know how to use necessary equipment. These findings align with current adult-focused studies (Planey, 2019).

Furthermore, relevant literature supports the need for increased accessibility of hearing health support. A recent study looked at training community health workers about hearing loss and hearing care to help with care and support in underserved areas (Sánchez et al., 2017). Families from our study would likely benefit from well-informed community health workers.

This study had several limitations. First, the subject group was small. All subjects were Pennsylvania residents. Benefits vary state-to-state, so findings may not be generalizable across state borders. We did not collect data on race, ethnicity, or income. Finally, our questions required subjective answers and may be interpreted very differently person-to-person.

3.3 Conclusions

In conclusion, several overarching themes were discovered in this study, both in the quantitative and qualitative portions. First, youth with hearing loss are underdiagnosed and undertreated. Community characteristics are strongly associated with receipt of services, and there are significant racial and socioeconomic disparities surrounding accessing hearing care services. Efforts to reduce these disparities are necessary

Parents shared goals for promoting self-advocacy among their children, parents worry about paying for services after insurance is up when the child turns 21, and the COVID-19 pandemic brought a lot of barriers to hearing for these children with masks and strict school regulations. Participants who self-reported as living in a rural area experienced geographical barrier to care. Several parents reported frustration with lack of proper education and accommodation in the school setting. Self-advocacy emerged as an important theme and was necessary in the school setting, in doctor's visits, and many other spheres of life. Furthermore, a communicative, positive relationship with health care providers, primarily the audiologists, contributed to high parent/patient satisfaction.

The results of our qualitative study offer insight into disparities observed in the quantitative study. Specifically, financial barriers, even among families with very good coverage,

were considerable. In addition, rurality, not assessed in our quantitative study, posed a major barrier to obtaining care across all settings. Finally, our findings show that children and their caregivers could potentially benefit from additional support across settings, specifically knowledgeable and qualified providers, whether in the primary, specialty, or school settings.

Our findings suggest implications for nurses in multiple practice settings. In the primary care setting, nurses ideally should act as educators and advocates. Across care settings, nurses can provide emotional support to families through the diagnostic and treatment processes. For families whose children receive a hearing loss diagnosis, nurses can play a pivotal role in ensuring understanding of clinical information and reinforcing the importance of treatment for social, educational, and interpersonal wellbeing and growth. Nurses have the potential to be strong advocates to ensure patients have adequate resources to seek out, obtain, and then adhere to treatment recommendations. The ability of nurses to fulfill these roles is reliant on having up-to-date knowledge in hearing care and an awareness of its importance.

Future research should address root causes for delayed diagnoses and receipt of services; additionally, more effective treatment options and equal access to care are essential goals. Research should investigate why children are not being diagnosed and referred to audiology in a timely manner by primary care providers and address this gap.

Appendix A Qualitative Study Recruitment Flyer

Appendix B Interview Guide

Access to Care Among Patients with Hearing Loss

Interview Guide

Introduction

My name is Mandy Cooper, and I am an undergraduate researcher at the University of Pittsburgh School of Nursing. Thank you for participating in my study! Today I would like to discuss your experiences with treatment for [your or your child's] hearing loss. I am particularly interested in understanding your satisfaction with the care received and any preferences you may have related to treatment. While your answers will be confidential, they will be shared within the research team. They will be transcribed and any information linking your answers to you will be removed. Your answers will then be aggregated with those of other interviewees before any information from this study is shared outside of the research team. Your participation is voluntary, and you are free to stop the interview at any time. Our conversation should take 30 minutes or less. *Voluntary participation recorded

In order to ensure the accuracy of our notes and to allow for transcription, I would like to record the call. May I begin the audio-recording now? Okay great, let's get started, then!

*These questions will be either directed at a family member or the patient, depending on the developmental appropriateness of the patient.

1. **Tell me about your/your child's history with hearing loss.**
    a. What type of hearing loss are you/your child diagnosed with?
    b. How long have you/your child received care for that hearing loss?
    c. Tell me about any other clinics or outpatient centers you/your child have sought care from. (How did you get a referral to an audiologist? Tell me about that experience, ex. PCP interventions)
2. **Tell me more about the treatment(s) you/your child has received for their hearing loss.**
    a. Were you/your child prescribed an amplifying device or a type of hearing aid or a cochlear implant?
    b. How has your/your child's treatment for hearing loss changed over time?

i. Did you/your child have more frequent visits at a younger age, taken more seriously with age, etc.

c. Did you/your child ever encounter any barriers when getting access to treatments for the hearing loss? (Financial, geographical, transportation etc.)

d. How would you describe your/your child's support system/do you have a support system?

3. Describe your/your child's experience with their treatment services (ex. Hearing aid).

a. How did the clinician include you and your child in the decision-making process for treatment?

b. Please describe any goals for hearing loss treatment. Articulate goals for treatment (probes: ex. To participate more meaningfully in conversation/classroom discussion, etc.)

c. How did you/your child benefit from this device/treatment?

i. Academic, social interactions, participate in more activities than before (prompts)

d. Overall, would you say you notice a difference in your/your child's ability to hear and communicate with the treatment options they receive?

i. Tell me how the treatment made a difference

4. Did your clinician ask for your/your child's input when prescribing a treatment?

a. How were you/your child included in this decision?

b. How satisfied are you with how your provider handled your/your child's care?

c. Do you/your child feel like you/your child were listened to during treatment appointments/services? How did the physician demonstrate active listening/show that they understood your concerns.

5. **What facilitates good care?**
    a. Describe good care as it relates to treatment for hearing loss.
        i. Support groups, clinicians are able to answer questions…
    b. What behaviors showed that your provider was knowledgeable?
        i. Prompt in case they disagree; what led you to believe they were not knowledgeable?
    c. What types of fears and concerns did you/your child have about receiving treatment?
        i. Probes: hearing aid not working as well as hoped, etc.
    d. How were those fears and concerns addressed by the provider?

Conclusion

6. **Is there anything else you would like to share about the topics we have just discussed?**

Appendix C ICD-10 Codes

H90.0	Conductive hearing loss, bilateral	**H90.6**	Mixed conductive and sensorineural hearing loss, bilateral	**H90.A21**	Sensorineural hearing loss, unilateral, right ear, with restricted hearing on the contralateral side
H90.1	Conductive hearing loss, unilateral with unrestricted hearing on the contralateral side	**H90.7**	Mixed conductive and sensorineural hearing loss, unilateral with unrestricted hearing on the contralateral side	**H90.A22**	Sensorineural hearing loss, unilateral, left ear, with restricted hearing on the contralateral side
H90.11	Conductive hearing loss, unilateral, right ear, with unrestricted hearing on the contralateral side	**H90.71**	Mixed conductive and sensorineural hearing loss, unilateral, right ear, with unrestricted hearing on the contralateral side	**H90.A3**	Mixed conductive and sensorineural hearing loss, unilateral with restricted hearing on the contralateral side
H90.12	Conductive hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side	**H90.72**	Mixed conductive and sensorineural hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side	**H90.A31**	Mixed conductive and sensorineural hearing loss, unilateral, right ear with restricted hearing on the contralateral side
H90.2	Conductive hearing loss, unspecified	**H90.8**	Mixed conductive and sensorineural hearing loss, unspecified	**H90.A32**	Mixed conductive and sensorineural hearing loss, unilateral, left ear with restricted hearing on the contralateral side

H90.3	Sensorineural hearing loss, bilateral	**H90.A**	Conductive and sensorineural hearing loss with restricted hearing on the contralateral side	**H91.0**	Ototoxic hearing loss
H90.4	Sensorineural loss, unilateral with unrestricted hearing on the contralateral side	**H90.A1**	Conductive hearing loss, unilateral, right ear with restricted hearing on the contralateral side	**H91.1**	Presbycusis
H90.41	Sensorineural hearing loss, unilateral, right ear, with unrestricted hearing on the contralateral side	**H90.A11**	Conductive hearing loss, unilateral, left ear with restricted hearing on the contralateral side	**H91.2**	Sudden idiopathic hearing loss
H90.42	Sensorineural hearing loss, unilateral, left ear, with unrestricted hearing on the contralateral side	**H90.A12**	Conductive hearing loss, unilateral, left ear with restricted hearing on the contralateral side	**H91.3**	Deaf nonspeaking, not elsewhere classified
H90.5	Unspecified sensorineural hearing loss	**H90.A2**	Sensorineural hearing loss, unilateral, with restricted hearing on the contralateral side	**H91.9**	Unspecified hearing loss

Appendix D Procedure Codes

S0618	Audiometry for hearing aid evaluation	**V5252**	Hearing aid, digitally programmable binaural, ITE	**L8690**	Auditory osseointegrated device, includes all internal and external components
S2230	Implantation of magnetic component of semi-implantable hearing device on ossicles in middle ear	**V5253**	Hearing aid, digitally programmable binaural, BTE	**L8691**	Auditory osseointegrated device, external sound processor, excludes transducer/actuator, replacement only, each
S2235	Implantation of auditory brain stem implant	**V5254**	Hearing aid, digital, monaural, CIC	**L8692**	Auditory osseointegrated device, external sound processor, used without osseointegration, body worn, includes headband or other means of external attachment
S8270	Enuresis alarm, using auditory buzzer and/or vibration device	**V5255**	Hearing aid, digital, monaural, ITC	**L8693**	Auditory osseointegrated device abutment, any length, replacement only
V5008	Hearing screening	**V5256**	Hearing aid, digital, monaural, ITE	**L8694**	Auditory osseointegrated device, transducer/actuator, replacement only

V5010	Assessment for hearing aid	**V5257**	Hearing aid, digital, monaural, BTE	**G0268**	Removal of impacted cerumen (one or both ears) by physician on same date of service as audiologic function testing
V5011	Fitting/orientation/checking of hearing aid	**V5258**	Hearing aid, digital, binaural, CIC	**G8565**	Verification and documentation of sudden or rapidly progressive hearing loss
V5014	Repair/modification of a hearing aid	**V5259**	Hearing aid, digital, binaural, ITC	**G8567**	Patient does not have verification and documentation of sudden or rapidly progressive hearing loss
V5020	Conformity evaluation	**V5260**	Hearing aid, digital, binaural, ITE	**G8568**	Patient was not referred to a physician (preferably a physician with training in disorders of the ear) for an otologic evaluation, reason not given
V5030	Hearing aid, monaural, body worn, air conduction	**V5261**	Hearing aid, digital, binaural, BTE	**69209**	Removal impacted cerumen using irrigation/lavage, unilateral
V5040	Hearing aid, monaural, body worn, bone conduction	**V5262**	Hearing aid, disposable, any type, monaural	**69710**	Implantation or replacement of electromagnetic bone

					conduction hearing device in temporal bone
V5050	Hearing aid, monaural, in the ear	**V5263**	Hearing aid, disposable, any type, binaural	**69711**	Removal or repair of electromagnetic bone conduction hearing device in temporal bone
V5060	Hearing aid, monaural, behind the ear	**V5264**	Ear mold/insert, not disposable, any type	**69714**	Implantation, osseointegrated implant, temporal bone, with percutaneous attachment to external speech processor/cochlear stimulator; without mastoidectomy
V5070	Glasses, air conduction	**V5265**	Ear mold/insert, disposable, any type	**69715**	Implantation, osseointegrated implant, temporal bone, with percutaneous attachment to external speech processor/cochlear stimulator; with mastoidectomy
V5080	Glasses, bone conduction	**V5266**	Battery for use in hearing device	**69717**	Replacement (including removal of existing device), osseointegrated implant, temporal bone, with percutaneous attachment to external

					speech processor/cochlear stimulator; without mastoidectomy
V5090	Dispensing fee, unspecified hearing aid	**V5267**	Hearing aid or assistive listening device/ supplies/accessories, not otherwise specified	**69718**	Replacement, osseointegrated implant, temporal bone, with percutaneous attachment to external speech processor/cochlear stimulator, with mastoidectomy
V5095	Semi-implantable middle ear hearing prosthesis	**V5268**	Assistive listening device, telephone amplifier, any type	**69745**	Suture facial nerve, intratemporal, with or without graft decompression; including geniculate ganglion
V5100	Hearing aid, bilateral, body worn	**V5269**	Assistive listening device, alerting, any type	**69930**	Cochlear device implantation, with or without mastoidectomy
V5110	Dispensing fee, bilateral	**V5270**	Assistive listening device, television amplifier, any type	**81430**	Genome sequencing, including genes specified in the code descriptor that may be associated with hearing loss
V5120	Binaural, body	**V5271**	Assistive listening device, television caption decoder	**81431**	Genetic testing looking for alterations in STRC

					and DFNB1 genes or deletions in GJB2 and GJB6 genes, which can indicate hereditary hearing loss
V5130	Binaural, in the ear	**V5272**	Assistive listening device, TDD	**92565**	Stenger test, pure tone
V5140	Binaural, behind the ear	**V5273**	Assistive listening device, for use with cochlear implant	**92567**	Tympanometry, impedance testing
V5150	Binaural, glasses	**V5274**	Assistive listening device, not otherwise specified	**92568**	Acoustic reflex decay test
V5160	Dispensing fee, binaural	**V5275**	Ear impression, each	**92575**	Air conduction stimulation test, different tone pitches
V5170	Hearing aid, cros, in the ear	**V5281**	Personal FM/DM system, monaural, (one receiver, transmitter, and microphone)	**92577**	Caloric vestibular testing
V5171	Hearing aid, contralateral routing device, monaural, in the ear (ITE)	**V5282**	Personal FM/DM system, binaural (two receivers, transmitter, and microphone)	**92579**	Audiologic function test; battery tests to evaluate hearing loss in infants and toddlers
V5172	Hearing aid, contralateral routing device, monaural, in the canal (ITC)	**V5283**	Personal FM/DM neck, loop induction receiver	**92582**	Conditioning play audiometry
V5180	Hearing aid, cros, behind the ear	**V5284**	Personal FM/DM, ear level receiver	**92583**	Audiologic function test; 3 years and older select

					pictures that correspond with sounds played
V5181	Hearing aid, contralateral routing device, monaural, behind the ear (BTE)	**V5285**	Personal FM/DM, direct audio input receiver	**92587**	Distortion product OAEs (procedure testing)
V5190	Hearing aid, contralateral routing, monaural, glasses	**V5286**	Personal blue tooth FM/DM receiver	**92588**	Comprehensive diagnostic evaluation (cochlear mapping, min 12 frequencies)
V5200	Dispensing fee, contralateral monaural	**V5287**	Personal FM/DM receiver, not otherwise specified	**92590**	Hearing aid examination and selection (monaural)
V5210	Hearing aid, bicros, in the ear	**V5288**	Personal FM/DM transmitter assistive listening device	**92591**	Hearing aid examination and selection (binaural)
V5211	Hearing aid, contralateral routing system, binaural, ITE/ITE	**V5289**	Personal FM/DM adapter/boot coupling device for receiver, any type	**92592**	Audiologic function test
V5212	Hearing aid, contralateral routing system, binaural, ITE/ITC	**V5290**	Transmitter microphone, any type	**95293**	Hearing aid check
V5213	Hearing aid, contralateral routing system, binaural, ITE/BTE	**V5298**	Hearing aid, not otherwise classified	**95294**	Electroacoustic evaluation for hearing aid
V5214	Hearing aid, contralateral routing system, binaural, ITC/ITC	**V5299**	Hearing service, miscellaneous	**92595**	Electroacoustic evaluation for hearing aid

V5215	Hearing aid, contralateral routing system, binaural, ITC/BTE	**V5336**	Repair/Modification of augmentative communicative system or device	**92596**	Evaluation of speech, language, voice, communication, and/or auditory processing
V5220	Hearing aid, bicros, behind the ear (BTE)	**L8613**	Ossicula implant	**92601**	Diagnostic analysis of cochlear implant, younger than.7 years of age; with programming
V5221	Hearing aid, contralateral routing system, binaural, BTE/BTE	**L8614**	Cochlear device, includes all internal and external components	**92602**	Younger than 7 years of age, subsequent re-programming
V5230	Hearing aid, contralateral routing system, binaural, glasses	**L8615**	Headset/headpiece for use with cochlear implant device, replacement	**92603**	Diagnostic analysis of cochlear implant, age 7 years or older; with programming
V5240	Dispensing fee, contralateral routing system, binaural	**L8616**	Microphone for use with cochlear implant device, replacement	**92604**	7 years or older, subsequent re-programming
V5241	Dispensing fee, monaural hearing aid, any type	**L8617**	Transmitting coil for sue with cochlear implant device, replacement	**92626**	Evaluation of auditory rehabilitation status (1st hour)
V5242	Hearing aid, analog, monaural, CIC (completely in the ear canal)	**L8618**	Transmitter cable for use with cochlear implant device or auditory osseointegrated device, replacement	**92627**	Evaluation of auditory rehabilitation status (each additional 15 minutes)
V5243	Hearing aid, analog, monaural, ITC (in the canal)	**L8619**	Cochlar implant, external speech processor and	**92630**	Auditory rehabilitation; pre-lingual hearing loss

			controller, integrated system, replacement		
V5244	Hearing aid, digitally programmable analog, monaural CIC	**L8621**	Zinc air battery for use with cochlear implant device and auditory osseointegrated sound processors, replacement, each	**92633**	Auditory rehabilitation; post-lingual hearing loss
V5245	Hearing aid, digitally programmable analog, monaural ITC	**L8622**	Alkaline battery for use with cochlear implant device, any size, replacement, each	**92640**	Special diagnostic otorhinolaryngologic procedures
V5246	Hearing aid, digitally programmable analog, monaural ITE (in the ear)	**L8623**	Lithium ion battery for use with cochlear implant device speech processor, other than ear level, replacement, each	**92650**	Auditory evoked potentials; screening of auditory potential with broadband stimuli, automated analysis
V5247	Hearing aid, digitally programmable analog, monaural BTE	**L8624**	Lithium ion battery for use with cochlear implant or auditory osseointegrated device speech processor, ear level, replacement, each	**92651**	Auditory evoked potentials; for hearing status determination, broadband stimuli, with interpretation and report
V5248	Hearing aid, analog, binaural, ITC	**L8625**	External recharging system for batter for use with cochlear implant or auditory osseointegrated device, replacement only, each	**92652**	Auditory evoked potentials; for threshold estimation at multiple frequencies, with interpretation and report (do not report with 92651)

V5249	Hearing aid, analog, binaural, ITC	**L8627**	Cochlear implant, external speech processor, component, replacement	**0212T**	Hearing disorder evaluation using both air and bone conduction modes to test the hearing threshold level of the pt and measures ability to recognize familiar words and repeat them
V5250	Hearing aid, digitally programmable analog, binaural, CIC	**L8628**	Cochlear implant, external controller component, replacement		
V5251	Hearing aid, digitally programmable analog, binaural, ITC	**L8629**	Transmitting coil and cable, integrated, for use with cochlear implant device, replacement		

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