**Exploring the Stories of Parents' Experiences
With Infant Hearing-Loss Screening and Diagnosis in the United States**

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Keywords

Early Hearing Detection and Intervention, Pediatric Hearing Loss, Newborn Hearing Screening, Narrative Sensemaking, Audiology

Abbreviations List

hearing loss, HL; Early Hearing Detection and Intervention, EHDI; Centers for Disease Control and Prevention, CDC; Joint Committee on Infant Hearing, JCIH; United States, US

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Abstract

Objectives. For the past 20 years, birthing hospitals in the United States have required newborns to undergo a hearing loss screening prior to leaving the hospital. Since the initial newborn hearing screening mandates, there has been much outcome research documenting the successes and barriers of the program. However, we know little about the experiences of their parents during the time between screening and diagnosis. We propose that elucidating the parents' experiences with newborn hearing loss screening and diagnosis—via their own stories—is a first step toward understanding their varied experiences and has the potential to ultimately improve hearing healthcare for both children and their families. Thus, to better understand the early hearing screening and detection experience from hearing parents' perspectives, we asked the following research question: what are parents' experiences with the early hearing loss screening and diagnosis of their infants in the US?

Design. The current study employed a prospective, cross-sectional qualitative design. Specifically, we gathered stories from 13 hearing parents who each have a child born in the United States and diagnosed with hearing loss no later than 14 months of age between the years of 2016 to 2020. We used thematic analysis to uncover common themes across parent narratives. Saturation was reached at Interview #4; thus no further sampling was needed.

Findings. Two major themes emerged from the data: (1) hearing healthcare experiences and (2) parents' early experiences during the period between their child's newborn hearing loss screening and diagnosis. Subthemes were also uncovered. Three emergent subthemes related to healthcare experiences included: (1) downplayed newborn hearing screening referrals, (2) clinician-centered care, and (3) medical expenses and health coverage. The three subthemes of the second theme were: (1) parent-to-parent support, (2) "mom guilt", and (3) a new reality.

Conclusion. The present study's narrative accounts from parents about their infants' early hearing detection experiences revealed several, different subthemes that emerged from the same, mandated newborn experience in US families. These findings highlight important moments throughout the hearing loss screening and detection process that could benefit from more effective, family-centered hearing healthcare. This knowledge also facilitates the field's move toward improved education of future and current providers and a family-centered approach that could address concerns and expectations of new parents at the very start of their newborns' hearing loss journeys.

Exploring the Stories of Parents' Experiences with Infant Hearing-Loss Screening and Diagnosis in the United States

Hearing loss (HL) is the most prevalent disorder screened for in newborns in the United States (US; Korver et al. 2017). Of those screened, it is estimated that 1 to 6 newborns out of every 1000 have a detectable HL (Centers for Disease Control and Prevention (CDC) 2020). A diagnosis of permanent HL not only affects newborns, but also their parents. This is particularly relevant because over 90% of children with HL are born to parents with typical hearing (Mitchell & Karchmer 2004), many of whom have never personally encountered HL and its long-term impacts. Thus, a diagnosis of HL in infancy can often cause disruption in families' and parents' lives (e.g., Fitzpatrick et al. 2008; Hardonk et al. 2011; Young & Tattersall 2005), which is reflected in the stories they tell themselves and others. This is understandable because when people experience major disruptions to their lives, they often turn to storytelling to make sense of their experience (Becker 1997). However despite previous qualitative work exploring parents' experiences with early HL diagnosis and intervention across the globe (e.g., Elpers et al. 2016; Gilbey 2010; Magnuson & Hergils 1999; Nickbakht et al. 2021; Russ et al. 2004; Schmulian & Lind 2019; Yee et al., 2018), little is known about US parents' personal narratives centered on their experiences during the period of time between their newborns' HL screenings and ultimate diagnoses. Attending to parents' stories is useful because they can reveal subjective insights while unburdening the patient (Zharias 2018). In the present qualitative study, we thus aimed to explore hearing parents' narratives of their early experiences with their newborns' HL screenings and diagnoses. Uncovering such perspectives will enhance the field's current understanding of hearing parents' experiences in the US during this important time for families and, ultimately, such stories could help professionals improve the counseling and support they provide to new

parents at the very start of their newborn's HL journey.

Infant Hearing Screening in the US

In 2007 the Joint Commission on Infant Hearing (JCIH) set forth the following recommendations: (1) infants should be screened for HL no later than 1 month of age, (2) infants who screen positive for HL should undergo a full audiologic evaluation no later than 3 months of age, and (3) infants diagnosed with permanent HL should be enrolled in early intervention services no later than 6 months of age. These recommendations are commonly referred to as the *1-3-6 standard* and they remain in place to this day.² This standard was adopted by Early Hearing Detection and Intervention (EHDI) programs—state-run organizations that oversee the early detection, diagnosis, and intervention of HL in the US—and its implementation has resulted in positive outcomes for newborns and their families nationwide (CDC 2020; JCIH 2019). For example, universal hearing screening and diagnosis improved access to pediatric audiological care, timing of services, and earlier intervention (Chung et al. 2017; Larsen et al. 2012; Muñoz et al. 2011; White et al. 2010). However there is little documentation of the parents' stories at this point in their pediatric HL journey even though their subjective experiences are deeply intertwined with the newborns' early screening and diagnosis of HL process.

Family-Centered Care and Personal Narratives

In the 1980's the concept of person-centered care was introduced to US healthcare (Greene et al. 2012) and it has long been hailed as an ideal approach to care provision because it aims to place patients in the role of active partner with their clinicians (Kuo et al. 2012).

² The 2019 JCIH statement included the notable revision that state programs meeting the 1-3-6 standard should adjust to a 1-2-3 standard. This revised standard suggests that (1) infants screened for HL no later than 1 month of age, (2) infants who screen positive for HL undergo a full audiologic evaluation no later than 2 months of age, and (3) infants diagnosed with permanent HL should be enrolled in early intervention services no later than 3 months of age to provide best care for infants with a detectable HL at birth.

However, research has also shown that health care professionals continue to utilize a clinician-centered approach in their practices instead of a person-centered one. Audiologists are no exception (Jones 2021; William et al. 2019). One possible solution toward improving such limiting health care practices includes working to employ a person-/family-centered approach to audiological care by making time for patient and family narratives.³

Patient narratives about their healthcare journeys are a key component to person-/family-centered care as they can help shift the clinician's goal from problem solving to understanding (Charon, 2001; 2006; Zaharias et al., 2018). Research (Nickbakht et al., 2021) has shown, this approach leads to families and hearing health care providers establishing open communication as providers listened to parents, provided empathy, and advocated for them throughout the early intervention process. Thus, gathering parents' perspectives about their experiences during the time of their infants' HL screening until diagnosis could give critical insights regarding the parent experience. Such insight could subsequently allow clinicians to foster person-/family-specific support for these families even before intervention begins (Nickbakht et al.; Russ et al. 2004).

Parents have preconceived notions and ideas about their children before they are ever born. For typical hearing parents in particular, these ideas are often threatened with the possibility and/or confirmation of HL in their newborns (Young 2010). Parents utilizing hospital birthing services in the US often learn about the newborn hearing screening program within the first 48 hours of their babies' lives. Then based on results from this screening, parents may also learn that their newborn is at risk for permanent HL. With this news, parents' expectations for

³ This practice is known as narrative medicine or narrative-based medicine (NBM); a term coined by Rita Charon (2001). NBM is "...a fundamental tool to acquire, comprehend and integrate the different points of view of all the participants having a role in the illness experience." (Fioretti et al. 2016, p. 8)

themselves and their baby begin to quickly shift (Young). This shift may involve ideas about their newborn's future development, roadblocks that their child and family may face in the future, or the types of support their child may require throughout their life. Research has shown that along with this shift many parents with typical hearing experience stress and abrupt challenges that accompany parenting an infant with HL (Fitzpatrick et al. 2008; Green 2020; Hardonk et al. 2011; Pipp-Siegel 2002). It thus becomes necessary for these parents to make sense of their feelings and the unexpected HL—a disability with which they have little to no experience. One way parents begin to make sense of this new HL diagnosis and the accompanying healthcare process is by sharing stories about their experiences with others (Koenig Kellas 2014).

Parents' Experiences with their Infants' Hearing Loss Diagnoses

Previous research showed that parents' experiences varied across the newborn HL screening and diagnostic process (Danahauer et al. 2008; Elpers et al. 2016; Fitzpatrick et al. 2008; Russ et al. 2004; Gilbey 2010). For example, Fitzpatrick and colleagues conducted semi-structured interviews with 27 Canadian parents to explore the needs and service delivery of parents after they received a HL diagnosis for their child. Parents were asked the following questions: (a) What were your needs following diagnosis of your child's HL? and (b) If you could redesign the system, what would be the important components of a model? Their findings revealed that parents were generally positive about the services received during their infants' HL diagnosis but reported a lack of support for and education about their child's HL. The parents reported that their newborns' HL screening results were delivered bluntly and without empathy by health care providers. They also reported feeling shocked and lost about the next steps to take with their newborns after receiving the hearing screening results. In Russ and colleagues (2004)

found that an infant HL diagnosis introduces new, and often unexpected, information and experiences into the lives of families with a child with pediatric HL. In their study, 82 parents with typical hearing from Australia completed questionnaires that revealed they experienced a variety of strong emotions such as denial, shock, and even self-blame following the initial diagnosis of HL in their newborns. Finally, Elpers and colleagues (2016) interviewed parents from rural Kentucky regarding their experiences with newborn hearing screening and HL diagnosis and found that they faced numerous challenges as they navigated pediatric hearing healthcare. Although these studies are important as they have laid a valuable foundation for understanding, this work is limited in that it solely relied on parents' semi-structured interviews as opposed to their raw, personal stories. Personal stories (i.e. narratives) place the people of interest at the center of the study and privilege "the meanings that they assign to their own stories...[Thus] narratives may come closer to representing the context and integrity of those lives than questionnaires" than semi-structured interviews (Anderson & Kirkpatrick 2016, p. 631).

The subjective narratives of parents across the US during HL screening and diagnosis are currently unknown despite the great improvements that have been made to infant hearing healthcare since the JCIH standards were first implemented in 1994. Without knowledge of parents' direct narrative experiences, our ability to improve upon and provide sound, family-centered hearing healthcare is limited. Research increasingly shows that the implementation of family-centered care by providers improves patient experience and increases adherence to prescribed interventions (Dudley et al. 2015; Kuo et al. 2012). Uncovering parents' experiences is crucial to the success of healthcare and treatment clinicians provide families, thus identifying potential improvements in patient outcomes (Frost et al. 2010; Kreuter et al. 2007; Russ et al.

2004; Smith & Sparkes 2008). For example, Clark and colleagues (2021) found benefits that patient narratives brought to clinical work including building provider awareness to the unique and individual situation of each patient and family. Such findings in the field of pediatric audiology could be foundational in improving clinical care, revealing what resources and support parents need, or reinforcing what current practices have worked well in the clinician-parent relationship, such as family-centered care.

Purpose of the Present Study

Even though parents are key to providing sound family-centered care and ensuring long-term success in their children with HL, what we know about their experiences at the onset of their families' pediatric HL journeys in the US is missing from audiology research. Thus, to better understand parents' experiences and prioritize their perspectives, we posed the following research question: what are parents' experiences with the early HL screening and diagnosis of their infants in the US?

METHODS

In our qualitative study we focused on eliciting personal narratives from parents to uncover their experiences during their infants' early HL screening and identification. We chose a narrative approach because it prompts participants to share their personal stories and experiences. Such narrative reflections allowed parents to reflect broadly on their experiences while also connecting observations from birth to their infants' HL diagnosis (Anderson & Kirkpatrick 2016). The narratives also allowed the participants to share other contextual factors such as specific characters and the settings in which events occurred related to the newborn HL screening and diagnosis in the US that are typically not elicited during a semi-structured interview (Riessman, 2008).

Study Design

The current study used a prospective, cross-sectional qualitative design utilizing narrative interviews.

Sampling

We used snowball sampling in this study given the relatively low incidence of pediatric HL. When we reached saturation (i.e. the point in which no new themes arose) during thematic analysis [TA; (Braun & Clark 2006)], no further sampling was needed. Saturation was reached at Interview #4 (see Verification Procedures).

Parents were eligible to participate in the study if they met the following inclusion criteria: (1) aged 18 years or older; (2) parent a child with HL born in the US and diagnosed with HL no later than 14 months of age between the years of 2016 to 2020; (3) report typical hearing and (4) communicate confidently in spoken English.

We recruited parents of children with HL by distributing letters to pediatric audiologists and hearing health care clinics across the US, posting information via social media and the lab website, and word of mouth. Parents contacted the lab if they were interested in participating in the study and researchers sent them a *REDCap* (Harris et al. 2009; 2019) questionnaire to assess their eligibility, collect demographic information, and obtain informed consent for the study.

After eligible parents completed the questionnaire, we contacted them to schedule a time for the interview.

Participants

We interviewed 13 parents in total for the present study. Thirteen adults (12 females; 1 male) with typical hearing, who parented a child with HL, and resided in various locations across the US participated in the study. Table 1 displays detailed demographic information for the

Table 1. Parent Participants Demographic Information

Participant Pseudonym, Interview No.	Gender	Age*	Marital Status	Race	Family Income	Education	Residence	Native Language
Charlotte, #1	F	30	Married	White	\$50,001 - \$60,000	4-year degree	California	English
Fay, #2	F	29	Married	White	\$75,001 - \$100,000	Graduate degree	Mississippi	English
Carolina, #3	F	40	Married	White	Over \$100,000	Graduate degree	New Jersey	English
Wendy, #4	F	35	Married	White	Over \$100,000	Graduate degree	Maryland	English
Amanda, #5	F	36	Married	White	Over \$100,000	Graduate degree	Pennsylvania	English
Helen, #6	F	34	Married	White	Over \$100,000	Graduate degree	Iowa	English
Warren, #7	M	43	Married	White	Over \$100,000	Graduate degree	California	English
Lily, #8	F	38	Married	White	Over \$100,000	4-year degree	Utah	English
Leslie, #9	F	40	Married	White	Over \$100,000	Graduate degree	Colorado	English
Andi, #10	F	34	Other	Other	\$60,001 - \$75,000	Graduate degree	California	English
Amy, #11	F	31	Married	White	\$35,001 - \$50,000	High school or GED	Colorado	English
Tiffany, #12	F	32	Married	White	Over \$100,000	4-year degree	Minnesota	English
Melanie, #13	F	39	Married	White	Over \$100,000	Graduate degree	California	English

*Age is reported in years

parent participants and Table 2 summarizes the characteristics of the present sample's children (M age at interview = 25.7 months; SD = 12.5 months). Parents ranged in age from 29 to 43 years (M = 35.5 years; SD = 4.2 years). Note that only 1 participant identified as male; however, like the other participants, he was the primary caregiver. Despite an attempt to recruit a heterogenic sample reflecting a range of demographic characteristics; parents' gender, ethnicity, marital status, education, income, and native language are relatively homogenous in the present study. Table 3 summarizes the characteristics of the present sample (see Limitations and Future Directions for further discussion).

Table 2. Participant's Children's Demographic Information

Child Pseudonym, Interview No.	Age at Interview	Gender	HL Diagnosis Date	Diagnosis Location	HL Type and Configuration	PTA at Diagnosis	Listening Device
Louis, #1	3	M	11/2016	California	Unilateral, Sensorineural	AS NR	BCHA
Kyle, #2	4	M	03/2016	Mississippi	Unilateral, Sensorineural	AD 53	HA
Salem, #3	0:3	F	08/2020	New Jersey	Bilateral, Sensorineural	—	HA
Peter, #4	2	M	06/2018	Maryland	Bilateral, Sensorineural	—	HA
Violet, #5	1:10	F	01/2019	Pennsylvania	Bilateral, Sensorineural	AS 52, AD 53	HA
Sam, #6	2	M	07/2019	Iowa	Unilateral, Sensorineural	AS 53	HA
Alex, #7	2:11	M	02/2018	California	—	—	—
Chandler, #8	1:2	M	11/2020	Utah	Bilateral, Sensorineural	AD 93, AS 98	CI
Lincoln, #9	1:2	M	02/2020	Colorado	Unilateral, Sensorineural	AD NR	None
Cade, #10	1:8	M	07/2019	California	Bilateral, Permanent Conductive	AU 18	BCHA
Carson, #11	2	M	02/2019	Colorado	Unilateral, Sensorineural	AD 65	HA
Ben, #12	1:11	M	05/2019	Minnesota	Unilateral, Sensorineural	AD 110	N/A
Sarah, #13	4	F	05/2016	California	—	—	—

*ages are reported in years or years:months; —, data unavailable; AS, right ear; AD, left ear, AU both ears/not ear specific; PTA, pure tone average of 500, 1000, and 2000 Hz in dB HL; NR, no response at equipment limits; BCHA, bone conduction hearing aid; HA, hearing aid; CI, cochlear implant; N/A, no device

Procedure

Procedures for this study were reviewed and approved by the university's Institutional Review Board.

Phase I

When a parent reached out to the lab showing interest in participating, they were sent a link to a *REDCap* questionnaire via email. This questionnaire included an IRB-approved letter of informed consent, a Health Insurance Portability and Accountability Act (HIPPA) release form, and a series of demographic questions. Once the *REDCap* questionnaire was completed, we scheduled an interview with the parent.

Table 3. Characteristics of the Parent Sample (N=13)

		Participants N = 13	
		n	%
Gender	F	12	92
	M	1	8
Marital Status			
	Married	13	92
	Other	1	8
Total Family Income			
	\$35,001 - \$50,000	1	8
	\$50,001 - \$60,000	1	8
	\$60,001 - \$75,000	1	8
	\$75,001 - \$100,000	1	8
	Over \$100,000	9	68
Education			
	High school diploma or GED	1	8
	4-year degree	3	23
	Graduate degree	7	53
	Doctorate	2	16
Ethnicity			
	White	13	100
Native Language			
	English	13	100

Phase II

The first author conducted all parent interviews. He is a white, male, native English speaker with typical hearing. He is not a parent. At the time of the interviews, he had 1.5 years of graduate training in clinical audiology and qualitative research.

Semi-structured interviews occurred over *Zoom*, an online video conference program. Only the participant and interviewer were present for each interview. The interviewer followed the same narrative interview protocol/script without deviation for each participant (see Supplemental Appendix for protocol). This minimized any potential direct or indirect interviewer influences. At the beginning of the interview, the interviewer briefly introduced himself as a student researcher working on his clinical research project required for fulfillment of the doctorate of audiology degree. The interviewer then confirmed that the participant gave their informed consent via the email questionnaire. Next the interviewer gave a uniform prompt to each parent and the parent narrated their experiences. Finally, as the story progressed, the interviewer asked follow-up questions/presented additional prompts to allow the parent to expand on any experience they did not cover in their initial response. Throughout the interview, the interviewer remained silent to minimize any influence on the parent's narrative. All interviews were recorded using the *Zoom* online recording feature; the audio recordings were saved for later transcription.

Phase III

After each interview's completion, research assistants and the interviewer transcribed the audio recordings verbatim. During the transcription process, all identifying information (e.g., proper names and places) mentioned by the participants were replaced with pseudonyms. Following the initial transcription, the first author/interviewer re-listened to all the audio files to

ensure the transcripts' accuracy. The final 13 de-identified transcriptions yielded a total of 123 pages of single-spaced text. None of the transcripts were returned to the parents for comment or correction. Finally, each child's HL was confirmed via their official audiological reports. These hearing healthcare data can be found in Table 2.

Data Analysis

Thematic Analysis

In collaboration with two additional researchers from the lab⁴, we used inductive thematic analysis (Braun & Clark 2006) to identify, analyze, and describe common themes and subthemes across the parents' narratives specifically dealing with the early HL screening and diagnosis processes.

The unit of analysis in the present study was the transcribed dialogue from a single parent's narrative. Thematic analysis began with the three researchers independently and repeatedly reading through the transcribed narrative interviews while actively looking for meanings, patterns, and similarities to define codes (Braun & Clarke). Next, each researcher grouped the codes into broad categories and identified the subsequent themes that emerged from each parent's narrative response. Researchers #1 and #2 then shared the themes they uncovered, as well as collaboratively labeled and documented each theme and accompanying subthemes.

Researcher #3 was consulted to answer questions about the interviews and help argue through

⁴ Researcher #1 is the second author. She is a white, female, native English speaker. She has an asymmetrical, mild unilateral HL in her left ear and is a parent of a child with typical hearing. She has over 20 years of experience working with parents of children with HL and 5 years of experience with narrative analysis. Researcher #2 is a white, female, native English speaker. She has typical hearing and is not a parent. She has 3 years of experience in narrative analysis. Researchers #1 and #2 did not have any interaction with the parents, only their de-identified transcripts. The first author was Researcher #3 and engaged in the thematic analysis. Again, he is a white, male, native English speaker. He has typical hearing and conducted all the interviews. He primarily contributed to the verification procedures during analysis. Researcher #4 is a white, female, native English speaker. She has typical hearing and is not a parent. This is her initial experience with narrative analysis.

disagreements between Researchers #1 and #2. Researchers identified themes and subthemes by considering the saliency or strength of importance of a subject as expressed in the parent narratives. Researcher #4 was then recruited to independently review the parent narratives and identify counterexamples to each of the subthemes (if they were present). Researchers #1 and #2 lastly shared the exemplars they identified for each subtheme and its accompanying counterexamples. Ultimately, all researchers came into agreement regarding the themes, subthemes, and exemplars that emerged from the parent narratives. As with all interpretive research, we recognize how our experiences contextualize our interpretation of the findings. Thus, we acknowledge and disclose our positionality and engaged in verification procedures to meet the criteria for trustworthiness: (a) credibility, (b) transferability, and (c) confirmability (Lincoln & Guba 1985).

Verification Procedures

To establish the validity of our analysis, we engaged in four interrelated verification procedures: (1) peer debriefing, (2) investigator triangulation, (3) audit trail, and (4) exemplar identification (Lincoln & Guba). During peer debriefing, we discussed differences in our independent findings and came to a final agreement across all defined themes and subthemes. We then engaged in investigator triangulation when Researchers #1 and #2 discussed the findings with Researcher #3 and collectively solidified the categories. We debated through differences in our findings and came to a final agreement across all defined themes and subthemes (Lincoln & Guba). We defined 2 themes and 6 subthemes after the analysis of all 13 interviews in succession. Saturation was reached at Interview #4; meaning that no additional themes emerged during analysis of the 9 remaining narratives (Fusch & Ness, 2015; Guest et al., 2016). Throughout analysis, we kept detailed notes in a *Microsoft Excel* workbook to track codes

and decision-making when identifying major themes and subthemes. Finally, researchers identified (and agreed upon) parent exemplars that best illustrated each subtheme that emerged from the semi-structured interviews (i.e. exemplar identification), as well as counterexamples.

FINDINGS

Themes and Subthemes

Using thematic analysis, we uncovered parents' experiences relating to their infants' early HL screening and diagnosis. Two, mutually exclusive, major themes emerged from the data: (1) hearing healthcare experiences and (2) parents' early experiences with their child's HL. Subthemes were also uncovered. Three emergent subthemes related to healthcare experiences included: (1) downplayed newborn hearing screening referrals, (2) clinician-centered care, and (3) medical expenses and health coverage. The three subthemes of the second theme were: (1) parent-to-parent support, (2) "mom guilt", and (3) a new reality. See Table 4 for a list of themes, subthemes, and short descriptions of each subtheme.

Hearing Healthcare Experiences

One major theme that emerged from the parents' narratives—*hearing healthcare experiences*—focused on their interactions with healthcare and its professionals during the infant HL screening and diagnosis processes. This theme and subthemes were particularly salient as they revealed parents' interactions with hearing health care personnel and systems.

Downplayed newborn hearing screening results. All but 1 of the parent narratives revealed how various health care professionals downplayed their newborns' hearing screening results and subsequent referrals for follow-up audiological diagnostic testing. Specifically, parent narratives revealed that after the parent(s) learned that their newborn did not pass the hearing

Table 4. Subthemes and Accompanying Descriptions

Theme	Subthemes	Description
<i>Hearing healthcare experiences</i>	Downplayed newborn hearing screening results	When the baby does not pass the initial hearing screening, the provider directly tells the parent “not to worry” or that it is likely “due to fluid”.
	Clinician-centered care	Parent feels their hearing health care provider did not listen to them or demonstrate empathy. The provider did not take time to answer parent’s questions and was driven by their personal goals, instead of the families’ goals
	Medical expenses and health coverage	The provider gives HL diagnosis and immediately discusses insurance coverage or financial obligations when the parent was not prepared for the discussion.
<i>Parents' early experiences with their child's hearing loss</i>	Parent-to-parent support	Parent reached out to a social media group for emotional and informational support on how to navigate life as a parent of a child with HL.
	“Mom guilt”	Mother feels responsibility and guilt for her potential in-utero contributions to her baby’s HL.
	A new reality	Parent had an emotional initial reaction receiving a HL diagnosis. Parent has concerns about how HL will affect their child as they grow up.

screening, the health care providers—including physicians—told the parent(s) “not to worry” or be concerned about the screening results. No counterexamples were found for this subtheme.

Helen shared her experience after her newborn did not pass their second hearing screening, “I remember being in the hospital and kind of being a little bit worried about that [failed screening] and thinking, ‘I wonder if there is something up with that,’ but then she [the postpartum nurse] was just reassuring that he likely just had fluid in his ears from birth.” (Interview #6) After multiple, additional hearing screenings prior to leaving the hospital, Helen was told that her baby passed his hearing screening. But as time went on and her baby grew, she became worried about

his hearing. Helen made an appointment with an otolaryngologist to have her 10-month-old's hearing re-screened; neither ear passed. "And so, we met with the ENT [ear-nose-throat physician/otolaryngologist], and the ENT was like, 'Well, he just had some respiratory illnesses. It could just be related to that. His ears look fine. Let's check—check his hearing again in 6 weeks.'" (Interview #6) Amy, shared a similar experience.

Alright, so my son—ummm—automatically failed his first hearing test. The newborn screening at the hospital. Ummm—I wasn't too concerned. Honestly—ummm—the, the technician seemed like she really had her hands full. She—she got like the chords mixed up. Then, at first, she thought it was the left ear, but then she's like, 'No, no wait, it's the right ear.' And she just seemed kind of frazzled. And she was like, 'It's no big deal, just come back in a couple of weeks we'll do another test. There's usually fluid in their ears that like moves around and stuff.' And I was like, that's fine. I wasn't really concerned. (Interview #11)

Clinician-centered care. Parent narratives also revealed notable clinician-centered interactions with hearing health care professionals—particularly when considering the professionals' bedside manner, timeliness, ability to answer questions, or empathize with the parents. Instead of putting the parent and/or family at the center of care, these providers and their priorities dictated the appointment's agenda. Leslie reported this experience when her newborn son's hearing was screened by an audiologist.

She [the audiologist] said he failed the test again—ummm—and he—and she—she said that there was definitely an issue. And at that point I was crying and very emotional again—ummm—there was just absolutely no bedside manner from her. Like, there was no pat on the hand, you know words of encouragement, 'Here's a

tissue.’ Nothing. There was nothing. She looked at me blankly and just said there was an issue. (Interview #9)

Helen’s narrative also reveals a negative experience with a pediatric hearing health care provider after her son’s initial HL diagnosis (following several screenings, despite JCIH’s guideline recommending no more than 2 screenings):

So, we go back up [to the hospital] and she, the audiologist—and I love her to death—but you know she kind of came at me really quick, and was like, ‘Well we’re getting nothing from the right side, and the left side is, you know, probably in the moderate-to-severe range. So, we’ll go ahead and aid the left side. I don’t know, it could be auditory neuropathy on the right side. I’m not really sure. Yeah. So, we’re going to have to...’ And I have literally like—I have—like—both my husband and I have master’s degrees and—like—I have no idea what you’re saying, Honey. Like, absolutely no idea what you’re saying. Ummm—and so I remember being—just being, like, so overwhelmed. Like—I don’t know what you’re saying. (Interview #6)

While these clinician-centered experiences were most salient and frequent across the present narrative corpus, 6 parents presented counterexamples highlighting person-centered care. One of these counterexamples emerged when Leslie shared an interaction between herself and an empathetic nurse during genetic testing that contrasts with her aforementioned interaction with the audiologist:

Even the nurse that took this swab had more bedside manner than this audiologist that I dealt with. She gave me a hug—again this was before coronavirus really got crazy—but she gave me a hug. And she assured me like, ‘Even if it is CMV

[cytomegalovirus]—like—you will deal with this. You are strong.’ She gave me words of encouragement and I will never forget that she was so sweet to me.

(Interview #9)

Medical expenses and health coverage. The present narratives revealed that financial discussions between audiologists and parents about hearing healthcare expenses occurred early in the HL screening and diagnosis process. This subtheme was particularly salient in parent narratives where health care providers aimed to discuss insurance and payment options immediately after a HL diagnosis. Carolina’s experience immediately following her newborn daughter’s HL diagnosis exemplified this subtheme:

She [audiologist] gave me this pamphlet. On the first page it was all about insurance, and I was like, why are we talking about insurance now? Like, I’m really worried about my child. What does this mean for her world? What—I—I can’t even process talking to my insurance company. Well, then I find out, like, insurance is a whole thing. And so—you know—I have to go to a different audiologist because insurance only covers this one kind of hearing aid. (Interview #3)

This subtheme also emerged from Charlotte’s experience immediately following her baby’s HL diagnosis, “Our insurance at that point didn’t cover any hearing aids whatsoever. So, we were really kind of reeling about—well—does he *need* hearing aids? How do we go about getting those and affording those if he does need them? And it was a lot to process without a lot of information.” (Interview #1)

While parents’ narratives revealed that providers emphasized the family’s responsibility for hearing healthcare and listening devices, Wendy’s narrative revealed a counterexample.

Instead of discussing the family's direct financial obligations or expectations following the HL diagnosis, her baby's audiologist educated them about US federal programs and financial aid that could support the costs of future hearing healthcare. "And then the state reaches out to contact you about different services that you may be eligible for or have access to free of charge."

(Interview #4)

Parents' Personal Experience with Their Child's Hearing Loss

This second theme emerged from parents' narratives of their own thoughts, emotions, and reactions to childhood HL.

Parent-to-parent support. This subtheme reflects parents' need for support from other parents, and the actions they took to get this support as they navigated the HL screening and diagnosis processes. The parent-to-parent support subtheme was particularly salient when parents narrated their needs for advice, emotional support, and validation from parents undergoing similar experiences. This is what Charlotte shared in her story:

I went out and found some of those things [parent support groups] on my own, specifically Hands and Voices, our local chapter of that. And also—online parent groups I found to be very helpful. So, through a little bit of elbow grease, I was able to fill that need [for support]. But I think that those things [parent support groups] are really important for parents to have—an outlet—in terms of someone who is looking at things—not necessarily purely clinically, but also kind of a humanist perspective. (Interview #1)

One parent, Wendy (Interview #4), shared how she sought out advice from another parent of a child with HL regarding how to prepare for a sedated auditory brainstem response (ABR) test. She shared, "I reached out to several supports to kind of get advice on how other people

managed it”. It was from that peer that she learned tips for preparing her baby for their own upcoming ABR. Wendy also shared, “I joined a—like a—Facebook group. Like, a support group of parents of children with hearing loss. And I think that’s been helpful in a way to kind of validate and normalize experiences, and kind of, learn from other people—their process.”

(Interview #4) No counterexamples were found for this subtheme.

Mom guilt. Mothers in this study described feelings of guilt when their infants’ HL was confirmed. Their narratives revealed they were grieving the loss of their babies’ hearing, but even more so they repeatedly reflected on their pregnancies in an attempt to determine their own potential contribution to the HL. Some mothers even went so far to reveal specific time points in pregnancy that they could have caused the HL in utero. Wendy said, “I keep going back to, like—I was a little over 40 weeks pregnant and my mom and I went to the movies. And the movie was so loud. Like jarringly loud. And I keep going back to—like, was that why my son can’t—can’t hear? Or did that contribute to the loss?” (Interview #4) On two separate occasions during Amy’s narrative, she reflected on the guilt she experienced regarding her baby’s HL. After telling about her experiences having her son’s hearing tested in the sound booth, Amy shared,

You know, as a mom you feel responsible for, like, growing your child correctly. And like—I felt like I had failed him somehow because he was born with the hearing loss. So, I—even though it’s—I know it’s nothing I did. I still had a lot of guilt—ummm—as the mom. Being like—I don’t know—feeling responsible for any defects he may have had. You know? ...I think at the beginning it was like—just from the parent’s standpoint—it was really hard, just being guilty—feeling guilty. Feeling like I had failed him and—and [trembling voice] that there was

nothing really I could do. Like, nothing I'm going to do is going to improve his hearing loss. You know—there's no way to fix it.

While mom guilt was a salient subtheme, not all parents had this same sense of responsibility and/or guilt. One parent shared that she and her husband were not surprised about their baby's HL. Amanda stated, "My husband, Bob, and I were both carriers for GJB2—umm—Connexin 26—or whatever the genetic—umm—hearing loss gene. But neither of us, like, paid attention to it at all. And we're, like—I—it didn't even really register for me at all until she failed her hearing screening test." (Interview #5) Another counterexample came from the sole male participant. His narrative did not reveal any feelings of responsibility or guilt regarding his child's HL. This makes sense given that he was not the birthing parent and the subtheme of guilt/responsibility that emerged from our corpus was directly related to pregnancy.

A new reality. Parents' narratives also highlighted their personal perspective on their children's HL, future implications of the diagnosis, and their own views of their children. We found no counterexamples for this subtheme. This subtheme was most salient as parents shared their reflections on pediatric HL and the ways their perspectives changed over time. Andi shared some of her emotional reactions as she initially processed the reality that her baby had HL, "And then, right after he was born—he was in our bed—and I looked at his ears and they were different. And it was a total shock and [quiet weeping] it was very emotional because we just didn't expect anything different about him." (Interview #10) Parents also shared their initial reactions following news of the HL diagnosis. Melanie shared, "Like, she [the audiologist] made it out to be, like, 'You're gonna be okay!' Like, 'Best case scenario!' And I'm like—NO. Not best-case scenario. Like, you're telling me there's some—something wrong with—with my child. Like, she's not perfect. And I'm sorry, but she is perfect in—in my eyes. Like, it was—it

was—it was the hardest day of our lives.” (Interview #13) As time passed and parents continued through their journeys with pediatric HL, their perspectives changed. For example, in contrast to the narration of her initial feelings while lying in bed with her baby, Andi said “I—I basically came away from that—I think he was like 8 weeks old or maybe 6 or 7 weeks old at that point. And finally, I kind of came away being, like—okay. He’s healthy. There’s nothing wrong with him at all. He was born with this difference. You know?” (Interview #10)

DISCUSSION

The present study explored hearing parents’ narratives of their experiences with their infants’ hearing screenings and ultimate diagnoses of HL in the US to better understand parents’ subjective experiences. Thematic analysis of the 13 parents’ narratives revealed two major themes: (1) hearing healthcare experiences and (2) parents’ early experiences with their child’s HL. Within these two themes the follow subthemes emerged: (1) downplayed newborn hearing screening referrals, (2) clinician-centered care, (3) medical expenses and health coverage, (4) parent-to-parent support, (5) “mom guilt”, and (6) realization of child’s HL and its effects.

The present study’s personal accounts from parents about their infants’ early hearing detection experiences revealed a number of different subthemes that emerged from the same, US newborn hearing screening mandate. These findings compliment past data (Danahauer et al. 2008; Elpers et al. 2016; Muñoz et al. 2011; Sapp et al. 2021; White et al. 2010) and contribute new information about hearing families’ direct, personal experiences with the *1-3-6* standards. For example, previous studies found that parents often interacted with clinician-centered professionals (Danahauer et al. 2008; Fitzpatrick et al. 2008; Russ et al. 2004; Gilbey, 2010) who downplayed newborn hearing screening results and the need for subsequent follow-up testing (Elpers et al. 2016; Sapp et al. 2021; White et al. 2010). While our study also revealed subthemes

that permeated parents' stories and have yet to emerge from the early HL screening and identification literature (i.e. medical expenses and health coverage, parent-to-parent support, and mom guilt). In this regard, the present study supports newer research that illustrates the importance and value of personal narratives in audiological practice (e.g., Barker et al. 2020, 2021; Steinberg et al. 2007; Ritter et al. 2020). Furthermore, the present findings revealed important moments early on in families' pediatric HL journeys when providers could intervene via enhanced family-centered approaches to care—something parents themselves have divulged as important.

The most prominent subtheme to emerge (across both themes of hearing healthcare experiences and parents' early experiences with their child's HL) was downplayed newborn hearing screening referrals. This theme is also a robust across the literature. Other studies (Elpers et al. 2016; Sapp et al. 2021; White et al. 2010) have echoed this finding that hearing screening results and the need for potential, subsequent follow-up care is poorly communicated with parents. This finding is especially concerning because downplayed screening referrals appear to be a common experience across the US and a roadblock to achieving EHDI's 1-3-6 standards. Suspicion of such a roadblock has been held by hearing health care providers nationwide for years and is further confirmed by findings from other studies where parents' perceptions and understanding of the hearing screening outcomes/follow-up care was unrealistic and/or inaccurate (Elpers et al. 2016; Pynnonen et al. 2016; Tattersall & Young 2006).

The second subtheme uncovered in our thematic analysis was that parents experienced more clinician-centered than family-centered interactions with providers as they navigated the HL screening and diagnosis process. The finding that parents' health care was primarily clinician-centered rather than family-centered is also consistent with previous work (Danhauer et

al. 2008; Fitzpatrick et al. 2008; Russ et al. 2004; Gilbey, 2010). For example, in Young and colleagues' work, parents expressed desires for (and appreciation of) providers who allow for more opportunities to ask questions, explicitly demonstrate empathy, and provide individualized care [i.e. specific to their families' needs (Tattersall & Young 2006; Young 2010)].

Medical expenses and health coverage was the final subtheme that emerged from our parents' narratives within the theme of hearing healthcare experiences. To our knowledge no study to date has reported on parents' financial worry or stress during the newborn hearing screening and early HL diagnosis process. However, parent concerns about when discussions of insurance coverage or financial obligations occurred were salient in our corpus. Parents shared that providers emphasized the family's responsibility for payment/insurance coverage very early in their babies' hearing health care journeys, at a time when the parents themselves had more pressing concerns about their child's hearing. This is notable because families who are unable (or threatened by the potential inability) to cover the costs of newborn hearing screening in the US experience significant stress and are often the same families who do not seek a full audiological evaluation following a "failed" newborn hearing screening (Hedderly et al. 2003; McManus et al. 2010; Russ et al. 2004; Zan & Scharff 2015). These findings regarding financial worry and distress parallel previous work noting financial concerns centered on the acquisition or use of listening devices in adult patients (e.g., Ritter et al. 2020; McCormack & Fortnum, 2013).

The subtheme of parent-to-parent support was the first to emerge from our second theme: parents' early experiences with their child's HL. Narratives revealed that parent support provided families with advice, comfort, empathy, as well as perspectives on HL and child development. These findings make sense given that previous research demonstrated benefits of parent-to-parent support for parents of children with newly diagnosed with health challenges (Dahan et al.

2020; Hall et al. 2015) and HL in particular (Henderson et al. 2014). In our narratives, though, parents revealed they deeply valued the benefits of peer-to-peer connection even *before* an actual HL diagnosis occurred. This is remarkable given that hearing health care providers often encourage parent-to-parent interactions *following* the initial diagnosis of pediatric HL (Nickbakht et al. 2021).

Our mom guilt subtheme was uncovered as parents shared some of their initial emotions and thoughts about their newborns' HL. It is the first of its kind to be formally documented in the pediatric HL literature despite being referenced for years by clinicians and families across the globe (e.g., Gardiner et al. 2018; Gilbey 2010; Kampfe 1989; Luterman 1997). The strong sense of responsibility for and guilt about their newborns' HL is also like that felt by other mothers of children with chronic illness (Cardão et al. 2021; Gilbey 2010; Korver et al. 2017; Lee & Lee 2021; Steinberg et al. 2014). Our final subtheme of a new reality is also the first of its kind to be documented in the pediatric HL literature. It too, however, is a colloquially familiar one [think Emily Perl Kingsley's popular essay "Welcome to Holland" (1987) that is shared among hearing families affected by childhood HL]. This finding of a new reality mirrors the findings of past research exploring parents' perspectives on their children's various disabilities and their emotional reactions when they came to accept the reality of their child's health differences and diagnoses (Cardão et al. 2021; Hedderly et al. 2003; Kandel & Merrick 2003; Kerr & McIntosh 1998).

Improving Infant Hearing Loss Screening and Diagnosis Experiences Through Family-Centered Care and Provider Education

As previous studies have suggested (Friehe et al. 2003; Nickbakht et al. 2021; Schmulian & Lind 2019; Shulman et al. 2010), expanding provider support and implementing counseling

techniques could lead to improved parent experiences and clinical outcomes for children with HL. However, many clinical practices that employ a clinician-centric approach to care fall short in providing support, information, and hearing healthcare to families (Farre & Rapley 2017). One remedy may be family-centered care emphasizing narrative medicine. Opportunities for a family-centered approach to care are numerous throughout the newborn hearing screening and HL diagnosis process. Parent narratives and the themes that emerged from our current corpus suggest that attending to the stories parents tell might be particularly useful for pediatric hearing healthcare providers. Especially, because they could use them as a tool to drive necessary improvements in models of family-centered hearing healthcare (Kuo et al., 2012).

When hearing health care providers make time for parents to share their stories, it allows an opportunity for the core concepts of family-centered care—dignity and respect, information sharing, participation, and collaboration—to naturally drive the family's care provision (Johnson & Abraham, 2012). The current narratives suggest that such practitioner behaviors are particularly important during the newborn hearing screening experience. This is often the first encounter that parents have with hearing health care professionals and the time at which they may receive down-played results that yield detrimental, delayed diagnoses. A family-centered approach to providing hearing screening results could include clinicians using patient/family friendly language, encouraging follow-up care, answering questions, and offering empathy as needed. Hearing health care providers are also encouraged to collaborate with other professionals/fields (i.e. interprofessional health care team; Schwartz et al. 2016) to best support families as they navigate the HL screening and diagnosis process. For example, introducing a patient navigator (Bush et al. 2017), social worker, or financial/billing specialist early on could be key to supporting parents' well-being and their children's later development (Eisenhower et

al. 2009). Clinician-facilitated parent-to-parent support following the newborn's referral for a diagnostic hearing evaluation may also benefit families by providing families access to connections within a close geographic location as well as psychological support through the lived experiences of other parents. Such connections could help parents by validating their emotions, building trust, and coping with the challenges associated with pediatric HL (Ainbinder et al. 1998; Pasold et al. 2010; Roman et al. 1995).

The narratives within our corpus revealed that for some parents with typical hearing, a newborn HL diagnosis can be an exceptionally difficult experience that provokes strong emotions. This was particularly salient within the subthemes of mom guild and a new reality. One way health care providers could implement family-centered care during this time of diagnosis is by explicitly inviting patients to tell their stories as they mindfully listen (Clark et al. 2021; Kuo et al. 2012; Nickbakht et al. 2021). The audiologist could recast any portions of the parent's story necessary to ensure their proper understanding. Then the family and clinician can move forward together with shared planning for the next steps in care. The field of narrative medicine suggests several benefits of making time for patient stories during clinical care. These include supporting patient education, improving health decision-making skills, building provider awareness (Charon 2001; 2006). It stands to reason that similar storytelling (on the part of the patient/family) and storylistening (on the part of the care provider) behaviors could lead to notable improvements in family care during the time of early HL diagnosis as well as initial screening.

Finally, one important implication of the current findings is the need for improved education targeting both current and future hearing health care providers. Education focused on improving practitioners' communication with families of newborns who fail their hearing

screenings is particularly needed (e.g., EHDI's updated training module targeting hearing screeners' communication with families⁵). Provider training is also needed when it comes to executing diagnostic evaluations with infants. This need is illustrated by Wendy's statement from our corpus, "...we went to the audiologist at our health care facility and was kind of nervous because she—I wasn't—she seemed a little apprehensive to be working on such a tiny baby." (Interview #4) and corroborated by recent research by Sapp and colleagues (2021). They showed hearing health care quality, speed, and accuracy was improved by training educational audiologists on diagnostic testing for infants. Lastly, one way to facilitate a move in the direction of improved person-/family-centered care is via the mindful implementation of counseling skills during audiological care. An important place for such education to begin is in university graduate programs as they prepare audiology students for future practice (Luterman 2020).

Limitations and Future Directions

The present study offers valuable information regarding parents' narrative experiences with their infants' hearing screenings and ultimate diagnoses of HL but is not without limitations. The chief limitation of this study is related to our homogenous sample. The most recent census data states that 36% of adults in the US have a college degree (US Census Bureau 2020); however, our study had a far greater percentage in our sample (92%). Furthermore, parents who are not white, middle- or upper-class socioeconomic status potentially would have different experiences with their newborn's hearing screening and HL diagnosis than what is presented in the current study as they face other systemic challenges to healthcare (Andersen et

⁵ On 1 October 2021 the Early Hearing Detection and Intervention's National Technical Resource Center introduced an updated version of their *Newborn Hearing Screening Training Curriculum (NHSTC 2020)*. The training includes a well-developed module focused on screeners' communication with families and providers. This course can be viewed instantly online for individuals who are not interested in earning continuing education units. The training can be found here <https://www.infanthearing.org/nhstc/index.html>

al. 2002; Hall et al. 2015; Weinick & Krauss 2000). The stories of Black mothers centered on newborn hearing screenings could be especially fraught with challenges given what is already known about the morbid risks associated with their labor, birth, and post-natal experiences (Altman et al. 2019; Collins et al. 2021).

In conjunction with demographics, volunteer bias could have influenced the themes we uncovered. The parents who volunteered to participate in our study may have been individuals who had exceptionally negative experiences (compared to the general population of hearing parents with deaf infants) and as such were more motivated to share their experiences to inform research and influence possible change. It is also important to note that parents did not hail from all states across the US. EHDI programs in the US are administered and overseen at the state-level. This means there are varying levels of state support throughout the newborn hearing screening and early diagnosis. These program differences could impact parent experiences during newborn hearing screening and throughout the HL diagnosis process. Another limitation of our study is the variance in timelines for when parents were interviewed in relation to when their child's hearing was screened and diagnosed. Some parent's infants were recently diagnosed while others were years beyond diagnosis. (The youngest infant was 3 months at the time of the interview. The oldest infant was 4 years at the time of the interview. See Table 2.) These temporal differences could affect parents' memories of events, the emotional aspects of their narratives, and what they chose to share about their experiences. Lastly, it is possible that some parents felt restrictions on what was appropriate to share with the researcher in the context of each interview.

It is our long-term goal to use these narratives in a way that allows us to better understand parents' EHDI experiences and improve family-centered hearing healthcare—particularly during

infant hearing screening and HL diagnosis. Further qualitative research exploring the unrestricted narrative accounts of *all* hearing parents' experiences during the EHDI process is thus needed.

Future studies could utilize a mixed methods or quantitative approach to validate improvement in health outcomes and satisfaction for parents when audiologists utilize counseling skills rooted in person-/family-centered care. While another study motivated by our findings could employ narrative therapy as a method of supporting parents during their and their family's pediatric hearing healthcare journey and explore the intervention's potential, long-term benefits to the parents and their children.

Conclusions

In the present study, hearing parents shared their stories surrounding their infants' early hearing screenings and HL diagnoses. Because we focused on narratives, parents were able to create logic out of complex events (Becker, 1997; Koenig Kellas, 2014) and we were able to uncover previously undocumented subthemes that exemplify their perspectives during the newborn HL screening and diagnosis process. This knowledge moves the field of pediatric hearing healthcare closer toward a family-centered approach that could address concerns and expectations surrounding newborn HL, while simultaneously working toward JCIH's goals (2019) of the earliest HL detection, diagnosis, and intervention for these children.

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Appendix

Interview Probe

Today, I'm going to ask you to tell me the story about your early experiences as a parent of a child with hearing loss. I'm particularly interested in your experiences during your baby's newborn hearing screening at the hospital and during their follow-up diagnostic appointment. During your story, I will remain quiet until you reach the end. After your story, I will ask you some follow-up questions.

There's no right way to tell your story but I am interested in hearing about it from the beginning and then step-by-step until the end...Like any novelist, you can edit the chapters of your story you already wrote—you can add more detail or retell certain sections, whenever and however you would like. I'm also interested in the cast of characters. In other words, who was the healthcare provider who first informed you of your baby's hearing loss and who was with you during the experience or who was with you during this first visit to the pediatric audiologist?

Ok, now it's time for you to tell me your story. Why don't you start by telling me about when you first learned your baby failed the newborn hearing screening? Then please tell me about the follow-up appointment(s) with the audiologist and when it was confirmed that your baby has a hearing loss. Finally, end with telling about how your experiences with the difference healthcare provides shaped your ability to parent a child with HL.