**Exploring the Types of Stories Hearing Parents Tell
About Rearing their Children who use Cochlear Implants**

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ABSTRACT

Objectives. The majority of children born in the United States with hearing loss are born to parents with hearing. Many of these parents ultimately choose cochlear implantation for their children. There are now decades of research showing that these children's speech, language, listening, and education, seem to benefit from cochlear implantation. To date, however, we know little about the experiences of the parents who guided these children throughout their journeys. We propose that elucidating the types of stories these parents tell is a first step toward understanding their varied experiences and has the potential to ultimately improve healthcare outcomes for both children and their families. Thus, to better understand parents' experience, we asked the following research question: what types of stories do parents with hearing tell about rearing their children with hearing loss who use cochlear implants?

Design. In this prospective qualitative study, we employed a narrative approach. Specifically, we conducted narrative interviews with 20 hearing parents who are rearing young children (mean age = 5.4 years) born with hearing loss who use cochlear implants. We then used thematic narrative analysis to identify recurring themes throughout the narratives that coalesced into the types of stories parents told about their experiences.

Results. Thematic narrative analysis revealed five story types: (1) stories of personal growth, (2) proactive stories, (3) stories of strain and inundation, (4) detached stories, and (5) stories of persistence.

Conclusions. In the present study, different types of stories emerged from parents' experiences that share common events—a family's baby is identified at birth with unexpected permanent hearing loss, the family chooses to pursue cochlear implantation for their child, and then the family raises said pediatric cochlear implant user into adulthood. Despite these

similarities, the stories also varied in their sensemaking. Some parents told stories in which a positive life narrative turned bad whereas others told stories in which a narrative of surviving turned into one of thriving. These findings specifically contribute to the field of hearing healthcare by providing professionals with insight into parents' sensemaking via the types of stories they shared centered on their perceptions and experiences following their child's diagnosis of hearing loss and their decision to pursue cochlear implantation.

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On average, three in every 1,000 babies born in the United States (US) are diagnosed with permanent hearing loss (HL; CDC, 2003) and 90% of the children born with HL are born to hearing parents (Mitchell & Karchmer, 2004). Many of these parents subsequently choose cochlear implants (CIs) as an intervention for their children (NIDCD, 2012). Research has consistently demonstrated that CIs are an efficacious treatment for children with HL (Choi et al., 2017; Dillon et al., 2004; Marshark et al., 2007; Spencer et al., 2003; Tomblin et al., 2005). Coping with their children's HL and subsequent cochlear implantation can nonetheless result in negative ramifications for parents, who report feeling overwhelmed and inadequate (Blank et al., 2020; Fitzpatrick et al., 2008; Flaherty, 2015; Kurtzer-White & Luterman, 2003; Zaidman-Zait, 2007; 2008). On the other hand, researchers have also found that these feelings often evolve into more positive ones as their children grow and their communication and self-reliance improve with extended CI use (Kumar et al., 2015). Regardless of the variation noted across caregivers' response to parenting children with HL, a HL diagnosis in infancy often causes a disruption in the family's and parents' lives that is reflected in the stories they tell about their experiences (e.g., Fitzpatrick et al., 2008; Hardonk et al., 2011; Scharp et al., 2018).

When people experience major disruptions to their lives, they often turn to storytelling as a way to make sense of their experience (Becker, 1997). Attending to these stories is useful because they simultaneously construct and reflect the narrator's identities (McAdams, 2006). Pinpointing these variations in identity is particularly useful considering that they frequently correspond to individuals' psychological, physiological, and relational health (Koenig Kellas, 2018). Existing studies point to the major variations in these identity constructions (see

Pederson, 2014; Scharp & Beck, 2017; Scharp et al., 2020). Thus, the goal of the present study was to understand the types of identity constructions that hearing parents of young children with CIs produce when sharing stories about their parenting experiences. A better understanding of these parents will enhance the field's current understanding of this population and, in the long-term, such stories might also ultimately help clinicians improve the counseling and support they provide to parents of young children with HL.

Parents' Experiences Rearing Pediatric CI Users

Cochlear implantation is an efficacious treatment for children with HL. There is robust evidence demonstrating these children's remarkable progress in speech production (Dillon et al., 2004), speech perception (Choi et al., 2017), language skills (Tomblin et al., 2005), reading (Spencer et al., 2003), and academic success (Marshark et al., 2007) throughout childhood. Despite the communication successes noted in children with CIs, the experiences parents have while coping with the impact of pediatric HL and cochlear implantation are likely an important variable that also affect the development of their children who use CIs. Just as researchers have noted in the parents of children with other chronic health conditions (Cohen, 1999; Cousino & Hazen, 2013; Pinquart, 2018; Reed-Knight et al., 2018). To date, some researchers have already taken the first steps to explore parental influences on pediatric CI users. They have specifically focused on parents' influence on pediatric CI users' executive functioning (Holt et al., 2013), speech (Holt et al., 2012; Kirkham et al., 2009), listening development (Noblitt, et al. 2018), and language skills (Blank et al., 2020; Holt et al., 2012; Kirkham et al., 2009; Moeller, 2000). Although this focus corresponds with the original intent of the CI device—to support speech and language development—such a view of development restricts our ability to learn about functional, holistic outcomes in children with CIs.

There is also a notable body of international research that utilized standardized questionnaires with the aim to better understand parents' expectations, experiences, and decision making centered on raising their children who use CIs. For example, in 2001 Nikolopoulos and colleagues' longitudinal questionnaire data from parents in the United Kingdom showed that their preoperative expectations were met or surpassed when it came to their children's communication, listening, and speech and language skills. Brazilian parents' receptiveness to the intervention process positively correlated with both their and their children's CI experiences (de Moura Silva et al., 2019). While data from Incesulu and colleagues' (2003) closed-set questionnaire revealed that parents in Turkey reported the CI decision making process to be one of the most stressful experiences of their parenting process. Though all of these studies provided a valuable foundation for better understanding parent experiences, they are limited. Specifically, when researchers employ either open- or close-ended questionnaires (as in the aforementioned studies) they are making decisions about what events in the parent-CI-experience are valuable. Those values are then directly expressed in the questions they compose and choose to ask parents (Ackroyd & Hughes, 1992). Such final data sets are thus often more a reflection of the researchers' preconceptions as opposed to the parents' direct experiences. The method of narrative inquiry could alternatively help uncover the nuance and detail of these parents' perspectives and experiences absent of the researchers' confines (Langellier, 1989; Wang & Geale, 2015). However, few studies to date have gathered and explored the individual stories of adults with hearing who parent children who are deaf and use CIs via a personal narrative approach.

Personal Narratives

Personal narratives (or stories) are one way to understand people's individual experiences and sensemaking. For many people, narrative is a method of thinking in addition to a means of transcultural communication that allows us to organize information and experiences (White, 1981). Storytelling also helps people make sense of their lives and develop reasons or justifications for complex events, such as a chronic illness (Llewellyn-Beardsley et al., 2019) and disability (Goodley & Tregaskis, 2006). This is especially notable in narrative medicine (Charon, 2001) where practitioners gather stories from patients as a means to connect on a more person-centered level. The stories of parents raising children with disabilities are particularly powerful, as they are the ones continually navigating the world around them in complex ways to negotiate and advocate for their children (Goodley & Tregaskis, 2006).

A small number of researchers to date have recognized the value of such a qualitative approach and employed it to improve the field's understanding of parents' perspectives and experiences during the pediatric CI process. For example, there is Mostafavi and colleagues' (2017) phenomenology study with parents and Punch and Hyde's (2011) mixed-methods study that utilized interviews with parents, teachers, and children. Nonetheless, much of the existing research in the audiological literature continues to prioritize quantitative approaches without recognizing that many aspects of person-/family-centered healthcare provision are difficult to study using experimental design (Dixon-Woods & Fitzpatrick, 2001; Russ, et al., 2004). This scarcity of qualitative narrative research is particularly disadvantageous in the field of pediatric aural rehabilitation where the patient's family—and their needs for coaching their child to success—should be seated at the center of care (Kuo et al., 2012). Scharp and colleagues (2018) recently took an important step in contributing to such qualitative research. For their study, they analyzed weblogs ("blogs") written by parents of pediatric CI users and uncovered four parent

identities: (1) advocates, (2) resilient parents, (3) obedient worriers, and (4) matter-of-fact narrators. The authors suggested, that these identities could help determine possible parent reactions to their children's HL diagnosis and treatment. These identities were also foundational for improving theoretical and clinical insights into parents' perspectives and experiences following their children's diagnosis of HL and cochlear implantation. However, recent research (Scharp et al., 2020) shows that people's narrative identities are different from the types of stories they tell. Scharp and colleagues' (2018) use of online narratives (i.e. blogs) also limited the initial insights gained from these parents. For instance, online data, although beneficial in some ways, does not allow researchers to solicit additional information about narrator's account. Such a limitation can subsequently extinguish opportunities to understand the nuance of a person's experience and/or to understand how they made meaning of a particular event. In addition, their study did not lend itself to uncover and document demographic characteristics of the parent authors. This lack of demographic information makes it difficult for researchers and clinicians alike to know/understand the cultural framework within which the parental identities emerged and employ the identities in a way that may improve family-centered care. We propose that a valuable next step is to extend Scharp and colleagues' work and gather real-time narratives directly from a diverse group of hearing parents that can be typed via narrative analysis.

Purpose of the Present Study

Despite the fact that parents are key to providing sound family-centered care and ensuring success in pediatric CI users, what we know about who they are and their perspectives is limited. Given the great variation across caregivers' responses to parenting children and the fact that parenting experiences can mean different things to different people depending on their point of view, it is likely that the types of stories parents told about rearing their children with

HL who use CIs would vary across families. To better understand the experiences of parents of young children with CIs, we asked the following research question: what types of stories do parents with hearing tell about rearing their children with HL who use CIs?

METHODS

Study Design

We employed a prospective, cross-sectional qualitative design utilizing narrative interviews for the present study.

Sampling

We employed snowball sampling in our study given the low incidence of pediatric HL. When we reached saturation (i.e. no additional themes emerged during analysis of the narratives) no further sampling was needed. Saturation was reached at Interview #7 (see *Verification procedures* for more details).

People were eligible for participation in the study if they (1) were 18 years old or older; (2) resided in the US; (3) communicated comfortably using spoken English; (4) reported having hearing within normal limits; and (5) parented a single child with HL who was no older than 10 years, received at least one CI at 2 years of age or younger in the US, and had at least 6 months of CI experience. We aimed to recruit a heterogeneous sample with regard to age, gender, socioeconomic status (SES), and residence. We thus recruited participants for the study in the following manners: (1) distributed letters to audiologists across the US for them to share with their pediatric patients' families, (2) posted fliers in local, public spaces, (3) posted fliers on social media and lab websites, and in local newsletters, and (5) word of mouth. Potential participants were instructed to contact the research lab if they wanted to participate and met the

inclusion criteria. After they reached out, a researcher sent an email to the parent with a survey link (see *Phase I* below for more details).

Participants

Twenty adults (18 females; 2 males) with hearing, who parent a child with HL who uses a CI(s), participated in this study and resided in various locations across the US. Four of the parents were married to each other (participants #3 and #4; #18 and #19).¹ These parents ranged in age from 26 – 45 years ($M = 36$ years; $SD = 5.4$ years). All participants identified as either White or Mexican. Table 1 displays detailed demographic information for the parent participants.

Table 1. Parent participants' demographic information.

Participant	Age	Gender	Marital Status	State of residence	Total Family Income	Education	Race	Native Language
Pam, #1	35	F	Married	Utah	\$75,001-\$100,000	4-year degree	White	English
Ruby, #2	31	F	Married	Utah	\$60,001-\$75,000	Graduate degree	White	English
Jane, #3	35	F	Single	Utah	\$75,001-\$100,000	4-year degree	White	English
Alex, #4	35	M	Married	Utah	\$75,001-\$100,000	4-year degree	White	English
Sydney, #5	28	F	Single	Illinois	\$10,001-\$25,000	Some college	Mexican (and Egyptian)	English
Jill, #6	44	F	Married	Idaho	Over \$100,000	4-year degree	White	English
Quinn, #7	38	F	Married	Florida	Over \$100,000	4-year degree	White	English
Paige, #8	38	F	Married	New York	Over \$100,000	Graduate degree	White	English
Katie, #9	26	F	Married	Philadelphia	\$35,001-\$50,000	4-year degree	White	English
Jennifer, #10	37	F	Married	Wisconsin	\$75,001-\$100,000	2-year degree	White	English
Candace, #11	29	F	Single	Florida	\$35,001-\$50,000	Graduate degree	Mexican	Spanish
Diane, #12	38	F	Married	Idaho	\$60,001-\$75,000	4-year degree	White	English
Rose, #13	45	F	Married	Utah	Over \$100,000	Graduate degree	White	English
Vanessa, #14	36	F	Divorced	Idaho	\$25,001-\$35,000	Some college	White	English
Courtney, #15	34	F	Married	Iowa	\$50,001-\$60,000	4-year degree	White	English
Carmen, #16	29	F	Married	Iowa	\$50,001-\$60,000	Some college	White	English
Leah, #17	42	F	Married	Iowa	\$35,001-\$50,000	High school diploma	White	English
Ron, #18	40	M	Married	Illinois	Over \$100,000	Graduate degree	White	English
Kendall, #19	41	F	Married	Illinois	Over \$100,000	Graduate degree	White	English
Ava, #20	31	F	Married	Georgia	\$60,001-\$75,000	Graduate degree	White	English

Note: participant = parent's pseudonym and interview number for the present study; ages are reported in years; F = female; M = male

Note that 45% (9 of the 20 participants) were 35 to 40 years of age. The majority of our participants were White (90%) and only 1 parent reported their native language as something other than English. A disproportionally high (relative to the US population at large) number of

¹ Note that we allowed parents from the same household to be included in our data set because we were interested in gathering individual stories from individual parents. Although two parents may be sharing the same experience centered on the same child, their experiences will be their own and reflect their own, individual identities and current well-being (Bartle-Haring et al., 1999; Deković & Buist, 2005).

participants had college degrees (35%) and graduate degrees (35%). Furthermore, 7 of these parents reported a total family income of \$50,001 or greater, likely placing them in the middle-

Table 2. Characteristics of the parent sample (N = 20)

	participants (N = 20)	
	<i>n</i>	%
Gender		
Female	19	95
Male	1	5
Marital Status		
Single	3	15
Married	16	80
Divorced	1	5
Total Family Income		
\$10,001-\$25,000	1	5
\$25,001-\$35,000	1	5
\$35,001-\$50,000	3	15
\$50,001-\$60,000	1	5
\$60,001-\$75,000	3	15
\$75,001-\$100,000	3	15
Over \$100,000	3	15
Education		
High school diploma	1	5
Some college	3	15
2-year college degree	1	5
4-year college degree	8	40
Graduate degree	7	35
Ethnicity		
Hispanic or Latino	2	10
Not Hispanic or Latino	18	90
Native Language		
English	19	95
Spanish	1	5

class income or higher within the US's economic class system (Rose, 2016). Table 2 summarizes the characteristics of the present sample. Despite an attempt to recruit a heterogenic sample reflecting a range of demographic characteristics; parents' gender, ethnicity, and native language were relatively homogenous in the present study (see *Limitations and Future Directions* for further discussion).

Procedure

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

Phase I. When an individual reached out to the lab and expressed interest in participating, they were sent a link to the aforementioned *Qualtrics* (2020) questionnaire via email. The potential participant then completed the questionnaire to confirm they met the study's inclusion criteria. This questionnaire included an IRB-approved letter of informed consent, a Health Insurance Portability and Accountability Act (HIPAA) authorization form, and a series of 18 demographic questions. After each individual completed the questionnaire, a researcher then scheduled a narrative interview with them.

Phase II. A female researcher with 2 years of graduate training in clinical audiology and narrative interviewing, conducted the majority of interviews ($n = 13$). The third author, also a female researcher with 3 years of graduate training in clinical audiology and narrative interviewing, conducted the remainder of the interviews ($n = 7$). Both researchers are White, native English speakers, with hearing within normal limits. Neither researcher is a parent.

Both researchers followed the same narrative interview protocol/script without deviation in order to minimize any potential direct or indirect influences of the researchers (see Appendix for the protocol). Interviews were conducted face-to-face ($n = 1$) in the first author's lab or via

telephone ($n = 19$)². At the beginning of the interview, the researcher briefly introduced herself as a student researcher working on her clinical research project to earn her doctorate of audiology degree. She then confirmed that the participant gave their informed consent via the email questionnaire. The researcher then asked the parent to "...tell me the story of your experience deciding to implant you child..." (see Appendix for detailed script). Throughout the narrative interview the researcher remained silent as possible in order to minimize their influence on each participant's narrative.

All interviews were recorded using either a *Marantz Professional PMD661 MKII* or a *Tascam DR-05* portable handheld digital-audio recorder with a *Shure Professional SM81-LC* microphone. Only the researcher and participant were present during the interview. Following the interview, the participant was compensated for their time, either with \$25 cash or a \$25 electronic gift card. The mean interview time was 37 minutes; 23 seconds, with a range of 18 minutes; 32 seconds to 1 hour; 14 minutes; 5 seconds. All participants completed the interview and remained in the study. No repeat interviews were conducted.

Phase III. After the completion of data collection, we uploaded the audio files from the digital recorders to an *Apple iMac* computer. Research assistants then used *Microsoft Word* on an *Apple iMac* computer running *Express Scribe Transcription Software Pro v 6.10* in combination with an *INFINITY Foot Control* transcription foot pedal and *Sennheiser HD 280 Pro* circumaural headphones to transcribe the recorded interviews. During the transcription process all transcripts were de-identified, accordingly all proper names and places mentioned by the participants were replaced with pseudonyms. The 20 completed transcriptions yielded a total of 414 pages of single-spaced text. None of the transcripts were returned to the participants for comment or

² Research suggests that interview modality does not seem to impact the quality of interviews (Carr & Worth, 2001; Stephens, 2007).

correction. Finally, we contacted each child's audiologist to confirm their diagnosis of HL and CI use. These healthcare data can be found in Tables 1 and 3.

Data analysis

Thematic narrative analysis. For the qualitative aspect of the study, the authors³ coded the data and employed thematic narrative analysis (TNA) to identify the types of stories the hearing parents of children with CIs shared. TNA is a corresponding method of analysis used when employing a narrative approach. Riessman (2008) originally developed the method to examine narratives that are intact, as opposed to identifying the themes within a narrative. Thus, the unit of analysis in the present study was the transcribed dialogue from a single parent's story. This means instead of attending to the themes within a narrative, we "typed" the entire narrative as an identity construction. We followed an adapted TNA procedure (Braun & Clarke, 2006) to assign story type to each of the 20 participating parents' narratives based on this unit of analysis. In order to assign the story types, we engaged in the following steps: 1) became familiar with the data, 2) identified emergent themes, 3) defined and named the themes, 4) generated and labeled emergent story types based on the commonalities across each of the narratives, and 5) located compelling exemplars. 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).

³ It is important to note that the first author is a White, female, native English speaker. She has hearing within normal limits and is a parent to a hearing child. She has over 20 years of experience working with parents of young children with hearing loss and 5 years of experience in narrative analysis. The second author is an Asian, female, native English speaker. She has hearing within normal limits and is not a parent. She has years of experience in the field of health communication and a decade of narrative analysis. Neither the first nor second author had interactions with the present study's participants, only their de-identified narratives.

Verification procedures. To verify our qualitative findings, we employed the following five procedures common in rigorous qualitative research: 1) referential adequacy, 2) peer debriefing, 3) investigator triangulation, 4) audit trail, and 5) exemplar identification (Lincoln & Guba). Referential adequacy was accomplished by first splitting the data after Interview #11. Analysis of the first 10 interviews was independently and thoroughly conducted by the first and third authors. During peer debriefing, we discussed differences in our findings and came to a final agreement across all defined themes and codes amongst the first and third authors. We then engaged in investigator triangulation when the first and third authors discussed the findings with the second author, where collectively they solidified the categories and decided on final theme labels. In other words, we debated through differences in our findings and came to a final agreement across all defined themes and story types (Lincoln & Guba). We defined nine themes after the analysis of the first 10 interviews. Saturation was reached at Interview #7, which then allowed us to continue with referential adequacy. Thus, we then analyzed the remainder of the data, which included 10 more interviews; no additional themes emerged during analysis of these remaining narratives. Throughout the analysis, we kept detailed electronic notes in *NVivo* software (QSR International, 2018) to track codes and decision-making when identifying the story types (i.e. audit trail). Lastly, we found exemplars for the parents' narratives to best illustrate each story type that emerged from the corpus (i.e. exemplar identification).

RESULTS

Story Types

Five, mutually exclusive, story types emerged from the current qualitative data set: 1) stories of personal growth, 2) proactive stories, 3) stories of strain and inundation, 4) detached

stories, and 5) stories of persistence. See Table 3 for brief descriptions of the themes and story types that arose from the TNA.

Table 3. Story types and contributing narrative themes.

story types	contributing themes
Stories of personal growth	
	<i>worried</i>
	<i>discouraged</i>
	<i>overjoyed</i>
Proactive stories	
	<i>accepting</i>
	<i>decisive</i>
	<i>proactive</i>
Detached stories	
	<i>detached</i>
	<i>restricted</i>
Stories of strain & inundation	
	<i>discouraged</i>
	<i>frustrated</i>
	<i>sad</i>
Stories of persistence	
	<i>surviving</i>
	<i>determined</i>
	<i>committed</i>

Stories of personal growth. Stories of personal growth were the most robust and salient story type to emerge from the present corpus. These stories follow a classic framework: (1) they begin with a turning point; (2) then a crisis is introduced, and (3) finally there is a resolution reflecting positive change in the parent's life.

In this study, for example, Kendall's narrative begins with a clear turning point and crisis in the life of this parent with hearing—the diagnosis of her newborn baby's HL.

And I can remember—um—I was driving home and she called, and she said, “We have the results from—from Alex’s hearing test.” And—um—was I in a place where I could talk about the results? So—I can remember [CRYING] pulling over to the side of the road and I can remember Stephanie telling me that Alex had profound hearing loss in both ears [CRYING]. And essentially that—um—that what it boiled down to (once we got all the final numbers) was that I would have to be a jet airplane or a vacuum cleaner for my son to hear me. Um—so—I guess—when you talk about emotions—um—my biggest fear at that point in that time was that I could—that I would—never connect with Alex in the same way that I connected with his older brother because of the lack of—of sound. And the reason I say that is my family is a—a long line of musicians and [CRYING]—so—that was part of—of—that was at the core of how I communicated with people—was through music. And I was not sure that I would ever have that connection with Alex. (Kendall, Interview #19)

As Kendall’s narrative nears the end, her negative experiences fade however, and her story of growth reveals an eventual overcoming with a more positive outlook toward the future.

So far, he’s done fine that route [undergoing cochlear implantation]—um—um—but just—um—I can remember the sigh of relief last year when he started reading. That’s when I really felt like he’s gonna be okay. He’s—you know, that’s—that’s the point in time where I really thought, “We got it. We got it there.” I mean—it’ll always be a mountain to climb, but I feel like that was the first time I felt like we really—um—we’d climbed the hardest part of the mountain and we’re seeing some really nice views at that point [CRYING]. (Kendall, Interview #19)

Overall, stories of personal growth took a redemptive turn, such that parents were able to learn important lessons and ultimately overcome their distress (McAdams, 2006).

Proactive stories. The proactive stories revealed parents who work to control their children's hearing healthcare outcomes by immediately taking steps to intervene and respond to their infants' HL diagnosis, rather than grieving or waiting to be instructed on what steps to take. Proactive narratives revealed parents who seemed to "hit the ground running" while going above and beyond when advocating for or meeting their child's needs. Ruby's proactive story reflects these parenting behaviors.

We called everyone. And we just saw the benefit of giving Drew the option to hear. And we knew that with the right support and intervention and early implantation, we just had a feeling that—uh—Drew would be okay with cochlear implants. And—uh—we definitely wanted him to be mainstreamed and he's living in a hearing world—in a hearing family—and—uh—we figured we would support him any way he wanted to go when he got older. But for now, we're just giving him the best option. Um—let's see—so Drew was implanted—his birthday's in [month] so he turned one in [month] and was implanted in [month]. And—so—he—um—that was about a year and a half ago. And—um—we had been learning all kinds of strategies—you know, before he turned one—from early intervention, about things that we were already practicing and putting into our routine. Um—as far as bombarding him with language and narrating our day and all these things that we were already practicing, so when he was implanted, we already had all these strategies in place. And we feel like that we've—we feel like we've had a lot of support with early intervention and our audiologist and

teleintervention through [state university]. And—um—the strategies that we’ve learned have made it very—um—wouldn’t say easy—but—um—it’s been very simple. I guess? Very clear and—and simple to incorporate some of Drew’s therapy and practice into our regular routine. Um—so—we are (for the last—really the last two years) we have been just [LAUGHTER]—we just talk all the time in our house. And we are constantly working with Drew and reinforcing his speech goals. And we probably look at speech assessments and milestones at least twice a month to see where Drew is and where the gaps are—and trying to catch him up to—um—where a typical 2.5-year-old should be. And at this point he—I believe he would fall right in the normal range for his speech and language. Um—and he’s hearing—uh—right about normal to mild hearing loss. So—he’s doing remarkably well, and we couldn’t be happier with the progress. Having said that—uh—what you can’t see on paper is the amount of work it’s taken to get him where he is. So—we’re constantly working and practicing and worrying [LAUGHTER] about his progression as he gets closer to preschool. (Ruby, Interview #2)

Detached stories. The third type of story we identified was the detached story. Unlike other stories, parents who told these types of stories sound as if they are conveying a report about their child, rather than their own personal experiences. When these parents were asked to describe their experiences and “tell [their] story of [their] experience deciding to implant [their] child”, they recounted facts and details regarding their child’s HL, medical appointments, and CI treatment. Take for instance, the following narrative from one parent, Vanessa, that reveals her daughter’s birth wrought with a number of complications in addition to HL.

Um—Sadie was born...she was emergency c-section. She—um—they don't know—um—why she was—when she came out, she was bleeding underneath her skin. Um—she was life-flighted to [state university]—the university of [state] medical center hospital there—and—um—she—um—started having seizures along the way and—so—um—she was given medicine for that. Um—later on we learned that she had called—it's called thrombocytopenia—where her blood doesn't clot—um—when it was supposed to. Sadie was—before she could go home from the hospital—we stayed for six weeks in the NICU. Um—before she could go home from the hospital we did—um—her hearing test like every normal child. Um—Sadie failed that tw—twice or three times and—um—so—then we were referred to—um—the audiologist to go back and get a hearing test done. Um—we did that hearing test—um—two or three—two times—I think—um—'cause they wanted her to be asleep while they did the process—the hearing test. Um—then—after we—um—it—both attempts were she—that she couldn't hear anything. Then they referred us to—um—the audiologist to talk about cochlear implants. Um—my husband and I—um—I went to the appointment and talked to—um—the audiologist. We also talked to an ENT surgeon and—um—talked about what it all entailed and how—how it would work and everything to that. Um—in the meantime Sadie had hydrocephalus. We find out that she had hydrocephalus—which is—um—pressure in her brain. (Vanessa, Interview #14)

As one can note from Vanessa's story, parents sharing detached stories seem to almost situate themselves as third-party narrators to own families' experiences. Where a listener might anticipate an emotional reaction in their stories, these narrators lacked them almost all together.

Stories of strain and inundation. Next the stories of strain and inundation emerged.

This story type reflected themes that were opposite to those that emerged in the positive stories of personal growth. Rather these stories revealed parents who seemed continually stressed and overwhelmed by their children's HL, CI use, and its accompanying intervention. In other words, despite the passage of several years after the birth of their children, these narratives reflected parents who seemed to have surrendered to the number of challenges they face associated with caring for their children with HL. These stories of strain and inundation often begin with descriptions of the child's HL diagnosis that emit a tone of doubt for the future, grief, and even guilt. For instance:

And then I also had a lot of blame that I put on myself—like, “Maybe I should’ve not drank so much sugary drinks during pregnancy. Or maybe I should have exercised more. Or maybe I didn’t eat just right.” I just—like—was blaming myself for his—um—problem [hearing loss]—like—I—I don’t know the right word for this. Cause it’s not—it’s not a problem [NERVOUS LAUGHTER], but it was at the time...Um—so—while I was pregnant with him, I did have gestational diabetes. So—I’m like—I was blaming his hearing loss on my diabetes and I just was all sorts of [NERVOUS LAUGHTER] screwed up—emotionally—blaming myself for his diagnosis. (Jane, Interview #3)

Often these feeling continue to be expressed throughout the duration of the parents' stories. It makes sense that this is the case, because within their stories of strain and inundation parents often reported that they did not feel as if they received enough support from the healthcare professionals (e.g., nurses, audiologists, physicians) they interacted with during their

journeys. This lack of support seemed to contribute to parents' continued frustration and sadness parents shared throughout their narratives. For example,

I'm like, "Okay—he's—there's just some fluid stuck in his ear." And then we went back to the hospital for his next test. And he failed again. And then I was like, "What do I do now?" And they just—they handed me pamphlets and I'm just like—it wasn't very comforting. Like—it was the next step, but it wasn't very comforting. I was like—'cause I was devastated. [NERVOUS LAUGHTER]

(Jane, Interview #3)

Unlike stories that acknowledged difficulty but ultimately concluded positively, these stories of strain and inundation ended on a negative note. In other words, stories of strain and inundation lacked the redemptive quality evidenced by other narrative types.

Stories of persistence. Finally, stories of persistence emerged from the story corpus. These parents' stories revealed that no matter what challenges they faced through the children's HL and CI journey, it was both necessary and sufficient for them to persist and (ultimately) ensure their children's best care. In the following exemplar, Courtney, describes some of the challenges her family faced both at the time of her son's HL diagnosis and during his time in school. Despite these challenges, she persisted on her son's behalf.

So—I was [age] and had given birth to my son and—um—was actually alone in the hospital the—the second night. And they asked if they could take him to the nursery so I could sleep. Um—and they did. And at about 4:00 in the morning, a young girl came in, shook me awake, threw a pamphlet at me, and said, "Your kid can't hear. You're gonna have to see the pediatrician in the morning." Um—which, needless to say, was fairly devastating to a young woman with her first

child—um—anticipating everything to be absolutely perfectly—you know—to go perfectly. Um—so—I of course was like, “What do you mean? What do you mean that he can’t hear?” And she was like, “All I can tell you is that he did not pass his newborn hearing screening in either side and you’re gonna have to have follow-up. Um—here’s the name of an audiologist and the pediatrician will be in to see you at, like, 8:00.” And of course, I was like, “Well, what time is it?” “4:00 in the morning.” So—that was horrible—probably four of the worst hours [NERVOUS LAUGHTER] of my life—waiting. Um—just waiting. (Courtney, Interview #15)

Courtney continued about the challenges she faced as her son grew older:

Um—I felt like we weren’t given much of a choice at that point. Uh—and that was very difficult. Um—the teacher, the preschool teacher, we just had a very bad experience with that particular teacher—did not understand cochlear implants. She did not care to understand cochlear implants. Um—at this point, we had started—um—noticing behavioral issues that—uh—upon talking to—I—I had a couple friends that we met in therapy. So, I had three or four other moms—all boys, all the exact same age, all implant—planted at the same time. All four kids were going through the same—um—emotional and behavioral issues at the same time, as they consistently have. Um—and so—you know—we had done research. And research—and we just—we really couldn’t find a lot on behavioral issues on kids with cochlear implants and any kind of school format, let alone a public-school format. Um—and in the end, the preschool teacher—um—put my son in time-out on a cot for three hours. Uh—and that was kind of my breaking point

and I was just like—you know—he’s not coming back. This is ridiculous—like—I live three blocks from the school. There’s absolutely no reason for my 4-year-old to be in time-out and—um—she just said, “He—he wasn’t listening. He won’t listen.” Uh—and I felt like I had addressed that issue with her numerous times...Like—this is difficult enough for him, having someone that doesn’t sign and he doesn’t have that added—um—communication ability and she would—like—they would be out at recess and rather than—um—her going over to the area that he was at and saying—you know, “Jack, your mom’s here.” She would just talk into her [personal FM] microphone. Uh—and that was just really, really—the preschool was a very frustrating experience for me. Um—there was another kiddo in his class with a disability at the time. And the other mom was having even more issues than I was. And she ended up actually being fired [the preschool teacher]—um—because she locked our kids—uh—in a room by themselves for hours on end—um—which is not acceptable, I don’t think, to anyone. Um—[LAUGHTER] that—that you would do that to any 4-year-old. Um—so—she ended up being fired. (Courtney, Interview #15)

In this example, it is clear that Courtney had to garner resources, rely on her social network, and continuously advocate for her child. Indeed, stories of persistence evidenced the narrators resolve to face the challenges that might negatively impact their children’s lives.

DISCUSSION

In the present qualitative study, we typed the stories of parents rearing young children with HL who use CIs. As we predicted, parents shared a variety of story types. Specifically, thematic narrative analysis of the 20 narratives revealed the following five story types: (1) stories

of personal growth, (2) proactive stories, (3) stories of strain and inundation, (4) detached stories, and (5) stories of persistence.

The present study's personal accounts from parents of children with HL who use CIs revealed that there are a number of different types of stories that emerge from experiences that share common events—a family's baby is identified at birth with unexpected permanent HL, the family chooses to pursue cochlear implantation for their child, and then the family raises said pediatric CI user into adulthood—but varied in meaningful ways. Findings from the present study both compliment and extend what we know about these parents' experiences. For example, Scharp and colleagues (2018) found that parents constructed themselves as worriers, advocates, and resilient people. While our study also revealed the ways these concepts (e.g., worry, advocacy, resilience) permeated different types of stories. Specifically, the current findings illustrate the ways that these concepts permeate many different types of narratives but take different turns and coalesce into different combinations. By focusing on story types in the present study, we presented narrative arcs that avoid essentializing people's experiences into a singular identity. In this regard, the present study supports new research that illustrates why it is important to not only study identity constructions but also story types (Scharp et al., 2020). Furthermore, the present findings not only extended those of Scharp et al. (2018) but also the work from both the fields of narrative research and audiology.

The most prominent story type from the present study—stories of personal growth—commonly occurs in the field of narrative research (Lilgendahl & McAdams, 2011). There redemptive stories of personal growth are also closely linked to adults' positive well-being and self-transformation (Bauer & McAdams, 2004), similar to the transformation noted in the parents

of Nikolopoulos and colleagues' longitudinal study (2001) exploring their views and expectations of pediatric cochlear implantation.

The proactive stories in our study reflected themes that harken to those of the advocate in Scharp et al. (2018). In particular, their advocate identity echoed notions put forth in research addressing uncertainty and chronic illness (Brashers, 2001) showing that people will shield themselves from the effects of uncertainty by developing structure and routines. Indeed, proactive stories featured a narrator who foregrounded productive action (e.g., reinforcing speech goals) while backgrounding negative emotions (e.g., worrying but still working and practicing). This resilience behavior is evidenced strongly in Ruby's story (Interview # 2) as she sought information, set goals, made plans, and enacted them.

The detached stories that emerged from the present corpus are particularly remarkable. This story type reflects many of the same themes noted in Scharp and colleagues' (2018) matter-of-fact narrator—a new identity that had not been noted in the literature beforehand. In the future, researchers should try to better understand the why and to what end narrators tell stories in this detached way, especially considering detached stories typically evidenced less of the characteristics that make narratives coherent (e.g., detail orientation, cause-effect, congruence of affect, sense-making; see Baxter et al., 2012). Because narrative coherence often reflects mental well-being, it is also possible that detached stories potentially reflect parents inability to cope with the impact of HL and CIs (Fisher 1987; Labov, 1999).

Recall the stories of strain and inundation reflected parents who seemed to have surrendered to the number of challenges they face associated with caring for their children with HL. These stories most closely resemble what McAdams (2006) calls contaminated narratives. Contaminated narratives typically begin with the narrator sharing a positive event (e.g., the birth

of child) only to take a negative turn as the story unfolds. People who tell these types of narratives tend to make sense of their situations in a negative light, without a glimmer of hope. Because narratives simultaneously reflect and construct reality, these types of stories might not only be reflecting a troubled narrator but further their distress (see Koenig Kellas, 2018).

Finally, stories of persistence showed that despite initial difficulties these parents faced, they survived their trials through hard work and perseverance. Similar to stories of personal growth, perseverance stories were also redemptive (McAdams, 2006). Indeed, hard work is one of the most traditional paths to redemption (see McAdams; Pederson, 2013). In contrast to contaminated narratives, these stories of persistence illustrate redemption in progress.

Implications for Family-Centered Hearing Healthcare

Given that the types of stories people tell both reflect and construct well-being (Koenig Kellas, 2018; McAdams, 2006) the present findings suggest that attending to the types of stories parents tell might be particularly useful for pediatric hearing healthcare providers. Especially, because they could use it as a tool to drive necessary improvements in models of family-centered hearing healthcare (Kuo et al., 2012). Research (Case, 2000) shows us that overlooking these parents' perspectives and experiences inhibits healthcare providers' ability to engage in family-centered care (Kuo et al., 2012). Without such care not only will the children likely suffer, but their parents will as well (Kuhlthau et al., 2011). For example, researchers (e.g., Ezzy, 2000; Riessman, 2015) showed that when narrative medicine was employed as a means to empower people to separate themselves from their problems, patients were able to "rewrite" their stories, make changes to their thought patterns, and improve their health and well-being. It stands to reason that similar intervention could ultimately take place in the context of pediatric aural rehabilitation with parents.

When hearing healthcare 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). For example, parents who tell detached stories might not recognize the important role they play in helping their children succeed with their CIs. Parents who tell this type of story might benefit from additional counseling by their care providers in the context of a family-centered approach to managing their child’s HL and intervention. Hearing healthcare providers could utilize the International Classification of Functioning, Disability and Health framework (WHO, 2001) to guide their care as they work closely with the parents to better understand their experiences and educate them about opportunities for engagement.

Alternatively, parents who share stories of personal growth may have made meaningful changes in their lives early on in their children’s journeys and those changes resulted in ideal family-centered, pediatric hearing healthcare. Parents who told stories of strain and inundation may not be getting such care. Research shows that such contaminated narratives are associated with poor well-being (e.g., anxiety and depression; McAdams, 2006) and parents’ health and well-being directly impact their children’s health and well-being (Eisenhower et al., 2009). Thus, these parents might also benefit from transdisciplinary approach to their child’s hearing healthcare that includes mental health support.

Limitations and Future Directions

The present findings offer valuable insight into parents’ experiences with their young children who use CIs, but there are limitations that should be considered for future studies. A chief limitation of the current study is our homogeneous participant sample. The lack of diversity across parents’ demographic characteristics does not allow us to account for the ways that the

different characteristics might intersect. The current story types (gathered from primarily White parents) do not likely account for all families seeking hearing healthcare services for their children, as people of color face disparities in access to and quality of healthcare that White people do not face in the US (Hall et al., 2015). Thus, their experiences and stories could likely differ from the parents in the current study. Furthermore, this begs the question, did only the present sample lack demographic diversity, or do we have a bias to implant children from wealthy White families in the US? This concept has been explored previously. In fact, one study (Stern et al., 2005) exploring demographic data gathered in 1997 found that deaf children who were White and Asian were implanted at proportionally higher rates than children who were Black and Hispanic. These White and Asian children were also more likely to live in areas made up of individuals earning higher median incomes than the Black and Hispanic children with severe to profound sensorineural HL.

Another limitation of the current study pertains to the timeline and context of the parents' stories: some parents were further along (both emotionally and temporally) in their children's journeys than others. Because individuals' stories are constantly in flux, it is possible that the parents' story types will evolve and might shift into another type that emerged from this study.⁴ For example, a parent with a story of strain and inundation might meet an early interventionist who teaches them how to positively affect their child's development and subsequently evolves into a parent with a story of growth. Finally, there may be parent participants whose narratives (shared in a different context) reveal different story types. Such parents may not have felt comfortable talking about their experiences with our researchers. Consequently, parents who had

⁴ It is worth pointing out that although this flux is limiting in the research context, it can be beneficial in the clinical context. Afterall, narrative medicine capitalizes on such flux when it aims to teach patients (in this case, parents) how to recast their contaminated narratives into redemptive ones and subsequently improve their overall health and well-being.

more positive experiences during their children's HL journey might have been more likely to share their experiences. Thus, there could be story types that were missed from parents who chose not to fully participate in their interviews.

Ultimately, it is our long-term goal to employ these stories in a way that allows us to better understand these parents' experiences and improve family-centered hearing healthcare. In order to do so, further qualitative research exploring the unrestricted personal accounts of *all* people parenting children with HL is necessary. Future studies of interest would employ a mixed-methods approach and gather additional quantitative data from the parents and/or children (e.g., health and well-being outcomes) that could enrich the information garnered from the parents' narratives. Such future studies would then have the potential to directly affect clinical care by answering valuable questions such as: do the types of stories parents tell about their experiences raising their children who use CIs directly affect the children's outcomes?

Conclusion

In the present study, allowing parents to share their stories has contributed to the field of hearing healthcare by providing professionals with insight into parents' sensemaking via the types of stories they shared centered on their perceptions and experiences following their child's diagnosis of HL and their decision to pursue cochlear implantation for their children. This knowledge is a step toward being able to develop more effective, family-centered hearing healthcare that can best address concerns and expectations surrounding pediatric HL and CIs.

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Appendix: Interviewer's Narrative Interview Script

As you know, we're recording stories about parents' decisions to pursue cochlear implantation. Would you mind if I audio recorded this interview and took brief notes? [Wait for participant's confirmation response.] Ok, I'm going to turn on the recorder now and confirm your permission to record.

TURN ON THE RECORDER

I am conducting this interview as a part of a collaborative research project at Utah State University. Would you mind if I audio recorded this interview and took brief notes? [participant responds]

Before our meeting, I sent you the link to a questionnaire. I see that you consented to participate in this study – is this correct? [participant responds]

Do you have any questions before we begin? [participant responds]

I am interested in learning more about your experience as a parent who choose cochlear implantation for your child with hearing loss.

Remember that you do not have to share anything or answer any question(s) that you are not comfortable with. You can stop your story at any time if you so choose. Once our interview is recorded it will be transcribed and your information will not be attached to the recording or the transcript in any way. Your name will not appear in the data, nor will the names of your family members. Pseudonyms will be used in any papers written for any publications or class presentations. Are you ready to begin?

Today, I'm going to ask you to tell me the story of your experience deciding to implant you child. 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 else was present during your child's hearing loss diagnosis and your decision-making process to implant your child or who else have you talked to about your child's hearing loss and cochlear implants?

Ok, now it's time for you to tell me your story. Why don't you start by telling me about when your child was diagnosed with hearing loss and when it was recommended that they undergo cochlear implantation. Then please share with me how your decision-making process unfolded and when you made the choice to follow through with cochlear implantation. Finally, end with telling me about how raising a deaf child with cochlear implant(s) affects your day-to-day life.