

Family Impact of Pediatric Hearing Loss: Findings from Parent Interviews and a Parent Support Group

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Abstract: Parents experience numerous stressors tied to their child's diagnosis as deaf or hard of hearing (DHH). This study sought to inquire about the lived experiences of parents with children who are DHH to determine the types of supports that should be provided within an audiology care coordination system. Semi-structured phone interviews were conducted with parents of children under the age of five who are DHH and patients of the Division of Audiology at Cincinnati Children's Hospital Medical Center (CCHMC). Interview findings determined focus group questions, which were facilitated in a parent support group with parents of children who are DHH and seen by the division. The results revealed parents' reactions and adaptations to their child's hearing health needs, as well as helpful supports and services. An audiology care coordinator (ACC) and a local parent support group were two of four supports identified as helpful in navigating their child's hearing health care. The findings of this study lend context for the types of support services pediatric institutions can provide to help families when their child is identified as DHH through a care coordination approach.

Key Words: deaf or hard of hearing, care coordination, family support, parent needs, support services

Acronyms: ABR = Auditory Brainstem Response; ACC = audiology care coordinator; BCMH = Bureau of Children with Medical Handicaps; BTE = behind the ear; CCHMC = Cincinnati Children's Hospital Medical Center; CI = cochlear implant; CMV = Cytomegalovirus; DHH = deaf or hard of hearing; FAC = Family Advisory Council; FL3 = Family Leadership in Language and Learning; HL = hearing loss; LSL = listening and spoken language; NICU = neonatal intensive care unit

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Hearing loss is one of the most common congenital birth defects, yet nearly all parents with children who are deaf or hard of hearing (DHH) have typical hearing and no experience with the implications of hearing loss (Centers for Disease Control and Prevention, 2010; Jackson & Turnbull, 2004; Mitchell & Karchmer, 2004). This lack of experience may explain initial feelings of shock and unpreparedness in parents that are cited throughout the literature (Kurtzer-White & Luterman, 2003; Jackson & Turnbull, 2004; Yoshinaga-Itano & Abdala de Uzcategui, 2001; Young & Tattersall, 2007). Parents with children who are DHH also

experience greater levels of stress around communicating with their child, making decisions about education for their child, selecting hearing devices, and maintaining hearing devices (Dammeyer, Hansen, Crowe, & Marschark, 2019; Dirks, Uilenburg, & Reiffe, 2016; Fitzpatrick et al., 2015; Hintermair, 2000; Lederberg & Golbach, 2002; Quittner, 1991; Quittner et al., 2010; Quittner, Glueckauf, & Jackson, 1990; Ward, Hunting, & Behl, 2018). Since it has been documented that parents' psychological well-being is paramount to cognitive and social-emotional outcomes in children (Calderon, 2000; Hintermair, 2006), it is crucial

to understand the types of support services needed by parents with children who are DHH.

In the literature, parents have noted a desire for more information about their child's hearing loss and social-emotional and cognitive development (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Henderson, Johnson, & Moodie, 2014; Jackson, 2011; Jamieson, Zaidman-Zait, & Poon, 2011; Yucel, Derim, & Celik, 2008). In addition, more dissemination of educational, childcare, community, and financial resources is needed (Jackson, 2011; Jamieson et al., 2011; Yucel et al., 2008), as well as comprehensive information about services and support at different points in their child's life (Ward et al., 2018). Further, information about navigating the health care system and building competence in caring for children with hearing loss are parent needs noted in the literature (Henderson et al., 2014). Parents have also requested resources for the well-being of the entire family (Henderson et al., 2014). In a comprehensive literature review, Jackson & Turnbull (2004) found that deafness can have various adverse impacts on the family unit. Family interactions, family resources, parenting, and support services are all domains of family life that are impacted by having a child who is DHH. Fortunately, family involvement in early intervention has been found to promote successful outcomes by the age of five (Moeller, 2000), perhaps because parents can vocalize their needs and gain access to supportive resources.

A quality improvement survey administered by the Division of Audiology at Cincinnati Children's Hospital Medical Center (CCHMC) revealed that families rely heavily on support from the in-house audiology care coordinator (ACC). Audiology care coordination is a relatively new strategy employed by pediatric institutions to provide comprehensive, coordinated care, yet to our knowledge, there is no published research on care coordination in audiology practice. In primary care, care coordination is considered an approach to care that meets patients' needs and enhances the capabilities of care-takers (Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014). Care plans are determined by family needs, roles, responsibilities, and desired outcomes (Antonelli, McAllister, & Popp, 2009; National Quality Forum, 2010). In the literature, care coordination has been defined as "the deliberate organization of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of health care services" (McDonald et al., 2007, p. v). Wagner, Gupta, & Coleman (2014) identified the goals and common features of successful programs that use care coordination. Successful care coordination exhibits accountability of the organization in coordinating their patients' care, clear and shared understanding of roles and responsibilities of all parties, support when patients go elsewhere for care, and timely transfer of relevant and understandable information. These findings are extended by Van Houdt, Heyrman, Vanhaecht, Sermeus, & De Lepeleire (2013) who found that clarity of

roles and responsibilities, quality of relationships, mutual respect and collaboration, and information exchange between health care providers and families are key characteristics of care coordination.

In local practice, care is coordinated primarily by the ACC but also in concert with audiologists and staff. Some of the services that are coordinated by our ACC and providers are:

- Providing telehealth services for patients, especially for those who live out-of-state.
- Disseminating a newsletter to inform parents about hearing health and resources.
- Sharing a Facebook group for parents of children with hearing loss.
- Collaborating with an Audiology Family Advisory Council (FAC) to facilitate hearing health care by clarifying and communicating needed areas of support, developing contextualized care plans, and identifying and disseminating resources for families with children who are DHH in ways that are family-accessible and content appropriate.
- Providing binders with written information for all families, including funding/financial resources, helpful websites for learning about hearing loss, contact persons, information about hearing devices, early intervention, and more.

The ACC serves as the primary point of contact for families and is responsible for providing and informing families of all these resources. Practically, the role of the ACC involves acting as a primary messenger of information and source of support. Patients receive a one-on-one experience with the ACC through regular check-ins and correspondence. This ensures that even families who are too overwhelmed to seek advice on their own receive social support. If families come to the ACC with questions, the coordinator is responsible for responding to families in an accurate and timely fashion. Other responsibilities of the care coordinator include connecting families to other specialists and medical staff, sharing written information regarding all sources of support (e.g., funding/financial resources, support groups with other families with children or parents who are DHH, information about hearing devices, and early intervention), and organizing all hearing-related appointments in an efficient manner, especially for traveling and out-of-state patients. The ACC also connects traveling and out-of-state families with resources for support near their hometown.

In the Family Leadership in Language and Learning (FL3) Needs Assessment report, parents indicated that they would benefit from coordinated, trusted resources; contact with and support from other parents who share their lived experiences; access to role models who are DHH; invitations to participate in parent activities; appointment reminders; and connections to early intervention (Ward et al., 2018)—all of which are resources and services provided by our in-house ACC. When asked where they receive these supports, parents responding to the

FL3 Needs Assessment indicated top providers were audiologists, early intervention staff, family support organizations, physicians, and website or social media. However, when asked what would make accessing these supports easier, the most common response was to have one contact such as a family support coordinator. These findings highlight the utility and necessity of an ACC in pediatric practice, as well as further research to define the role and evaluate outcomes of having an ACC.

Due to positive feedback on audiology care coordination at CCHMC and in the literature, this follow-up study takes a deeper look at the needs of families with children who are DHH to maximize support services provided by the care coordinator. We contribute to the literature on audiology care coordination by exploring the impact of having a child identified with hearing loss including sources of support that have facilitated their experience. Our hope is that inquiring about a wide spectrum of experiences, practical and emotional, will provide a broader, more holistic view of the experiences met by families with children who are DHH. Therefore, the purpose of this study is to (a) explore the experiences of parents with children who are DHH, (b) uncover helpful existing and needed support services for families of children who are DHH, and (c) make recommendations for coordinating these supports in pediatric institutions.

Method

Participants

Participants of this study included 13 mothers and one father of children who are DHH under the age of five ($N = 14$). In the first phase of data collection, purposive sampling was employed to identify parents of children under five years old who are DHH and received hearing health care from the Division of Audiology at CCHMC. These parents were selected based on their ability to provide information-rich cases about their experiences. Of the ten parents invited for a phone interview, eight agreed to participate (see Table 1). The eight interview participants were mothers ranging from 20–40 years old and the majority ($n = 7$) identified as Caucasian while one identified as Hispanic and Native American. Three mothers were high school graduates, two held college degrees, and three held graduate (master's) degrees. As a note of interest, two mothers worked in the education field (art teacher and special education teacher) while three held positions in healthcare (RN manager, nurse practitioner, and research administration). Two others were employed by the service industry (clerk and server) and one mother identified as a stay-at-home mom. In the second phase of data collection, an additional five mothers and one father recruited from a parent support group participated in a follow-up focus group to determine and refine the interview themes. All focus group parents had children under the age of five who were DHH and were patients of the Division of Audiology at CCHMC.

Data Collection and Analysis

This study has been granted a Non-Human Subjects Determination by the Cincinnati Children's Hospital Medical Center Institutional Review Board for research conducted by the Division of Audiology with parents of patients as part of an evaluation of the division. Consent for participation in tape-recorded interviews and focus groups was obtained prior to each interview or focus group session.

Semi-structured interviews. Individual phone interviews were conducted using a semi-structured interview guide. The questions related to the overall experience of being the parent of a child who is DHH, barriers and challenges, and helpful resources that assist or would assist in managing their child's hearing impairment. All interviews were conducted by the same interviewer, who is a researcher with a background in community-based and participatory approaches to health research and several years of experience conducting qualitative health research. The interviewer was contracted from a division outside of Audiology (Division of Research at CCHMC), to limit bias and encourage candidness from participants. All interviews were audio-taped and transcribed verbatim by the interviewer directly after each interview.

Interview data was analyzed by the primary contracted researcher using thematic analysis as described by Braun & Clarke (2006). In the first phase, the audio-taped interviews were transcribed and read twice with initial ideas written as notes. Using this initial list of ideas about the data, phase 2 involved the construction of initial codes that appeared important or meaningful to the experience of having a child who is DHH. The literature review assisted in identifying points of interest in the data. Phase 3 involved sorting these initial codes into themes and collating all of the relevant codes within the identified themes. In phase 4, overarching themes were eliminated if there was not enough data to support them, or collapsed if two separate themes related to one another. Other themes were broken down into separate themes as necessary. In phase 5, themes were defined, refined, and given a title by identifying and capturing the essence of each theme's meaning. Two members of the research team (both audiologists, one of which was the division care coordinator) and an expert in parent needs for children who are DHH reviewed the themes independently to enhance the credibility of the study findings. The entire research team discussed their independent reviews and worked together through democratic discussion to establish a final codebook representative of the interview themes.

Focus Group. The interview findings guided the design of a focus group guide which inquired about concepts emerging from the interview data. The contracted interviewer facilitated the focus group, which centered on questions related to thoughts and feelings associated with their child's hearing loss, the family impact of the hearing loss, barriers and challenges regarding their child's hearing

Table 1**Family Impact of Pediatric Hearing Loss: Parent and Child Demographics at Time of Interview**

Age of Patient	Parent Hearing Status	Gender of Parent	Gender of Child	Child's Hearing Loss	Child's Characteristics	Device Use
24 months	Typical hearing	F	F	Fluctuating slight-mild bilateral	<i>Fit at age of 27 months*</i> – Down syndrome; chronic otitis media with effusion; multiple sets of pressure equalizing tubes; speech and language delay.	Bone conduction device; no longer wearing.
11 months	Typical hearing	F	F	Left Unilateral moderate to severe, sensorineural	<i>Fit at 7 months</i> – Typical speech and language development per parent report; recommended speech evaluation to confirm.	Monaural Behind the Ear (BTE) aids; no longer wearing.
30 months	Typical hearing	F	F	Moderate to severe U-shaped bilateral, sensorineural	<i>Late Identification – Fit at 20 months</i> – Delayed receptive and expressive language; enrolled at area school for Listening and Spoken Language (LSL); biological sibling (below) has hearing Loss (HL).	Bilateral BTE aids; wears consistently.
14 months	Typical hearing	F	M	Moderate bilateral, sensorineural	<i>Fit at 4 months</i> – Receptive language within typical limits; expressive language mildly delayed; biological sibling (above) has HL.	Bilateral BTE aides; wears consistently.
10 months	Typical hearing	F	M	Profound bilateral	<i>Implanted at 14 months</i> – Receptive and expressive speech delays; enrolled in area LSL program.	Bilateral Cochlear Implant (CI); wears consistently.
25 months	Typical hearing	F	M	Typical hearing	Initially diagnosed in another state with bilateral hearing loss. Determined to have typical hearing at CCHMC – discharged from speech therapy.	None.
13 months	Typical hearing	F	F	Moderate rising to mild bilateral mixed	<i>Fit at 7 months</i> – Cleft Palate; Stickler Syndrome; delayed speech and language.	Bilateral BTE aids; wears inconsistently.
17 months	Typical hearing	F	M	Profound bilateral	<i>Implanted at 12 months</i> – Cytomegalovirus (CMV); delays in speech and language; enrolled in area LSL program.	Bilateral CI; wears consistently
21 months	Typical hearing	F	F	Moderate to severe, conductive	<i>Fit at 3 months</i> – Bilateral ear canal atresia/stenosis; global developmental delays.	Bilateral BTE aids; wears consistently.

*Trial with a bone conduction device (BCD) due to chronic fluctuations with conductive hearing loss— parent opted to try management with a BCD at 27 months to avoid additional surgeries.

loss, and support services that have been helpful or would be helpful in managing their child's hearing impairment. The focus group discussion was audio-taped and transcribed verbatim by the facilitator shortly after the focus group session concluded. The focus group data was thematically coded by the facilitator using thematic analysis (Braun & Clarke, 2006). In this process, findings were triangulated with the themes from the interview data to further refine the overarching themes and enhance the credibility of the thematic categories. A final codebook was reviewed by the two previously mentioned members of the research team who are experts in parent needs for children who are DHH. Phase 6 of thematic analysis continues in this article as we use our thematic map to tell a story about the burden costs of parenting a child with hearing loss.

Results

Six major themes emerged from the interview and focus group data, falling into three overarching concepts: Reactions and Adaptation to Hearing Loss, Barriers and Challenges, and Supports (see Table 2). Each subtheme within the categorical themes represents individual stressors or strains on the parent that impact their lived experience, and existing or needed support services. This section elaborates on each theme in relation to their subthemes.

Reactions and Adaptation to Hearing Loss

Many parents reported feeling shocked when first learning that their child was identified as DHH, primarily because they held no previous knowledge about hearing loss and

Table 2

Family Impact of Pediatric Hearing Loss: Summary of Interviews and Focus Group Findings

Overarching Concept	Theme	Subtheme	Description	n	Quote as Evidence of Subtheme
Reactions and Adaptation to Hearing Loss	Reactions and Adaptation to Hearing Loss	It Gets Easier	Parent's description of adapting to child's hearing loss—it is difficult at first, but it gets easier.	7	<i>"It's been difficult at times but with the help of my doctors that we have for him, and his therapist and everybody that has helped us through it, it has been a bit easier for us to get through it emotionally and physically."</i>
		Shocking	Specific term used to describe first learning about child's hearing loss and not having previous knowledge about hearing loss, nor knowing anyone who has undergone this experience.	6	<i>"I have two other kids, they're older than my daughter and they have normal hearing. For me, it was a complete shock because neither side has hearing loss."</i>
		Concerns about Child Development	Concern about child's cognitive, physical, and social-emotional development compared to typical hearing children; not wanting child to be bullied or live a difficult life.	7	<i>"I'm afraid of what his life is going to be like. Are people going to pick on him, because not only is he going to have this hearing aid on, he's going to have these little ears? That is what I worry about."</i>
		Social Implications	Parents' desire to expose child to others with hearing impairment, encouraging others to ask about condition instead of judging.	6	<p><u>Quote 1:</u> <i>"I think it's beneficial for her to meet other people, adults or kids, who have the same sort of thing just because she does have two older brothers who don't have the same situation and she will be mainstreamed in school, so she probably won't be around other kids, outside of our friends and seeing them in the audiology department."</i></p> <p><u>Quote 2:</u> <i>"To be honest if I see people looking at them and not asking, I get angry. I want to be like ' Just ask what is up with his ears, because it's rude to stare."</i></p>
Barriers and Challenges	Use of Hearing Devices	Financial Coverage	Difficult in obtaining insurance or financial coverage for hearing devices.	6	<i>"That was a shock that insurance didn't cover the ABRs and regular audiology appointments. We had spent several hundreds of dollars before being approved for BCMH and even then still waiting to get reimbursed for some of the costs. I can't believe most insurance companies don't cover hearing, especially in children, yet they cover things like Viagra. So frustrating especially for those of us on very tight budgets."</i>
		Hearing Aid Retention	Difficulty keeping hearing aids on children.	10	<i>"When he first got the CIs, he was a stinker and would just throw them off all the time. He still does that."</i>
		Ear Molds	Excessive time for the remaking of child's ear molds.	5	<i>"We just wish ear molds could be made quickly and on-site so we could get them right away, that would be awesome."</i>
		Managing Devices	Stress associated with managing child's hearing devices.	6	<i>"When we first got them, they would monitor how long he had them on and he would average an hour a day. I would get so frustrated, I'm like 'He needs at least seven to eight hours for a full day, even with naps and stuff like that.' It's getting people to understand they need to stay on even if he goes to bed, that kind of stuff."</i>
	Scheduling	Making Appointments	Not enough time in parent schedule for appointments.	8	<i>"I think it was those kinds of stresses and impact when you're thinking about appointments and who can make the appointments."</i>
		Number of Appointments	Too many appointments in the first year for all service providers related to hearing.	8	<i>"You have to go see a pediatrician, you have to go talk to a geneticist. We did all of our appointments in one day, like eight appointments in one day, trying to get social worker, oral rehab, all that stuff."</i>
	Financial Costs	Overall Cost of Services	Overall cost was considered burdensome.	9	<i>"I was terrified... 'What are we going to do?' We had family members—both sets of parents offered to loan us money, but not everyone has family support where they would just be able to get that money."</i>
		Hearing Devices	Cost of hearing devices was considered burdensome.	6	<i>"My insurance—and I have the insurance for our whole family—said that for his hearing aid, they would cover 100% or a maximum of \$3,000. Well, he has Bahas and has two of them. They are approximately \$10,000."</i>

Table 2 cont.

Family Impact of Pediatric Hearing Loss: Summary of Interviews and Focus Group Findings

Supports	Education /Resources	Support Groups	Sought support from other groups of parents after learning about child’s hearing loss.	6	<i>“There’s huge groups out there if I want to talk to people in other countries or across the country—but to have local parents, seeing the same departments, the same doctors, possibly the same schools, that’s huge.”</i>
		Internet Research	Parents sought to teach themselves about child’s hearing loss through internet research.	7	<i>“I was googling the minute after the NICU staff left the bedside.”</i>
	Healthcare Team	Audiology Care Coordinator	Considered a helpful asset of medical team due to timely communication, having questions answered, connecting to other specialists, organizing appointments in an efficient manner for patients, and overall support.	12	<i>“She actually came when [child] had surgery, she showed up at Children’s downtown. We weren’t expecting her. she stayed for two, three hours and talked to all of us. She just goes above and beyond. If I have a question or concern and she doesn’t know the answer, she’ll talk to whoever she needs to and gets right back to me. She just always takes the time to research and find the correct answer.”</i>
		Audiologists, Doctors, Specialists, Nurses, and Staff	Considered helpful facilitators or care due to timely communication, having questions answered and quality of care.	12	<i>“The one-on-one experience with them, you don’t get that anywhere else. They check on you and make sure you’re doing okay. [Child] has been chewing through his ears [hearing aids], so I called [provider] the other day. She answered my phone call right then and there, took the time to talk to me. You don’t get that anywhere else.”</i>

Note. N = 14. CI = cochlear implant; ABR = Auditory Brainstem Response; BCMH = Bureau of Children with Medical Handicaps; NICU = neonatal intensive care unit.

did not know anyone with the condition ($n = 6$). Several parents also expressed concern for their child’s cognitive, physical, and social-emotional development compared to children with typical hearing, and feared their child would live a difficult life ($n = 7$). One mother expressed anxiety for potential bullying due to physical differences in the appearance of her child’s ears. In the focus group, she said, “I’m afraid of what his life is going to be like. Are people going to pick on him, because not only is he going to have this hearing aid on, he’s going to have these little ears? That is what I worry about.” However, half of the parents also agreed with the sentiment that managing their child’s hearing loss gets easier with time. As stated by a mother, “It’s been difficult at times but with the help of my doctors that we have for him, and his therapist and everybody that has helped us through it, it has been a bit easier for us to get through it emotionally and physically.” To normalize and adapt to the issue, parents expressed a desire to expose their child to other children and adults who are DHH ($n = 6$). Although there were several issues parents grappled with, their child’s hearing loss became more manageable as families adapted to their child’s hearing needs.

Barriers and Challenges

The second overarching concept, Barriers and Challenges, contains three major themes: Use of Hearing Devices, Scheduling, and Financial Costs, which are described further.

Use of hearing devices. A number of parents complained about the excessive time it takes for remakes of their child’s ear molds as well as setting aside time in their personal schedules to pick up the ear molds ($n = 5$). At least half of the parents communicated frustration with the management of their child’s hearing devices ($n = 6$), keeping hearing aids on their child ($n = 10$), and

obtaining insurance or financial coverage for hearing devices and services ($n = 7$). One mother expressed shock and frustration that her insurance didn’t cover Auditory Brainstem Response (ABR) tests and regular audiology appointments. “We had spent several hundreds of dollars before being approved for Bureau of Children with Medical Handicaps (BCMh) and even then, still waiting to get reimbursed for some of the costs. I can’t believe most insurance companies don’t cover hearing [technology], especially in children, yet they cover things like Viagra.” She was just one of many parents who conveyed both shock and frustration at the high cost of hearing devices and limited knowledge about financial assistance to cover them.

Scheduling. A majority of parents ($n = 8$) felt they did not have enough time in their schedules to make or attend appointments. In reference to the challenges she has experienced with her child’s hearing loss, one mother remarked, “I think it was those kinds of stresses and impact when you’re thinking about appointments and who can make the appointments.” Parents pointed out the excessive number of appointments in the first year for all service providers related to managing their child’s hearing loss. “You have to go see a pediatrician, you have to go talk to a geneticist. We did all of our appointments in one day, like eight appointments in one day, trying to get social worker, aural rehab, all that stuff.” Setting aside time in their personal schedules for a large quantity of appointments in the first year after identification of hearing loss and thereafter was a shared struggle among many parents in the interviews and focus group.

Financial costs. According to most parents ($n = 9$), the overall cost of services related to their child’s hearing loss was considered burdensome. One mother conveyed fearfulness in response to the cost of her child’s hearing

services. “I was terrified... ‘What are we going to do?’ We had family members—both sets of parents offered to loan us money, but not everyone has family support where they would just be able to get that money.” The cost of hearing devices specifically was a concern for a subset of parents ($n = 6$). According to one father, “My insurance—and I have the insurance for our whole family—said that for his hearing aid, they would cover 100% or a maximum of \$3,000. Well, he has Bahas and has two of them. They are approximately \$10,000.” Even for parents who have insurance benefits that cover the cost of hearing aids, the entire cost may not be covered, creating a frightening and stressful experience.

Supports

The overarching concept of Supports contains two major themes: Education/Resources and Healthcare Team. The section below elaborates on these themes in relation to their subthemes.

Education/resources. Parents identified the different types of education and resources they used after learning about their child’s hearing loss. Some of the parents ($n = 6$) joined support groups with other parents who have children who are DHH. One mother expressed gratitude for the support group in which this focus group was conducted. “There’s huge groups out there if I want to talk to people in other countries or across the country—but to have local parents, seeing the same departments, the same doctors, possibly the same schools, that’s huge.” A majority of parents ($n = 7$) also claimed to have conducted internet research to learn more about their child’s hearing loss. In the words of one mother, “I was googling the minute after the NICU staff left the bedside.” Other types of support from audiologists and listening and spoken language (LSL) schools or programs, were also mentioned in the focus group discussion—however, support groups and internet research were noted as the most common resources for learning about and coping with their child’s condition.

Healthcare team. The ACC was overwhelmingly noted by parents as an exceptional addition to the medical team ($n = 12$). She was praised for her overall support and timely communication with parents in need. One mother commented “She actually came when [child] had surgery, she showed up at Children’s downtown. We weren’t expecting her. She stayed for two, three hours and talked to all of us. She just goes above and beyond” and that if she has a question or concern, “She just always takes the time to research and find the correct answer.” The ACC was also appreciated for connecting parents to other specialists and organizing appointments in an efficient manner, especially for out-of-state patients. Most parents ($n = 12$) also noted audiologists, doctors, specialists, nurses, and staff in the Division of Audiology at CCHMC as helpful due to their promptness in communication and overall quality of care. One mother noted, “The one-on-one experience with them, you don’t get that anywhere else. They check on you and make sure you’re doing okay.”

Nearly all parents agreed that the entire healthcare team helped improve their experience with their child’s hearing health needs.

Discussion

This study queried parents of children who are DHH about their personal experiences with their child’s hearing loss. The thematic analysis revealed various challenges and supports as they managed, adapted, and coped with their child’s hearing loss. This section will discuss each theme that emerged from parents’ personal stories as they relate to the literature as well as implications for clinical practice and care coordination in pediatric audiology.

Reactions and Adaptation to Hearing Loss

Parents reported feeling shocked and unprepared when their child was identified as DHH, especially because they have typical hearing and do not know any parents with children who are DHH. Feelings of shock and unpreparedness are typical for parents who first learn about their child’s hearing loss (Jackson & Turnbull, 2004; Kurtzer-White & Luterman, 2003; Yoshinaga-Itano & Abdala de Uzcatogui, 2001; Young & Tattersall, 2007), especially because most parents have typical hearing and no prior experience with the implications of hearing loss (Centers for Disease Control and Prevention, 2010; Jackson & Turnbull, 2004; Mitchell & Karchmer, 2004). Additionally, parents in this study expressed concern about the physical, cognitive, and social-emotional development of their children as have other parents throughout the literature (Fitzpatrick et al., 2008; Henderson et al., 2014; Jackson, 2011; Jamieson et al., 2011; Yucel et al., 2008). Though parents in the present study expressed initial shock, their child’s hearing loss became easier to manage over time with consistent communication and support from the care coordinator and providers. Reliable and well-coordinated care systems provide access to resources such as childcare, community, and financial resources that are vital to parents of children who are DHH (Jackson, 2011; Jamieson et al., 2011; Yucel et al., 2008) and can help alleviate the stress around managing hearing loss. ACCs can be essential messengers of information and sources of support for parents who must manage their child’s hearing loss. Pediatric institutions should consider creating care coordinator positions within their audiology practices, or, developing policy that allows for more thorough coordination in practice. The FL3 Needs Assessment supports our finding that a primary contact through which support is coordinated, such as a family support coordinator, would be helpful in managing a child’s hearing health care (Ward et al., 2018).

Use of Hearing Devices

Hearing devices was one of the largest themes that emerged from the interviews and focus group discussion. Similar to parents in the literature, parents in this study expressed stress around communicating with their children, maintaining devices, and making decisions

about hearing devices (Dammeyer et al., 2019; Dirks et al., 2016; Fitzpatrick et al., 2015; Hintermair, 2000; Lederberg & Golbach, 2002; Quittner, 1991; Quittner et al., 2010; Quittner et al., 1990; Ward et al., 2018). Parents were also frustrated with the task of training family and friends in their child's hearing device management. However, parents mentioned the local support group as a safe and resourceful place to learn about hearing devices, especially from one of the members who is deaf herself. Parents became aware of the support group from the care coordinator and audiologists who managed their child's audiology care. The ACC and audiologists also shared written information about hearing devices, early intervention, and resources for support near their hometown area to help families understand their options and how to manage hearing devices. To help parents navigate obstacles related to hearing devices, coordinated care systems can connect parents with resources for teaching the entire family about hearing devices.

Scheduling

Many parents expressed frustration with the number of appointments in the first year for all services related to hearing. The hassle of scheduling and making time for hospital appointments has been mentioned in another study on stressors for mothers of children who are DHH (Jean, Mazlan, Ahmad, & Maamor, 2018). Additionally, taking time off from work and traveling for medical appointments are other barriers related to scheduling for parents of children with hearing loss (Henderson et al., 2014). Parents in the present study discussed juggling their own work schedules with their child's medical appointments, especially those who were traveling far distances. Though scheduling barriers are sometimes inevitable, one helpful resource parents identified for navigating scheduling barriers was the ACC. Parents were pleased with how she organized appointments in an efficient manner, particularly for traveling parents. Although healthcare systems can be rigid in operating structure, this is one demonstration of how care coordination can alleviate the burdens of parents.

Financial Costs

Parents felt a great deal of fear regarding finding ways to afford their child's hearing care. This is an area where parents can use assistance with resource and health care system navigation (Dammeyer et al., 2019; Dirks et al., 2016; Fitzpatrick et al., 2015; Hintermair, 2000; Lederberg & Golbach, 2002; Quittner, 1991; Quittner et al., 2010; Quittner et al., 1990; Ward et al., 2018) as well as dissemination of community and financial resources (Jackson, 2011; Jamieson et al., 2011; Yucel et al., 2008). In the focus group, parents mentioned that they learned about financial resources from other parents in the support group, which helped ease their fears. As mentioned previously, many of the group members became connected with the support group by the ACC and other providers in the Division of Audiology at CCHMC. The division also offers a parent binder to all families of children. It includes written information about funding

and financial assistance, as well as resources to support parents during early intervention and beyond. Coordination in pediatric institutions can help ensure all families receive information about the different supports available. This study showed that having personnel for care coordination facilitates comprehensive support to all families who receive treatment in our division.

Education/Resources

Support groups and internet research were the most highly discussed educational resources in this study. It is no wonder that parents considered the support group helpful. Social support is one of the most important mediators of parental stress (Asberg, Vogel, & Bowers, 2008; Lederberg & Mobley, 1990; Sarant & Garrard, 2013) and recommended for inclusion in care models for children who are hearing-impaired (Dirks et al., 2016). Support from other families with children who are DHH was noted as a valuable resource in the FL3 Needs Assessment (Ward et al., 2018). Support groups allow parents to share educational, childcare, community, and financial resources which are needed by the community of parents with children who are DHH (Jackson, 2011; Jamieson et al., 2011; Yucel et al., 2008). Support groups also advocate for hearing-related issues and may build parental empowerment, confidence, and competence in caring for a child with hearing loss (Henderson et al., 2014). Parents confirmed these findings in their discussions within the focus group. Audiology practices should consider identifying parents who may be interested in starting a support group, or providing information to patients about current support groups. Formal systems or positions for care coordination can help disseminate this information to families.

Although there is scarce literature on the role of parent internet research on child hearing health, one study found that the most searches for hearing loss related information are conducted by mothers (Porter & Edirippulige, 2007). However, the study found that parents did not always visit the most reliable websites. It may be helpful for practitioners to be aware of parents' tendencies to conduct internet research and offer reliable sources for them to peruse at home. The FL3 Needs Assessment indicated that parents desire online resources for learning about and managing their child's hearing loss (Ward et al., 2018). The ACC in our division is responsible for providing helpful websites for parents to read about their child's condition. This ensures that parents are receiving accurate information to make informed decisions for their child's hearing health.

Healthcare Team

Parents in this study spoke at length about the ACC as one of the most helpful supports. They repeatedly commented on how she goes "above and beyond" to provide social support, communicate in a timely fashion, answer questions, connect them to other specialists, and organize appointments in an efficient manner. Parents also identified other personnel in the Division of

Audiology at CCHMC as helpful (audiologists, doctors, specialists, nurses, and staff) due to the “one-on-one” and interpersonal care they received from these practitioners and staff. This type of support is in accordance with research that finds parents need health care systems with strong service coordination (Fitzpatrick et al., 2008; Jackson, 2011; Yucel et al., 2008) and a highly integrated and coordinated health care model in general (Hintermair, 2006; Fitzpatrick et al., 2008; Ward et al., 2018).

Implications for Clinical Practice and Care Coordination

Families need access to social support, financial assistance, and information about hearing devices, education, and communication with providers. In local practice, the Division of Audiology at CCHMC provides these services by emphasizing dual ownership between the family and service provider. Patients are encouraged to consistently attend appointments and come prepared to ask any and all questions that come to mind. Asking questions and having access to the appropriate contacts is a vital aspect of family involvement in hearing health care. The ACC serves as a primary contact that addresses concerns and connects patients with specialists and medical staff. The coordinator also regularly contacts parents in case they are too overwhelmed to seek advice on their own. Parents appreciate the open lines of communication and personal care they receive from the coordinator, as noted in the interviews and focus group. The coordinator also shares written information with parents regarding support groups, financial assistance, hearing device assistance, early intervention, and more. As mentioned in the introduction, the Division of Audiology at CCHMC also provides telehealth services, a newsletter, information about a Facebook and parent support group, and an FAC.

In 2015, audiologists at each CCHMC audiology location were asked to nominate potential parents to join the FAC with the goal of bringing together a diverse group of parents to help guide audiology practice from a patient experience perspective. Parents are from different locations around Cincinnati; have children with different types and degrees of hearing loss; use varying types of technology to assist with hearing; and communicate with their children via sign language, listening and spoken language, or a combined approach. Their children attend private or public schools. The FAC has suggested many changes to improve the patient experience in audiology such as updating the web page to make it easier to navigate, online scheduling for audiology appointments, a Facebook group, and changes to the cochlear implant program initial appointment paperwork. The FAC has also shared their experiences in learning their child was DHH and how they were impacted by the news. One parent shared that she appreciated how the audiologist told her that her daughter was deaf. The audiologist said that she had concerns about hearing and would need to do more testing. This allowed the parent to slowly come to terms with the fact that her daughter’s hearing may

not be typical. All parents agreed that they wanted to interact more with families with children who are DHH. They suggested an annual event, such as a picnic, where their children could interact with others with hearing differences and the creation of Facebook group exclusively for parents of children who are DHH. They also wanted to create a road map for new parents to educate them on the appointments that their child may need and why they were needed during the first years after diagnosis of hearing differences. The FAC also suggested the creation of a parent manual containing information about types of hearing loss, assistive technology, communication modes, and education choices.

Although hiring care coordinators to facilitate these services may not be feasible in some pediatric institutions, care coordination can still be integrated in hearing health care. We encourage further research on audiology coordination to develop a consistent coordination system across pediatric institutions. As the literature grows, evaluation of care coordination practices could help measure the benefits of care coordination. We recommend parent partnership in the design of care models and support services to ensure hearing health care is tailored to family needs. At a minimum, this can be accomplished through parent engagement and surveys for program improvements. In our personal experience, the FAC has been instrumental in collaborating with parents to improve care delivery. Support groups are also a resourceful place to learn about parents’ experiences and encourage parent engagement in hearing health care. Pediatric institutions may consider partnering with schools to disseminate support services and improve existing services. Future research should explore additional ways to obtain parent and stakeholder perspective and feedback.

Limitations and Future Directions

The Division of Audiology at CCHMC was limited in the number of patients who fit the criteria for the study, resulting in a smaller sample size than desired. Although demographic information about focus group participants was unavailable, all are patients of CCHMC with what appeared to be similar backgrounds to our interview participants. We plan to conduct more focus groups with our support group network in the future, which will allow us to better coordinate collection of demographic information without sacrificing anonymity. Although this study would have benefited from more data, a strength of this study was the robust information we received from focus group interaction that augmented the themes we had collected through the individual interviews. The findings from the focus group validated the themes we had already identified through the interviews and expanded our understanding of parent needs and supports. Though the focus group had an ideal number of participants, future studies should seek to attend multiple support groups to capture different voices and life experiences. Most parents in this study were Caucasian middle-class mothers. Attending various support groups and recruiting from other institutions may help capture the different life experiences of parents of

patients who are DHH. Finally, because some participants had children who were identified with hearing loss up to five years prior, there may have been inaccuracies in recollection of memory. Future studies should record parent experiences after identification of hearing loss and several other time points in the child's development, as these experiences likely differ at different stages of hearing intervention.

Conclusion

Hearing loss comes with many challenges for families who must accommodate their child's new hearing health needs. This study investigated the impact and experience of parenting a child who is DHH, as well as supportive resources for successful early hearing intervention and family well-being. Although parents struggled with using hearing devices, affording services, and adapting to their child's hearing loss, care coordination provided by an ACC and providers at CCHMC made a positive impact on the overall family experience. The consistency of the study's themes with the literature provides the opportunity to focus improvements in care coordination for families with children who are DHH. Audiology institutions should continue contributing to the growing literature on audiology care coordination by detailing and evaluating how family support services are coordinated within their own audiology care systems.

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