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eHealth Education and Support for Pediatric Hearing Aid Management: Parent Goals, Questions and Challenges

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Abstract

Purpose: To investigate parent goals, questions, and challenges that emerged during coaching

phone calls in an eHealth program designed to provide education and support for hearing aid

management.

Methods: Coaching phone calls were audio-recorded, transcribed and qualitatively analyzed for

emergent themes within the categories of goals, questions, and challenges.

Results: Emergent themes revealed parent goals were focused on self-efficacy, routines, device

care and child development. Emergent themes for questions revealed parents asked questions

related to the device care, audiology appointments, confirmation of learning, and child

development. For challenges emergent themes revealed parents' own struggles (e.g., with

emotions), issues related to working with their audiologist, child factors and anticipated

challenges.

Conclusion: The eHealth intervention allowed parents to raise questions and discuss their

challenges in a supportive environment. Supportive accountability helped participants identify

and address barriers to hearing aid management based on their priorities and current challenges.

Providing supplemental learning support, in addition to routine audiology visits, can help parents

develop more effective hearing aid management routines.

Key Words: Pediatric, hearing aids, education, support, eHealth

Introduction

Each year in the United Stated thousands of parents are given the news that their infant has a permanent hearing loss. The most recent data from the Center for Disease Control and Prevention (2021) report 6,432 newborns were identified with hearing loss in 2018. This is often unexpected news as more than 90% of children who are deaf or hard of hearing are born to parents with typical hearing (Mitchell et al., 2004). For children who are developing spoken language, consistent audibility through well-functioning hearing devices is essential. In fact, children have been found to have accelerated language outcomes when they use their hearing aids 10 or more hours per day (Tomblin et al., 2015). Behavior change needed to incorporate new habits into daily life, however, can be challenging. More frequent contact with the provider for support can promote behavior change (Nelson et al., 2012) and incorporating supportive accountability within an eHealth model (Mohr et al., 2011) has been shown to facilitate habit change in weight-loss programs and management of diabetes (Ozaki et al., 2019; Dennison et al., 2014; Rasekaba et al., 2018; Moin et al., 2015). An eHealth program that includes more frequent contacts with parents and supportive accountability may help audiologists target their support based on gaining a deeper understanding of issues of importance to parents and the barriers they face with hearing aid management. Parents have a central role in the intervention process and young children depend on their parents for auditory access. There has been evidence over time, however, that parents of young children experience practical and emotional barriers that interfere with hearing aid use and daily management routines. Parents have shared having feelings of anxiety with hearing aid maintenance, including changing batteries, cleaning earmolds and earmold insertion, and struggled with seeing the benefits of hearing aid use (Sjoblad et al., 2001). Challenges with hearing aid wear time has been described (Russ et al., 2004) and low average

hours of use per day has been documented (e.g., M=8 hours, Walker et al., 2013; M=<5 hours, Jones, 2014; M=4.6 hours, Muñoz et al., 2014). Environmental setting (Moeller et al., 2009), as well as child behavior, fear of losing the hearing aids, feelings of frustration, confusion and lack of confidence (Muñoz et al., 2016) have been found to contribute to hearing aid use problems for young children. Research has also shown that as few as one-quarter to one-third of parents check hearing aid function daily (Muñoz et al., 2013; Muñoz et al., 2019), putting children at risk for sub-optimal access to speech sounds. This is an important problem to address, because without effective routines in place, audibility is compromised.

Research on hearing aid management to date has illustrated that parents experience challenges and that these challenges negatively influence audibility for young children. There is a gap in the literature; however, related to goals and questions parents have about navigating routines to address hearing aid management in their daily lives. Additionally, there is evidence that audiologists have practice gaps related to educating and supporting parents in their role managing hearing aid maintenance tasks (Meibos et al., 2015). For example, Meibos et al., (2015) found that many audiologists reported wanting more training related to counseling, while also feeling like they did not have enough time in appointments to effectively counsel parents. Parents of young children have indicated wanting more education and support than they received, including training on maintenance of the hearing aids, how to keep hearing aids on when their child did not want to wear them, and how to teach others hearing aid management skills (Muñoz et al. (2016). Given that most parents are unfamiliar with hearing loss (Mitchell et al., 2004), it is not surprising that integrating hearing aid management tasks into daily routines can be challenging. It is clear that parents need support that extends beyond teaching them how to execute necessary skills (e.g., putting the hearing aid on, listening to the hearing aid). It is less clear, however, what audiologists can do to be effective in supporting parents in overcoming the barriers they experience.

An eHealth parent intervention to provide education and support may be an effective approach to consider for pediatric hearing aid management. In a scoping review of parental experiences using eHealth in a neonatal intensive care unit (NICU), Siani and colleagues (2017) found an increase in parental knowledge, satisfaction with NICU services, and that in general parents found it easy to use the eHealth platform. These results revealed benefits of using an eHealth intervention with parents when they are navigating the stressful experience of having a child in the NICU. Identification of hearing loss can be a stressful time for parents and the process of learning new information and skills can be daunting. Audiologists are expected to help parents navigate through this stressful time, acting as coaches and guides through a hearing loss diagnosis, subsequent monitoring and hearing device follow-up (Joint Committee on Infant Hearing, 2019).

Audiologists traditionally provide parents with education and support for amplification management and use during office visits. The frequency of appointments, however, may not be sufficient to adequately meet the learning needs of parents. An eHealth approach may be well suited to support the learning process for implementation of effective hearing aid use and care routines. Telehealth research on teaching parents how to manage hearing aids is limited. Muñoz et al., (2017) conducted a small longitudinal study to provide remote education and support to increase hours of hearing aid use for young children. Study findings showed that remote services resulted in increased hours of hearing aid use. Gomez et al. (2019) found similarly positive results with remote education for adults learning to use hearing aids. First time hearing aid users that received weekly training videos about hearing loss and hearing aid management had higher

self-efficacy, that is, greater confidence in their ability to manage hearing aids and hearing loss, compared to those who did not receive the weekly trainings. Past research has analyzed behavior change among adult hearing aid users (Armitage et al., 2017; Sawyer et al., 2019); however, there is a lack of research related to behavior change among parents of children with hearing aids.

Muñoz et al. (2021) conducted a pilot randomized controlled trial (N = 82) to compare an eHealth hearing aid management education, and support program, to treatment as usual for parents of young children. Findings for differential change over time revealed significantly higher scores for parental knowledge, confidence, and monitoring of hearing aid function in the intervention group compared to treatment as usual. Hours of hearing aid use improved slightly during the study for both groups. Parents in the intervention group completed a six-week eHealth program that paired video tutorials with weekly phone coaching. The phone coaching incorporated supportive accountability to improve program adherence. Mohr et al. (2011) described supportive accountability as providing support for and measuring small consistent actions rather than emphasizing an overall outcome. A human factor (i.e., phone call) was added to further support accountability, legitimacy and creation of a bond (Mohr et al., 2011). Providing supportive accountability through an eHealth study allows both parents and providers a setting to promote habit change and provide education, while still being efficient and family-friendly.

Given the improved outcomes for the parents in the intervention group of the Muñoz et al. (2021) study, the purpose of this study was to conduct a qualitative analysis of the coaching phone calls to specifically explore parent goals, challenges, and questions. This adds to the literature by describing parent experiences specific to navigating hearing aid management, in the

context of an ehealth program, to provide valuable insights for audiologists in their work to support parents as they build capacity with managing daily hearing aid routines. This is important, as parents are central to the intervention process and have a key role in supporting audibility for children who use hearing aids.

Methods

This qualitative study was completed using a sub-set of the data collected in the larger Muñoz et al. (2021) study; a complete description of the methods and participant demographics is available in this publication. The Utah State University Institutional Review Board approved this study.

Participants

Parents of children who use hearing aids were recruited through flyers posted in clinics, on social media, Google advertisements, and through state Early Hearing Detection and Intervention programs from September 2019 through August 2020. The study period included the first six months of the COVID-19 pandemic. Parents were eligible if they had a child with a behind-the-ear hearing aid, aged 42 months or younger, had access to the internet, and if they were proficient in English. Participants were given incentives (Amazon eGift card) for their time to complete study surveys that took place at three time points (i.e., \$10 baseline, \$10 eight weeks, \$30 twelve weeks). A total of 82 parents were included in the study with 41 parents being randomized to the intervention group; see Table 1 for participant demographic information. Of these 41 participants, 4 were lost to follow-up after baseline assessments. One participant discontinued the intervention prior to post-treatment but provided data at post-treatment and

follow-up (i.e., that individual received a lower dose of the intervention). Group randomization was done after completion of the baseline measures.

Intervention Procedure

The eHealth program was six weeks in duration. Parents had a scheduled coaching phone call each week (see Appendix A for coaching guide) and were assigned video tutorials to watch prior to the phone call (see Table 2). The video series was developed by our research team at Utah State University. Health literacy was considered to facilitate parent understanding (e.g., reading level, captioning, narration). Parent and professional focus groups provided feedback to further inform content and usability (Whicker et al., 2020). All videos are freely available on our website (www.heartolearn.org).

Reminder texts were sent out the business day before the scheduled phone calls and included the date and time of their next phone call, as well as a reminder to watch the tutorial videos. Links for weekly tutorial videos were provided via email or text based on participant preference. Phone calls were audio recorded. The intervention was conducted by members of the research team and included an experienced pediatric audiologist (KM) and five graduate students who were enrolled in a specialized pediatric audiology training program; one coach was assigned to each parent based on parent and coach availability. Student coaches had also completed two counseling courses, prior to providing coaching, as part of their degree. Templates were created to guide coaching phone calls and to remind the coaches to adhere to key elements of the protocol. The coaches asked parents what they liked about the videos, what they learned, and if they had questions. Additionally, coaches were encouraged to use general counseling strategies, including asking open-ended questions to increase their understanding of parent challenges (e.g., what questions do you have?; How did ____ [in reference to what the parent was working on] go

for you this week?), responding to emotions expressed by parents, and to guiding parents in action planning to address their challenges. The process was discussed by the research team weekly. In order to check the fidelity of the intervention 20% of the session recordings were randomly chosen to be reviewed and scored by two members of the research team who did not provide the intervention. Both raters agreed that each randomly selected call was conducted with the use of the target counseling skills and completed all intervention objectives (for a full description see Muñoz et al., 2021).

During the first phone call coaches asked parents about their goals, challenges they were currently experiencing with hearing aid management and use, and what they wanted to work on. Phone calls during weeks 2 through 5, coaches asked about the participant's views on the videos, discussed their questions, and inquired about progress on their goals. Coaches guided participants, responded to and validated parent emotions, and supported parents throughout the intervention. During the final phone call, coaches inquired about challenges that parents anticipated for the future.

Analysis

The audio recordings were transcribed by a research assistant. A thematic analysis, as described by Braun et al. (2012), was performed to identify emergent themes for the categories of parent goals, questions parents asked, and challenges reported. The Max Weber Qualitative Data Analysis (MAXQDA) software was used to assist in the qualitative analysis (VERBI Software, 2019). The first author read the transcripts and coded emergent themes for each category (i.e., goals, questions, challenges) that parents raised in regard to hearing aid care and use. The first and second authors met regularly to confirm coding decisions. This was an iterative process for coding of phone calls and for determining themes and sub-themes. Memos in the

software were used to document the reason for individual coding decisions and general coding decisions were recorded in the software Logbook (VERBI Software, 2019).

The frequency of the themes that emerged for each category (i.e., goals, questions, challenges) was calculated per phone call. If a parent raised an issue multiple times within a call, it was only counted one time for that call. There were a few miscellaneous items in each category that did not fit the emergent themes. Miscellaneous responses occurred with the following frequencies goals 12/147; questions 23/203; challenges 52/902. The frequencies reported in the results represent those identified from the emergent themes. Responses coded as miscellaneous were excluded from tables and overall analysis in order to provide a clearer picture of primary issues identified.

Results

Emergent themes for parent goals, questions and challenges are described in this section with supporting quotes to illustrate what parents talked about during the coaching phone calls. See Appendix B for an additional sample of quotes. The frequency of each theme and subtheme for the three categories (i.e., goals, questions, challenges) is provided in Table 3.

Goals

During the first phone call and as needed in subsequent calls, the coaches asked parents about their goals to determine parent priorities. Four themes emerged: self-efficacy, developing routines, device care, and child development.

Self-Efficacy

Self-efficacy was the most common goal, representing 44% of all goals, and encompassed parents' desire to learn about hearing loss, hearing aids, and to gain confidence in order to help their child. Parents expressed various reasons that fueled their goals. For example, some parents stated feeling at a loss as to what to do because no one in their family had ever had a hearing loss, while others voiced wanting more knowledge so they could be a better advocate for their child. Parents expressed that they wanted to learn about hearing aid functionality and increase their general knowledge about hearing aids and hearing loss.

"[We want] to understand them [hearing aids] [so we] can utilize them the best way possible while she [child] has them... neither one of us [the parents] have family members that have had hearing loss" [P70]

"My ultimate goal is just to... know that I'm really doing the right thing in managing his hearing aids, to make sure that they're working properly" [P39]

"Just to be more on top of... not just trusting whatever the doctors are saying... being more knowledgeable in myself so I can be more of an advocate for her [child]" [P23]

Parents also talked about their desire to increase self-efficacy related to their child's hearing aid use. They described wanting to feel more comfortable handling the hearing aids and inserting them.

"I hope that it [hearing aid management] will feel more normal... to all of us...
especially my husband, he is really struggling with them... he's not able to put them
[hearing aids] in without worrying it's hurting him [child] because he [child] does kind
of get a little fussy when we're putting them in" [P68]

Parents also voiced wanting to be more confident so that they can be an effective advocate for their child. Furthermore, they recognized that their child will need to learn how to be a good self-advocate and that they have a role in advocating for their child and ultimately in helping their child learn.

"We want to make sure that... we are educated and...[we] have to like advocate for him until he can advocate for himself" [P76]

"I'm hoping to learn more and just kind of be better advocates for her [child] and better understand like what we can do, what we should be aware of, and how to help her along the journey" [P78]

Having the confidence to teach others (e.g., extended family members, nannies, daycare providers, teachers) was another important goal for parents. Parents talked about the need for individuals other than themselves to care for their child on a routine basis and made goals to teach them.

"Teaching other people how... to put his hearing aid in and how that's important... I shouldn't be the only one doing that [putting the hearing aid in]" [P6]

"hopefully... I can better educate others. I know my one daycare, there's a teacher there that just had a kid and they just found out that their son has hearing loss" [P38]

Developing Routines

Parent goals, related to routines, reflected approximately one-quarter of the goals. Parents expressed the desire to improve daily habits for hearing aid wear time and device management.

Parents stated they struggled in remembering to put the hearing aids on their child and with

including time to perform hearing aid management tasks. Parents were in different places regarding the steps that they felt they were ready to take.

"we're just working on trying to keep them in as much as possible" [P97]

"wearing... hearing aids four to five hours a day... to six or seven by the end of this week" [P81]

"I believe that we're very close to ten hours... but I want to make sure... that we're hitting that [wear time]" [P86]

"putting them [hearing aids] on first thing in the morning" [P68]

"relocating the hearing aid container" [to help them remember to put the devices on in the morning] [P12]

Device Care

Parents voiced a range of goals related to taking care of the hearing aids, representing 21% of the goals. Overall, the goals centered around cleaning and maintaining hearing aids. This included battery knowledge, cleaning the hearing aids, using the dry aid kit, performing a listening check to monitor hearing aid function, and goals related to learning how to troubleshoot problems that arise with the hearing aids.

"The... goal is... paying attention to how clean those ear molds are and also kind of inspection of the hearing aids themselves" [P68]

Parents set goals centered around regularly performing listening checks and checking device functionality.

"I guess be more mindful of doing like the sound tests... that's a priority and a goal of mine to do consistently" [P42]

"To kind of educate myself... knowing if problems arise, like if molds are too small, what do I look out for... [to be] more aware of what could go wrong, [an] awareness of problems" [P39]

Child Development

Goals centered around child development occurred with the least frequency (13%); however, some parents had goals related to their child's speech development, as a result of consistent hearing aid use, others simply wanted to encourage their child as they navigate having a hearing loss. Speech development goals related to parent's desires for their child to develop spoken language and enter their neighborhood school. Parents also expressed wanting their child to learn how to put on and maintain their hearing aids, as well as for their child to understand what their hearing aids were for and how their devices are helping them.

"So that's our goal... speech and language and to make sure he's [the child] hearing everything that he should be hearing" [P39]

"to learn how to manage... his equipment... in an age-appropriate way... and start being part of the process you know beyond just telling us... if it's working or not but like start seeing him help take care of his hearing aids or put them in or fix it it's hanging off his ear" [P85]

"something I've wanted to do is spend a bit... of time with her after she puts them in and just kind of reinforce that it's good that she's wearing them and that I'm glad that she's wearing them" [P69]

Questions

Parents asked a variety of questions throughout the study. Questions arose for various reasons, including from the instructional videos they watched, concerns or challenges they were experiencing, and a desire for more information. Four themes emerged: device care, audiology, confirmation of learning, and child development.

Device Care

The majority of questions asked by parents were related to the management of devices, representing 63% of questions. Parents raised questions on a range of issues including use of tools (e.g., listening tube), accessories (e.g., FM systems), how to determine when there is a problem with device function, issues related to hearing aid use (e.g., retention), earmold challenges, batteries, and hearing aid repairs.

"Do you use that [dry aid kit] every night" [P35]

"What parts should we be cleaning? What should we be looking for?" [P41]

"I usually grab his hearing aid and put it up to my ear... is that an effective method... or should I be using this listening tube?" [P35]

"Every time she [child] pulls her shirt on... her hearing aid comes off, so she just [takes] them out and she's just done with them. Is there like a tape or tricks to get [them] to stay?" [P78]

"Does the battery linearly deplete in terms of charge or is it kind of a quick drop off?"

[P9]

"Are the Lysol wipes... too harsh for the molds?" [P1]

Audiology Appointments

Some parents (15%) asked questions related to services they received from their audiologist for the hearing aids. The questions were focused on hearing aid programming and hearing testing. Parents expressed a desire for more information or clarity on what they should expect.

"I was wondering about the-the RECD, is that something that they [audiologist] do normally that we would see in their notes? If it hasn't been done like is that something that we should mention to them?" [P47]

"Can he still wear his hearing aid with the tubes? And will the settings have to get changed?" [P21]

"They're doing an ABR at the same time as they're putting tubes in, and I-I guess I'm confused... I'm trying to figure out whether or not if they do the ABR immediately after putting tubes in, will that affect his ABR results with him having tubes in his eardrums?"

[P81]

Confirmation of Learning

This theme accounted for 13% percent of the questions parents asked. Some of the questions arose from discussion about the instructional videos as well as other information when parents wanted to confirm their understanding. Sometimes parents would answer their own question but would still want clarification.

"When he [child] hits three, he's no longer eligible for early intervention, right?" [P82] so, I'm doing it right with the ear mold, right?" [P42]

"They didn't take it all the way apart, but they took the batteries out. Are we supposed to be taking the batteries out?" [P32]

Child Development

Nine percent of the parents asked questions related to their child's development. This included speech and language development, their child's self-confidence and ability to be at peace with their hearing loss, the effect of the device on ear health, and questions about how to teach their child's peers and related professionals about the hearing aids.

"What do we tell him as parents to build his self-confidence that there's nothing wrong with him?" [P82]

"I was wondering if you had any info on like ear sores? I know that's why she doesn't wear them when she's sleeping but she didn't, and she still got one" [P69]

"Does the school provide training or would I go in and talk to them and show them how to do everything?" [P35]

Challenges

Parents discussed a wide range of challenges during the coaching phone calls. Four themes emerged for challenges related to the parent, provider, child, and anticipated challenges.

Parent

About half of the challenges parents expressed (53%) were related to what they were experiencing managing the hearing aids. Parents brought up personal challenges that they experienced as a result of their child having a hearing loss, issues related to device care, their emotions, developing routines, and finances. Struggles with device care was the most common

challenge raised. Parent comments displayed a lack of knowledge in regard to cleaning and device maintenance. They expressed difficulty keeping hearing aids on their child, which parents acknowledged, impacted wear time. Parents experienced difficulty teaching other care takers how to manage devices.

"Every time she pulls her shirt on... her hearing aid like comes off, so she just puts them out and she's just done with them... I had to cut her tubing for her molds, and I think I cut it too long, so just like little things like that that I feel like I'm really just uniformed on" [P78]

"The only thing is, is that I don't know how to explain it to my dad. He still just doesn't understand because he's like 'well he's got one good ear; he should be good'" [P40]

"I would come [to daycare] or my husband would come to pick him up and they would be like 'uh, his hearing aid's somewhere' and... would have to go find it" [P81]

"I need to do a better job... with my mother. She's just not comfortable. She's afraid she's going to mess it [hearing aids] up and I feel like maybe there's some tips in there that I need to do with her or like they suggest, have [her mother] watch a video, or a couple videos, so [she will] know" [P55]

Parents expressed their emotions frequently throughout the study. Emotions such as worry, frustration, uncertainty and stress were commonly brought up by parents. Parents expressed concern about their child's speech, language and auditory development. They were uncertain about using hearing aids, the effect they were having on their child and what the future would bring. Frustrations about retention, putting in the hearing aids and a disagreement between spouses regarding hearing aids were expressed. Parents expressed feeling overwhelmed,

especially while their child was being diagnosed with hearing loss. Many parents voiced that they did not have confidence in their abilities to care for the hearing aids.

"[I] worry about... his [child] hearing ... getting worse or if there's something wrong"
[P48]

"it is so draining when you're asking... questions and you're trying to find help for them [child] and... doctors can't even necessarily answer... questions, you're just... waiting to see how she [child] does" [P69]

"it's just so overwhelming... I always describe it as drowning... I remember her [audiologist] talking and... [shaking] my head like 'you have to pay attention this is important'. There was just so much information at one time" [P41]

"my husband, to be real honest with you, irritates the hell out of me sometimes...
explaining to him... we are doing it [putting the hearing aids in] because he's getting
some more access than he would if he wasn't putting them [hearing aids] in." [P6]

"I think it's frustrating because we don't really know... how much these hearing aids are helping" [P6]

Parents described challenges related to developing routines. Many parents wanted to solidify their morning routine so as to increase wear time. Other parents struggled to develop consistent routines and often did not remember to put the devices on their child due to busy schedules. For example, some parents were also working, while taking care of their child, other parents had multiple children and would forget to put the hearing aids on their child during the morning rush, trying to get older siblings off to school. Some parents honestly expressed that they would just forget to put on the devices.

"I'll take them [hearing aids] out at night and realize that the battery is dead and she's [child] probably been walking around with a dead hearing aid" [P19]

"she [nanny] didn't put it [hearing aids] on for some reason, I forgot to ask her why"
[P12]

"I was focusing solely on her with her hearing loss... through splitting that attention [with a newborn sibling], ... It's [putting the hearing aid in] not going to feel like my first priority in the morning" [P19]

Parents also expressed challenges paying for device programming, care and testing. Insurance coverage was also a challenge expressed by some parents.

"they [clinic] wants us to do more hearing tests, but it's just so expensive with our insurance that we haven't done it... so that is a concern for me, I wonder if it [hearing aid] is working or if his [child] hearing loss is worse or not... eventually, I think we are going to have to do a hearing test, it's just so expensive" [P41]

"getting second opinions or third opinions... that's kind of easier said than done...
there's another audiologist that... does even more pediatric audiology here in town... but
she doesn't work with Medicaid" [P48]

Related to Audiologist

Challenges with providers, mostly audiologists, accounted for 33% of reported challenges. Parents expressed issues with their own lack of knowledge, difficulty with scheduling and time restraints within appointments, restrictions in getting services with coronavirus (COVID-19), access to a pediatric audiologist, and having a negative relationship

with their provider. Lack of knowledge showed up as parents talked about the things that they learned from the assigned videos. They would say that they had not learned about an aspect of device care or use before or that they didn't remember what their audiologist had taught them.

"I actually learned [from the video] the right way to take them [hearing aids] off... to be more careful and more sensitive when pulling them out" [P83]

"The audiologist probably should have gone over all of that stuff. Like... testing the hearing aids to see if they're working... it was our speech therapist actually that encouraged me to start doing it [listening checks] more regularly... our audiologist has never asked if I check them" [P48]

Scheduling and time restraints involved issues with parents being able see their providers when they needed to, the time it took them to travel for audiology appointments and the time demands of seeing multiple providers. Some scheduling issues were attributed to COVID-19 shutdowns, when clinics were unable to see patients. Parents also expressed frustration with early intervention delays due to the shutdowns.

"she's [audiologist] overwhelmed... even trying to see her is always a chore" [P81] "burn out from constant appointments... my son just turned seven months and he averages 1.5 appointments per week" [P9]

"they're [earmolds] definitely loose. I knew he [child] needed new ones even before everything shut down [due to COVID] and now it's just getting worse" [P84]

Having access to an audiologist was a challenge that came up. Some families specifically wanted a pediatric audiologist. Additionally, some parents expressed difficulties in their relationships and interactions with their audiologists.

"we don't have anybody closer to us than three hours" [P41]

"four-hour drive away [to audiologist]" [P46]

"Well, the first person [audiologist] felt very kind of offending... It just felt like we were talked down upon and with this one [current audiologist] they're talking with us and understanding like 'hey, she has down syndrome' and other issues that she may have, and they want to work with us" [P12]

"Our third child didn't pass his hearing test – he was a preemie. So, we went down to [the clinic] and we just did not have a very good experience... we just felt like they didn't have any compassion or empathy... they were just kind of like, 'so he needs hearing aids', and we were like 'woah, time out, what?' ... It's [current clinic] probably an hour and forty-five minutes from where we live to get down there, but it's worth it. They give us any and all the information that we... ask [for]" [P65]

Child Factors

Ten percent of the challenges parents voiced were related to their child. Parents raised challenges related to their child's development, behavior, communication with their child, how their child is hearing in different types of environments, and issues specific to children who had multiple disabilities.

"he'll [child] at least tell us... he'll sign like, 'fix it, fix it, fix it'... especially when the behind the earpiece... comes forward... he doesn't quite have the dexterity to like push it back behind his ear" [P85]

"my biggest frustration... right now is understanding when he's having a hard time hearing me or when he's just ignoring me" [P81]

"It's hard for me to see her face sometimes and the blank looks... in a loud environment... I can just tell that she did not get it and I'll ask her, 'did you understand?' and she's like, 'no' or... other people will ask her something and she shrugs her shoulders" [P44]

"She's fighting the bottle because she's teething right now. It's just everything right now, with her down syndrome and the last thing on my mind right now is cleaning the hearing aid" [P12]

Anticipated Challenges

Anticipated challenges were explored during the final coaching phone call and encompassed issues that participants were not currently experiencing but thought that they would encounter in the future. Parents raised concerns that they anticipated with school years being challenging, and how their child will feel interacting with their peers.

"I'm going to worry about losing them [hearing aids]" [P68]

"It'll be more interesting to see how she responds when she's in a full classroom... like the four to one daycare ratio... I'll be curious to see how she's able to adapt to that"

[P47]

"You really don't want your kid to be the one outed... and looked at differently when they [child] get out and their persona and body image and going through the teens... I think that's going to be a big challenge" [P6]

Discussion

The purpose of the current study was to qualitatively explore goals, questions, and challenges related to hearing aid management expressed by parents who participated in the intervention condition of an eHealth education and support study (Muñoz et al., 2021).

Understanding parent priorities and the issues they face in day-to-day management can help audiologists identify better ways to support audibility for children using hearing aids. The model of cumulative auditory experience describes how spoken language development is negatively affected by hearing loss and that interventions to address malleable factors that influence auditory access can minimize those negative effects (McCreery & Walker, 2017). Parent education and support is a malleable factor that can be addressed through eHealth intervention. The eHealth intervention provided (Muñoz et al., 2021) was found to positively influence parent hearing aid management. In the current study parents' provided insights that are valuable, such as their desire to increase self-efficacy, their questions surrounding device use and their personal challenges related to their child's devices. These findings reveal ways to enhance how audiologists have traditionally provided learning support.

The most common concerns centered around self-efficacy, hearing aid use and care.

Offering an eHealth approach in order to provide support for parents may be a viable option for busy clinics and overbooked pediatric audiologists. It was clear from the goals created, questions asked, and challenges expressed, that many parents are not retaining the information provided at appointments regarding device care and troubleshooting. This study provides insight on how audiologists can better support parent hearing aid education. It also suggests that audiologists may not sufficiently support parents as they try to implement new habits. Our study suggests that

opportunities for repetition, whether during an in-person visit or through eHealth, is important for parent education and confidence building.

Parents also expressed negative emotions, such as frustration and stress, related to interactions with their audiologist. This provides critical insights for how audiologists partner with parents and the elements they include in their standard hearing aid services. For example, parent-to-parent support is recommended to help parents adapt and adjust (American Academy of Pediatrics, 2021); however, many pediatric audiologists have reported that they do not include this information (Meibos et al., 2015). Family-centered care is critical for developing a therapeutic relationship that can effectively identify parent challenges, as well as guide and support parents as they learn (JCIH, 2013).

An eHealth approach for parent hearing aid management education and support can facilitate positive behavior change. The structured approach in the current study (i.e., assigned videos and scheduled phone calls) offered support to parents over time, provided an opportunity to reinforce learning, improved parent understanding and confidence, as well as guided parents in identifying and addressing barriers they were experiencing in integrating new routines in their daily life. In other areas of healthcare, patients have reported needing emotional, informational, and practical support to be able to effectively self-manage their condition (Zuidema et al., 2015; Coffey et al., 2016). Behavior change theories have shown that health-related behavior change is difficult, even when it is desired, and providers can positively influence treatment adherence barriers when they guide patients in addressing challenges (Mostofsky, 2014). Timely access to learning and adjustment support for parents who are learning how to manage hearing aids represents an important factor in providing audibility for children.

Family-centered care is a core element of early intervention and eHealth may offer additional opportunities to reach other caregivers. An eHealth model is well-suited to providing guidance for other individuals who are also primary caregivers. Often times mothers attend audiology appointments and have the burden of teaching others. Physical distance from the audiologist is another factor that can interfere with opportunities to provide family-centered care. An eHealth approach to family care can help bridge the gap between parents and audiologists when distance is a barrier to frequent care. Information and coaching, as provided in the current study, would allow parents to gain the skills and knowledge to maintain and troubleshoot issues with the hearing aids. It would also help them establish habits and overcome barriers to hearing aid use.

Even though the current study demonstrated the need to provide remote support to parents for hearing aid management, audiologists are often limited in the scope of support they can offer. For example, parents raised concerns about what to expect for their child in the future. Parent-to-parent support provides important insights from a parent who has had similar experiences and can offer hope and empathy in a way that an audiologist typically cannot. Approximately half of the parents in the study reported receiving information related to parent-to-parent support (Muñoz et al., 2021). The need for increased information in regard to parent-to-parent support is also evident in a previous study (Meibos et al., 2015) where less than half of the participants were provided parent-to-parent support information. Guidance related to parent support provided for professionals (JCIH, 2013; 2019). Providing parent-to-parent support information for caregivers represents a gap in practice that needs attention.

Challenges with hearing aid management are common and the need to address parent challenges can be anticipated and incorporated into the care plan. Audiologists have a role in

educating and supporting parents as they learn how to integrate their child's hearing aids into their daily lives. Early identification of hearing loss, through newborn hearing screening and early amplification, has become the standard of care. These two components are essential for consistent audibility, thus providing developmental advantages for children with hearing loss.

There were limitations to the study that should be mentioned as clinical implications are considered. The parents in the intervention were primarily mothers who were white and had received a college education. The experiences of a diverse population of caregivers may yield different issues and priorities that were not revealed in this study. It should also be noted that findings were related to the video instruction and coaching that participants received. As a result, these findings cannot be generalized to all hearing management topics as they represent topics raised by parents in this sample. The issues raised by the parents during the phone calls were likely influenced by the videos they were assigned to watch each week; however, parents did have opportunities to raise other issues of importance they were facing related to hearing aid management. During the coaching phone calls, practical issues and challenges were primarily discussed. Parents' internal barriers, those related to their thoughts and emotions, were not specifically targeted in the intervention and were likely missed and represent an aspect of intervention that needs further research.

Future research is needed to better understand variables that influence parent learning and capacity building, including intervention length, frequency, and delivery. Parents may have different preferences for how they learn, and this may influence effective approaches for how education and support is individualized. Research focused on addressing internal barriers is needed to better understand how these barriers impact daily management and how to effectively

support parents in overcoming these challenges to improve hours of hearing aid use and overall hearing aid maintenance adherence.

Conclusion

The coaching phone calls provided in the eHealth intervention offered benefits to parents. Parents had the opportunity to identify and address barriers to hearing aid management within the context of supportive accountability over time based on their priorities and current challenges. Providing more frequent learning opportunities, in addition to treatment as usual, can help parents develop more effective hearing aid management routines.

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Table 1. Participant Demographics

Caregiver and Child Information (N = 41)	% (n)	M (SD)
Caregiver		_
Relationship to child - mother	89 (33)	
Race - white	78 (29)	
Education level – college educated	77 (30)	
Annual income		
More than \$80,000	49 (18)	
\$41,000 - \$80,000	27 (10)	
Less than \$41,000	19 (7)	
Prefer not to answer	5 (2)	
Child		
Current age in months		16 (11.40)
Gender - female	38 (14)	
Degree of hearing loss (parent reported)		
Mild	14 (5)	
Moderate	57 (21)	
Severe	19 (7)	
Profound	11 (4)	
Additional disabilities - yes	30 (11)	
Race - White	76 (28)	

Table 2. eHealth research study schedule

Week	Weekly Activity		Minutes		Weekly Total
	Video 1	Video 2	Videos	Call	
1	Initial phone call		0	30	30
2	Coping and Planning	Developing new Routines	31	10	41
3	Hearing Aid Care Guide	Hearing Aid Use	20	10	30
4	Signs of Hearing Difficulty	Hearing Aid Batteries	9	10	19
5	Hearing Aid Settings	Teaching Others	12	10	22
6	Final phone call		0	30	30

Table 3. Emergent themes for parent goals, questions, and challenges

Categories	Themes and Sub-Themes	Themes %(n)	Sub-Themes %(n)
Goals	Self-Efficacy	44 (54)	
	Knowledge		44 (24)
	Advocacy		22 (12)
	Hearing Aid Use		19 (10)
	Teaching Others		15 (8)
	Developing Routines	22 (27)	
	Wear Time		64 (17)
	Development of routines		36 (10)
	Device Care	21 (25)	
	Cleaning/maintenance		56 (14)
	Checks		32 (8)
	Troubleshooting		12 (3)
	Child Development	13 (16)	, ,
	Speech Development	, ,	62.5 (10)
	Encouragement		37.5 (6)
Questions	Device Care	63 (88)	, ,
	Properly Functioning		23 (20)
	Tools and Accessories		22 (19)
	Batteries		22 (19)
	Wear Time		20 (18)
	Earmold		9 (8)
	Repair		4 (4)
	Audiology Appointments	15 (22)	
	Programming		86 (19)
	Testing		14 (3)
	Confirmation of Learning	13 (18)	
	Child Development	9 (12)	
	Development		42 (5)
	Device Effect on Ear Health		33 (4)
	Education/Intervention		25 (3)
Challenges	Effect on Parent	53 (272)	
	Device Care		53 (145)
	Emotions		31 (85)
	Developing Routines		13 (35)
	Finances		3 (7)
	Related to Audiologist	33 (171)	
	Parental Lack of Knowledge		61 (105)
	Time Restraints/Scheduling		12 (21)
	COVID		12 (21)
	Access to Pediatric Audiology		9 (14)
	Negative Relationship		6 (10)
	Child Factors	10 (49)	
	Development		37 (19)
	Behavior		35 (17)
	Environment		18 (9)
	Multiply Involved		10 (5)
	Anticipated Challenges	4 (19)	

Call 1 Questions and Comments to Address with Participants:

- Can you tell me about what motivated you to participate in this study?
 [Actively listen, ask follow-up questions as needed, and record response]
- 2) Thank you for sharing with me why you want to be a part of this study.

 Like I said, our goal is that this will be a learning experience for you.

 As such, I'm wondering if we can set some goals. Based on some of the things you just said, it sounds like you are struggling with

 ______ [individualize to them]. Am I understanding your concerns? [Actively listen, ask follow-up questions and validate their emotions, if needed] At the end of this study what do you hope will be different? [actively listen, summarize their goals, record responses]

These sound like good goals, and I am excited to see what you can accomplish. So, let's get started! The first week you will watch two videos - the first is called Coping & Planning and the second is called Developing New Routines. It will take you a total of 30 minutes to watch the videos. Would you prefer to receive a text or an email with the video links each week? [note their preference] Ok, right now, I am texting/emailing you the link to the first two video tutorials that I want you to watch by next [date]. Do you see them in your text messages/inbox [allow time for participant to check]. After you watch those, I would like to call you next week and hear what you have to say. When is a good time I can call you? Thank

you back on [date and time]. Does that sound right? [end phone call]		
Questions and Comments to Address with Participants:		
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have now as you move forward with your child's hearing aids?

[actively listen, respond to emotions raised, record response]

What challenges do you anticipate? [actively listen, respond to emotions raised, provide guiding response, if needed, record response] Thank parent and end call.

Appendix B

Parent Quotes

	GOALS
Self-Efficacy	"I want to understand how hearing aids work better" [P41]
	"any time we can learn something that would enhance our experience or enhance his
	abilities we take that [opportunity] as a win" [P85]
	"his hearing loss is not the kind that's going to get better so better to educate myself,
	so that I can better educate my family [about hearing loss]" [P97]
	"My ultimate goal is just to really know that I'm really doing the right thing in
	managing his hearing aids, to make sure that they're working properly" [P39]
	"more confidence with the hearing aids and putting them on her [and] different
	types of ways to help cope and manage her hearing process as she gets older" [P83]
Routines	"my goal I feel like could be 8 [hours]" [P41]
	"I don't do it [check hearing aids] as quite as often as recommended" [P42]
	"we are currently working on starting to wear them for short trips in the car" [P81]
	"continue with having her wear them as much as possible, making it a really positive
	experience for her and a really positive thing for her to do" [P70]
Device Care	"He [child] gets really sweaty when he's outside in the summer time playing. Like
	maybe learn more about how much moisture I should worry about and how I would
	know if there was water damage" [P48]
	"Just checking like the earmolds and stuff. I do do that but I guess I don't do it as quite
	as often as recommended" [P42]
	"To just make sure that the habits become actually habits with cleaning and
	maintaining them" [P46]
	"checking them in the morning honestly if I don't do it before she puts them in it's
C1 '1 1	not going to happen" [P19]
Child	"develop [their] verbal skills" [P47]
Development	"our goal is for her [child] to be mainstream" [P70]
	"we're still working on our goals making sure that-that he understands what they're
	for" [P97]
D : C	QUESTIONS
Device Care	"I was curious what is the listening tube?" [P76]
	"When should it [desiccant tablets] be changed? How do you know?" [P68]
	"What's an FM system?" [P82]
	"Is this common practice for schools to provide them [FM systems]?" [P41]
	"ten hours is a lot of wear time is that really feasible at a young age?" [P41]
	"We have not been taking the battery out of the hearing aid when we put them in the
	drying container is that something we should be doing?" [P76]
A 1: 1	"Are they [earmolds] uncomfortable if they are too small?" [P97]
Audiology	"Is that your understanding that we don't need to ever take them [hearing aids] out if
Appointments	we're concerned about something being too loud?" [P86]
	"at what age do kids get to have volume control on their hearing aids?" [P84]
	"Is that [RECD] literally like the gap between the ear mold and the ear? Like sound
	might be escaping or what?" [P79]

	"with the results from the graphing, do they have what the average hearing is and then		
	do they do a display of what the patient's hearing is? [P70]		
	"our biggest question from the videos was on bone conduction testing. I don't know		
	that's something that we've seen or had done or plan to have done. I was just		
	wondering if you had any comments?" [P9]		
Confirmation	"Interesting. What's it called? A pilot cap?" [P35]		
of Learning			
of Learning	"you kinda just dig it into the hole and then dig out the ear wax?" [P12]		
C1. 1.1	"the dryer should take care of the rest, right?" [P1]		
Child	"blabbering lasted for a couple of days and then went to almost nothing, I'm not sure if		
Development	that's normal or not" [P82]		
	"Are there studies that say – that have outcomes for putting them in special program		
	versus mainstreaming them while they're young in daycare or not really?" [P21]		
	"I guess [child] has her first ear infection and she had some antibiotics and the ear		
	infection didn't go away. I don't know if that's more common in-in kids with hearing		
	aids or if there's something that we did that could of like exposed her to it? [P47]		
	"that left ear that the aid is on is super pussy apparently, like behind the TM. So, is		
	there anything now that we should be doing?" [P21]		
	CHALLENGES		
Effect on	"we get to spend very little time with them [children] over the weekend but then we		
Parent	have Friday, Saturday, Sunday that's like our real time of spending family time it's		
	kind of tough for us cause we're not used to it [hearing aid routines]" [P82]		
	"last Friday [the child] pulled apart his mold and then took the hard part that actually		
	connects the tubing to the hearing aid and he bit down on it and flattened it" [P81]		
	"she's one of four, so she is not the only one who needs things, especially the mornings		
	are pretty tough for us. Just kind of choosing to get up even though I feel so tired and		
	then trying to remember everything that I have to do to get everyone ready, it can be		
	challenging" [P69]		
	"I think it's frustrating because we don't really know how much these hearing aids		
	are helping" [P6]		
	"my wife owns a nonprofit so she's working, also taking care of the baby and trying to		
	balance both but sometimes she'll have pressing deadlines and the hearing aid habit		
	just falls off her radar" [P12]		
	"our insurance is every three months for him this last time he was actually three		
	weeks without a hearing aid because the old one just didn't' fit anymore and it was		
	bugging him, so he'd always rip it out. And then it takes two weeks to get it made"		
	[P40]		
Related to	"We could go to the audiologist at the medical center but I don't like her it's not a		
Audiologist	personal thing but she's also not a pediatric audiologist" [P97]		
Audiologist	"I didn't get any information like she jus gave me the backpack and was like 'here,		
	there you go" [P94] "Given that that [appointment] has been rescheduled multiple times and they have not		
	"Given that that [appointment] has been rescheduled multiple times and they have not		
	seen him in a year, so we were a little surprised when they were finally able to keep		
	the appointment" [P85]		
	"the audiologist tries to explain but it's a lot of information when you're in an		
	appointment, so it's nice to kind of learn about it outside of that" [P79]		
	"the battery compartment, I didn't know I was supposed to clean that" [P44]		

	"I didn't know how to clean it [hearing aid] before this video at all they		
	[audiologist] handed it to you like 'there's a tool in there to clean this, this and this'		
	and I never cleaned it because I wasn't sure how to go about it" [P41]		
Child Factors	"I was driving in the car and he [child] literally was like 'oh, ok mommy' and I was		
	like 'you know I didn't say anything'. And so it's already showing me that there are		
	times that he'll just go along with whatever like that's the canned response not		
	because [he] understands it so that's one of my concerns" [P85]		
	"we have wars about hearing aids in my house I can usually get them in for about an		
	hour or so [then] they're pulled out and if I try to put them back in there comes time for		
	a temper tantrum" [P81]		
	"it gets pretty muggy down here during the summer when it's hot" [P35]		
	"we have the highway noise and I noticed that if I leave the door closed he's more		
	likely to leave his hearing aids in" [P97]		
	"my daughter has some other things going on besides audiology but even with just all		
	the audiology appointments, it's so tiring" [P69]		
	"my daughter has some delays that's [repeating Ling sounds] also kind of beyond		
	her right now, so having something like a little stethoscope would be nice" [P46]		
Anticipated	"it looks like [the child] will be in a private preschool that his brothers were all in in		
Challenges	terms of the FM system I'm kind of anticipating a little push back with that" [P86]		
	"he's gonna miss out on hearing when his friends are whispering in between each		
	other or the teachers talking not in a loud voice" [P82]		
	"[the child] getting older and maybe him accepting it [hearing loss]" [P39]		