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Rural Family Perspectives and Experiences with Early Infant Hearing Detection and Intervention: A Qualitative Study

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Abstract

Infant hearing loss has the potential to cause significant communication impairment. Timely diagnosis and intervention is essential to preventing permanent deficits. Many infants from rural regions are delayed in diagnosis and treatment of hearing loss. The purpose of this study is to characterize the barriers in timely infant hearing healthcare for rural families following newborn hearing screening (NHS) testing. Using stratified purposeful sampling, the study design involved semi-structured phone interviews with parents/guardians of children who failed NHS testing in the Appalachian region of Kentucky between 2012 and 2014 to describe their experiences with early hearing detection and intervention program. Thematic qualitative analysis was performed on interview transcripts to identify common recurring themes in content. 40 parents/guardians participated in the study and consisted primarily of mothers. Demographic data revealed limited educational levels of the participants and 70 % had state-funded insurance coverage. Participants reported barriers in timely infant hearing healthcare that included poor communication of hearing screening results, difficulty in obtaining outpatient testing, inconsistencies in healthcare information from primary care providers, lack of local resources, insurance-related healthcare delays, and conflict with family and work responsibilities. Most participants expressed a great desire to obtain timely hearing healthcare for their children and expressed a willingness to use resources such as telemedicine to obtain that care. There are multiple barriers to timely rural infant hearing healthcare. Minimizing misinformation and improving access to care are priorities to prevent delayed diagnosis and treatment of hearing loss.

Keywords

Infant hearing loss; Rural healthcare; EHDI; Barriers to healthcare access; Appalachia

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Introduction

Congenital hearing loss is a common disorder in the US, with an incidence of 1.4 in every 1000 infants screened at birth [1]. Since the first newborn hearing screening (NHS) programs were established in the early 1990s, there has been great progress in screening guidelines, diagnosis and amplification processes and supportive services for families. In the 2009 early hearing detection and intervention (EHDI) data, the CDC reported that over 97 % of all newborns were screened for hearing loss [1]. However, despite advances in care over the last 20 years, further improvement in early intervention services remains an “urgent priority” according to the American Academy of Pediatrics [2]. Congenital hearing loss has significant negative effects on a child’s language development and also has socioeconomic implications [2–5]. These consequences are consistent across all degrees of hearing loss from the mild to the profound. The US Preventative Services Task Force (USPSTF) recognizes the deleterious effects that pediatric hearing loss has, including difficulties with communication skills, behavioral problems, psychosocial development and reduced academic achievement compared to normal-hearing children [6]. It has been well established that early diagnosis and treatment of hearing loss lead to significant improvements in hearing and language development [2–10]. Thus, the Joint Committee on Infant Hearing, the American Academy of Pediatrics and the National Institute of Health have instituted universal NHS and recommend that all infants be screened by 1 month of age, those who fail should be diagnosed by 3 months of age and those diagnosed with hearing loss should receive early intervention services as soon as possible following diagnosis, but no later than 6 months of age [2, 7, 11]. Earlier identification of hearing loss leads to early intervention, which can yield language, cognitive, communication and social skills that are consistent with hearing age-matched peers [5, 10].

Although NHS has been widely implemented, there are significant barriers to timely infant hearing healthcare. Many infants are lost to follow-up after the NHS [3] and then may be delayed in receiving definitive diagnostic testing and subsequent intervention. The disparities in access to care that exist for some lower socioeconomic populations increase their risk of being delayed or lost to follow-up [3]. In particular, patients in rural areas, such as Appalachia, face increased disparity due to geographic isolation [11, 12]. The Appalachian region of the United States experiences some of the most striking healthcare disparities and has long been stricken by poverty and extremely poor healthcare access [3, 12–14]. The National Institute of Health has designated the Appalachian population as a special population of interest due to disparities in outcomes [15]. There is some indication that delayed infant hearing healthcare in rural regions may related to factors such as socioeconomics, travel distance, lack of education and accessibility of care [3]. The purpose of this study is to qualitatively assess the perspectives and experiences of rural parents/guardians on infant hearing healthcare who accessed the EHDI system following a failed newborn hearing-screening test.

Methods

The internal review boards of the University of Kentucky (protocol 11–0872-P3H) and the Kentucky Cabinet for Health and Family Services (protocol CHFS-IRB-CCSHCN-FY12–

49) approved this study. Inclusion criteria included Appalachian parents/guardians of children who failed the NHS in Kentucky from 2012 to 2014 and were receiving or had received pediatric hearing healthcare through the state-supported EDHI clinics. In coordination with the audiology staff from rural Appalachian EHDI clinics, we utilized a stratified purposeful sampling method to recruit participants who were at different stages in accessing the EDHI system. This included 3 different groups of participants: (1) parents/guardians of children had failed a screening test and subsequently passed outpatient testing, (2) parents/guardians of children who failed a screening test and were still in the diagnostic process at the time of the interview, (3) parents/guardians of children who failed a screening test and were diagnosed with hearing loss. We developed a semi-structured open question interview script based on previously published pilot parental questionnaire data [3]. We contacted all study candidates by phone and verbal consent was obtained and we then conducted a single telephone interview with participants. The interview data collected included family demographics (relationship to child, county of residence, type of insurance, parental/guardian educational level) along with family experiences as they progressed through the EHDI system. Questions of progression through the EHDI system regarded family knowledge of in-hospital screening results, the process of follow-up testing, receipt of diagnosis and an evaluation of any further intervention the child received. Specific inquiries were made regarding barriers in the EHDI process that either complicated or prevented the recommended outpatient diagnostic testing at the EHDI clinic. If a child received a diagnosis of hearing loss during the EHDI process, participants were asked additional questions regarding the timing of treatment. Finally, participants were asked around their attitudes towards infant hearing loss in general and the importance of early intervention services. Based on the reported county of residence, we also assessed the rurality of the participants' counties using the US Department of Agriculture Rural–Urban continuum Beale coding system [16].

With the permission of the participants, all interviews were recorded and transcribed. From these transcriptions, thematic qualitative data analysis was performed to identify the barriers faced by individuals and extract commonalities across interviews. Data were managed and analyzed using NVivo qualitative data analysis software (QSR International, Melbourne, Australia). All transcripts were read in full to obtain a general sense of the material. With the assistance of the qualitative data analysis software, we then performed open coding in which a code word or phrase is assigned to a segment of text. Line-by-line coding was performed to ensure full inclusion of all possible data. After transcripts were coded line-by-line, the resulting codes were categorized into clusters of related themes to reduce redundancy and identify overarching categories. Constant comparative analysis allowed several recurring themes to emerge from these categories. This inductive framework guided the remainder of information gathering. The coding process continued until no new themes emerged. During the coding and analysis processes, illustrative quotes were identified and collected separately. With this, significant quotes were easily retrievable, allowing us to clearly demonstrate code data and compare participant perspectives and experiences regarding emerging themes. Participants' responses are reported in quotations in the results section. The transcripts were coded and data analyzed by 2 people. Data was comparable between

interviews and consistent with preliminary questionnaire data [3]. The themes were consistent across the 3 different participant groups.

Results

Participant Characteristics

The number of participants was 40, all of whom lived in Appalachian counties of Kentucky. The demographic information of the participants is displayed in Table 1. All 40 participants had accessed infant hearing healthcare within rural Appalachia through state-funded EDHI clinics. 29 participants reported that their was found to have normal hearing on follow up testing, two participants were in the process of diagnostic testing at the time of the interview, and nine participants reported that their child was diagnosed with hearing loss and were receiving ongoing treatment with hearing aids at the state-funded clinic. According to the Beale classification, all of the participants resided in rural Appalachian counties with 85 % residing very rural counties. 20 participants were from counties of a Beale code of 7 (urban population of 2500–19,999, not adjacent to a metro area) and 15 were from counties with a Beale code of 9 (completely rural or less than 2500 urban population, not adjacent to a metro area). Regarding the timing hearing healthcare, 7 of the 9 children with hearing loss were diagnosed after the recommended age of 3 months and 6 of those 9 children received hearing aid amplification after the recommended age of 6 months.

Poor Communication of Newborn Hearing Screening Results

With this finding of children receiving hearing healthcare after the recommended ages, the participants reported on poor communication about infant hearing screening results. Several participants reported that did not receive results of the infant hearing screening while in the hospital. Communication of the results for those participants occurred from a few days to a few weeks after discharge. Participants expressed concern over the lack of communication and confusion about the test results. One participant mentions how shocking it was to receive a letter several days after leaving the hospital saying her daughter had failed, after she was under the impression that all was well:

“So they had come out and told us that they did her newborn hearing test, but now they did not tell us that she had failed her hearing test at the hospital. I didn’t know that until after we came home and we got a letter. Yeah, because I panicked out. I thought you know that she might deaf or you know something like that. Yeah, because they didn’t, they didn’t tell us at the hospital.”

Another participant that received the screening results in the mail, discussed how difficult it was to understand what the results actually were:

“The way they had it on the paper, it was confusing because I thought it had said that the right ear, you know the right ear had problems but when I showed it somebody, they said, oh no, that it was just meaning that she passed on both but you had to watch and take, you know I mean check it more often because risk factors were there. I thought the risk factors were just on the right ear and they said no, it was overall.”

This participant continued to follow up with specialists for months, but she reported that she was not told that her daughter had hearing loss that warranted hearing aids until she was almost 2 years old. Miscommunication of hearing screening or testing results may play a role in delayed diagnosis and treatment.

Difficulty with Follow-Up Appointments

There is significant variation in what families are instructed to do following a failed screening test at the hospital. While some are referred directly to a hearing center while some families must navigate the system alone. Most of our participants had their initial follow-up appointment scheduled by the hospital, which simplified the initial step for them. When asked about follow-up difficulties, these families typically reported that they had no trouble. One participant who had their initial follow-up appointment for hearing testing scheduled by the hospital prior to discharge expressed the ease of the follow-up in the following comments:

“They had already set up the appointment, they had already written the referral so pretty much all we had to do was show up.”

Others were given information or a phone number to set it up on their own, and this worked out well for the subjects while placing more responsibility on the family. One participant was advised to go to a state-support EHDI clinic (referred to as a Commission Clinic), however this was not enough information, and time was wasted as a result. She reported:

“They just said you have to go to commissions and I said, well where are those at? And she said there’s one in Prestonsburg, there’s one in you know wherever; she told me about 3 different ones. And I said, well Prestonsburg is closer to me. So I thought you know they’re all going to have all the same programs; well they didn’t. ...It was just a big mess. I mean it would’ve been easier if somebody could’ve told me Prestonsburg doesn’t have it instead of telling me you know there’s all kinds of different areas that have commissions. Like [if someone had] said, the only commission that has the audiology program, audiology program is Hazard, it would’ve been a whole lot helpful. And I was starting to freak out when I was calling to make the appointments and they were saying we don’t have that program, I was starting to like panic like.”

There were also participants that were not given any information on how or where to follow-up for diagnostic testing. This posed an immediate barrier in obtain the recommended testing. They had to go through extra steps to proceed along the road to diagnosis, such as finding out where to go and getting the appointment, but also, who to ask to point them in the right direction. One participant reports that she was on her own to figure out her child’s follow-up:

“They really didn’t tell me [what to do]; you know they just said follow up with his pediatrician and where he was a newborn, I really wasn’t for sure where I was going to take him.”

Another participant was told to wait until for 3-months before obtaining outpatient diagnostic testing:

“And they said that they gave me a number and stuff to a hearing specialist. And I had to wait until he was like 3 months old before I could take him there.”

Inconsistencies with Recommendations from Healthcare Providers

Several participants had difficulties regarding recommendations for the child’s care from the pediatrician or primary care provider. Furthermore, participants expressed concern that healthcare professionals did not expedite the hearing healthcare and even ignored concerns for infant hearing loss. One participant reported:

“They [the pediatrician] didn’t really think that he totally had hearing loss; a lot of people kind of doubt that so it’s mainly been my choice to actually keep following up with it because a lot of people don’t take it that seriously. I don’t think the pediatrician is as scared about it.”

Another participant felt marginalized by her pediatrician and reported:

“Every time that I had a concern, [the pediatrician] just played it off like I was a paranoid new parent...you know I’m a new parent and I worry about everything and it’s okay, don’t you know, all that and I was just kind of like, I’m not being paranoid; there’s something wrong, there’s something wrong with my baby.”

One participant did not receive timely therapy because the pediatrician was unaware of the programs offered. The mother did not find out her child could receive therapy through First Steps, a state program to help children with hearing loss, until she switched pediatricians. She reported:

“I didn’t know what First Steps was, I didn’t know...I kept asking [the pediatrician] like is there any kind of like home health or anything... And she kept saying no. And I said, well what about physical therapy? And she said that...there wasn’t nothing you could do for it. Well then when I went through the second pediatrician, he got him in physical and occupational therapy at the hospital and in First Steps. What frustrates me is now...he’s only about 2 or 3 months behind which is great, but if I were to, if she would’ve told me when he was born that I could’ve put him in...therapy, then he’d have been in it for an extra 4 months.”

Lack of Resources

All of the participants were from very rural areas of Kentucky, many several hours away from the necessary clinics. Twenty-five of the forty participants addressed travel distance as a significant barrier in this area of healthcare. Since most outpatient infant hearing testing is performed when the child is sleeping, obtaining sleep-deprived testing on infants after a 1–4 h car ride creates some diagnostic challenges. One participant expressed frustration over this challenge by reporting:

“Yeah it was just kind of out of the way because we had to go an hour, we had to drive an hour and when they’re newborn, and they do that, they want them to be like asleep so they can be quiet, and so she would sleep the whole way there because it took an hour to get there...then she wakes up and they can’t do the test.”

Another participant reports how the distance affects the extended family to travel for hearing healthcare:

“And if we have to go to Lexington, then my dad takes the day off work and takes us. Because my husband works third shift so he’s asleep during the day. So, so my dad, his job is a little more lenient... you know it’s a big trip, so he’ll go with us.”

Additional follow-up exams perhaps pose the greatest risk of delays in those families who do not have a consistent mode of transportation. Without a personal vehicle, many families did not have a way to travel to their appointments due to the extreme distances and lack of public transportation in such rural areas. One participant describes why she had difficulty keeping her son’s follow-up appointments:

“At the time we didn’t have you know like a dependable vehicle and stuff. Like the vehicle we had, it didn’t have any air in it or any, you know anything like that; it was just hard. Stuff like the distance and you know how we had to get there and it was like a little stressful.”

One participant who was a grandmother also had difficulties with transportation and reported the problems for the family. From faulty transportation to limited resources, this participant addresses her daughter’s inability to follow through with recommended testing for the infant:

“The first one or two that we didn’t [go] to; we had to reschedule because of our car broke down. The brakes just was bad on the car and we was afraid to put the babies in it... Whenever you’re a single parent; you know you ain’t always got the cash to work on stuff right away.”

Another grandmother participant reported financial constraints as a factor in delayed care for her grandchild:

“Sometimes it’s hard to get the money to get down there, but you know like I said, she’s working now and the father left them all so I’m helping her. And she moved in with us, had to stay with us for a while and where I don’t work and stuff, my husband didn’t, wasn’t working at the time, it was just difficult to get there and she had to reschedule it but she did take her to it.”

Insurance Coverage Delays

Some participants reported that delays in hearing healthcare because of insurance coverage concerns. With a majority of the participants on state-funded Medicaid programs, there was a consistent theme of insurance barriers in timely receipt of care. One participant faced trouble when trying to get hearing aids for her son, who was already delayed in diagnosis until he was 6 months old. He received amplification when he was about 8 months old and insurance played role in this, as she reported:

“The audiologist, had tried to get in contact with them but they would never answer and she would keep leaving messages, and then finally, after like 2 weeks and she’d already ordered them... they still hadn’t approved it yet. That’s why it took so long.”

Another grandmother participant was faced with a dilemma with the insurance problem:

“Well I’ll tell you what I had to do; I had to have [the insurance] changed because ... the doctors up here ... they wouldn’t take that no more.”

Conflict with Work or Family Responsibilities

Many participants reported difficulties following up due to work, school and other home responsibilities. Caring for the needs of an infant with healthcare problems caused significant changes in lifestyle for a number of the participants. Whether it was inability to take time off to travel to appointments, to juggle other children’s needs and coordinate travel, or to continue on in schooling when the child requires numerous follow-up appointments. Work responsibilities were common barriers for many families. These issues resulted in delays and quitting of jobs and continued education, which then leads to exacerbated financial difficulties. When one grandmother participant took custody of her granddaughter and became her sole caregiver and stated:

“I had to quit my job when I brought her home.”

Similarly, for a participant who was a young mother it was impossible to continue on in school while caring for her son who was diagnosed with hearing loss. The follow-up and attention he needed prevented her from finishing her degree, and her husband’s job could not allow him to help enough for her to continue:

“Well I was still in school; that made it difficult. That’s why I took time off. Because I had a lot to do with him and I just figured it was more important than school and school would always be there so. But now that I’m not in school, then it’s a whole lot easier because all I had to do was him.”

Another participant reported limited family support in following through with hearing healthcare:

“If I’d had to take [her] to Lexington, you know maybe stay all night or something like that, I’d ... had to have somebody watch the baby because my husband worked in the coal mine so he couldn’t watch her and go work.”

Hearing Healthcare Knowledge and Willingness to Seek Care

The participants were asked questions about their knowledge about hearing rehabilitation options for children with hearing loss as well as their attitudes regarding hearing screening and the importance of follow-up after a NHS test. 50 % of the participants had no knowledge of treatment options for hearing loss such as cochlear implants. 100 % of the participants felt that following up after a newborn hearing-screening test was of extreme importance. Many participants conveyed a sense of urgency for hearing evaluation in spite of barriers to timely care. The option of utilizing telemedicine to obtain hearing healthcare was also discussed with participants and they unanimously expressed a desire to utilize a resource such as this. In spite of the difficulties, one participant expressed her concern and desire to follow up quickly:

“So I, you know right when they told me, I wanted to take him right away. I wanted to find out right away what was going on.” (1280)

A personal history of hearing loss led one participant to seek care:

“I have hearing problems so I didn’t want to you know delay stuff so. I believe there’s things that help because they’re all the time coming up with something that they resources and who you can talk to and stuff...you know there’s a lot of things to make it better you know like you just have to, if the opportunity comes, grab it.”

Participant consistently expressed desire to help their children regardless of the challenges for the entire family. One participant reported that:

“If he has hearing loss, I’ll make sure that all of us learn sign language and everything else. I’ll try anything for him.”

Another participant was optimistic about seeking help and reported that:

“I think there’s things that you can do to help...-where there’s a will there’s a way. That’s how I see it.”

Discussion

Early diagnosis and treatment of congenital hearing loss is crucial in preventing developmental delays in communication. It is vital to follow the standard recommendations of timely screening prior to 1 month of age, diagnosis by 3 months and intervention by 6 months of age [2, 7, 11]. Appropriate management of an infant with congenital hearing loss is complex and requires much coordination from multiple parties including the child’s family, pediatrician, audiologists and specialist physicians. This coordination is difficult even in resource-rich settings. This difficulty is greatly exaggerated in an extremely rural setting with few providers and scarce resources, such as the Appalachian region of Kentucky. Infants from rural communities, such as Appalachia, are at a significant risk of being delayed in diagnosis and treatment of congenital hearing loss [3, 4, 8, 11]. Low socioeconomic status, low education level of parents, public health insurance coverage, and extreme rural residence all contribute to delays in hearing healthcare [3]. The demographics of the participants demonstrated an unfavorable breakdown with regard to education level and insurance coverage. All participants lived in counties considered rural and nonadjacent to a metro area, and nearly all lived in counties considered the most rural, according to county Beale codes [16]. Results revealed that there are multiple shared barriers among the families of children who failed the NHS and live in rural communities. Many families failed to receive accurate information regarding the timing and process of follow up. It was often found that providers lacked the appropriate knowledge to care for a child with hearing loss or to direct families through the hearing healthcare system. Participants also reported limited access to local resources, and distance was a problem due to long travel time and multiple trips required. Other financial issues were related to insurance coverage and work responsibilities. These obstacles prevented children from meeting crucial benchmarks in the timeline of hearing healthcare. These obstacles did not diminish the participants’ willingness to seek hearing healthcare for their child.

Resources such as telemedicine could directly address some of the distance concerns for some of the participants [17]. Nearly all of the study participants welcomed the idea of

telemedicine, and a few reported they already utilize it for other aspects of their child's care. While more research must be done on outcomes, telemedicine has great promise for providing high-quality infant hearing healthcare that does not necessitate that the patient and provider been in the same location [18]. This technology could ameliorate the discrepancies in provider density and resources between rural and urban areas [18]. Further research needs to be performed to explore options and implement change to improve access to care for rural families.

We made every attempt to obtain data from a range of participants who have accessed the hearing healthcare system at differing levels and at different times. An interview study such as this has inherent bias such the subjectivity of responses, as well as the comfort of the participant in sharing their true feelings. Responses also rely on the parents' recollection of past events and may not fully gauge the barriers. There is also concern for selection bias, in that those families with the worst socioeconomic status may not have been able to participate by phone due to lack of resources or a functional phone. Thus, these results may underestimate the obstacles that families encounter. Considering the confinement of this study to Appalachian Kentucky, these results may not be generalizable to other rural regions. However, certain barriers such as low education levels, socioeconomic gaps, insurance coverage and geographic restraints are common themes across regions of health care disparity, and likely will require multiple approaches to address this healthcare problem.

Conclusions

Infant hearing loss is a significant public health concern. This condition is treatable; however, many families in rural communities are delayed in diagnosis and treatment. This qualitative study involving families who have experienced firsthand the challenges of this diagnostic and treatment process reported multiple barriers to timely rural infant hearing healthcare. Minimizing misinformation and improving access to care are priorities to prevent delayed diagnosis and treatment of hearing loss.

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Table 1

Demographics of participants

	Number of participants (%)
Total participants	40
Gender of participants	
Female	38 (95 %)
Male	2 (5 %)
Relationship to child undergoing hearing healthcare	
Mother	30 (75 %)
Father	2 (5 %)
Grandmother	8 (20 %)
Insurance status of participant and child	
Medicaid (state-funded)	28 (70 %)
Private	8 (20 %)
Both private and state-funded	3 (7.5 %)
No insurance	1 (2.5 %)
Educational status of participant	
No high school degree or GED	8 (20 %)
Completed high school/GED	9 (22.5 %)
Attended some college	15 (37.5 %)
Completed college degree	4 (10 %)
Unknown	4 (10 %)