

Introduction

- Congenital hearing loss is seen in 1.8 per 1,000 newborns screened.
- Delays in infant hearing loss diagnosis and intervention result in consequences that are lifelong such as delays in language, social development, and cognition. Early detection is vital to easing these challenges.
- Current EDHI guidelines recommend that children be screened within 1 month of birth for hearing loss, preferably prior to discharge from the hospital. Infants who fail initial screening should follow up with a specialist before 3 months of age for additional testing.
- In 2016, of all children referred for diagnostic testing only 47.5% of children nationally and 60.1% of children in Kentucky followed up within 3 months. There are many contributing factors that lead to missed follow-ups with these barriers being particularly prevalent in geographically isolated communities such as Appalachian Kentucky.
- Patient navigation (PN) is seen as possible intervention to this problem. PN was first utilized in oncology and cancer treatment. PN has shown to be the only efficacious approach to decreasing infant hearing testing and non-adherence. Previous studies have demonstrated decreased loss to follow up and decreased time to first appointment with the implementation of PN. This study looks at the thoughts and opinions of parents who have participated in our pilot study on patient navigation in hearing healthcare for newborns.

The Patient Navigator

- Those that we employed to serve as navigators for this study are not medical experts but have been trained and some have firsthand experience with infant hearing healthcare.
- The PN's were recruited from communities local to the participating clinics. The clinics that were used for recruiting participants were all state-funded clinics called the Office for Children with Special Healthcare Needs (OCSHCN).

Research Aims

- The aim of this qualitative analysis was to investigate parent sentiments with regards to the PN program. Additionally, we looked to determine how PN did or did not help parents with follow-up testing appointments.

Methods

- Key informant interviews with parents (N=20) of newborns who were referred for diagnostic hearing testing after a failed newborn screening were audio-recorded and transcribed verbatim.

Education level	
Some High School	2
Completed High School	3
Some College	5
College Degree	8
Graduate Degree	2
Marital Status	
Single (Never Married)	7
Divorced/Separated	1
Married/Domestic partnership	12
Income	
<\$20,000	6
\$20,000-\$39,000	7
>=\$60,000	7
Child's Insurance	
Medicaid	12
Private	5
Uninsured	2
Other	1
Race	
White	15
Black/African American	1
Asian/Pacific Islander	1
Native American	1
Two or more races	1
Did not disclose	1

Methods, continued

- An iteratively refined codebook was developed by the research team with emerging themes from the transcripts. Using the qualitative software ATLAS.ti, two coders independently examined a sample of transcripts line-by-line. Discrepancies were resolved by discussion, and the codebook was further refined until the final version was reached.
- Final coded transcripts were reviewed by the research team to identify how the themes and connections can be translated into programmatic adaptations.

Results

- The interviews revealed key feedback on parents' preferences of patient navigation and their experiences with their diagnostic testing appointment.

1) Parents revealed that PN helped remind parents of appointment times and details.

"She kinda...like made sure that I knew where the clinic was at, where I was going. She confirmed the appointment time and obviously the place so...we made sure that we were all on the same page so we didn't miss the appointment and I felt like the appointment was...just as important to her as it was to me." -26 year-old mother

2) PNs were able to provide answers to questions, supply needed information, and offer emotional support from their own firsthand experiences.

"She called me and she talked about her experience and it was a little bit more comforting knowing that she had went through the same thing and she kind of explained what would happen. and pretty much answered any of the questions that I had." -24-year-old mother

"Really good job of making me feel comfortable with what was going on and not, you know, panic about this, or, you know, be anxious about the test that she's made me feel comfortable. I felt more comfortable going into it into it you know she explained that if she didn't pass that this center would be able to help her get the resources that she needed and the lady that called also made me feel comfortable and confident that they really wanted me to get some support and resources that I needed early on." -28-year-old mother

3) Parents overall agreed that PNs were supportive leading up to the appointment. Parents also reported that they would recommend the PN program to other parents due to the level of support provided.

"It's a free program that's going to be very helpful, [they] are preparing a child for that initial hearing test just to kind of ease their mind because it is a very stressful time to be a new parent, or even if it is their second or third child. It's always scary when something's wrong so having some kind of support system that's not an immediate family member, and it's not going to be somebody that's going to be judgmental in any way they're just simply there to help ease your mind to kind of talk you through everything. So, it's kind of nice to have that outside support system for somebody that's gone through that program before, and that can kind of talk you down and not send you looking on the internet for issues." -30-year-old mother

Results, continued

4) Parents also provided suggestions for improving the PN program which included changes to mode and frequency of contact. Some parents suggested email or text as alternate contact methods instead of phone calls, but some parents still preferred the phone calls for the more personal interaction

"I think text or email would be beneficial to just be another way, that way you didn't have to carve out a specific time in your day to talk to somebody on the phone and you could kind of do it discreetly, you know, if you're at work or anything like that." -24-year-old mother

"I personally liked it. I felt like it made it more personable. And that like I was actually being heard and like that, you guys genuinely cared. So, I like that a lot better than probably like an e-mail, which just felt like more of like a corporate thing, I guess. A text is probably fine too, because it's still personable because it is through my, like my personal phone, I guess. Umm, so yeah I...thought calling was great." -24-year-old mother

5) Parents with higher levels of income and education preferred fewer phone calls. Some parent also felt that initial contact from the PN was needed, but would like to opt-in for more phone calls either weekly or bi weekly.

"I probably wouldn't have needed the weekly contact. I think having that one conversation with her before that appointment maybe like two weeks... before my appointment would have been enough. I don't think that like having that weekly conversation just for that first introductory hearing appointment, would have been necessary kind of would have been a little bit overkill." -30-year-old mother

6) Most parents reported that they did not need any additional resources leading up to the appointment, but some parents would have liked additional information about the diagnostic appointment in addition to what the PN provided to them.

Conclusions and Future Directions

- The PN program was well received by parents and proved to adequately support parents leading up to the appointment.
- The feedback provided in this study indicates that future use of PN programs should be customizable to each parent's needs.

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