

EXPLORING THE STORIES OF PARENTS'
EXPERIENCES WITH EARLY HEARING-LOSS
SCREENING AND DIAGNOSIS IN THE UNITED STATES

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1- 6 newborns, out of every 1000, has a detectable level of HL

(CDC, 2016)

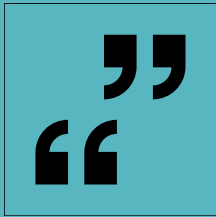


over 90% of children with HL are born to parents with typical hearing

(Mitchell & Karchmer, 2004)

BABIES WITH HEARING LOSS (HL)

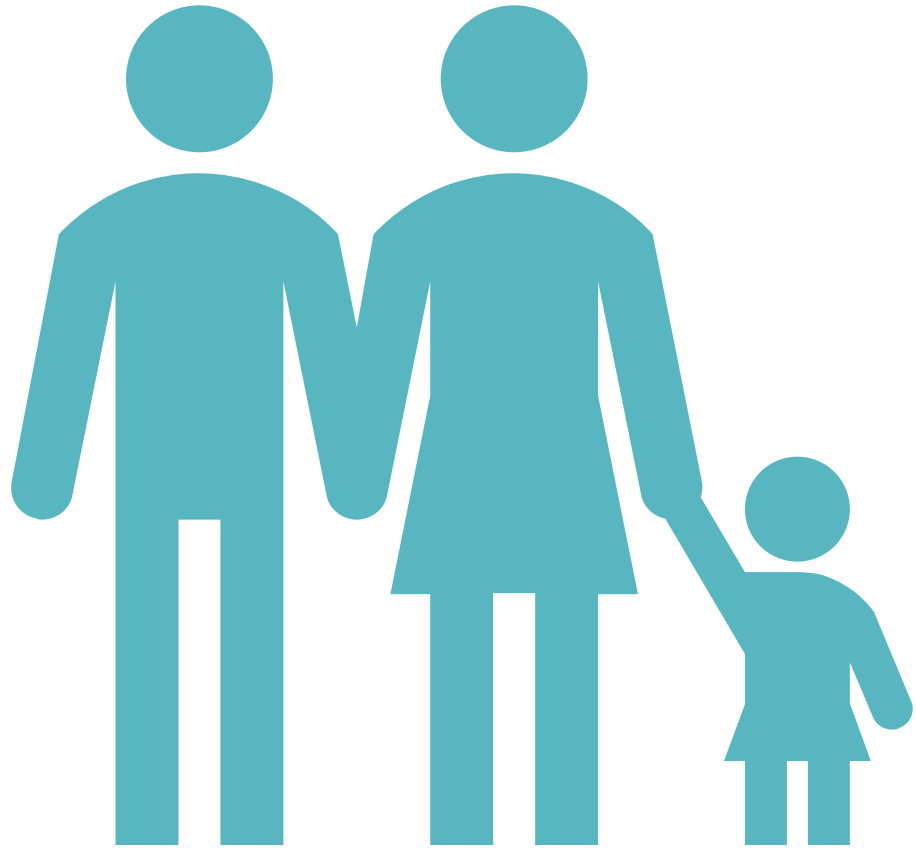
PARENTS AND STORYTELLING



“We organize our experiences into narratives and assign meaning to them through storytelling. Narratives thereby help constitute and construct our realities and modes of being.” (Smith & Sparkes, 2008, p. 18)



Purposes include: therapeutic, process emotions and events, develop/change identity, chronic illness sensemaking



THE PROBLEM

RESEARCH QUESTION

What types of stories do parents of children with hearing loss tell about their infant's early HL screening and diagnosis?





prospective narrative
qualitative study



approximately 20 parents



gather parent stories with
follow up questions

METHODS

PRELIMINARY FINDINGS

CHARLOTTE MOTHER OF LOUIS, INTERVIEW #2

Screening/Follow up screening

“We went back to the hospital when he was around two months old. No, excuse me, two weeks old—to get that follow-up test. And it really wasn’t clear to me exactly how the tests were performed because I wasn’t there with him when he was an infant—when he was...actually, excuse me, not an infant—a newborn...on our first day in the hospital, right after he was born, I wasn’t there when he [hearing screener] conducted the test. So going into the [follow-up] testing [two-weeks later] was interesting—to see how it was actually performed, especially with such a small baby. And, unfortunately, the person who was conducting the test really wasn’t familiar with the science behind the test either. And, as someone who needs a lot of information, or appreciates a lot of information and a lot of detail, that was kind of disappointing to me because I didn’t have, you know, a real reference for what the results meant immediately. Obviously, the results needed to be reviewed by a doctor, but she [follow-up hearing screener] really couldn’t tell me much.”

MELANIE & SARAH, INTERVIEW #1

DIAGNOSIS

“Uhm, so, went to, uhm, meet with the audiologist, and they did a-again, it was a, she had to be asleep for like a half-an-hour, and uhm, they did a testing both bone conduction and a, I’m not sure, I wasn’t, I don’t remember. I was holding her, uh when they did the test and I know that she had to be asleep. And the audiologist, again, said that she had not passed the test. And, at that point she was diagnosed with a permanent hearing loss, sensorineural hearing loss in, in both ears. Uhm, it was moderate, uhm, was the way that the audiologist explained it. Uhm, very caring audiologist. Nice lady. But I remember her saying, that this was, uh, in the circumstances that this was the best possible diagnosis that you could possibly get. And, uh, to anybody ever becoming an audiologist out there, don’t ever tell that to a parent because that was the worst diagnosis for me. You’re telling a parent that there is something wrong with their child. It’s permanent, it was nonreversible, it was something she was not going to outgrow or get better or go away. And she told me it was, it was like the best possible diagnosis we could get as a parent because it was sensorineural and it was not likely to progress ever. It would stay, uhm, stay where it was, and she would be able to wear hearing aids for the rest of her life and we’d be fine. Like, she made it out to be, like, ‘You’re gonna be okay!’ like, ‘Best case scenario!’ [sarcastic excited voice] And I’m like, no, not best-case scenario. Like, you’re telling me there’s some- something wrong with, with my child, like she’s not perfect. And I’m sorry but she is perfect. In, in my eyes. Like, it was, it was, it was the hardest day of our lives.”

WARREN & ALEX, INTERVIEW #9

SCREENING AND DIAGNOSIS

“It was very, very, very emotionally stressful at that time. Ummm...It’s very hard. Ahh, one of the first things that we learned—and I think that, that we...I had known it from, from...ummm...the past—is that, you know, kids have a window to acquire language. And...ummm...that, you know, if you don’t act quickly to expose them to an accessible language...ahh...then they run the risk of having language deprivation. And...ahh...honestly, like, two, three, four weeks between appointments...ummm...started to really make us sweat. And...uh...it was really tough to kind of sit on our hands and play with our baby. And, of course, care for our older son as well...ummm...wondering when we would begin to—ummm, wondering when we would begin to, you know, know more and, and formulate a plan...”

TAYLOR & LEO, INTERVIEW #3

STORY SUMMARY

“I mean it’s just like I said. It’s like, I didn’t...it didn’t...there’s a lot that parents— there’s just a rush of emotions. The unknown. The craziness. And thankfully, like, oh yeah—we did have a really good audiologist who we still see. And she...she was just very...like, ‘Look, like, you’re doing the best you can. You’re doing a good job. And, like, this is why this technology exists.’ And uhm...just never really condemning or belittling any choice I make when it comes to my child’s treatment. Like, they push for preschool when he was three and I was like, ‘Nope, he’s not ready for that and I’m not ready for that. So, we’re not gonna do it.’ And she just was—and has been—very respectful of my choices.”

SIGNIFICANCE AND FUTURE DIRECTIONS

- Finish gathering stories until saturation
- Engage in Thematic Narrative Analysis (TNA)
- Provide better person/family centered care
- Further research on intervention options/support for parents and families



THANK YOU

Dr. Brittan Barker
Mary Morrell

QUESTIONS

