Exploring the Identities of Hearing Parents Who Chose Cochlear Implantation for their Children with Hearing Loss

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More than 90% of children with hearing loss (HL) are born to hearing parents.
(Mitchell + Karchmer, 2004)

Choosing cochlear implantation for an infant is a complex and difficult decision for hearing parents.
(Hardonk, et al., 2010)

PEOPLE CONSTRUCT IDENTITIES BY TELLING STORIES.
Paying closer attention to parents’ stories could result in a family-centered, therapeutic target with long-term positive effects on pediatric cochlear implant (CI) recipient’s holistic development.

Disclosures
We have no financial relationships with any commercial interests.

We framed the present study in an interpretive narrative approach (Koenig Kellas, 2014).

- There are many ways to study narratives.
- Narratives do the work of simultaneously reflecting and constructing a person’s identity.
- Thus, the parents’ stories can create, repair, or even destroy identities all the while negotiating personal agency (Nelson, 2001).

Research Question:
What types of identities do hearing parents construct when telling stories about their children’s hearing loss identification and CI intervention?

Methods
Gathered narratives from 20 hearing parents (2 fathers) of children who were implanted no later than 2 years old (mode = 1 year) and used their CIs for at least 1 year (Mage of children = 5.20 years). Interviews took place in person or via the phone. Finally, we transcribed the interviews.

Conducted Thematic Narrative Analysis (TNA; Riessman, 2008) and assigned one identity to each parent by: 1) gaining familiarity with the data, 2) identifying emergent themes, 3) defining and naming the themes, 4) generating emergent identities, and 5) locating evocative exemplars.

Engaged in four standard verification procedures: 1) referential adequacy, 2) investigator triangulation, 3) audit trail, and 4) exemplar identification. [Note: saturation was reached by Interview #11.]

Findings.
Four identities emerged from the parents’ stories.

1. the proactive parent
2. the resilient parent
3. the vulnerable parent
4. the detached parent

Proactive Parents
immediately jumped into action when they learned of their children’s HL diagnosis and CIs as a treatment option. These parents asked questions, engaged in independent research, educated others, and sought opportunities to ensure their children’s best care.
We called everyone. And we just saw the benefit of giving Drew the option to hear. And we knew that with the right support and intervention and early implantation, we just had a feeling that – uh – Drew would be okay with cochlear implants and – uh – we definitely wanted him to be mainstreamed and he’s living in a hearing world – in a hearing family – and – uh – we figured we would support him any way he wanted to go when he got older. But for now, we’re just giving him the best option...And – um – we had been learning all kinds of strategies – you know – before he turned one [year] from early intervention about things that we were already practicing and putting into our routine – um – as far as bombarding him with language and narrating our day and all these things that we were already practicing so when he was implanted we already had all these strategies in place.

Ruby, mother of Drew, Interview #2

So far, he’s done fine that route [CIs] – um – um – but just – um – I can remember the sigh of relief last year when he started reading. That’s when I really felt like he’s gonna be okay. He’s – you know – that’s – that’s the point in time where I really thought, “We got it. We got it there.” I mean – it’ll always be a mountain to climb, but I feel like that was the first time I felt like we really – um – we’d climbed the hardest part of the mountain and we’re seeing some really nice views at that point [mom starts crying].

Kendall, mother of Alex, Interview #19

...she didn’t hear. Um – so – that’s why we stayed on this path [pursuing CIs] – e – even – even though she seemed – like – to be hearing so well. We were still – we were excited to go on the path for this experience and – so – at a year she got the – the CIs put in and a m – a month later she got them activated and she had a response that very first day.

Katie, mother Lisa, Interview #9

So – I was 22 and had given birth to my son and – um – was actually alone in the hospital the – the second night. And they asked if they could take him to the nursery so I could sleep. Um – and they did and at about 4:00 in the morning, a young girl came in, shook me awake, threw a pamphlet at me, and said, “Your kid can’t hear. You’re gonna have to see the pediatrician in the morning.” Um – which – needless to say – was fairly devastating to a young woman with her first child – um – anticipating everything to be absolutely perfectly – you know – to go perfectly. Um – so – I of course was like, ‘What do you mean? What do you mean that he can’t hear?’

Courtney, mother of Jack, Interview #15

Resilient Parents

immediately expressed their initial distress and despair about their children’s HL diagnoses. Instead of remaining upset however, these parents overcame their uncertainty and negative emotions to support their children.

Vulnerable Parents

described their experiences with their children’s diagnosis and CI treatment as sad and frustrating. These parents seemed to lack a strong support system, despite being susceptible to emotional harm/challenges.
Um – but when – when we found out she was deaf, it was really hard [mom starts crying]. I’m sorry – I’m crying. And I felt like it was my fault. And I just – I feel really bad for her cause she’s – she’s gonna have a really hard time in life because – I mean – let’s – let’s face it – the – the world is hearing. And I just feel so bad that she can’t hear and – and sometimes she can’t do things like – you know – other kids can do.

Leah, mother of Sophia, Interview #17

Detached Parents described their children’s experiences with relatively flat affect. These parents told their stories almost as if the events were happening to people other than themselves.

Um – Sadie was born – um – she was emergency C-section. She – um – they don’t know – um – why she was. When she came out she was bleeding underneath her skin. Um – she was life-flighted to – the university medical center – hospital there – and – um – she – um – started having seizures along the way and – so – um – she was given medicine for that. Um – later on we learned that she had called – it’s called thrombocytopenia – where her blood doesn’t clot – um – when it was supposed to…Um – before she could go home from the hospital we did – um – her hearing test like every normal child. Um – Sadie failed that tw– twice or three times…

Vanessa, mother of Sadie, Interview #14

Parents in the present study constructed four pervasive identity types.

▪ These findings have valuable implications for better understanding the experiences of parents raising pediatric CI users.
▪ Identifying and understanding these parents’ identities is a first step toward improving clinicians’ abilities to help families seek out, implement, and follow-through with family-centered hearing healthcare.

Thanks!

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Paper presented by Dr. Brittan Barker at the 16th Symposium on Cochlear Implants in Children, Hollywood, FL.
Verification Procedures

- 20 interviews
- Referential Adequacy
  - 10
  - 10
- Investigator Triangulation
- Audit Trail
- Exemplar Identification

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