

# Social Identity and Grief in Mothers With Cochlear Implants Following the Birth of a Baby with Hearing Loss

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## ABSTRACT

Several researchers have explored the experiences of grief and social identity in hearing parents following a child's diagnosis of hearing loss. The extant literature paints a picture of the lived experiences of these 90 percent of mothers of children with hearing loss (Scharp et al., 2018; Flaherty, 2015; Horne, 2015; Peñaranda et al., 2011).

*What about the other 10 percent?*

## SUBJECTIVITIES

At least three facets of my identify will directly shape my relationship with this project, both limiting and expanding my role within it. I am the hearing mother of a child with unilateral hearing loss (HL), the sister of a cochlear implant (CI) user, and a listening and spoken language specialist.

Watching my sister experience deep grief and a reconciling of her own social identity in response to her first daughters' diagnoses of HL, my eyes have been opened to the disparity of evidence-based understanding and empathy extended to this uniquely situated group. Because of my own positionality, I discern that it is most appropriate for me to inquire about the grief process of mothers with CIs who have chosen listening and spoken language for their children.



Child with CI at school

## STATEMENT OF THE PROBLEM

### Current Research

- Flaherty (2015) explored the experiences of 18 caregivers of children with HL
  - All discussed the trauma of learning of their child's HL
  - Fathers processed the diagnosis pragmatically and mothers, emotionally
- Scharp et al. (2018) reviewed 26 parent blogs to understand the identities of hearing mothers who chose CIs for their children
  - Thematic narrative analysis revealed 4 distinct identities: the advocate, the resilient parent, the obedient worrier, and the matter-of-fact narrator
- Hardonk et al. (2011) interviewed both deaf parents of 6 children with HL to understand their decision-making in whether to implant their children
  - Most concerned about surrogate decision-making and chose to let their children determine for themselves when they were older
  - Only 1 mother was a CI user and several parents identified as Deaf

**Do mothers with CIs who communicate through listening and spoken language grieve and experience social identity shifts following their child's diagnosis of HL in a way that is like hearing parents, like culturally Deaf parents, like both, or like neither at all?**

## PURPOSE OF THE PROJECT

The current inquiry seeks to create space for mothers with CIs who listen and talk and their experiences having children with HL. I hope to understand their evolution of social identity following the birth of a child with HL, particularly in relationship to their experience, if any, of grief. I hope to illuminate whether first person experience of HL uniquely affects the experience of mothering a child with HL. Specifically:

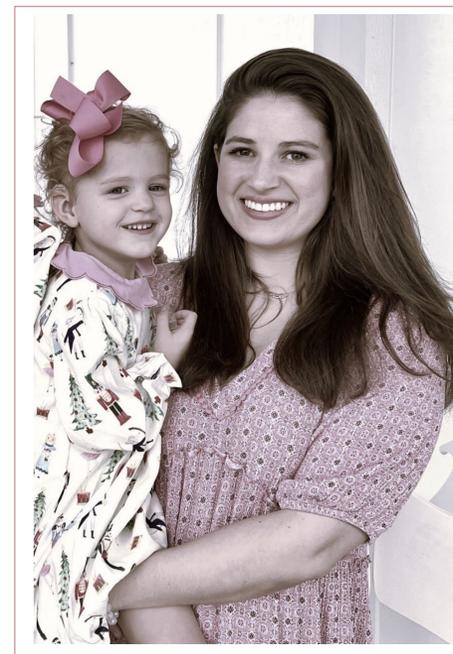
- How do mothers with CIs reflect on their social identity prior to having a child with HL?**
- How does a shared diagnosis of HL affect the grief experience of mothers with CIs following her child's diagnosis?**
- How does having a child with HL shape or evolve the social identity of mothers with CIs?**

## PROPOSED FRAMEWORK

I will recruit and interview three mothers who:

- Have unilateral or bilateral CIs
- Attended an auditory-oral school prior to mainstreaming and/or auditory-verbal therapy to learn to listen and talk
- Are between 21 and 40 years of age
- Have at least one child with diagnosed HL

Recruitment will occur through social media pages for mothers of children with HL, such as Hands and Voices.



Child grows up to have a daughter with bilateral CIs

Data will be collected through three, 60-minute, semi-structured interviews with each participant in-person or via Zoom. Interviews will center around social identity before and after having a baby with HL, as well as the experience of her child's diagnosis with HL.

Following the interviews, transcripts will be qualitatively analyzed using NVivo software. Analysis will include initial in vivo coding followed by thematic coding for focused coding. Coding will be analyzed to examine themes and connections for the development of a theoretical framework.

## CONCLUSIONS/SIGNIFICANCE

This project is intended to positively inform the counseling practices of medical, educational, and early intervention providers. As the population of mothers with CIs who listen and talk grows, practitioners must create space for them to share their experiences following a child's diagnosis of HL. They may be grieving or navigating social identity in a very different way than their hearing or Deaf counterparts. Even before this project is complete, practitioners should consider using these or similar prompts to guide the conversation, when contextually appropriate:

- Tell me about any significant experiences that you had growing up as a cochlear implant user.
- Tell me about a time growing up when you experienced feeling isolated.
- Tell me about a time growing up when you experienced really feeling like a part of something.
- Tell me about your experience learning that your child has a hearing loss.
- How has having a child with hearing loss changed the way that you understand and experience your own hearing loss?

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