

Qualitative Exploration of Caregiver Emotional Responses to Sensorineural Hearing Loss Diagnosis



Children'sSM
Healthcare of Atlanta



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Introduction

- Interdisciplinary project
 - Collaborators at Emory University School of Medicine and Children's Healthcare of Atlanta
- Caregiver emotional responses to hearing loss diagnosis
- Strengthening family support in the EHDI System of Care



Background of the Study

- Profound sensorineural (SNHL) impacts not only children but caregivers.
- Diagnosis is an emotional turning point.
- Understanding caregiver experiences improves:
 - Physician communication
 - Family-centered care
 - Resource allocation
 - EHDI system performance

The primary objective of this study was to examine the emotional experiences observed in caregivers of children with profound SNHL with a focus on grief and related emotional processes following the initial diagnosis.



Interview Guide Framework: Palliative Care Lens



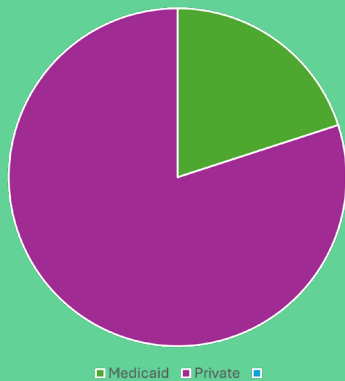
- The interview guide was intentionally modeled after palliative care research frameworks used to explore emotional adjustment following life-altering diagnoses.
- Although childhood hearing loss is not terminal, it can represent a profound identity shift for families.
- The guide explored:
 - The narrative of diagnosis
 - Emotional response
 - Grief or loss experiences
 - Coping and functioning
 - Hopes — both short and long term
 - Daily concerns
 - Sources of support
- Palliative care research emphasizes that emotional adjustment is non-linear, complex, and deeply contextual.
- This framework allowed caregivers to define their own emotional experience without pathologizing it.

Participants

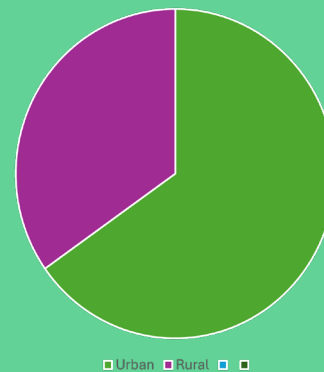
- Convenience clinical sample
- Caregiver characteristics (11 participants; rural/urban split)
- Child age range (≤ 3 years)
- Interview structure (10 semi-structured questions)



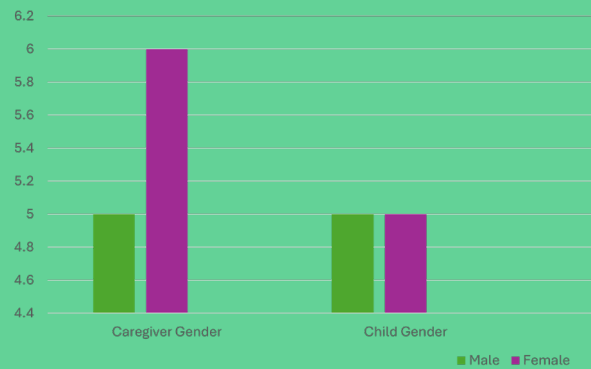
Insurance Type



Zipcode Classification



Gender



Methods and Materials

- Qualitative descriptive design
- Palliative-care–informed interview framework
- Semi-structured interview guide
- Interviews of Caregivers of children with profound sensorineural hearing loss



Analysis

- Audio- and video-recorded, transcribed verbatim
- Two independent coders (SB & NK)
- MAXQDA software to organize codes
- Peer debriefing sessions among the research and clinical team to enhance rigor and decrease bias.
- Thematic analysis was performed to identify cross-cutting themes



Results and Common Themes

- Several cross-cutting themes emerged related to the phases caregivers navigate after receiving the diagnosis, adjustments made to life, hopes, concerns, and access to support.
- Negative emotions common
- “Grief” not directly used. However, frequently cited codes included:
 - Overwhelmed, Anxious, Fearful, Sadness, Difficult, Confusion, Shock, Denial/Disbelief, Heartbreaking, and Acceptance
- Support significantly helped families navigate the different phases
 - Family, Mentor/Peer, Group Chats, Facebook Support Groups, Community Resources, Early Intervention, and Specialty Schools

MISUNDERSTANDING
SOCIAL EXCLUSION
AIPORT SECURITY
WATER DAMAGE
DAY-TO-DAY CONCERNS
ALARM RECOGNITION
LACK OF COMMUNICATION
BATHING
DAILY USE DAMAGE

INCLUSION
OPPORTUNITY
ACCEPTANCE
HOPES
NORMAL LIFE
FRIENDS

Common Themes

Group Chats
Facebook Family
Babies Can't Wait
SUPPORT
Atlanta Speech School
Specialty Schools Peer Acceptance
Georgia Pines
Early Intervention Schools

Disbelief **Sadness** Heartbreak
Anxious Denial
EMOTIONS
Overwhelmed
Acceptance **Fearful**
Confusion

Caregiver Concerns



- Safety concerns
- Device issues
- Acceptance (e.g., peers, teachers, society)
- Missing out on experiences
- Emergency awareness
- Minimized positive hearing tests worsening emotional reaction

Caregiver Hopes



- Social acceptance
- Technology advancements
- “Normal life”
- Urban vs rural differences
- Support-group influence on developmental optimism

Support

- Georgia Pines
- Babies Can't Wait (PART C EI)
- Atlanta Speech School
- Social media groups
- Rural travel/time barriers

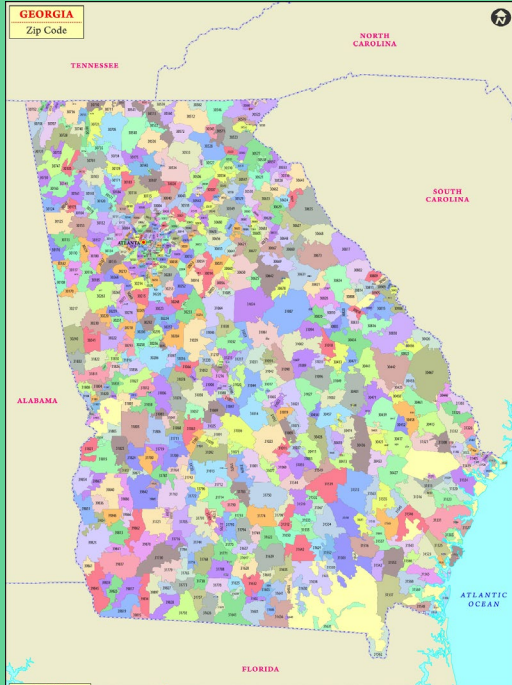


What This Means for EHDI?



- Emotional response is shaped by system access.
- Communication quality affects caregiver processing.
- Support reduces severity of distress.
- Rural families experience structural inequities.

Limitations



- Limited demographic data
- Zip code as SES proxy
- Non-random sampling
- Medicaid underrepresentation
- Small sample size

Future Directions

- Expand geographically
- Include more diverse samples
- Improve demographic data collection
- Explore caregiver differences
- Refine recruitment language



Implications for Strengthening EHDI Systems

- Improve diagnostic communication
- Implement family navigators
- Expand tele-support for rural families
- Normalize emotional processing
- Strengthen peer support access



Final Thoughts

- For EHDl to operate as a system of care, emotional support at diagnosis cannot be optional.
It must be built into infrastructure.
- When families receive:
 - Clear communication
 - Immediate connection to resources
 - Structural support
 - Interdisciplinary collaboration

They move from navigating appointments to envisioning thriving futures.



Contributors

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Questions?

Thank you!

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