

Experiences of Stress in Families of Children who are Deaf/Hard of Hearing Diagnosed with an Autism Spectrum Disorder

Dora Murphy-Courter, AUD

Rebekah Hudock, PhD,

Katie Bentley, BS,

Tanishia Williams, MD, PhD,

Jareen Meizen-Derr, PhD,

Susan Wiley, MD,

Lisa Hunter, PhD

Disclosure Information for All Presenters

- Neither I nor any member of my immediate family has a financial relationship or interest (currently or within the past 12 months) with any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients.
- I do not intend to discuss an unapproved/investigative use of a commercial product/device.

Learning Objectives

Describe differences in stress experienced by families of children who are Deaf/Hard of Hearing (Deaf/HH) with and without an autism spectrum disorder (ASD)

Identify strategies to support families with a child who is Deaf/HH with an ASD

Background

- Having a child with ASD has been linked with elevated levels of parental stress
- Families of children with the dual diagnosis have described challenges in accessing appropriate services for their child's unique needs
- Stress in families with children who are Deaf/HH with an ASD has not been reported in the literature

Background: Stress in families of children who are Deaf/HH

- In general, families felt positive about identifying a hearing loss at a young age
- Pressures related to achieving based on a “time-table”
- Families desire to avoid abnormal development and had greater dissatisfaction when it wasn’t clear how to best intervene for their child’s needs
- Families desire family-to-family support as well as receiving family-centered practice

Background: Stress in families of children who are Deaf/HH

- Using the Pediatric hearing impairment caregiver experience (PHICE), indicated parental stress changes over time
- At young ages/soon after identification, higher levels of stress around healthcare
- Older ages, higher stress around educational needs
- Communication needs was a common stress across ages/duration since identification

Background: Stress in families of children with ASD

- Parents of children with ASD experience large amounts of stress that may persist throughout a lifetime of caring for their child.
- Parents of children with ASD experience levels of stress that are higher than levels experienced by parents of other children
- Stress may result from child characteristics such as behavior problems or indirect sources and outcomes related to this stress such as marital strain, or increased anxiety, depression, or social isolation

change the outcome®

Baker-Ericzen, MJ, et al (2005). Research & Practice for Persons with Severe Disabilities 30(4), 194-204.

Dumas, J.E et al (1991). Exceptionality 2, 97-110.

Konstantareas, MM, & Homatidis, S. (1989). Journal of Child Psychology and Psychiatry, 30(3), 459-470.



Background

- The prevalence rate of autism spectrum disorders (ASD) in children who are Deaf/HH is approximately 4-7%, a much higher rate than the general population
- There has been minimal research on this group of children and families

Background Deaf/HH and ASD

- Beals' (one family) experience with EI
 - feeling pulled between communication modalities (oral vs sign) with deaf professionals
 - lack of focus and concrete guidance from ASD professionals
- In a targeted interview of 4 families,
 - families felt shuffled between providers (deaf/HH and ASD),
 - needed to focus more on behavioral needs,
 - experienced a lack of sign language environment within ASD programming

Study Objective

- To compare the experiences of stress of 3 groups of families:
 - Families of children who are Deaf/HH
 - Families of children with an ASD
 - Families of children who are Deaf/HH with an ASD

Methods

- Participants were identified through clinical and research registries
- 24 families within each category were mailed packets of questionnaires focused on demographic characteristics and parenting stress measures
- The study was approved by the Institutional Review Board

Questionnaires

- Qualitative questionnaire about supports were designed based on prior questions from a focus group

Stress Questionnaires specific to Deaf/HH:

- The Pediatric Hearing Impairment; Caregiver Experience (**PHICE**) was developed and validated by a pediatric otolaryngology fellow at CCHMC
- Includes domains of communication, education, emotional well being, equipment, financial, healthcare, social, and support

Questionnaires

Broad-based parental stress questionnaire

- The Parenting Stress Index-4th Edition (PSI)
- Includes Domains of Parent Characteristics and Child Characteristics.
- Within the Parent Domain there are seven subscales: Depression, Attachment, Restriction of Role, Sense of Competence, Social Isolation, Relationship with Spouse, and Parent Health.
- Within the Child Domain, there are six subscales: Adaptability, Acceptability, Demandingness, Mood, Distractibility/Hyperactivity, and Reinforces Parent

change the outcome®

Abidin, R. R. (1995). Parenting Stress Index: Professional manual. Odessa: Psychological Assessment Resources, Inc.



	Dual Diagnosis (n=6)	Deaf/HH Alone (n=4)	ASD Alone (n=3)
Child Age at Study (range)	7-20 yrs	11-17 yrs	9-12 yrs
Number of Children in Family (median/range)	2 (1-4)	3 (2-4)	1 (1-2)
Level of Parent Education			
High School	0	1	0
Some College	1	1	0
Completed College	3	0	2
Graduate School	2	2	1
Household Income			
<20,000	1	0	0
20,000-29,000	1	1	0
30,000-39,000	0	0	2
50,000-59,000	1	0	0
70-79,000	2	2	0
>80,000	1	1	1

change th

	Dual Diagnosis (n=6)	Deaf/HH Alone (n=4)	ASD Alone (n=3)
Child Age at Study (range)	7-20 yrs	11-17 yrs	9-12 yrs
Degree of Hearing Loss			N/A
Unilateral/Mild	2	1	
Moderate-Severe	0	1	
Profound	4	2	
Communication Mode			
Oral	2	4	2
Oral/Signing	1	0	0
Oral/Behavior	0	0	1
Signing/Behavior	2	0	0
Educational Setting			
Fully Mainstreamed	1	4	1
Partially Mainstreamed	4	0	2
Self-Contained	1	0	0

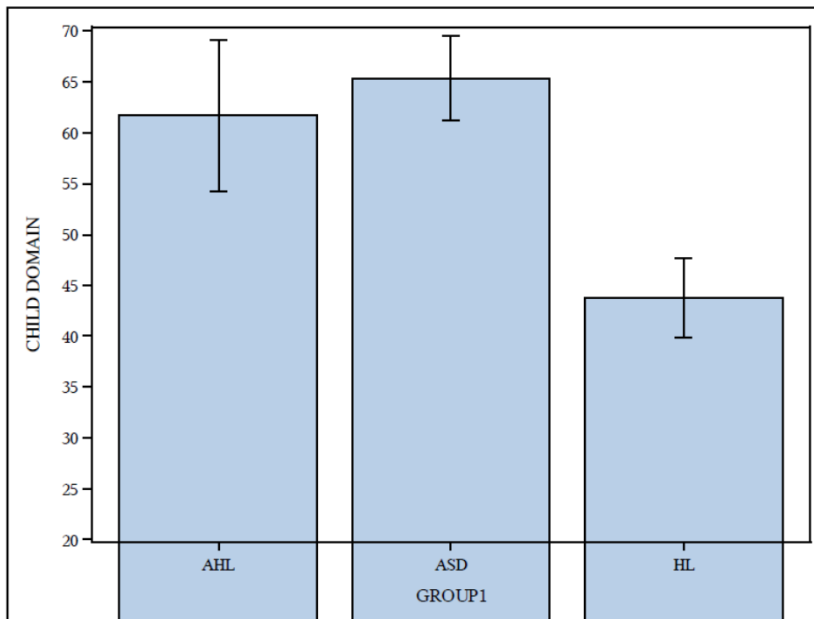
change the

Results: PSI

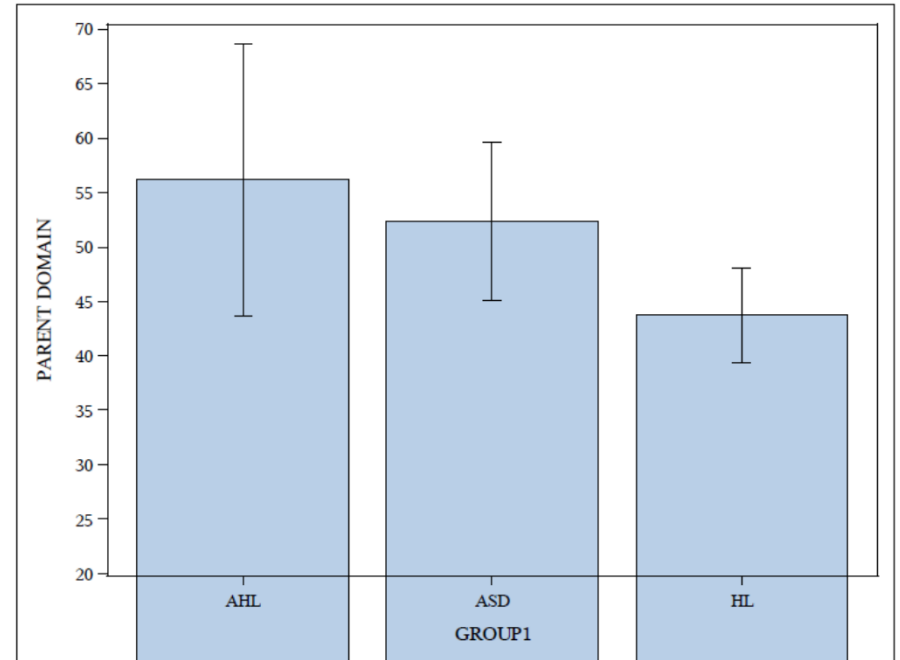
- Compared to the Deaf/HH only group, the dual diagnosis group had higher median Total Stress (41.5 vs 58.5, $p=0.02$) and higher Child Domain scores (43 vs 60, $p=0.02$).
- The dual diagnosis group was similar to the ASD only group in reporting stress
- Total scores were above the 85th percentile in 38% of the families (All were dual diagnosis or ASD respondents only)
- The deaf/HH only group did not have clinically elevated stress scores in any domains

PSI

Child Domain



Parent Domain



change the outcome*

Results: PHICE

- Families of children with the dual diagnosis had higher median scores on the PHICE than families of children who were solely Deaf/HH (total score 150.5 vs 179.5, $p=0.08$)
- Only two families reported high levels of stress in the communication domain, 1 dual diagnosis group and 1 in deaf/HH

In the Dual Diagnosis Group:

- 50% noted high levels of stress about their **child's future**
- 33% worried about **not doing enough** for their child and not attending to other family needs
- 33% indicated high levels of stress related to **childcare**

ASD Only Qualitative Questionnaire

How has the diagnosis in your child impacted your family?

- We don't take things for granted
- Increased reliance on routines, impact of therapy appointments
- Change in relationship with spouse

Where do you find support

- Family (x2)
- Therapists (x2)
- Friends
- Reading

ASD Only Qualitative Questionnaire

What resources/supports have you found helpful?

- Speech and OT
- Using picture schedules
- Accessing biomedical/DAN supports

What is on your wishlist?

- For people not to judge and be more understanding
- For my child to become more social, social skills, independence
- For my child to become independent and happy

Deaf/HH Only Qualitative Questionnaire

How has the diagnosis in your child impacted your family?

- The diagnosis was heartbreaking
- Major reorganization of the family, needed to understand navigating therapy, billing, sign language
- Diagnosis was difficult for some members of our family
- We needed a safety plan, including changing where our child sat in the car

Where do you find support

- Family (x2)
- School (x2)
- Friends
- Internet
- Books

Deaf/HH Only Qualitative Questionnaire

How has the diagnosis impacted communication decisions and strategies?

- We sent our child to an oral school
- The hearing loss turns a non-decision situation into a situation. We chose a cochlear implant route.
- Our child has troubles in loud settings (i.e. cafeteria), making friends

What resources/supports have you found helpful?

- Early Intervention supports (x2)
- FM system
- Bureau of Children of Medical Handicaps (State Title V program)

Deaf/HH Only Qualitative Questionnaire

What is on your wishlist?

- I have gotten my wish, for him to talk
- Transition successfully to high school and increase his circle of friends
- Increased ability to socialize, make friends
- Hear sounds for spelling words
- Waterproof Hearing Aid
- Better understanding of school system/professionals related to HL

Deaf/HH + ASD: Qualitative Questionnaire

How has the diagnosis in your child impacted your family?

- Physical and emotional toll
- Challenges in getting school to recognize both issues
- Parental feeling of social isolation from friends
- Frustration with lack of progress
- The family moved to be closer to services for child

Where do you find support

- Family (x4)
- Friends (x3)
- School

change the outcome

- Challenger league

Deaf/HH + ASD Qualitative Questionnaire

How has the diagnosis impacted communication decisions and strategies?

- Signs (child with cochlear implant)
- Always looking for communication strategy (i.e. I-pad)
- My child doesn't remember much that has been taught
- The dual diagnosis complicates sign language, we try all tools and follow his lead

What resources/supports have you found helpful?

- School (x2)
- Trial and Error
- I don't know anyone else with a child with a dual diagnosis

change the outcome

- ARC/Developmental Disability Services

Deaf/HH + ASD Qualitative Questionnaire

What is on your wishlist?

- Acceptance, tolerance by others
- Independence, healthy, happy, have a job
- To be able to communicate and function in a regular class
- Finding an educational setting which can meet all of his needs
- Finding a cause of the issue and fixing it

Results: Qualitative Questionnaire

Common Themes:

- Families from **all groups** described accessing supports from families, friends, therapists, and schools
- Families from all groups also wanted their child to achieve independence and happiness

Unique Themes:

- Families of children with the **dual diagnosis** tended to describe more challenges with feelings of isolation, broader ramifications, and communication needs
- Families of children with the **dual diagnosis and ASD** **only** described a desire for broader acceptance and understanding of their child's needs by others

Conclusions

- Families of children with the dual diagnosis of Deaf/HH and ASD report higher levels of overall stress than families of children with Deaf/HH alone
- A common concern among all families related to worries about their child's future
- Although limited by sample size (response rate of 18%), this exploratory study suggests a need to assess stress and more effectively support families with children with a dual diagnosis

Acknowledgements

- We would like to thank our policy partner, Ohio Center for Autism and Low Incidence (OCALI)
- And the families who participated