

Introduction

- Parents of children who are deaf or hard of hearing (DHH) experience psychosocial pressures like social isolation and parenting stress even in the best of times, all within the broader context of social determinants of health.
- These challenges have been compounded by the COVID-19 pandemic, which has limited in-person contacts outside the home, including access to hearing, speech, and language services.
- A rapid response to the unique challenges created by the COVID-19 pandemic is essential to inform provision of services for children who are DHH and their families in the context of ongoing shifts in the social/healthcare landscape.

Research Aims

The purpose of this study was to assess parents' (or other legal guardians') experiences with their children's hearing healthcare access and use during the first 6-8 months of the COVID-19 pandemic, as well as indicators of parent, child, and family psychosocial well-being and stressors.

Methods

- Kentucky parents/guardians of children ages 0-17 who are deaf or hard of hearing were recruited to participate in an online survey via social media ads, print ads placed in hearing healthcare offices, and direct invitations from hearing healthcare providers.
- The survey was active for 11 weeks from September-November 2020.
- Inclusion criteria: (a) participant lives in Kentucky; (b) age 18 years or older; (c) parent or legal guardian of a child who is deaf or hard of hearing (DHH) or in the process of being diagnosed for hearing loss; (d) child is 0-17 years old; (e) child is followed in hearing healthcare; (f) child lives at least half time in the participant's home; and (g) participant is willing to provide contact information for follow up survey.
- Eligible participants completed a 20-30 minute online survey which consisted of clinically validated measures as well as recently developed instruments to assess parent and child wellbeing: sociodemographic questionnaire; access to hearing healthcare; COVID-19 Exposure and Family Impact Survey (CEFIS); Multidimensional Scale of Perceived Social Support (MSPSS); Quality of Life in Neurological Disorders (Neuro-QOL): Positive Affect and Well-Being; Pediatric Symptom Checklist-17 (PSC-17); Parental Stress Scale (PSS); and Strengths and Difficulties Questionnaire (SDQ) - Prosocial Scale.
- Descriptive statistics were used to summarize participant characteristics and outcomes of interest, and bivariable tests explored associations among these.
- Qualitative themes were identified in open-ended survey responses. Using an exploratory sequential mixed methods approach, qualitative themes were used to elaborate upon quantitative findings.

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Results

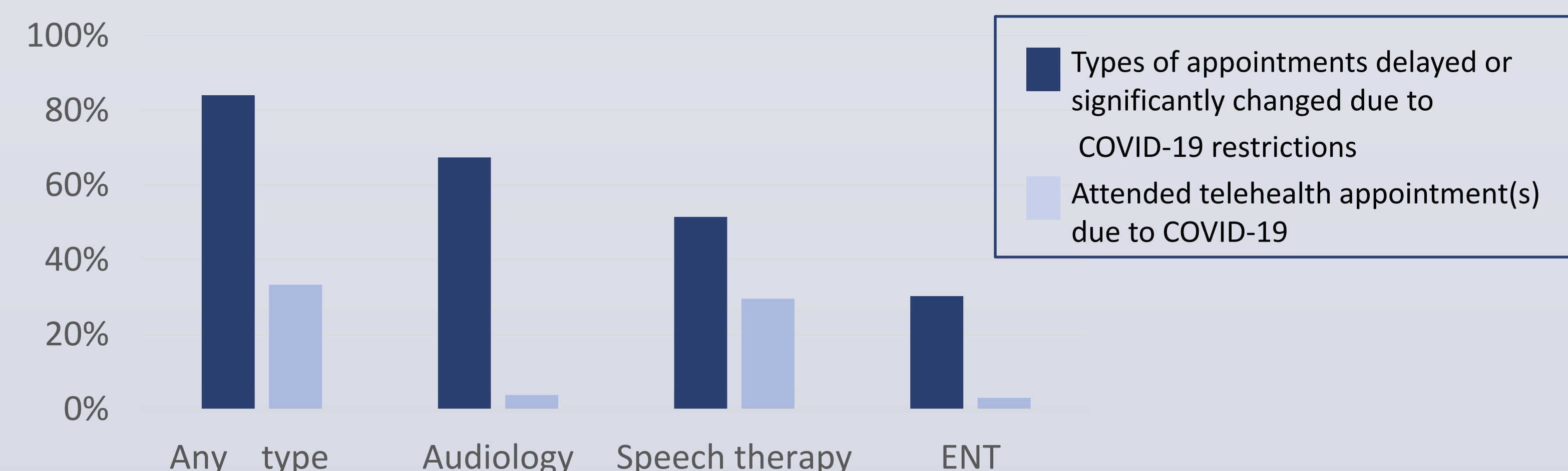
Of parents/guardians who completed the survey (n=132), 88% were female, 51% had college or graduate degrees, and mean age was 37 years (SD 7.6; range 23-60). Table 1 below illustrates additional child and family characteristics.

Child / Family Characteristics	n (%)	Child / Family Characteristics	n (%)
Child Gender		Child's Audiology Provider	
Female	62 (47%)	Private clinics	99 (75%)
Male	70 (53%)	State-funded clinics	29 (22%)
Child Age		Total Annual Household Income	
0-5 years	41 (31%)	<\$19,999	22 (17%)
6-12 years	74 (56%)	\$20,000-\$39,999	12 (9%)
13-17 years	17 (13%)	\$40,000-\$69,999	33 (25%)
Child Race		\$70,000-\$99,000	29 (22%)
White	114 (86%)	\$100,000+	31 (24%)
Black/African-American	7 (5%)	"How much of a problem is money for your family?"	
Other	11 (8%)	Very much	8 (6%)
Child Ethnicity		Somewhat	47 (36%)
Hispanic or Latinx	4 (3%)	A little	50 (38%)
Child's Hearing Device		Not at all	23 (17%)
Cochlear implant (CI)*	39 (29%)	County of Residence	
Hearing aid (HA)	78 (59%)	Metropolitan area	70 (54%)
Bone conduction device	11 (8%)	Rural/non-metropolitan	59 (46%)
Child's Highest Severity of Hearing Loss		Experienced any food, housing or transportation insecurity in last 12 months	
Mild or moderate	27 (20%)	Yes	36 (27%)
Moderately severe or severe	45 (34%)		
Profound	58 (44%)		

*child with 1 CI and 1 HA categorized as "CI"

Delays with Hearing Healthcare Appointments

Most families, 84% (n=111), reported a delay or significant change in their child's hearing healthcare. Many in-person appointments were delayed or rescheduled, and 33% of families reported attending a telehealth appointment during this time. Telehealth was most frequently utilized for speech therapy, compared to other hearing healthcare services.



Parent Experiences of Delays with Hearing Healthcare Appointments

"We did not have access to speech therapy at school from March until September, and our son was identified as deaf late, so missing 4 months of speech therapy at school and ongoing loss of private speech therapy seems like a lot of lost opportunity." - Mother of a 7-year-old boy with profound hearing loss and cochlear implants

"She had impressions for new ear molds for hearing aids but we weren't able to come in for a fitting for over 3 months. Information was mailed to us on how to do it ourselves but we didn't feel comfortable replacing without help from her audiologist." - Mother of a 6 year old girl with moderately severe hearing loss and hearing aids

"We were never given our 3 month follow up, which should have taken place in May. I got back in November but didn't feel comfortable going due to the rising numbers. We go back in 2021." - Mother of a 4 year old boy with moderate hearing loss and hearing aids

Results, continued

Impacts of Delayed Hearing Healthcare

Participants reported several negative impacts of delayed hearing healthcare illustrated in Table 2 below.

Impacts of Delayed Hearing Healthcare	Over all	0-5 yrs	6-12 yrs	13-17 yrs
Child wore a device that did not work properly	19%	22%	16%	19%
Child didn't wear a device they needed*	12%	27%	7%	0%
Child's language skills are declining	19%	24%	19%	0%
Missed educational opportunities*	26%	39%	23%	6%

*age categories significantly different at p < 0.05

Issues with Hearing Device
"He needed new ear molds for his hearing aids we were previously wearing, and we couldn't go get them. We ended up stopping wearing them."
- Mother of a 1 year old boy with profound hearing loss and a hearing aid

Language Decline
"My child's education was delayed and his reading and language has declined as a result."
-Mother of an 11 year old boy with severe hearing loss and hearing aids

School Challenges
"He had trouble hearing in his new second grade class. I needed to get it approved for him or his teacher to not wear a mask and I couldn't because of delays in appointments." -Mother of an 8 year old boy with profound hearing loss and hearing aid

Parent Experiences with Telehealth

Approximately 50% (n=64) of families had ever utilized telehealth appointments related to their child's hearing healthcare. Parents reported varied experiences with telehealth appointments, some positive and some negative.

"Telehealth is not practical for speech therapy. We also had bad internet at home with no cell service. We had to drive to other locations. We had our sessions in the back of a Ford Edge." -Father of a 5 year old boy with profound hearing loss and cochlear implants

"We decided to take a break from speech because telehealth was too difficult to maintain focus." -Father of a 4 year old girl with profound hearing loss and a cochlear implant

"Our clinic based therapy was seamlessly translated to teletherapy. It has worked great for our family because we are a long distance from the clinic anyway." -Mother of a 4 year old girl with profound hearing loss and cochlear implants

Parent Psychosocial Outcomes

In exploratory bivariate analyses, families with *very much or somewhat of a problem with money* and families with *food, housing, or transportation insecurity* showed a significant ($p \leq 0.10$) negative impact on the following psychosocial parent measures: CEFIS, MSPSS, Neuro-QOL, PSS, and loneliness.

Conclusions/Future Directions

- Families reported mixed experiences with hearing healthcare during COVID-19. Parents/guardians with financial, food, housing or transportation insecurity reported more negative impacts. Higher proportions of parents/guardians with children ages 0-5 reported severe impacts in hearing healthcare compared to parents of older children and adolescents.
- All participants will be re-surveyed 6-months after baseline; 40 parents will be invited to follow up interviews to provide deeper insights about their experiences; and 20 hearing healthcare providers and administrators will be interviewed to understand their perspectives on service delivery.
- Further analyses will identify actionable barriers and facilitators to service provision during this public health crisis, and we will rapidly disseminate findings to policy makers, healthcare providers, and other stakeholders.