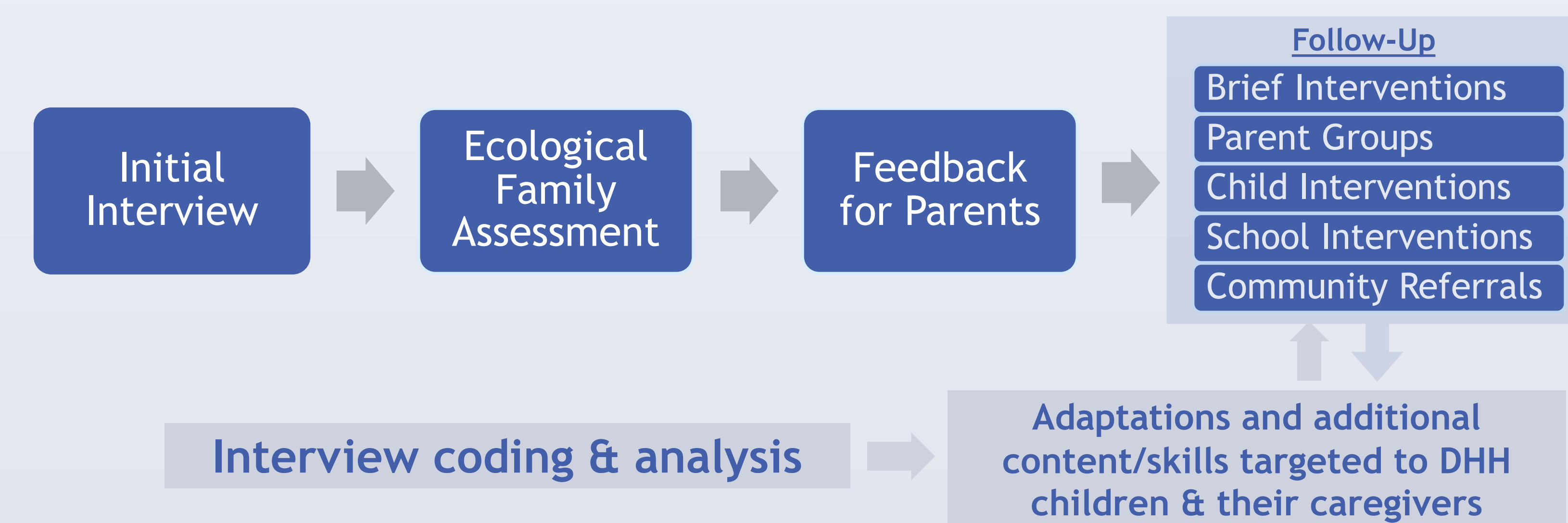


Introduction

- Children who are Deaf or Hard of Hearing (DHH) and use hearing aids or cochlear implants experience a significant disparity in both the prevalence of behavioral problems and in access to effective interventions.
- Behavioral parent training (BPT) programs are evidence-based interventions developed to prevent and treat disruptive behavior, but they are typically not accessed by or adapted for families with DHH children.
- The Family Check-Up (FCU) is an existing BPT that was used in this study for its flexibility and tailoring to individual families' needs.

Family Check-Up



Research Aims

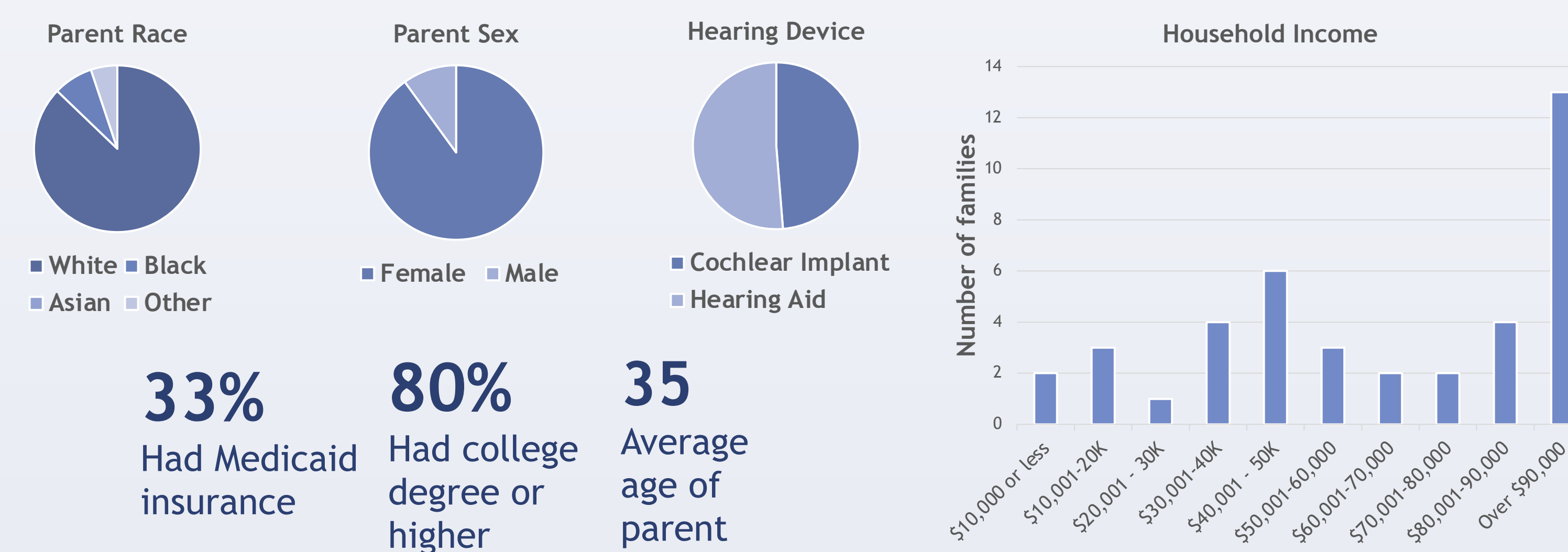
The purpose of this study was to conduct an in-depth qualitative thematic analysis of 40 parent interviews to inform the systematic adaptation of the FCU, to increase its acceptability and effectiveness for families with preschool-aged DHH children.

Methods

- Kentucky parents/guardians of children ages 2-8 who are deaf or hard of hearing were invited to participate in qualitative key informant interviews. Recruitment was through pediatric hearing healthcare practices and through connections from Community Advisory Board members. Purposive sampling ensured representation according to key demographics such as household income, parent's education level, and child's severity of hearing loss and type of hearing device used.
- 40 interviews were conducted from February of 2016 through March of 2018. Each interview participant was compensated \$25 for their time.
- Semi-structured interview guides included questions assessing (1) parents' perceptions of the need for an intervention; (2) their preferences for delivery (e.g., qualities and characteristics of the person delivering the intervention, location of program delivery); and (3) potential adaptations that would make a BPT program more relatable and useful to families with DHH children.
- The interviews were transcribed verbatim. The research team used content analysis to develop and iteratively refine a codebook. Multiple coders independently reviewed each transcript, and discrepancies were resolved by discussion. Interviews were coded in ATLAS.ti, a qualitative coding software.

Participant Characteristics

The information below illustrates additional child and family characteristics for the parents/guardians who participated in the interviews (n=40)



Results

What demonstrates a need for a parenting intervention for DHH families?

Typically, parents who can benefit from parenting interventions are experiencing behavioral challenges with their children, are unsure of their child's ability to comprehend or respond to requests, are expressing frustration or isolation, and/or are using inconsistent or other ineffective parenting strategies.

"He still throws some massive tantrums, and it's usually stemming from him not being able to communicate what he wants because his speech isn't quite there yet." - Mother of 4-year-old boy (137)

"My kid is broken. And I don't know how to help. That's where the emotive part kicks in. You're not sure if they came to you broken or you did other things that made it worse. You are not really sure how to tease that out, and you are not really sure how to get the help." - Mother of 6-year-old boy (112)

"I'm really bad with the reward thing... she's really spoiled because I felt sorry for her for the three years she couldn't hear. She's very spoiled. So the whole reward 'I'll buy you a toy if you do this,' that didn't work because she got it anyway whether she did it or not. It was really bad on my part because now I'm having issues with her... when she started school we did like stickers. . . but we would really get into it for like a week or two and then we're so busy and sports and school and I work two jobs, so it's hard to keep on track with stuff like that... however we can get by for the day is what we do." - Mother of 5-year-old girl (157A)

What are parents' preferences for the delivery of the BPT program?

Parents of young DHH kids are often accessing a multitude of services for their child, including but not limited to audiology, speech-language therapy, occupational therapy, and/or physical therapy. Young DHH kids also commonly experience comorbidities, including developmental delays and autism. Unfortunately, there are a lack of parenting programs available to parents of DHH children. As a result, it would be critical for a parenting intervention to be tailored to their preferences as much as possible.

Where: Most participants preferred in-home delivery of BPT or synchronized care... COVID has modified current model

"Again, that says to me [having FCU integrated with clinic services] for lack of a better term like 'one-stop shopping'" - Mother of 4-year-old girl (138A)

"I feel like once [you] see their home, this is why you are how you are. . . like I think you get a better understanding of maybe the behaviors because you see the home and home life. It makes things make sense" - Mother of 8-year-old girl (123)

Who: Most participants preferred individuals with DDH experience rather than trained mental health workers

"It's easier to hear from a person who says, 'Yeah I get it.' As opposed to, 'Well, my book says that...' Yeah your book doesn't know what it's like to have a deaf four-year-old." - Mother of 4-year-old boy (104)

Results, continued

How: Most participants recommended no more than six sessions with varied frequency

"Sometimes if you put a number to it like you have to do 14 sessions, then you feel overwhelmed because you're trying to fit all of that into life and you feel like you're being pushed into that" - Mother of 4-year-old girl (122)

What adaptations could make this BPT more relevant to families with young DHH kids?

Parents also shared perspectives on related issues that are not directly addressed in most parenting interventions. These, in addition to parent preferences about how a parenting intervention designed for them would be delivered, were the basis for adaptations we made to the existing FCU parenting intervention.

Communication

"It's really important for us to look at her when we talk. Because she reads lips really good so, she's just kind of putting together in my opinion the pieces of the puzzle. When you're talking to her it's not effortless for her. So, I feel like she works harder than most people have to work during the day, and she's just tired." - Mother of 4-year-old girl (138A)

Child Advocacy

"When he started basketball, I went before practice started the first time and talked to the coach ...if the processors aren't on he can't hear...yelling across the floor won't make a difference. You have to be closer to him because it's loud in here... just making others aware. We always go in and talk to his teacher at the beginning of the year and give her those same strategies." - Mother of 5-year-old boy (108)

Child Development

"I think you ask yourself a lot is he doing this because he's deaf and he's not hearing me or is he just being stubborn or acting out or doing things that are age appropriate?" - Mother of 5-year-old boy (111)

"It was really hard as a parent. When your younger child could interpret more than your older child and it was really sad. It was heartbreaking actually that... you could give a task to your younger kid and he could do it, and it would hurt me." - Mother of 5-year-old boy (164A)

DHH Specific Concerns

"He threw them. He leaves them in the car. They kept telling us to take them off in the car, but I feel like we talk more in the car because we live 30 minutes from anywhere we're going. So I always kept them on and then he would get mad and chuck it up front and I'd have to find it." - Mother of 5-year-old boy (108)

Conclusions/Future Directions

- Comparable to parents of typical hearing children, parents of young DHH children encounter challenging behaviors that they sometimes struggle to manage effectively that can lead to parents feeling frustrated, isolated, and concerned.
- Parents expressed preferences for the delivery of the FCU that sculpted the adaptations to better meet the needs of DHH children and their families.
- Findings were integrated to adapt the existing FCU parenting intervention in five ways to better meet the needs of parents of young DHH children: (1) the FCU interventionist, or "parent coach," is another parent of a DHH child; (2) resources on communication with DHH children; (3) resources on child development; (4) resources on advocacy and child self-advocacy; and (5) updated intervention materials that include examples and role-play scenarios specific to behavioral challenges of DHH children.
- The adapted FCU intervention is currently being tested in a randomized trial.

Acknowledgements

This project is supported by the National Institute of Deafness and Other Communication Disorders, National Institutes of Health (R01 DC016957, PI: Studts) and the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR001998. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.