

**Development of a functional assessment instrument
for youth with unilateral hearing impairment**

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Abstract

Background: Youth with similar degrees of hearing impairment may not perceive the same level of functional impairment. Once children are able to reliably report for themselves, patient-reported outcomes (PROs) instruments provide a method for health care providers to assess a patient's perceived functional impairment and assess responsiveness of this impairment to intervention. The aim of this qualitative research study was development of a draft item pool for assessing perceived physical function of youth with unilateral hearing impairment (UHI).

Methods: We conducted semi-structured qualitative interviews with youths with UHI. Each interview was audio-recorded, transcribed and excerpted for coding. We developed a codebook based upon review of the first five interviews, and established a final list of 11 codes based upon discussion amongst research team members. Two members of the research team double-coded the first 4 interviews independently, and discrepancies were resolved through consensus between the coders. In cases where discrepancies could not be resolved, Dr. Edwards broke the tie. Remaining transcripts were then single-coded and draft items developed based upon excerpt content. Item development criteria were used to craft items.

Results: Semi-structured interviews were conducted with 15 youths with UHI. Age of participants ranged from 11 to 17 years; 60% were male; and 47% used hearing aids. Independent coders were able to achieve greater than 90% agreement by

coding of third and fourth transcripts. There were 299 excerpts coded as physical function, from which 100 unique items were generated. Several common themes were found, including 1) Safety concerns related to cars and driving, 2) Difficulties with team-based or fast-paced physical activities, 3) Problems with sound localization, 4) Difficulties with attention, 5) Challenges using television and telephone, and 6) Youth opinions regarding hearing aid utility varied, with some reporting substantial benefit while others felt devices had been detrimental to hearing function.

Conclusion: Draft items for assessment of perceived physical function highlight some unique concerns of youths with UHI. Future goals for this project include final item selection and field-testing of the UHI functional assessment instrument.

Introduction

Unilateral hearing impairment (UHI) is estimated to affect at least 1 out of every 2000 newborns and between 1 - 5% of school-aged children and adolescents¹, with evidence of increasing prevalence over time². Because children with UHI often have intelligible speech, teachers, caregivers, and health care providers may not be aware of the impact of the hearing impairment on the children's daily lives. Youth with UHI report difficulty with sound localization and understanding speech in noisy environments^{3,4}. It has also been found that children with UHI have high rates of grade failure^{5,6} and poorer speech and language outcomes when compared to normal hearing peers^{7,8}. There has not been a clear consensus in the literature as to the best method for managing children with UHI^{9,10}, and there is persistent uncertainty as to how youth with UHI can optimally benefit from hearing amplification or assistive-listening devices.

Social Learning Theory

Children with sensory impairments such as hearing impairment may be at a disadvantage when engaging in learning and modeling behaviors. In 1977, Albert Bandura described a theory of social learning¹¹, in which children learn behaviors by adopting what they hear and observe from adults and older peers in their environment. Within this model, both academic learning and behavioral modeling require the child to pay attention to events unfolding in a variety of environments, including home, school, recreation and other surroundings. Children with UHI

almost certainly have increased difficulty absorbing information from their environment when it occurs in a situation that is unfavorable for their unimpaired ear. By compromising their ability to pay attention, UHI makes it more difficult for these children to engage in learning/modeling behaviors, which may impair their social participation and educational achievement, see **Figure 1**.

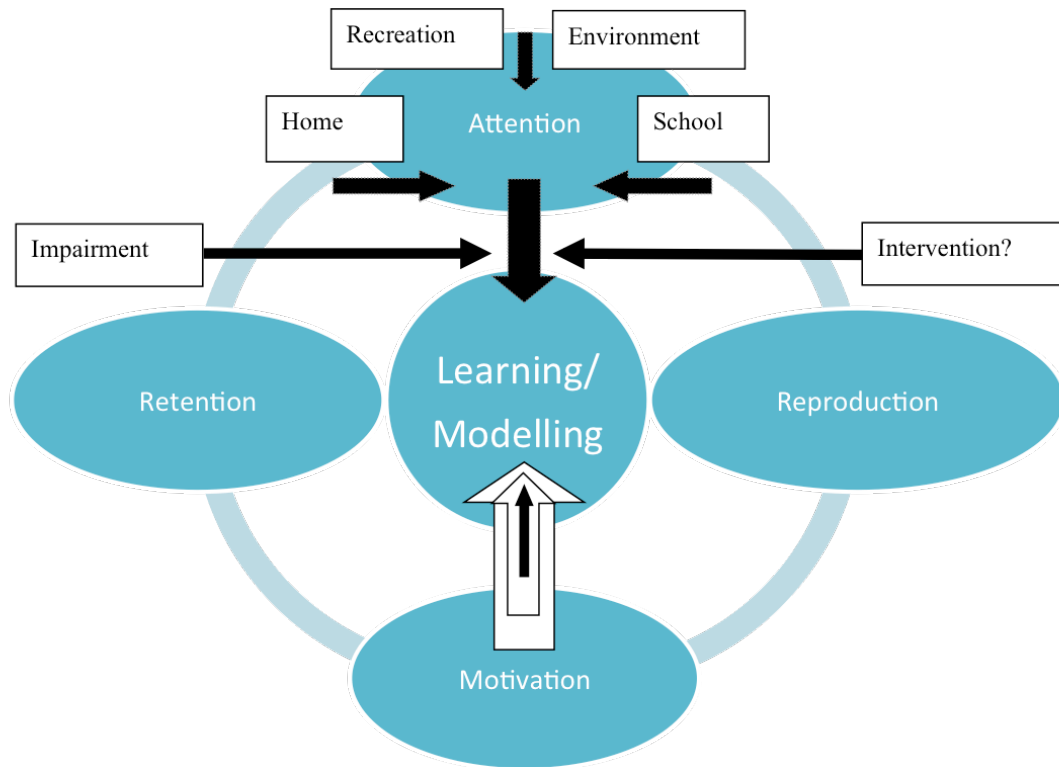


Figure 1: Conceptual Model describing potential impact of UHI

Hearing Aid Options

Based on this framework, there is a strong interest among hearing health providers in identifying effective interventions for children with UHI. There are a

variety of available assistive-listening devices: conventional hearing aids amplify sound in the impaired ear; Contralateral Routing of Signal (CROS) devices bring sound from the impaired ear to the better hearing ear. Surgical options include osseointegrated hearing devices, which are implanted into the temporal bone of the affected ear, and transform auditory signal into vibratory stimulus¹². Studies investigating and comparing outcomes using these devices are limited, especially in pediatric populations. As a result, there is currently little evidence upon which to base treatment recommendations.

Youth with hearing loss with similar hearing thresholds do not report the same levels of perceived functional impairment¹³. Once children are able to reliably report for themselves, patient-reported outcomes instruments (PROs) provide a method for health care providers to assess a patient's baseline perceived impairment and document responsiveness of this impairment to intervention.

Thus far, investigators have experienced difficulty when trying to reliably detect benefit with hearing aids in this population. Previous studies have used multiple assessment instruments prior to and following intervention, sometimes with conflicting results. Briggs et al. evaluated a small sample of eight children with UHI who were provided with a behind-the-ear (BTE) hearing aid¹⁴. The authors did not find significant improvement in speech discrimination, but hearing aid use resulted in significant improvement on the following parent-reported and patient-reported outcomes (PROs): 1) both the parent-form and the child-form of the Children's

Home Inventory of Listening Difficulties (CHILD), which measures a child's communication needs and listening skills in the home environment; 2) the Learning Inventory For Education (LIFE) student, which evaluates classroom listening situations, and 3) the Hearing-Related Quality of Life questionnaire (HEAR-QL), which evaluates quality of life in the domains of environment, activities and feelings. The study by Briggs et al. demonstrates how PROs can provide valuable information regarding treatment benefit. However, it may not be feasible to ask a large sample of youths to complete so many PROs when evaluating the treatment benefit of an assistive-listening device. It would be more efficient to have a condition-specific PRO for youth with UHI that could more succinctly capture their unique concerns. Currently however there are no condition-specific PROs available for assessing treatment for youth with UHI.

Patient-Reported Outcome (PRO) Development

Development of a PRO typically entails three phases: *I)* creation of instrument content based on the views of children and youth with a health condition or disability and their parents; *II)* assessment of cross-sectional measurement properties, including validity and reliability; and *III)* testing of the instrument in the context of treatment evaluations for confirmation of sensitivity to change and usefulness in research and potentially in clinical practice.

While there are validated PROs for youth with hearing impairment, such as the Youth Quality of Life Instrument – Deaf or Hard of Hearing module (YQOL-

DHH)¹⁵ and HEAR-QL,¹⁶ these instruments were developed based on content derived from youths who had bilateral hearing impairment (BHI). While there is undoubtedly some overlap in the impairments experienced by youths with BHI and UHI, youth with UHI report some unique challenges, which are described in this study. The existing outcomes instruments for youth with BHI may have some ability to measure impairment associated with UHI. For example, validation of the HEAR-QL included children with UHI¹⁷. However, an instrument developed specifically for children with UHI may contain some important differences from an instrument developed generally for hearing impairment.

The objective of this study was to qualitatively describe the impact of UHI, including efforts to distinguish how the impact of UHI differs from BHI. The information was then used to create draft PRO items to assess physical function of youths with UHI. A condition-specific PRO for youths with UHI is needed to determine whether these youth benefit from different assistive-listening devices.

Methods

Identification of Potential Participants

Institutional Review Board approval for this study was obtained from Seattle Children's Hospital. The hospital maintains an audiometric database that contains all audiogram results from 2007 to the present date. The audiogram database was queried to identify all youths between the ages of 11 to 19 who met the following eligibility criteria for UHI:

- Normal hearing in one ear as defined by pure tone average (PTA) (500, 1K, 2K, 4K) less than 30 decibels
- Abnormal hearing in one ear as defined by PTA (500, 1K, 2K, 4K) greater than or equal to 30 decibels

After the youths were identified, preliminary screening was performed using the electronic medical record so that the following exclusion criteria could be applied:

- Participants must be comfortable completing an interview in English
- Participants must not have a medical diagnosis associated with major developmental delay, such as trisomy 21

Recruitment Procedures

Opt-out fliers were then mailed to the home addresses of families of youths who met eligibility criteria for the study. The fliers provided the families with the opportunity to review a description of the study and to decline participation by calling the phone number provided. Two weeks after fliers were mailed, phone calls were made to the parents or legal guardians of the youths. Our research team was granted a waiver of signed consent to allow for collection of additional screening information over the phone, although verbal consent was always obtained. After ensuring all enrollment criteria were met, youths were given the opportunity to participate in a semi-structured interview. Signed consent/assent forms were completed at the beginning of the interview visits.

Semi-structured Qualitative Interviews and Coding/Analysis

Semi-structured interviews were conducted at Seattle Children's Hospital using a script that had received IRB approval, see **Appendix A**. Parents were given the option of being present depending on the preferences of the youth participant. Interviews were audio-recorded and transcribed. Dedoose software was used for thematic analysis (www.dedoose.com). A member of the research team (P.L.P.) reviewed each transcript to identify excerpts to be coded. A codebook was developed based on review of initial 5 interviews. The codebook went through multiple iterations to obtain a succinct list of codes upon which all research team members were in agreement regarding their meaning and comprehensiveness. Following development of the codebook, two research team members (P.L.P & R.J-G.) coded the first 4 transcripts. Discrepancies between coders were identified and resolved through discussion among the research team. In the event of persistent disagreement, Dr. Edwards broke the tie. A single coder (P.L.P.) coded the remaining 11 interviews.

Draft Item Generation

After coding was completed, all excerpts related to physical function were identified. Items were generated for each unique concept within the excerpts that contained a physical function code. After generation, the draft items were then reviewed to identify sub-domains of interest within the overarching domain of physical function. Because item generation from qualitative transcripts often results in an unacceptably large number of draft items, item selection criteria have been developed to prioritize which items are included in draft instrument. Based

on professional experience, the following selection criteria were applied by P.L.P. to prioritize selection of draft items: 1) Represents an area of importance to patients, 2) Is in the language of the patients with the condition, 3) Is likely to change with successful treatment of the condition, 4) Is likely to discriminate by severity of condition, and 5) Discriminates between known population groups.

Results

Participant Characteristics

Fifteen youths completed semi-structured interviews, see **Table 1**. Their ages ranged from 11 to 17 at time of interview, and 7 of them (47%) were using an assistive-listening device at the time of interview. Six of 15 (40%) had profound hearing loss in their affected ear. Only two had been diagnosed with hearing loss near the time of birth: one due to abnormal hearing screen, and the other due to the presence of microtia/aural atresia.

Table 1: Characteristics of interview participants

	Age at interview	Gender	Race/ethnicity	Degree of impairment	Age at diagnosis	Uses hearing aid
1.	11	M	Asian	Unavailable*	Birth	No
2.	11	M	White	Severe	6	Yes
3.	11	M	White	Moderate	8	No
4.	11	M	White	Profound	4	Yes
5.	12	F	White	Profound	Birth	Yes
6.	12	F	White	Profound	10	Yes
7.	12	M	White	Profound	8	Yes
8.	13	M	White	Profound	7-12 months	No
9.	14	M	White	Moderate	8	No
10.	14	M	White	Mild	10	No
11.	15	F	White	Moderate	8	No
12.	16	M	White	Moderate	5	Yes
13.	16	F	Black	Moderately severe	3	No
14.	16	F	Hispanic	Severe	3	Yes
15.	17	F	White	Profound	5	No

*Patient has aural atresia and osseointegrated hearing implant, which he does not use.

Coding Process

Initial review of excerpts resulted in a list of approximately 25 codes, which was then narrowed down to a final list of 11 based upon discussion amongst research team members. To facilitate generation of draft items for physical function assessment, specific codes were collapsed into more general codes for types of

function, including physical function. For example, codes for “safety” and “localization” were collapsed into the code for physical function, and a code for “communication” was collapsed into the code for social function. **Appendix B** contains the final list of 11 codes with definitions.

Double coding (i.e., independent coders coding the same transcripts) was completed for the first 4 transcripts. The first transcript contained a total of 105 excerpts. There was agreement between the coders on 85 (81%) of the excerpts. The most frequent differences of opinion involved application of codes for “physical function” versus “environmental barriers”, which occurred in 3 out of 20 discrepancies; codes for “quality of life” versus “psychological functioning”, which occurred in 3 out of 20 discrepancies; and codes for “social functioning” vs “stigma”, which occurred in 2 out of 20 discrepancies.

The second transcript contained 76 excerpts. There was agreement between the coders on 57 (76%) of the excerpts. Similar to the previous transcript, 2 of 20 discrepancies involved disagreement in application of codes for “psychological functioning” versus “quality of life”. In addition, 2 of 20 discrepancies involved application of codes for “social functioning” versus “psychological functioning.”

Agreement between coders improved by the third and fourth transcript. In both cases, there was agreement on more than 90% of the excerpts, and there were

no detectable patterns of disagreement. Based on this high degree of agreement, the remaining transcripts were coded by a single coder.

Perceived Differences between UHI and BHI

Because PROs have been previously developed for youths with BHI, an effort was made to identify how youths with UHI perceive their experience differs from youths with BHI, see **Table 2**. Youths with UHI described feeling “unbalanced” by having only one affected ear, but they also suggest that their perceived impairment may not be as severe as youths with BHI.

Table 2: Youths with UHI describe their perceptions regarding the differences between UHI and BHI

Identifier	Quote
Male, age 11	“Sometimes I can feel... unbalanced if I’m in a really loud place, and it can drain my energy that way. Uhm, whereas if I was in two ears, I would feel more balanced.”
Male, age 12	“You also have to put the ear that you can hear in towards the people you want to talk to. But if you had it on both sides, it’s probably a little bit harder to hear people normally.”
Male, age 16	“[Youths with BHI] have had to overcome what I’ve overcome, only more because they had it in both ears.”
Female, age 16	“I think there is just more technology for [youths with BHI] .”
Female, age 17	Referring to <i>Glee</i> TV episode: “[The character] was deaf in one ear, but he was literally ‘half-deaf’ on the TV show. And that is so inaccurate .”

Physical Function

Select excerpts related to physical function are listed in **Table 3**. Youths described difficulties with participating in events that involve fast-paced activities,

such as throwing a ball. They mentioned difficulties with navigating the environment in and around cars, whether driving or crossing the street. They also described the physical difference in sound quality and volume that occurs when their good ear is facing toward or away from an important sound source.

Table 3: Youths describe impact of UHI on physical function

“I would turn my head and something would be louder and then something would be quieter when I turned it again.”
“In soccer or baseball if they want to throw the ball to me and they're calling my name, I can't really tell where they are.”
“I would say that I need to be very careful crossing streets.”
“I'm always conscious of where will be the best spot for me to sit or stand so that I can hear the [group] best.”

In all, we identified 299 excerpts related to physical function. Many of the excerpts contained overlapping concepts, and 100 items were generated based upon unique themes expressed within the excerpts (see **Appendix C** for complete list of items that were generated). The items are scored on a 5 point scale ranging from 1 (never) to 5 (all the time). After development, the items were then grouped into sub-domains based upon thematic content. The following subdomains were created: activity/recreation, sound localization, body/ear position, attention, perception, media/technology, environmental barriers, safety, and hearing aid. The number of items in each subdomain ranged from 17 in the case of hearing aid, to 7 for attention.

Item selection criteria were then applied to identify the items that would be most effective to include in the final instrument. Because the instrument is designed for use by youths both with and without hearing aids, the items in the hearing aid subdomain were excluded. It might be possible to develop a separate instrument dedicated to hearing aid usage in the future.

Draft Item Pool

The physical function items that were generated reflected common themes, see **Table 4**. The youths described difficulties hearing coaches, friends and teammates when engaged in physical activity. They also reported difficulties with determining the location of sounds, stating that it is hard to tell where someone is when they call out, or that it is hard to locate a ringing phone. Positioning was described as an important means of accommodation. The youths state that they often have to think carefully about where to sit in a crowded or noisy environment because they are better able to hear whatever their fully functional ear is facing.

Regarding attention, the youths stated that they must give extra effort above that of their peers to pay attention and focus on tasks. This extra effort can result in feeling fatigued at the end of the school day. Some of the youths described UHI as limiting what they are able to do with their friends. They also have difficulty telling how loud sounds are, including their own voice when conversing.

Table 4: Themes identified during draft item generation

1. Difficulty navigating fast-paced activities	
<u>Sample excerpt</u>	"It's kind of hard listening in the direction while you're playing the sport, and teammates, you think they are saying your name, but they didn't."
<u>Sample item</u>	When I play sports, I have difficulty hearing my teammates as well as I need to.
2. Problems with sound localization	
<u>Sample excerpt</u>	"If somebody is calling my name, I can't exactly, ... I can't tell where they are."
<u>Sample item</u>	When someone calls my name, I have a hard time telling where they are.
3. Importance of head/body positioning	
<u>Sample excerpt</u>	"I will try to sit on the far right of the table so I can hear everything that's in front of me and to the left."
<u>Sample item</u>	When I enter a room, I must think carefully about where to sit in order to be able to hear everyone.
4. Difficulties with attention	
<u>Sample excerpt</u>	"Particularly in noisy environments, like a lunch room, when someone is talking to me on the side of my deaf ear, ... if they don't already have my attention, and they just try to start talking to me, 90% of the time I won't respond."
<u>Sample item</u>	When I am in a noisy room, it is hard for me to pay attention to friends or family who are talking to me.
5. Safety concerns with cars and driving	
<u>Sample excerpt</u>	"My parents have said that I'm an 'over-cautious' driver, and I am checking my blind spot because I can't hear if there is a car coming right next to me."
<u>Sample item</u>	When I am driving, I have a hard time hearing other cars as well as I need to.
6. Challenges using television and telephone	
<u>Sample excerpt</u>	"I think I have to have the volume up more than what somebody with full hearing; they wouldn't have to have it up so loud."
<u>Sample item</u>	I need to listen to the television at a louder volume than others in order to hear as well as I need to.

In addition, the youths state that they can have difficulty hearing their home television and often listen to TV and music at high volume. In terms of

environmental barriers to hearing, the youths described crowded, noisy rooms, such as the lunch cafeteria, as being particularly challenging situations. They also noted problems hearing when riding in a car or speaking with a large group of people. Finally, the youths described concerns regarding safety around cars or while driving.

Discussion

In this qualitative interview study, we found that youths with UHI often perceive their physical functioning to be negatively impacted by their hearing impairment. We found common themes in how youths described the ways in which their physical functioning is affected. They described difficulties with attention, fast-paced activities, sound localization, unfavorable positioning, driving safety, and certain forms of technology use. To our knowledge, this study is among the first to specifically investigate these issues in depth with youth with UHI. Therefore, it serves as an important first step in development of a condition-specific PRO for functional assessment of youth with UHI.

One previous study by Borton et al. explored similar questions within a focus group of three youths with UHI¹⁸. The authors found that these youths perceived barriers in educational and social settings, but reported adapting to their condition over time. At the time of the focus group, the youths seemed to downplay major differences in their experiences when compared with “normal kids”. Similarly, some

of the youths in our study described ways in which they feel their experiences are near typical. For example, a 16-year-old male in our study reported that youths with BHI have to overcome greater challenges than youths with UHI.

However, it is important for hearing health providers, teachers and caregivers to appreciate the ways in which UHI can negatively impact functional status. Previous studies suggest that this may be underappreciated. Studies using the Screening Instrument for Targeting Education Risk (SIFTER) compared teacher-rated performance of children with UHL to typical-hearing peers. These studies found that children with UHI received significantly lower SIFTER scores than their peers¹⁹, and there was a negative association between degree of hearing impairment and teachers' ratings of student performance²⁰, so that teachers were rating the children with the greatest degree of hearing impairment higher on SIFTER score than youths with UHI. In other words, the teachers were reporting poorer school performance among the youths with UHI when compared to youths with BHI.

The youths in our study described how UHI has important negative implications on day-to-day physical functioning, but based on the findings of the SIFTER studies, it appears possible that the challenges faced by youth with UHI are being overlooked. In addition, despite youths' abilities to adapt to challenges associated with UHI, studies have found that adolescents with UHI continue to have lower language scores than typical-hearing peers²¹. The authors of the Borton study

describe reticence among the youths about sharing certain aspects of their experience within a focus group setting. Stigma remains an important reason that youth may be hesitant to talk about functional limitations associated with their condition. Given this fact, a condition-specific PRO for youth with UHI may provide a more valid means for assessing baseline physical function and improvement with intervention among youth with UHI.

An instrument developed specifically for youth with UHI would contain some important differences from an instrument developed generally for hearing impairment. An instrument for UHI specifically would include more items exploring sound localization. The youths interviewed in this study describe how the quality and volume of sound changes with head movement, which can make it difficult to identify the source of a sound. Some of the youths in our study reported improvement in localization with hearing aid usage, but others did not. Johnstone et al. found that children and youths with UHI did not always report improvement in localization with hearing aid usage. In fact, the authors found that youths who were fit with hearing aids later in childhood or adolescence were more likely to experience bilateral interference with localization with hearing aids in place²². If there is the possibility that hearing aids may make localization worse, it might be important for a condition-specific PRO to have a high degree of sensitivity to perceived problems with localization.

The findings of this study also provide insight into important issues that should be addressed by hearing health providers during clinical encounters. For example, most of the youths stated that it was more difficult to hear important information if they were positioned in the back of the room, or with their good ear facing away from the sound source. It has been found that individuals with UHL must sit approximately half the distance away from a speaker as an individual with typical hearing to have similar speech discrimination²³. Therefore, providers should inquire as to whether children are receiving preferential seating in school. In addition, a number of youths reported listening to TV and music at high volume. This point is important to note because excessive noise exposure could put their residual hearing at risk²⁴, and parents may not be aware of this risk²⁵; therefore, it might be worthwhile to explore these behaviors further in future research.

The draft item pool generated through this research must still undergo reduction and prioritization to select a reasonable number of items for a draft PRO. To achieve this goal, our research team plans to seek expert opinion regarding item selection and also conduct cognitive interviews with youths with UHI. Once the draft PRO has been developed, validation will be performed to generate a final condition-specific instrument for use in clinical research. Ultimately, we believe that a condition-specific PRO will be able to capture differences in perceived benefit with assistive-listening devices, perhaps providing additional evidence as to which youths will find a device to be advantageous.

Limitations and Strengths

There are limitations to this study that should be addressed in future research. The current study only addresses physical function, so it will be important to also explore the impact of UHI on other forms of function: social, academic, and psychological. While, to our knowledge, no other studies have collected qualitative data from this number of youths with UHI, the sample size for this study was small, only including 15 youths. Future work should include additional interviews, with more diverse participants, to gain additional insight into the impact of UHI.

This study serves as an important first-step in development of a condition-specific PRO. It is among the first to use a one-on-one interview format for qualitative data-gathering. While focus groups are quite useful in that they allow for exchange of ideas among participants, one-on-one interviews typically allow more time for an individual to communicate his or her thoughts, perhaps facilitating more in-depth exploration of important issues. In addition, individuals may be more willing to share information with a single interviewer that they may not share with a larger group. For example, the Borton study stated that youths with UHI occasionally seemed hesitant to share their thoughts and experiences in a focus group setting.

We were also able to obtain a fairly even mix between participants who are currently using hearing devices and those who are not. One of our participants had even undergone surgery to implant an osseointegrated device, which he preferred

to not use. As we attempt to understand how intervention can best support youths with UHI, it is important that we include perspectives both from youths who find assistive-listening devices to be useful, and those who prefer not to use them. A future goal of our research is to determine if a PRO module can be developed specifically related to assistive-listening devices.

Finally, this study is among the first to allow youths with UHI to describe the impact of their condition in their own words. As our appreciation grows for the challenges they face, hearing health providers should continue to raise awareness about the ways in which UHI affects functioning.

Conclusion

Youth with UHI have unique concerns, and there is currently not a clear consensus regarding the best method for management of UHI. Development of a condition-specific PRO for youths with UHI is an important first step in establishing evidence-based guidelines for management of this condition. The validated UHI-specific PRO will serve as an important adjunct to standard audiological and cognitive outcome measures, allowing hearing health providers to assess the patient experience directly.

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APPENDIX A

UHL: Functional Assessment Instrument

Interview Script – UHL Youth

Introduction

Hello, I am _____. Thank you for speaking with me today.

The purpose of this project is to help us learn about youths with hearing loss in one ear and normal hearing in the other ear.

We would like to learn how hearing loss in one ear affects the lives of children and teenagers. We plan to write questions based on the answers from these interviews. These questions can help us understand how much a person's hearing loss is affecting his or her life. These questions may be shared with doctors and others who work with children and teenagers with hearing loss in one ear. I would like your help in creating these questions. We will provide you with a small gift, a \$25 gift card, for your time today.

Is it okay to tape this interview? Remember, you don't have to talk about anything that makes you uncomfortable.

1. How do you feel about your life?

PROBE IF Needed

- Do you feel that having single-sided hearing loss affects your life?
 - *If so,* Can you tell me how it affects your life?

2. How do you feel about your ability to do the things you want to do?

PROBE IF Needed

- Does having hearing loss in one ear ever keep you from doing something you wanted to do?
- Does having hearing loss in one ear ever keep you from doing things with other people?
- Does having hearing loss in one ear ever keep you from playing sports?

- Does having hearing loss in one ear ever keep you from enjoying TV or movies?
- Does having hearing loss in one ear ever keep you from enjoying music?

3. Do you feel that your hearing loss affects your ability to communicate with other people?

PROBE IF Needed

- Does having hearing loss in one ear ever keep you from joining a conversation with a group of people your age?
- How many people do you feel comfortable speaking with during a conversation?
- In what places do you feel more comfortable having a conversation?
- Are you able to tell the difference between two voices just by listening to them?
- Does having hearing loss in one ear ever make it difficult to tell if someone is happy or sad when s/he speaks to you?

4. Do you feel that having hearing loss in one ear has ever affected your safety?

PROBE IF needed

- Has there ever been a time when you were afraid because you had difficulty hearing?

5. How do you feel about the amount of freedom you have?

PROBE IF Needed

- Do you think your parents limit the amount of freedom you have because you have hearing loss in one ear?
 - *If so*, what makes you think that they limit your freedom?

6. How do you think that your hearing loss affects your time spent at home?

PROBE IF Needed

- How do background noises at home affect your ability to speak with family members?
- Do you feel your hearing loss makes a difference in how you get along with your family?

7. Does having hearing loss in one ear affect your time spent with friends?

PROBE IF Needed

- What activities do you usually choose to do with friends?
- How many friends do you like to hang out with at one time?
- Do you think that having hearing loss in one ear affects how you get along with any of your friends?

8. How do you think your hearing loss affects your time spent in school?

PROBE IF Needed

- Does having hearing loss in one ear affect your ability to participate in class?
 - What are your favorite/least favorite subjects in school and why?
 - How do you feel your ability to concentrate compares to your classmates?
- Do you or your teacher use tools, such as a speaker, to help you hear in the classroom?
 - [IF YES] Do you feel these tools in your classes make your life better?
 - Do they make your life worse in any way?

9. Have you ever tried a hearing aid?

[IF YES]

- What kind did you use?
- Did you like using it?
- What was the best thing about it?
- What was the worst thing about it?

10. How do you describe the differences between a person with hearing loss in one ear as compared to a person with hearing loss in both ears?

- Do you know anyone else with hearing loss in one ear?
 - [IF YES] Tell me about them
- Do you know anyone else with hearing loss in both ears?

- [IF YES] Tell me about them

11. How would your parents describe the way that having hearing loss in one ear affects your life?

PROBE IF Needed

- How do your parents feel you are doing at home? At school? With friends?
- How does this compare to your thoughts and opinions?

12. Do you ever have trouble telling where a sound is coming from? Or how far away a sound is?

[IF YES]

- Are there things that make this happen more often?
- Has this happened at home? At school? With friends?
- Has this ever limited your ability to do something that you wanted to do?

13. Has there ever been a time when you have been unable to understand something important that someone said or did?

[IF YES]

- Has this happened at home? At school? With friends?
- How did you respond to the situation?

14. What advice would you give a younger person who has hearing loss in one ear?

- If s/he was worried about school?
- If s/he was treated differently than his/her friends?

15. Does having hearing loss in one ear make you feel different from others? [IF YES] Could you tell me more about that?

16. Are there advantages to having hearing loss in one ear? [IF YES] Could you explain more about that?

17. Are there disadvantages to having hearing loss in one ear? [IF YES] Could you explain more about that?

18. In what ways do you think having hearing loss in one ear might impact your decisions and goals for the future?

Domains of interest

You have given me a lot of good information. Let's make sure we covered everything on my list. (This is a checklist)

Does your hearing loss affect this part of your life? How?

1. Home
2. School: Productivity/Success
3. Recreation: Sports/Television/Music/Movies/Trips (vacations)
4. Friends
5. Self Esteem
6. Environment: Safety/Home/Where to go
7. Communication
8. Accommodations

I want to thank you again for being in our study and helping us today. Please let us know if you have any further questions.

APPENDIX B:

List of final codes with definitions

Code	Definition
Physical functioning	Navigation of physical environment, participation in activities
Psychological functioning	How a participant perceives themselves or their situation
School functioning	Ability to accomplish educational goals, participate in school
Social functioning	Social interaction, engagement with individuals, including communication
Barriers to accommodation	Efforts to overcome hearing deficits
Environmental barriers	Aspects of physical environment that affect participant's ability to function normally
Hearing amplification devices	Comments related to usage of hearing aids or other amplification devices
Quality of life	Subjective sense of well-being
Positive consequences	Comments related to beneficial aspects of having UHI
Stigma	How individuals believes others perceive them or their impairment
Symptoms/side effects	Physical complaints associated with disease or treatment

APPENDIX C:

Physical Function Items (100 items):

Items in **bold** have been prioritized based upon item selection criteria.

Activity/recreation (10 items)

When I play outdoor games with friends, I cannot hear as well as I need to.

Because of my hearing, I cannot participate in activities as much as I would like.

When I play sports, I cannot hear as well as I need to.

When I play sports, I cannot hear my teammates as well as I need to.

When I play sports, I cannot hear my coach as well as I need to.

When I play sports, I have difficulty hearing my teammates call my name.

When I play sports, I have difficulty knowing where the ball is.

Skiing is difficult because I cannot hear people who are behind me.

When I am in PE, I have trouble hearing my teacher as well as I need to.

Acting in a play is difficult because I cannot hear as well as I need to.

Sound Localization (9 items)

I have trouble telling where a sound is coming from.

I have to turn my head to tell where a sound is coming from.

When someone calls my name, I have a hard time telling where they are.

When someone calls my name in a noisy place, I have a hard time telling where they are.

When a phone is ringing, it is hard for me to find it.

It is hard for me to find something by listening to it.

When I hear a sound, it is hard for me to tell how far away it is.

When a sound happens near my deaf/impaired ear, it is harder for me to tell where it is coming from.

I have to look around more than my friends in order to tell where a sound is coming from.

Body/ear position (9 items)

My hearing limits where I can sit or stand when I am with others.

When someone approaches me from behind, I have trouble hearing them coming.

I must sit in the front of the classroom to be able to hear as well as I need to.

When someone whispers into my deaf/impaired ear, it is hard for me to hear them.

When my deaf/impaired ear is facing a person, it is hard for me to hear them.

When I am trying to hear someone in a noisy place, I have to turn my head so that my good ear is facing their direction.

I must turn my head to be able to hear someone if they are speaking into my deaf/impaired ear.

I need to sit on one side of the classroom to be able to hear as well as I need to.

When I enter a room, I need to be careful to sit in a location where I am able to hear everyone.

Attention (7 items)

Loud noises distract me when I am trying to concentrate.

When a noise is bothering me, I am able to ignore it.

Because of my hearing, I am more tired than my friends at the end of the school day.

Because of my hearing, I have trouble paying attention as well as I need to.

I must ask others to repeat themselves because I do not hear them.

Because of my hearing, I must make extra effort to focus in class.

When I play with friends, I have to focus harder than they do in order to participate.

Perception (12 items)

I feel like I cannot hear as well as my friends.

Because of my hearing, I am unable to do things with my friends.

When I talk to other people, they do not know that I have impaired hearing.

My good ear is sensitive to loud sounds.

The hearing in my good ear is more sensitive than my parents' hearing.

I am able to hear high-pitched sounds in my good ear better than my parents.

I have difficulty whispering quietly because it is hard for me to hear how loud I am speaking.

I speak too loudly when I try to communicate in noisy places.

I have trouble hearing how loud sounds are.

My hearing is worse in the mornings.

I have to do things differently than my friends because of my hearing.

Because of my hearing, I do not know about important things.

Media/technology (15 items)

I have trouble hearing the TV at home.

I have trouble using headphones because of my hearing impairment.

I have trouble playing video games because of my hearing impairment.

I need to position my good ear toward the TV when I watch it.

I prefer to listen to the TV at a louder volume than my family.

I have trouble talking on the phone using my deaf/impaired ear.

Talking on the phone is uncomfortable because I cannot use my deaf/impaired ear.

I have to turn up the volume when I listen to headphones.

I have trouble hearing messages on the loudspeaker at school.

I use closed captioning to better understand TV and movies.

I need to rewind movies or TV shows because I have difficulty understanding them.

I have difficulty following the story when I watch TV at home.

When I talk on the phone, I am not able to hear as well as I need to.

I prefer to listen to music at a louder volume than my family and friends.

I prefer to listen to video games at a louder volume than my friends.

Environmental barriers (11 items)

When I am in a noisy room, it is hard for me to understand what other people say.

When I am in a noisy room, it is hard for me to hear as well as I need to.

When I get separated from my family in a crowded place, it is hard for me to find them.

I have more difficulty hearing when my good ear is covered.

When my good ear is covered, I am able to hear out of my impaired ear.

When I am in a car, it is hard for me to hear as well as I need to.

I do not hear people call me when they are in other rooms.

I have difficulty hearing when my family calls me for dinner.

I have trouble hearing my family at home when it is noisy.

When I am in a noisy place, it is hard for me to hear someone unless they are right next to me.

When I am with a group of people, I have difficulty hearing as well as I need to.

Safety (11 items)

When I am crossing the street, it is hard for me to hear cars.

I worry about my safety because I cannot tell where sounds are coming from.

I have trouble hearing alarms and sirens.

When I hear emergency sirens, it is hard for me to tell where they are.

When I am playing near the street, it is hard for me to hear cars coming.

When I ride my skateboard or bike, it is hard to hear cars coming up from behind me.

I look multiple times before crossing the street because I have trouble hearing cars.

I double-check my surroundings when I am near traffic because I have difficulty hearing cars.

I double-check my blind spot when driving because I have difficulty hearing other cars.

I am worried that when I drive I may not hear as well as I need to.

I worry about driving at night because I may not hear as well as I need to.

Hearing aid (17 items)

When I wear my hearing aid, I am better able to tell where a sound is coming from.

My hearing aids help me to hear when I play sports.

When I wear a hearing aid, I have more difficulty hearing as well as I need to.

When I wear a hearing aid, I am more distracted by noises.

When I wear a hearing aid, I still have difficulty hearing as well as I need to.

When I wear a hearing aid, I am able to hear when I sit in the back of a room.

When I wear a hearing aid, I am able to hear someone even if my deaf/impaired ear is facing them.

When I wear a hearing aid, it is difficult for me to adjust the volume as well as I need to.

When I wear a hearing aid, I can hear someone calling to me.

When I wear my hearing aid, I am able to concentrate.

When I wear my hearing aid, speech sounds clear.

When I wear my hearing aid, I am able to understand what others say.

When I wear my hearing aid, sounds are louder.

When I wear my hearing aid, sounds are more clear.

When I wear my hearing aid, I am better able to have a conversation in the car.

When I wear my hearing aid, I am better able to hear other cars when driving.

When I wear my hearing aid, I am able to hear as well as I need to.

References

- ¹ Lee DJ, Gomez-Marin O, Lee HM. Prevalence of unilateral hearing loss in children: The National Health and Nutrition Examination Survey II and the Hispanic Health and Nutrition Examination Survey. *Ear & Hearing*. 1998; 19(4): 329-332.
- ² Shargorodsky J, Curhan SG, Curhan GC, Eavey R. Change in prevalence of hearing loss in US adolescents. *JAMA*. 2010; 304(7): 772-8.
- ³ Bovo R, Martini A, Agnoletto M, Beghi A, Carmignoto D, Milani M, Zangaglia AM. Auditory and academic performance of children with unilateral hearing loss. *Scand Audiol Suppl*. 1988; 30: 71-4.
- ⁴ Ruschetta MN, Arjmand EM, Pratt SR. Speech recognition abilities in noise for children with severe-to-profound unilateral hearing. *Intl J Pediatr Otorhinolaryngol*. 2005; 69: 771-9.
- ⁵ Bess FH, Tharpe AM. Unilateral hearing impairment in children. *Pediatrics*. 1984; 74(2): 206-16.
- ⁶ Bess FH, Klee T, Culbertson JL. Identification, assessment and management of children with unilateral sensorineural hearing loss. *Ear and Hearing*. 1986; 7(1): 43-50.
- ⁷ Lieu J, Tye-Murray N, Karzon R, Piccirillo J. Unilateral hearing loss is associated with worse speech-language scores in children. *Pediatrics*. 2010; 125: e1348-e1355.
- ⁸ Lieu JE, Karzon RK, Ead B, Tye-Murray N. Do audiologic characteristics predict outcomes in children with unilateral hearing loss? *Otol Neurotol*. 2013; 34(9): 1703-10.
- ⁹ Kuppler K, Lewis M, Evans A. A review of unilateral hearing loss and academic performance: Is it time to reassess traditional dogmata? *Intl J Pediatr Otorhinolaryngol*. 2013; 77: 617-22.
- ¹⁰ Fitzpatrick EM, Whittingham J, Durieux-Smith A. Mild bilateral and unilateral hearing loss in childhood: A 20-year view of hearing characteristics, and audiologic practices before and after newborn hearing screening. *Ear Hear*. 2014; 35(1): 10-8.
- ¹¹ Bandura, A. *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall, 1977.
- ¹² Banga R, Doshi J, Child A, Pendleton E, Reid A, McDermott AL. Bone-anchored hearing aids in children with unilateral conductive hearing loss: a patient-career perspective. *Ann Otol Rhinol Laryngol*. 2013; 122(9): 582-7.
- ¹³ Patrick DL, Edwards TC, Skalicky AM, Schick B, Topolski TD, Kushalnagar P, Leng M, O'Neill-Kemp AM, Sie KS. Validation of a quality of life measure for deaf or hard of hearing youth. *Otolaryngol Head Neck Surg*. 2011. 145(1): 137-45.
- ¹⁴ Briggs L, Davidson L, Lieu JE. Outcomes of conventional amplification for pediatric unilateral hearing loss. *Ann Otol Rhinol Laryngol*. 2011; 120(7) 448-54.

-
- ¹⁵ Meyer A, Sie K, Skalicky A, Edwards TC, Schick B, Niparko J, Patrick DL. Quality of life in youth with severe to profound sensorineural hearing loss. *JAMA Otolaryngol Head Neck Surg.* 2013; 139(3): 294-300.
- ¹⁶ Umansky AM, Jeffe DB, Lieu JE. The HEAR-QL: quality of life questionnaire for children with hearing loss. *J AM Acad Audiol.* 2011; 22(10): 644-53.
- ¹⁷ Rachakonda T, Jeffe DB, Shinn JJ, Mankarious L, Fanning RJ, Lesperance MM, Lieu JE. Validity, discriminative ability and reliability of the hearing-related quality of life questionnaire for adolescents. *Laryngoscope.* 2014; 124(2): 570-8.
- ¹⁸ Borton SA, Mauze E, Lieu JE. Quality of life in children with unilateral hearing loss: a pilot study. *Am J Audiol.* 2010; 19(1): 61-72.
- ¹⁹ Dancer J, Burl N, Waters S. Effects of unilateral hearing loss on teacher responses to the SIFTER. *American Annals of the Deaf.* 1995; 140(3): 291-4.
- ²⁰ Most T. The effects of degree and type of hearing loss on children's performance in class. *Deafness and Education International.* 2004; 6(3): 154-165.
- ²¹ Fischer C, Lieu J. Unilateral hearing loss is associated with a negative effect on language scores in adolescents. *Int J Pediatr Otorhinolaryngol.* 2014; 78(10): 1611-7.
- ²² Johnstone PA, Nabelek AK, Robertson VS. Sound localization acuity in children with unilateral hearing loss who wear a hearing aid in the impaired ear. *J AM Acad Audiol.* 2010; 21: 522-534.
- ²³ Noh H, Park Y. How close should a student with unilateral hearing loss stay to a teacher in a noisy classroom? *Int J Audiol.* 2012; 51: 426-32.
- ²⁴ Weichbold V, Holzer A, Newesely G, Stephan K. Results from high-frequency hearing screening in 14- to 15-year-old adolescents and their relation to self-reported exposure to loud music. *Int J Audiol.* 2012; 51(9): 650-4.
- ²⁵ Sekhar DL, Clark SJ, Davis MM, Singer DC, Paul IM. Parental perspectives on adolescent hearing loss risk and prevention. *JAMA Otolaryngol Head Neck Surg.* 2014; 140(1): 22-8.