Perceived stigma and social relationships: Deaf and hard of hearing adolescent and parent perspectives

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Abstract

Perceived stigma and social relationships: Deaf and hard of hearing adolescent and parent perspectives

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Background: A quality of life (QoL) study is a multidimensional approach to understanding a person's assessment of their position in life. The Youth Quality of Life Instrument – Deafness and Hard of Hearing (YQoL-DHH) module measures adolescent QoL including in the perceived stigma and social relationship domains. Few studies have compared parent-report and youth-report results regarding QoL and no prior studies have focused specifically on perceived stigma and social relationships.

Methods: A multisite observational study titled "Hearing Loss and Quality of Life of Children and Youth" was conducted from 2007 to 2010. This original study, upon which the current study was based, was completed in two phases: (1) Qualitative interviews and focus groups to inform development of the YQoL-DHH module and (2) Quantitative measurement property testing through a self-administered questionnaire. The study population included both adolescents and parents: DHH youth ages 11-18 (n=230) and the parents/guardians of DHH children ages 5-10 (n=271). For the current study, a secondary data analysis was conducted using both phase 1 (qualitative) and phase 2 (quantitative) data. Qualitative data from the first phase were assessed for identification of primary themes. Quantitative data from the second phase were analyzed using simple and multiple linear regression. The models controlled for race/ethnicity and sex.

Results: The phase one qualitative analysis identified five primary themes: (1) Device-related stigma, (2) Assumptions about ability, (3) Sport-related barriers to social relationships, (4) Deaf vs. Hearing friends, and (5) Language barriers. The phase two quantitative results identified four primary findings: (1) Youth reported: assistive hearing devices were associated with higher stigma (r=0.93, p=0.03), (2) Parent reported: using signed languages was moderately associated with higher stigma (r=0.42, p=0.06), (3) Parent reported: A greater degree of hearing loss was associated with low social QoL (r=-0.20, p=0.05), (4) Use of signed languages was reported by youth as associated with low social QoL outside of school (r=-0.79, r=0.04) and reported by parents as a factor associated with high social QoL outside of school (r=0.47, p=0.05). In general, the parents reported higher negative stigma and lower social QoL compared to the youth report. Despite this discrepancy, the youth qualitative interviews showed indications of both the stigma and low social QoL found in the parent results. Conclusions: Results from this study indicate that assistive hearing devices, signed languages, and high degrees of hearing loss can negatively impact DHH youth QoL. These results can assist in home and school-based program interventions for DHH children and adolescents to reduce stigma and improve the quality of their social relationships.

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A. Background

Introduction

Adolescents with deafness and hard of hearing (DHH) experience unique developmental and psychological challenges compared to their hearing peers[1]. In the United States, 2 to 3 out of every 1,000 children are born with hearing loss in one or both ears[2]. Over 90% of these children are born into hearing families[3]. There are numerous decisions parents have to make after learning their child is deaf or hard of hearing. Unfortunately, there is little consensus about what decisions lead to the best outcomes for youth with DHH[4,5]. Despite improvements in newborn hearing screenings and increased early diagnosis, there are few evidence-based psychosocial interventions to improve DHH outcomes. Individuals with DHH are 21% to 39% less likely to enroll in college than those with normal-hearing[1]. Youth with DHH youth generally report lower quality of life (QoL), particularly in school and social interactions[1]. Research also shows that QoL can improve with appropriate interventions[1]. Understanding how QoL of youth with DHH is impacted can assist in identifying which interventions and future research is most needed.

Key Terms and Issues

The leading known causes of hearing loss at birth are genetics and pregnancy complications, such as prematurity or birth trauma[6]. After birth, the primary known causes of early hearing loss are meningitis and infections, such as measles and mumps[6]. Early identification of hearing loss can assist in efforts to develop an appropriate language for the DHH child. For example, children born into DHH families may be better suited to learn a signed language whereas children born to hearing parents would be more successful with utilizing a spoken language. Adequate language abilities are important for children to express their emotions and communicate their needs to their caregivers.

There are six primary languages used by people with DHH in the US, a range of spoken to visual:[7].

Method	Language(s)	Description
Oral	Auditory-Verbal; Auditory-Oral	Relies on both listening, visual cues, and lip reading.
Cued Speech	Cued Speech	Utilizes hand gestures along with verbal speech.
Manual/Signed	Manually Coded English (MCE)	Signed or finger-spelled words using the same sentence structure and grammar as English.
Manual/Signed	Simultaneous Communication (SimCom)	A mixture of speaking and signing English.
Manual/Signed	American Sign Language (ASL)	Signed or finger-spelled words with a unique sentence structure, word order, and grammar.
Total Communication	Total Communication (TC)	Use of signs, gestures, lip-reading, listening, and speech.

ASL is the primary visual language for the Deaf community in the United States. It is not an exact representation of English, but rather, has its own grammatical rules and is considered its own language[7]. Many DHH individuals who use ASL consider themselves to be bilingual and bicultural, as they use English with their hearing peers and ASL within the Deaf community[7]. On the opposite end of the language spectrum, individuals utilizing the AV approach aim to integrate completely into the mainstream and are not frequently exposed to ASL or Deaf culture[7]. The completely spoken approach uses assistive technology, such as a cochlear implant or hearing aid, and does not allow the child to read lips[7].

Depending on the severity of hearing loss, individuals with DHH have access to a few primary assistive technology devices. A cochlear implant (CI) is an electronic device that is implanted behind the ear under the skin and connects to a portion that sits on top of the skin[8]. It bypasses the damaged parts of the ear and sends signals directly to the auditory nerve, which the brain then perceives as sound[8]. A CI does not imitate sound exactly as a hearing person perceives it, but rather it creates a representation of sound. The other primary assistive device is the hearing aid, which is noninvasive and amplifies existing sound[9]. Both of these devices require adjustment time and training to assist in distinguishing between sounds. Additionally, both are worn on the outside of the ear and are visible to peers which may be a factor relating to perceived stigma.

A quality of life (QoL) study is a multidimensional approach to understanding a person's view on how their life is going. The World Health Organization defines QoL as,

> "…individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment[10]."

In regards to DHH youth, studying QoL can offer insights into how language, home environment, school type, and social success impacts their sense of well-being.

Significance

The Annual Data Early Hearing Detection and Intervention (EHDI) Program has been identifying an increasing number of babies with hearing loss at an early age[11]. This improvement in early identification is an important step towards improving DHH QoL. Early detection will promote early interventions and evidence-based approaches to supporting the healthy development of DHH children.

DHH youth home environment, language capabilities, and utilization of assistive technologies have all demonstrated influence on QoL[12, 13]. There are many issues deaf families and hearing families have to consider when learning that their child is DHH. For example, an early CI is associated with higher self-esteem compared to a child that received a CI at an older age[12]. Families face decisions regarding primary home language, type of school, and use of assistive technology. Parents of DHH youth need a comprehensive understanding of DHH QoL factors to offer optimal support to their child's development.

Psychosocial Development

Among peer groups, DHH youth face challenges relating to stigma and social relationships. Research has demonstrated that psychosocial difficulties are 3.7 times higher in

DHH adolescents compared to hearing children[12]. Psychosocial development includes both the psychological and the social aspects of lived experiences[12]. Research has demonstrated higher psychosocial challenges in DHH youth but the degree differs by individual characteristics. Generally, strong communication, regardless of language, is associated with fewer psychosocial difficulties[12]. These difficulties are more prominent in DHH children with additional developmental disabilities and among DHH adolescent boys[12]. Hearing loss in itself is not a strong predictor of QoL, but rather the context in which the child develops is.

Innovation

In DHH prior studies, results have varied depending on the methods utilized[12]. Two studies that used parent questionnaires to measure the child's psychosocial well-being reported higher ratings compared to the studies that used observations and video tapes of children[12]. Solely relying on parents to interpret and report their child's psychosocial difficulties may be an unreliable method to establish the status of DHH youth QoL.

Parents' perceptions of younger children's perceived stigma and quality of their social relationships may differ from the self-perception of the adolescent. Exploring this comparison may offer insight into differences in social priorities, interpretation of social interactions, and actions to achieve the social desires. Considering the complexities of DHH life, it is important to understand how parents and children interpret the experiences of developing as a DHH individual.

B. Specific Aims

Considering both the limitations of parent-report and the impact of communication challenges DHH youth face, comparing parent and child QoL-related perspectives may offer novel insights into the experiences of this population. This study addresses three key aims:

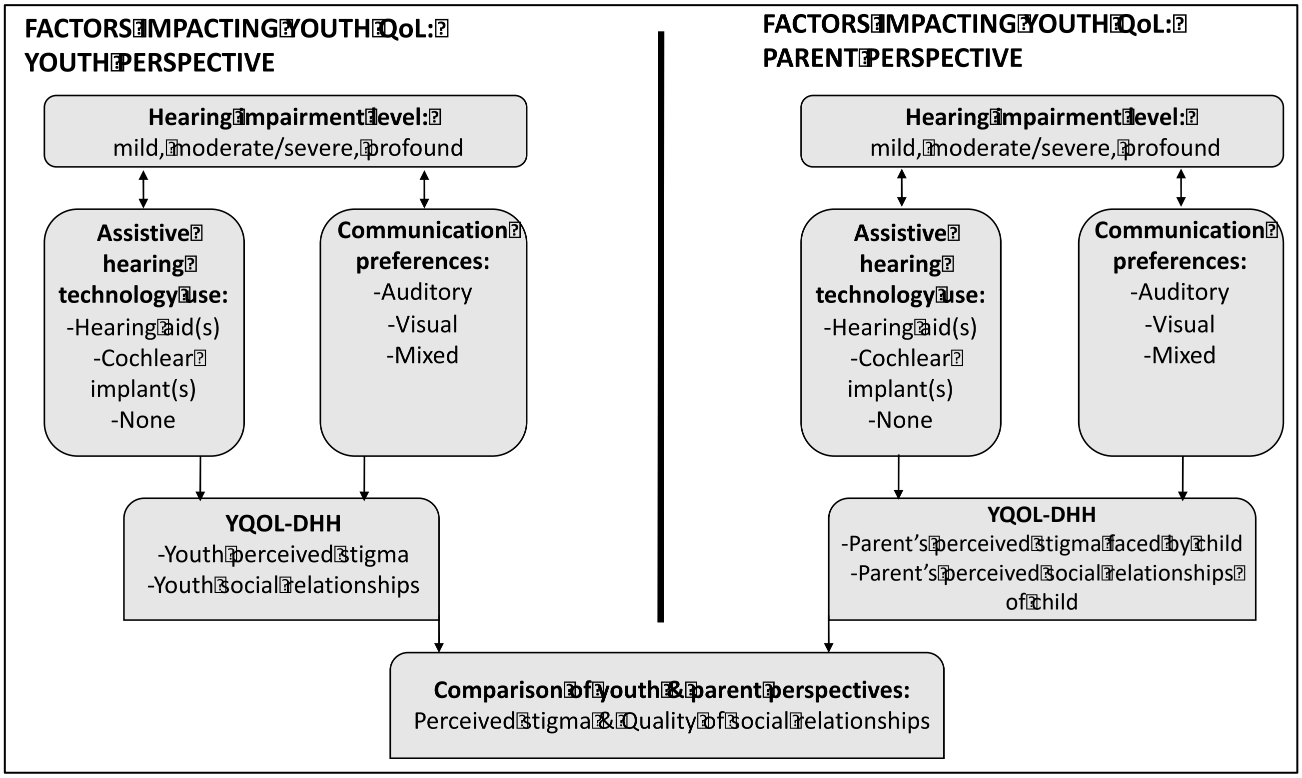
1. Identify key similarities and differences between child and parent perspectives of perceived stigma related to peers, friends, and strangers.
2. Identify key similarities and differences between child and parent perspectives of social relationships beyond the family unit.
3. Examine whether assistive hearing technology use, youth communication preference, and hearing impairment level are associated with differences in perceived stigma and social relationships.

The third aim targets characteristics of the individual that can be clearly identified by their peers. Assistive technology use is often seen in daily life, communication preferences will be apparent during a conversation, and hearing impairment may present itself during interactions. By possessing an identifiable trait such as these, QoL of DHH youth may be impacted.

C. Conceptual Framework

The conceptual model below depicts the hypothesized association between the DHH factors and the DHH QoL outcomes. The model examines how the predictors (hearing impairment level, assistive technology use, and communication preference) influence the youth or parent response to selected perceived stigma or social relationship questions. The youth and parent responses are then compared to identify key differences or similarities between the reported QoL domains, perceived stigma and social relationships.

The hypothesized interactions included in the model were informed by the literature stated previously. Namely, barriers to communication have demonstrated an impact on DHH QoL and the use of assistive hearing devices has been associated with experiences of stigma[12, 14]. The conceptual model considers the previous research regarding stigma and social relationships and explores the possibility of youth and parent differences in reported QoL.



D. Study Design and Methods

Study Design: A cross-sectional study was completed using the QoL Deaf and Hard-of-Hearing Children and Youth (YQOL-DHH) study completed in 2010. The data have been de-identified therefore IRB approval is not necessary for a secondary analysis.

Data Source: A multisite observational study titled "Hearing Loss and Quality of Life of Children and Youth" was conducted from 2007 to 2010. The study was completed in two phases: (1) Qualitative interviews and focus groups to inform the Youth Quality of Life Instruments and (2) Quantitative module psychometric testing through a self-administered cross-sectional questionnaire. The study population included both children and parents: DHH youth ages 11-18 (n=230) and the parents/guardians of DHH children ages 5-10 (n=271).

Youth Quality of Life Deaf and Hard of Hearing Instrument (YQoL-DHH): This instrument measures DHH-specific QoL in youth. It is comprised of 32 items in three primary categories: Participation, Self-Acceptance/Advocacy, and Perceived Stigma. The instrument is able to be implemented in various formats, such as paper and pencil, web-survey, ASL DVD, Pidgin Signed English (PSE) DVD, or an interview-administered ASL DVD for those with limited reading levels. After the video instruments are completed, two adult signers interpret translate the responses into English.

Study Setting & Population: The eligible population was limited to Washington State, Colorado, New Mexico, and Arizona. Participants had to have some degree of audiologist defined hearing loss, which was classified into the categories: mild (20 db HL to 40 dB HL), moderate (40 db HL to 55 dB HL), moderate-severe (55 db HL to 70 dB HL), severe (70 db HL to 90 dB HL), or profound (90+ db HL). Recruitment was purposive to gather a diverse sample and distribution of degree of hearing loss, technology use, and school type.

Phase I: Inclusion Criteria

<u>Children/Youth Report:</u> Ages 11-18 years, met the definition of DHH by their school, had an IEP, able to communicate in English/ASL/SEE/TC.

<u>Parent Report:</u> Had a child ages 5-10 years who met the definition of DHH by their school, and that child has an IEP, able to communicate in English/ASL/SEE/TC. Parents can be hearing or DHH and are not paired with youth respondents.

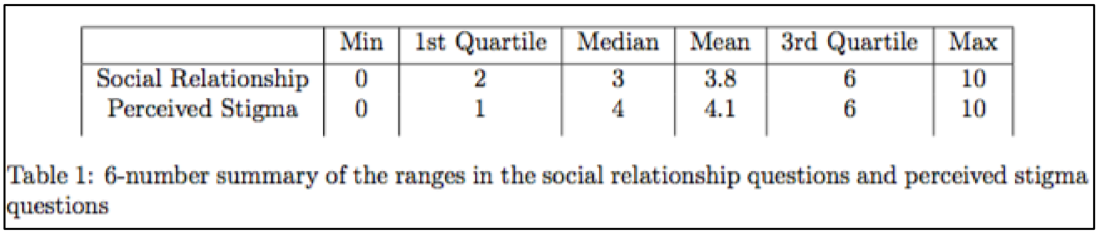
Phase I: Exclusion Criteria

Children/Youth: Parental report of physical/mental condition that impacts their child's QoL more than being DHH.

Parents: Reported their child has a physical/mental condition that impacts their QoL more than being DHH.

E. Quantitative Methodology

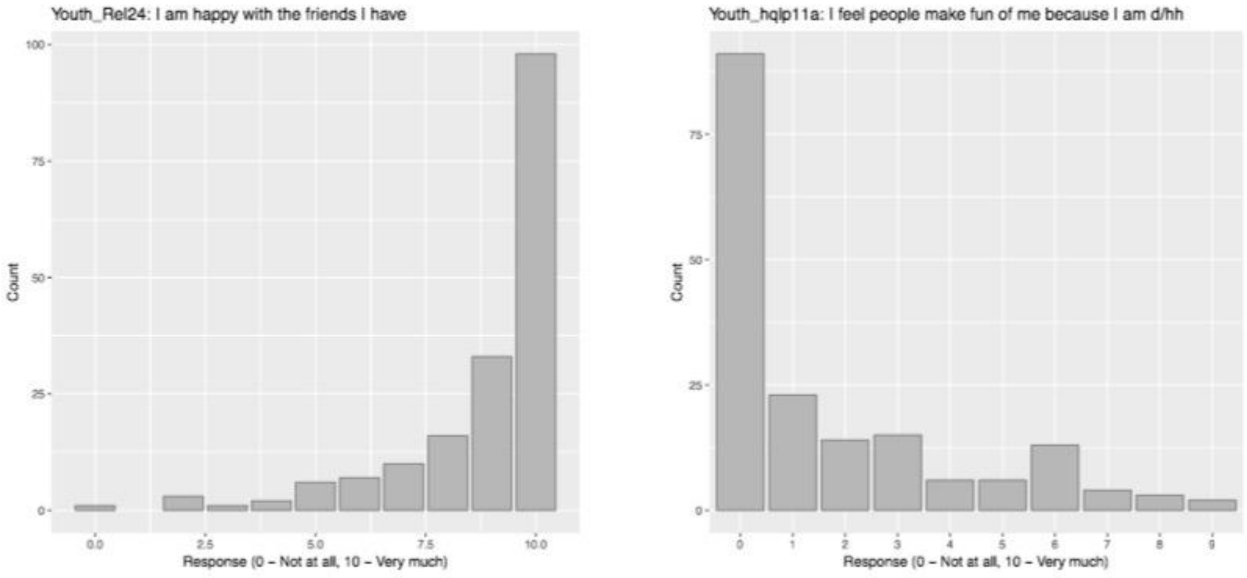
After removing all observations with missing data in any of the covariates, 209 observations remained. Several youth respondents whose answers to the related questions were purely random were not considered valid and therefore removed. For example, one of the youth answered (10,0,10,0,10) to the highly related 5 questions regarding social relationship. An intuitive way to identify these outliers was to look at the range of the answers to the questions in the social relationship group and in the perceived stigma group. The 6-number summary (minimum, 1st quartile, median, mean, 3rd quartile, maximum) of the ranges in the two question groups is shown in the following Table 1.



	Min	1st Quartile	Median	Mean	3rd Quartile	Max
Social Relationship	0	2	3	3.8	6	10
Perceived Stigma	0	1	4	4.1	6	10

Table 1: 6-number summary of the ranges in the social relationship questions and perceived stigma questions

From Table 1, the average range in both questions was not very large, but there were respondents with very large range and so those responses were identified as outliers. As an empirical rule, we excluded all points with a range larger than 8 in either of the two groups. As a result, we were left with 178 observations, which was enough since the number of variables was moderate. The distribution of the responses to two example questions is plotted in Figure 1.



(a) Question Rel24

(b) Question HQLP11a

Figure 1: Distribution of responses to questions Rel24 and HQLP11a

As can be seen from Figure 1, the responses to both questions are highly unbalanced. A large portion of respondents claim to be very satisfied in their social life and sense little discrimination.

A sequence of nested linear regression models was fitted to the data to address the skewness. The response variable and the level of hearing loss were treated as continuous variables. For the device variable, "not wearing any device" was considered the baseline group. For the language variable, "only spoken language" was used as the baseline group. For the sex variable, female was the baseline group. For the race variable, Caucasian was the baseline group. More specifically, the models being fit are as follow:

A simple linear regression model was fit between the response variable and each of the main variables of interest:

$$\text{Response} \sim \text{Hearing Loss Level},$$

$$\text{Response} \sim \text{Language Spoken},$$

$$\text{Response} \sim \text{Device Worn}.$$

In order to test for confounding effects, sex and race was added to each of the previous simple linear regression models:

Response ~ Hearing Loss Level + Sex + Race,

Response ~ Language Spoken + Sex + Race,

Response ~ Device Worn + Sex + Race.

The coefficients of hearing loss level, language spoken, and device worn were compared with those in the simple linear regression models. If the coefficients differed by 0.01 or more, the potential confounders were considered to have an effect.

All three variables of interest and the confounders were included in the multi linear regression model:

Response Hearing Loss Level + Language Spoken + Device Worn + Sex + Race.

Assistive Technology Use: This variable was relatively balanced. The category “None" indicates that the respondent is not wearing any device. We understood that the four categories of hearing device: cochlear implant (1 ear), cochlear implant (2 ears), hearing aid (1 ear), hearing aid (2 ears) are all visible, and thus is expected to increase perceived stigma. We thus decide to dichotomize this variable into a binary one: not wearing device and wearing device.

Language: Among the eight categories, English was the dominant language. Moreover, only the two categories corresponding to English and Spanish are purely spoken language. The languages in the other categories, such as ASL, MCE and PSE are all different kinds of sign language. We suspect that people will tend to feel less socially welcome and more discrimination if they use sign language compared to normal spoken language. Therefore, for this variable, we chose to dichotomize it into a binary one: only spoken (English, Spanish) and spoken/sign (all other six categories).

Confounders: For the potential confounder sex, we treated it as a binary variable. Caucasian was the dominant race, and the other three races were African American, Asian/Pacific Islander and Hispanic. To make this variable more balanced, we chose to dichotomize it into a binary one: Caucasian and non-Caucasian. For the potential confounder school, we treated it as a categorical variable. This confounder was only present in the parent dataset and was applied to the parent models. The assumption was that youth at schools for deaf children would have minimal perceived stigma and high quality relationships as many of their peers are DHH.

F. Quantitative Analysis:

Outcome Variables (Y): The outcome variables of interest were perceived stigma and quality of social relationships.

Explanatory Variables: **U** is an indicator of assistive technology use, **V** is an indicator of hearing loss severity (continuous), **W** is an indicator for communication preference, **Z** is an indicator for confounders (sex and race/ethnicity).

$$E\,[Y|X=x] = \beta_0 + \beta_1 u_{HA.1} + \beta_2 u_{HA.2} + \beta_3 u_{CI.1} + \beta_4 u_{CI.2} + \beta_5 u_{none} + \beta_6 u_{other} + \beta_7 v_{H.L.}$$

$$B_8 w_{English} + \beta_9 w_{ASL} + \beta_{10} w_{PSE/MCE} + \beta_{11} w_{Spanish} + \beta_{12} w_{Other.} + \beta_{13} z_{SexM} + \beta_{14} z_{SexF} + \beta_{15} z_{Cau} +$$

$$\beta_{16} z_{Hisp} + \beta_{17} z_{AfAm} + \beta_{18} z_{A/PI} + \beta_{19} z_{NatAm} + \beta_{20} z_{Other}$$

The independent variables for this aim were self-reported responses to the questions in the YQOL-DHH instrument. The model was run for each of the 11 questions of interest.

Aim	**Youth Self-Report Questions**	**Response Options**
Aim 1: Perceived Stigma [hqlp11a]	I feel people make fun of me because I am d/hh	0-Not at all, 10-Very much
Aim 1: Perceived Stigma [hqlp12a]	I feel people bully me because I am d/hh	0-Not at all, 10-Very much
Aim 1: Perceived Stigma [hqlp15a]	I feel people think I am dumb because I am d/hh	0-Not at all, 10-Very much
Aim 2: Social Relationships [Rel 24]	I am *happy* with the friends I have	0-Not at all, 10-Very much
Aim 2: Social Relationships [Rel 26]	I feel I *can take part* in the same activities as others my age	0-Not at all, 10-Very much
Aim 2: Social Relationships [Rel27]	People my age *treat me* with respect	0-Not at all, 10-Very much
Aim 3: Assistive Technology	What type of personal amplification do you currently use at home? (Binaural aids, one aid, CI one ear, CI 2 ears, other/specify)	0-No, 1-Yes

Aim 3: Language Preference	What language does your family use at home most often?	1-English, 2-ASL, 3-PSE or MCE, 4-Spanish, 5-Other, 6-English & ASL, 7-English & PSE or MCE, 8-English, ASL, and Spanish
Aim 3: Degree of Hearing Loss	Hearing Loss Degree – Audiograms	0-Normal, 1-Mild, 2-Moderate, 3-Moderate/Severe, 4-Severe, 5-Profound, 6-Unsure, 7-CI, 8-Unilateral High frequency only

Parent Model: To address each aim, the following model was tested:

Outcome Variables (Y): The outcome variables of interest were perceived stigma and quality of social relationships.

Explanatory Variables: **U** is an indicator of assistive technology use, **V** is an indicator of hearing loss severity (continuous), **W** is an indicator for communication preference, **Z** is an indicator for confounders (sex and race/ethnicity).

$$E\,[Y|X=x] = \beta_0 + \beta_1 u_{HA.1} + \beta_2 u_{HA.2} + \beta_3 u_{CI.1} + \beta_4 u_{CI.2} + \beta_5 u_{none} + \beta_6 u_{other} + \beta_7 v_{H.L.}$$

$$B_8 w_{English} + \beta_9 w_{ASL} + \beta_{10} w_{PSE/MCE} + \beta_{11} w_{Spanish} + \beta_{12} w_{Other.} + \beta_{13} z_{SexM} + \beta_{14} z_{SexF} + \beta_{15} z_{Cau} +$$

$$\beta_{16} z_{Hisp} + \beta_{17} z_{AfAm} + \beta_{18} z_{A/PI} + \beta_{19} z_{NatAm} + \beta_{20} z_{Other}$$

The independent variables for this aim were parent-reported responses to the questions in the YQOL-DHH instrument. The model was run for each of the 11 questions of interest.

Aim	Parent-Report Questions	Response Options
Aim 1: Perceived Stigma [bullied18p]	In the last 30 days, how often has your daughter/son been bullied?	0-Has not been bullied, 1-once, 2-2-3 times, 3-about once a week, 4-several times a week
Aim 1: Perceived Stigma	During the past month, how	0-Never, 1-Almost never, 2-

[pedsql_so82a]	much of a problem has your child had with other kids not wanting to be his or her friend?	Sometimes, 3-Often, 4-Almost always
Aim 1: Perceived Stigma [pedsql_so83a]	During the past one month, how much of a problem has your child had with getting teased by other children?	0-Never, 1-Almost never, 2-Sometimes, 3-Often, 4-Almost always
Aim 2: Social Relationships [hqlc19p]	How often did you observe or learn that your child spent time enjoying him/herself with children his/her age outside of school?	0-Never, 1-Rarely, 2-Sometimes, 3-Often, 4-Very often
Aim 2: Social Relationships [hqlc29p]	How often did you observe or learn that your child got invited to parties or play dates with children his/her age?	0-Never, 1-Rarely, 2-Sometimes, 3-Often, 4-Very often
Aim 3: Assistive Technology	What type of personal amplification does your child use at home?	1-Hearing aid (one ear only), 2-Hearing aid (two ears), 3-Cochlear implant (one ear), 4-Cochlear implant (two ears), 5-None, 6-Other
Aim 3: Language Preference	What is the primary language used at home?	1-English, 2-ASL, 3-PSE or MCE, 4-Spanish, 5-Other
Aim 3: Degree of Hearing Loss	How severe would you rate your child’s hearing loss?	1-Normal, 2-Mild, 3-Moderate, 4-Moderate/Severe, 5-Severe, 6-Profound

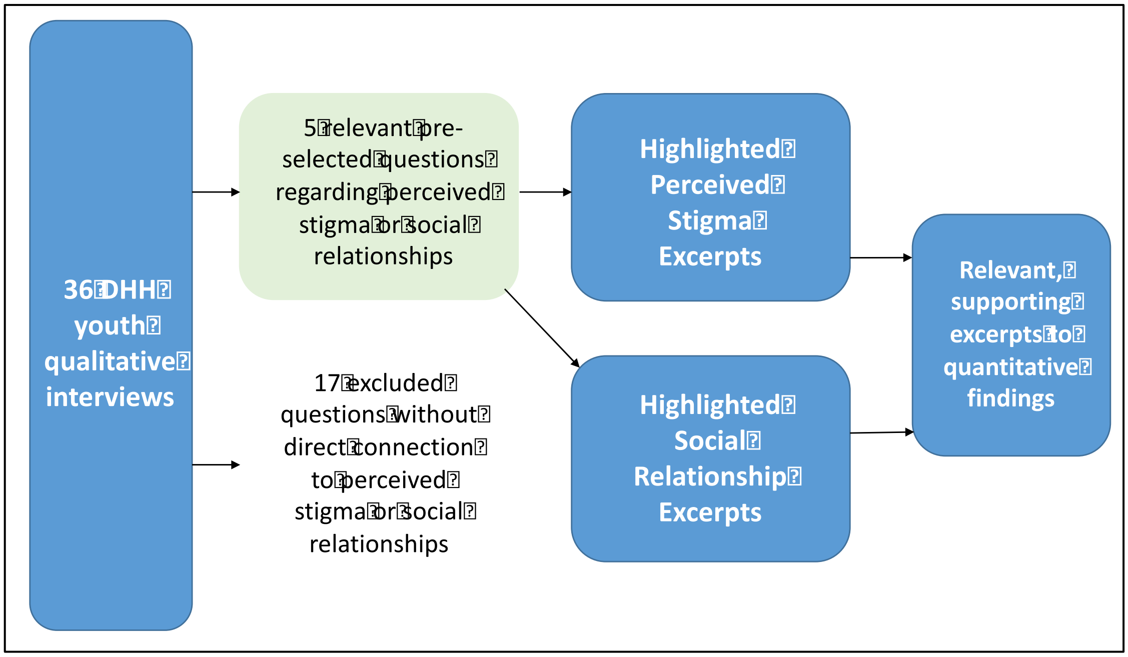
G. Qualitative Analysis:

Five semi-structured questions from the Phase I qualitative study instrument development were used for this qualitative analysis. These questions are:

Aim 1: Perceived Stigma	QUESTION: "Would you say people treat you differently because you are deaf or hard of hearing, either positively or negatively?" [IF YES]:	PROBE: "Who treats you differently?" PROBE: "How do you they treat you differently?" PROBE: "How do you know when you are being treated differently?" PROBE: "How does that make you feel?"
Aim 1: Perceived Stigma	QUESTION: "Do people seem curious about you?" [IF YES]:	PROBE: "How can you tell?" PROBE: "Why would you say they're curious about you?" PROBE: "How does it make you feel when people seem curious?" PROBE: "How do you respond to people's curiosity?" PROBE: "How do you wish people would respond to you?"
Aim 1: Perceived Stigma	QUESTION: "Does being deaf or hard of hearing make you feel different from others?" [IF YES]:	PROBE: "Could you tell me more about that?"
Aim 2: Social Relationships	QUESTION: "How do you think your friends affect your quality of life?"	PROBE: "Do you have a best friend?" PROBE: "What makes them your best friend compared to others?" PROBE: "Do you think that being ___ affect how you get along with any of your friends?" PROBE: "Any of the kids at school or in your

		neighborhood?”
Aim 2: Social Relationships	“QUESTION: How do you think that your family affects your quality of life?”	PROBE: “How is your family part of a good quality of life?” PROBE: “Do you feel your ___makes a difference in how you get along with your family?” PROBE: “Can your family be part of a bad quality of life?”

Out of the twenty-two possible questions, only the questions relevant to the three aims were selected for review. The participant responses were reviewed and categorized under social relationships or stigma which comprised a document to search for relevant quotes. The qualitative analysis approach was done to offer clarification, support, or context for the quantitative findings. A rigorous evaluation of the qualitative themes was not conducted nor was a qualitative analysis software used. Instead, a systematic method review of transcripts was conducted and is depicted below:



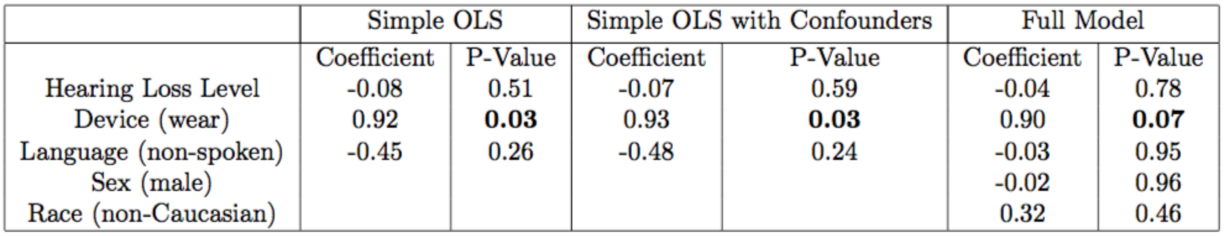
H. Quantitative Results

The following quantitative results are separated into perceived stigma results and social relationship results, each with youth and parent responses. The first column in each table lists the comparison group, the second column lists the simple linear regression coefficients and p-values, the third column lists the simple linear regression coefficients and p-values with confounders, and the third column lists the coefficients and p-values from the multi linear regression with confounders.

R 3.4.4. was used for analysis. P-values less than or equal to 0.06 were considered moderate evidence as p-values 0.05 or less were considered strong evidence of association between the predictors and outcome.

Aim 1: Perceived Stigma

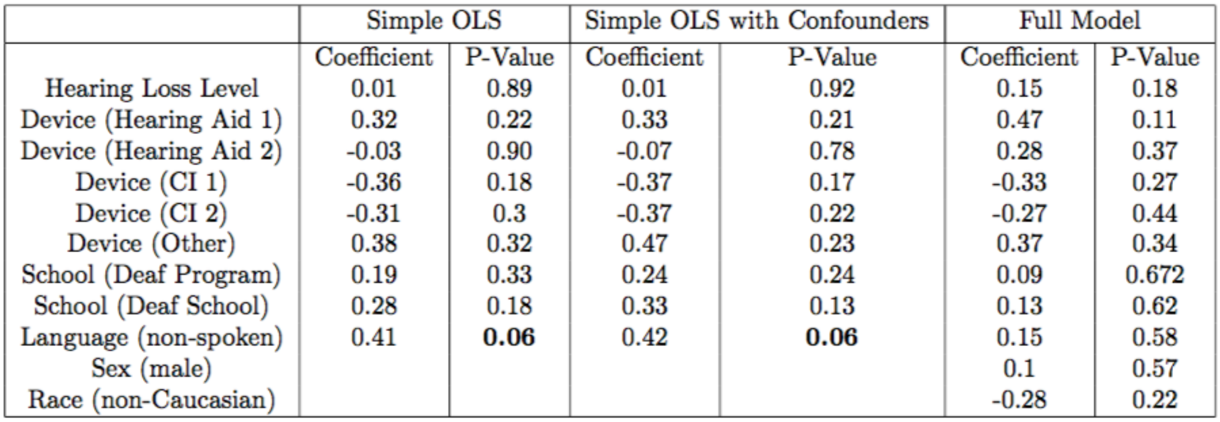
QoL Domain	Perceived Stigma
Group	Youth
Question	Hqlp11a: “*I feel people make fun of me because I am DHH”*
Results	



	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	-0.08	0.51	-0.07	0.59	-0.04	0.78
Device (wear)	0.92	**0.03**	0.93	**0.03**	0.90	**0.07**
Language (non-spoken)	-0.45	0.26	-0.48	0.24	-0.03	0.95
Sex (male)					-0.02	0.96
Race (non-Caucasian)					0.32	0.46

Interpretation: After completing a simple linear regression model, the presence of an assistive hearing device was found to be associated with more perceived stigma compared to those without a device (r=0.93, p=0.03).

QoL Domain	Perceived Stigma
Group	Parent
Question	Bullied18p: “*In the last 30 days, how often has your daughter/son been bullied?*
Results	

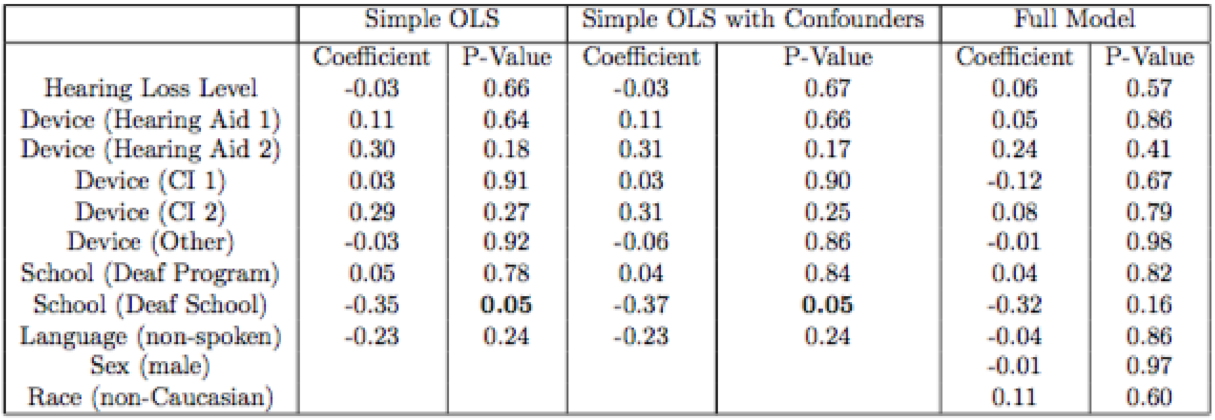


	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	0.01	0.89	0.01	0.92	0.15	0.18
Device (Hearing Aid 1)	0.32	0.22	0.33	0.21	0.47	0.11
Device (Hearing Aid 2)	-0.03	0.90	-0.07	0.78	0.28	0.37
Device (CI 1)	-0.36	0.18	-0.37	0.17	-0.33	0.27
Device (CI 2)	-0.31	0.3	-0.37	0.22	-0.27	0.44
Device (Other)	0.38	0.32	0.47	0.23	0.37	0.34
School (Deaf Program)	0.19	0.33	0.24	0.24	0.09	0.672
School (Deaf School)	0.28	0.18	0.33	0.13	0.13	0.62
Language (non-spoken)	0.41	**0.06**	0.42	**0.06**	0.15	0.58
Sex (male)					0.1	0.57
Race (non-Caucasian)					-0.28	0.22

Interpretation: A simple linear regression controlling for confounders found a moderate association between youth using a signed language more experiences with bullying (r=0.42, p=0.06).

QoL Domain	Perceived Stigma
Group	Parent
Question	Pedsql_so83a: "*During the past one month, how much of a problem has your child had with getting teased by other children?*"

Results



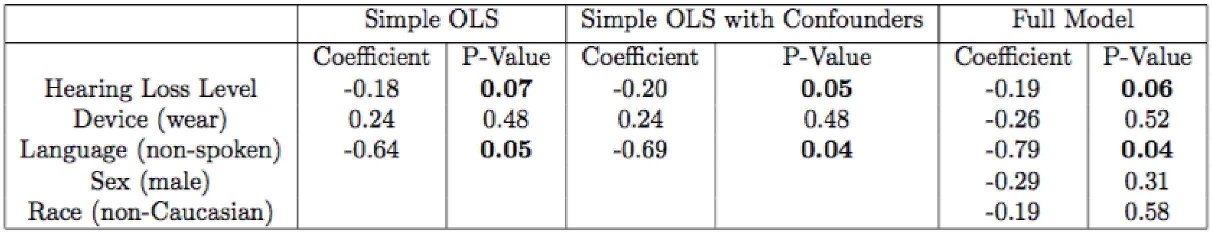
	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	-0.03	0.66	-0.03	0.67	0.06	0.57
Device (Hearing Aid 1)	0.11	0.64	0.11	0.66	0.05	0.86
Device (Hearing Aid 2)	0.30	0.18	0.31	0.17	0.24	0.41
Device (CI 1)	0.03	0.91	0.03	0.90	-0.12	0.67
Device (CI 2)	0.29	0.27	0.31	0.25	0.08	0.79
Device (Other)	-0.03	0.92	-0.06	0.86	-0.01	0.98
School (Deaf Program)	0.05	0.78	0.04	0.84	0.04	0.82
School (Deaf School)	-0.35	**0.05**	-0.37	**0.05**	-0.32	0.16
Language (non-spoken)	-0.23	0.24	-0.23	0.24	-0.04	0.86
Sex (male)					-0.01	0.97
Race (non-Caucasian)					0.11	0.60

Interpretation: The results for this question were only considered statistically significant after accounting for school type in a simple linear regression model. We found that parents of children enrolled in a deaf program were less likely to report that their child had been teased by other children (r=-0.37, p=0.05)

Aim 2: Social Relationships

QoL Domain	Social Relationships
Group	Youth
Question	Rel 24: “*I am happy with the friends I have*”

Results

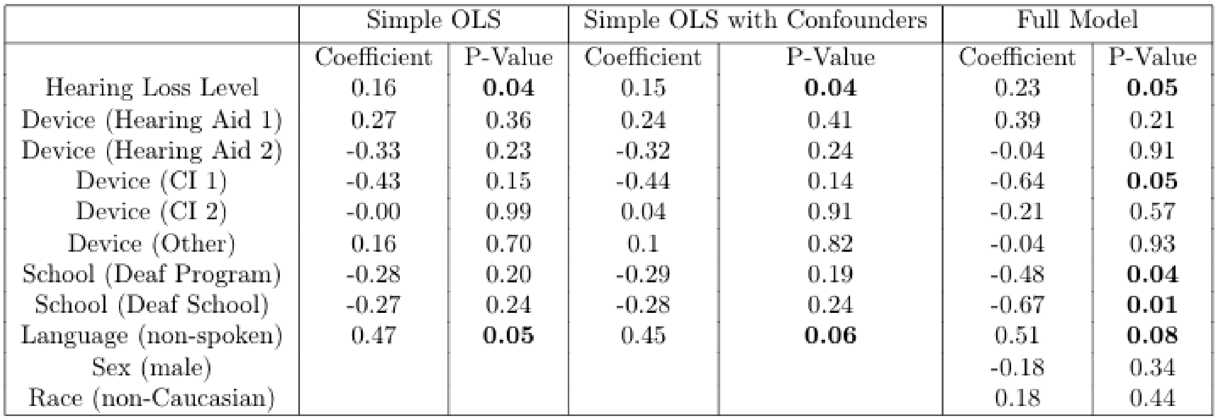


	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	-0.18	**0.07**	-0.20	**0.05**	-0.19	**0.06**
Device (wear)	0.24	0.48	0.24	0.48	-0.26	0.52
Language (non-spoken)	-0.64	**0.05**	-0.69	**0.04**	-0.79	**0.04**
Sex (male)					-0.29	0.31
Race (non-Caucasian)					-0.19	0.58

Interpretation: After performing a linear regression of the full model and controlling for confounders, we found that degree of hearing loss and language was significantly associated with the quality of social relationships (r=-0.20, p=0.05 and r=-0.79, p=0.04, respectively). Adolescents with more severe hearing loss reported worse social relationship quality than those will mild hearing loss; and adolescents using a visual, non-spoken language similarly reported worse social relationships compared to those using a verbal language.

QoL Domain	Social Relationships
Group	Parent
Question	Hqlc19p: “*How often did you observe or learn that your child spent time enjoying him/herself with children his/her age outside of school?*”

Results

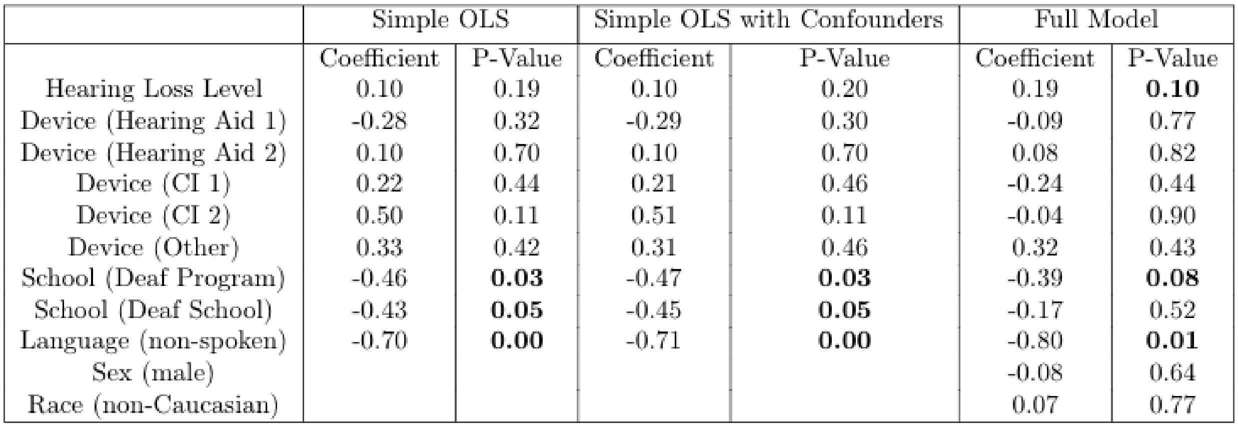


	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	0.16	**0.04**	0.15	**0.04**	0.23	**0.05**
Device (Hearing Aid 1)	0.27	0.36	0.24	0.41	0.39	0.21
Device (Hearing Aid 2)	-0.33	0.23	-0.32	0.24	-0.04	0.91
Device (CI 1)	-0.43	0.15	-0.44	0.14	-0.64	**0.05**
Device (CI 2)	-0.00	0.99	0.04	0.91	-0.21	0.57
Device (Other)	0.16	0.70	0.1	0.82	-0.04	0.93
School (Deaf Program)	-0.28	0.20	-0.29	0.19	-0.48	**0.04**
School (Deaf School)	-0.27	0.24	-0.28	0.24	-0.67	**0.01**
Language (non-spoken)	0.47	**0.05**	0.45	**0.06**	0.51	**0.08**
Sex (male)					-0.18	0.34
Race (non-Caucasian)					0.18	0.44

Interpretation: This question produced surprising results. First, higher degrees of hearing loss were associated with better social relationships outside of school (r=0.16, p=0.04). Second, youth with only one cochlear implant were less likely to have high quality social relationships (r=-0.64p=0.05). Lastly, signed languages were found to be associated with better social relationships in a simple linear regression model (r=0.47, p=0.05).

QoL Domain	Social Relationships
Group	Parent
Question	Hqlc29p: "*How often did you observe or learn that your child got invited to parties or play dates with children his/her age?"*

Results



	Simple OLS		Simple OLS with Confounders		Full Model	
	Coefficient	P-Value	Coefficient	P-Value	Coefficient	P-Value
Hearing Loss Level	0.10	0.19	0.10	0.20	0.19	**0.10**
Device (Hearing Aid 1)	-0.28	0.32	-0.29	0.30	-0.09	0.77
Device (Hearing Aid 2)	0.10	0.70	0.10	0.70	0.08	0.82
Device (CI 1)	0.22	0.44	0.21	0.46	-0.24	0.44
Device (CI 2)	0.50	0.11	0.51	0.11	-0.04	0.90
Device (Other)	0.33	0.42	0.31	0.46	0.32	0.43
School (Deaf Program)	-0.46	**0.03**	-0.47	**0.03**	-0.39	**0.08**
School (Deaf School)	-0.43	**0.05**	-0.45	**0.05**	-0.17	0.52
Language (non-spoken)	-0.70	**0.00**	-0.71	**0.00**	-0.80	**0.01**
Sex (male)					-0.08	0.64
Race (non-Caucasian)					0.07	0.77

Interpretation: In a linear regression model with confounders, signed languages were associated with poor social relationships (r=-0.80, p=0.01). From the simple model with confounders, children enrolled in deaf programs or schools also had poor social relationships as reported by their parents (r=-0.47, p=0.03 and r=-0.45, p=0.05, respectively).

Qualitative Results

The results from the qualitative interviews can offer context, clarifications, or counter examples for the quantitative results above. After completing the quantitative analysis, a systematic search was completed to identify qualitative data to contextualize and explain the quantitative results. A few excerpts demonstrating the adolescent's experiences are included for each aim.

Perceived Stigma Qualitative Themes

Device-related stigma: Experiences relating to stigma or negative comments regarding assistive-hearing devices was common among the youth respondents. These comments were typically experienced at younger ages and were made by peers who did not have knowledge regarding hearing devices. These comments were directed at both hearing aids and cochlear implants.

> *"I've had people ask me, "What the heck is that thing in your ear?"… I say, "It's kind of a computer in my ear that helps me hear better"… they freak out that I have this thing in my head. They tend to just stare at me bewildered that I have a computer in my head and they think it's a growth and icky." (ID#20030, high school, profoundly deaf)*

Assumptions about ability: The second common stigma-related theme was peer assumptions about ability. DHH youth reported that their peers felt they were unintelligent or had special needs because of their hearing loss. This was often associated with their speech, sound of their voice, or being separated from others at school for DHH programs.

> "*It definitely hurts because people think that way about me and they think I'm stupid…They think it limits my way of gathering knowledge, where it doesn't. It affects me a little bit, but it shouldn't be something that people should tease me about 'cause I honestly can't help it. How would you feel if I teased you because you were wearing glasses? You can't help the fact that your eyes aren't very well. I can't help the fact that my ears don't work very well." (ID#20030, high school, profoundly deaf)*

Additionally, DHH youth who attended mainstream schools, either previously or at the time of the interview, reported experiencing this to a greater extent compared to youth in DHH programs.

> *"in the old school they thought deaf people were (mentally retarded)… But in my school, more people understand about deaf people. There are a lot more deaf people at my school. Teachers and interpreters know signs. There is much more acceptance that deaf and hard of hearing can succeed in the hearing world. At the old school, they did not care, they wanted us to be in the hearing world. They did not care if deaf and hard of hearing succeeded in the hearing world." (ID#20010, high school, moderately deaf)*
>
> *"Because everybody makes fun of me and I just walk away because it doesn't even feel right. They actually say, "Oh my gosh, are you like retarded?" Every time they'd say,*

> *"You know you're special, right?" I'm like, "Yeah." They'd go, "Special Ed." I was like, "Whatever," and I just walk away." (ID#20037, middle school, profoundly deaf)*

Social Relationships Qualitative Themes

<u>Sport-related barriers:</u> Physical education, lunchtime sports, and after school sports are common settings for youth to build relationships with peers. DHH youth reported limitations to playing sports or engaging in outdoor activities due to their hearing loss. Common reasons for their inability to participate in sports included: assistive hearing devices could not get wet in a pool, assistive hearing devices could potentially be damaged by contact, assistive hearing devices would not fit under a helmet, youth were unable to hear coaches or teammates outside due to background noises and the wind, or youth were unable to understand coaches or teammates because they were too far away to lip read.

> *"I don't do many sports 'cause I want be careful. I don't want to get hit in the head and losing more hearing. So I don't really play sports that much…I've played volleyball, but have gotten hit in the head too many times and they said, "No more. We don't want you to get hurt and lose your hearing. I just resort to yoga or just calm exercises that don't involve me getting smacked in the head by a ball." (ID#20030, high school, profoundly deaf)*
>
> *"Well I'm trying to ask my mom if I can join the swimming team, the bowling team, like join a lot of teams and I can't do it because I won't be able to hear a teacher. I won't be able to have a sign language interpreter with me." (ID#20032, middle school, moderately deaf)*

<u>Deaf vs. Hearing friends:</u> Another barrier to building strong social relationships was the challenge communicating with hearing peers. Youth reported having both DHH and hearing friends and experiencing different relationships with each. Some hearing friends made efforts to sign, to talk slower, or to include their DHH friend in conversations. A few DHH youth reported having hearing friends at school and DHH friends outside of school.

> *"When I see deaf friends, I ask if I can get involved with that group. They said fine and welcomed me… Sometimes with hearing friends, they talk and forget to sign. But they understand and sign again when I remind them."*
>
> *(ID#20027, high school, profoundly deaf)*

Communication Barriers: The majority of profoundly deaf youth reported preferring DHH peers as their communication quality was higher than with their hearing peers. The DHH youth who reported communication barriers often described feeling left out of conversations with their hearing friends, which may impact the quality of their relationships.

> *"I tend to feel like the odd one out. I'm the only quiet one in the group. I'm just kind of staring off in the distance trying to focus. At some point, I'll usually give up. I get very, very tired when I'm focusing and it really just – if I'm working too hard on trying catch what people are saying, I tend to get tired and just kind of give up and let the conversation become like a background noise." (ID#20030, high school, profoundly deaf)*
>
> *"I feel more comfortable with deaf people. With hearing friends, we do use gesture, but it's hard and a struggle to talk and understand. Sometimes I get frustrated…It can be positive when we have fun, but still negative when it's hard to understand what they say. Sometimes they'll say something and I have no idea what they're talking about; sometimes I get it wrong and someone will have to explain. I sometimes really have no idea what they're saying." (ID#20020, middle school, profoundly deaf)*
>
> *"I'm standing with a group of my friends and they're talking about something I don't know what they're talking about, so I'm trying to catch up, but I only get like bits and pieces. So I'm not sure how to respond. I actually made an effort once trying to respond, when really I had said something the complete opposite and everybody just stopped and stared at me and they were like, "What? What? What do you mean?"…I was very embarrassed. So I definitely hesitate a lot. It's hard to keep up." (ID#20030, high school, profoundly deaf)*

I. Discussion

The most surprising finding from the comparison between the qualitative and quantitative analysis was that the parents reported more statistically significant results demonstrating poor social relationships or higher stigma, but the youth respondents described similar results in their interviews. The following are key results, supported by interview excerpts:

Finding 1: Use of assistive hearing devices is associated with more stigma.

This may be an intuitive assumption as a hearing device is a physical and easily recognizable difference between peers. Some adolescents reported they felt comfortable answering questions regarding their cochlear implants, classroom technology, or hearing aids. Others felt shame or embarrassment when they would have to explain the significance of the device, as this adolescent explained:

> *"I've had people ask me, 'What the heck is that thing in your ear?'…So I say, 'It's kind of a computer in my ear that helps me hear better.'…They tend to just stare at me bewildered that I have a computer in my head and they think it's a growth and icky."*

Finding 2: Using signed languages is associated with more stigma

The parents reported more bullying on behalf of their children than the youth respondents did. This could be explained by hearing peers pressuring their deaf friend to use spoken English to communicate or by strangers staring at deaf families using a signed language to communicate. This individual felt stigmatized at his old school that did not use sign language or encourage the teachers to learn signs:

> *"…in the old school they thought deaf people were (mentally challenged)…But in my school, more people understand about deaf people. There are a lot more deaf people at my school. Teachers and interpreters know signs. There is much more acceptance that deaf and hard of hearing can succeed in the hearing world. At the old school, they did not care, they wanted us to be in the hearing world. They did not care if deaf and hard of hearing succeeded in the hearing world."*

Finding 3: A greater degree of hearing loss is associated with worse social relationships

Many of the interviewed adolescents with mild to moderate hearing loss said that they could hide their deafness easily. The youth who had severe hearing loss had a more difficult time making friends and communicating because of their language barrier:

> *"I'm standing with a group of my friends and they're talking about something I don't know what they're talking about, so I'm trying to catch up, but I only get like bits and pieces. So I'm not sure how to respond. I actually made an effort once trying to respond, when really I had said something the complete opposite and everybody just stopped and stared at me and they were like, 'What? What? What do you mean?'…I was very embarrassed. So I definitely hesitate a lot. It's hard to keep up."*

Finding 4: Use of signed languages is associated with both poor and positive social relationships outside of school

The survey findings were contradictory, suggesting signed languages are associated with both better and worse social relationships outside of school. There are two plausible explanations. First, youth using signed languages may be enrolled in a deaf school or program and are therefore likely to have peers who use the same language. Alternatively, youth who use signed languages and are not enrolled in a deaf school or program may lack verbal English skills and therefore are unlikely to form close bonds with hearing peers. This individual explains the feelings he faces interacting with both communities:

> *"I feel more comfortable with deaf people. With hearing friends, we do use gesture, but it's hard and a struggle to talk and understand. Sometimes I get frustrated…It can be positive when we have fun, but still negative when it's hard to understand what they say. Sometimes they'll say something and I have no idea what they're talking about; sometimes I get it wrong and someone will have to explain."*

The findings of this analysis are generally consistent with prior research conducted in improving DHH QoL. Future studies should explore how QoL is different for DHH youth in mainstream versus deaf schools/programs. One potential confounder that was not explored in this study was the hearing level of the parents. Future studies could examine if DHH parents perceive their DHH child's QoL differently than hearing parents do. Additionally, research is needed to explore how DHH youth face barriers when they wish to participate in sports or outdoor activities. Although this was not asked in the youth or parent surveys, it was a consistent theme that emerged in the youth interviews.

Lastly, after reviewing the parent and youth data and identifying inconsistencies in the youth report, parent data might be considered to be more reliable. There were instances when youth respondents would randomly select responses while this was not found in the parent report. Future DHH research should consider the challenges of surveying youth and take calculated efforts to improve the reliability of the data.

J. Strengths and Limitations

One key strength of the study was the inclusion on both parent and child data and both quantitative and qualitative data. The parents reported overall higher perceived stigma and worse social relationships while the child participants confirmed these experiences in their qualitative interviews. The first limitation is that the child and parent surveys were not matched. The parents completing the survey were doing so on behalf of their younger children too young to complete it on their own. As this was a secondary data analysis, an additional survey could not have been completed. It was worthwhile to view the survey as “parent reported” and consider it as a possible addition for future youth research. A second limitation is that vast majority of respondents were Caucasian and spoke English and therefore results would only be generalizable to a similar population. There were not enough Spanish-speaking youth to comprise their own comparison group but these individuals may have faced unique barriers related to communication that were not identified. The third limitation is that the parents completing the survey were doing so on behalf of much younger children. These children were presumably experiencing different social and relationship circumstances compared to the youth ages 11-18 years. Lastly, the study instrument did not use the same wording for parent and child questionnaires which may have resulted in a discrepancy in interpretation.

K. Conclusion

The results from this secondary data analysis can help inform a few key stakeholders. Parents may consider how peer language and familiarity with assistive hearing devices impacts DHH QoL. For example, they may consider how a mainstream or DHH program/school would impact their child’s QoL as a DHH program/school would provide an opportunity to interact with more DHH peers. DHH peers would be familiar with other DHH languages and assistive hearing devices while their hearing peers might not have prior experiences with the DHH community. School officials could use this information to inform the development or expansion of deaf programs to build networks among the deaf students or address stigma in the Hearing student communities. Understanding which aspects of an adolescent’s life most significantly impacts their QoL will help determine which intervention or support system is needed.

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