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Quality of Life in Children with Unilateral Hearing Loss: A Pilot Study

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Abstract

Purpose—The objective of this pilot study was to investigate the health-related quality of life (HRQOL) of children with unilateral hearing loss (UHL).

Methods—The study was conducted in two stages among children age 6–17 years. In stage one, we conducted focus groups of children with UHL and their parents to elicit perceptions of how UHL affected the lives of these children. In stage two, a generic pediatric quality of life survey was used to measure HRQOL quantitatively in children with normal hearing, UHL, and bilateral hearing loss. Participants were recruited from the clinical and research populations of an academic otolaryngology department.

Results—The focus groups revealed that the children with UHL experienced barriers due to their hearing loss, but learned to adapt. Quantitatively, statistically significant differences between groups were not observed on the three main HRQOL scales (total, psychosocial and physical). Children with UHL had a significantly larger variance on the social functioning score than children with normal hearing and bilateral hearing loss.

Conclusions—UHL may affect the HRQOL of children; this possibility should be included when counseling parents. However, further research is warranted to determine whether our findings are generalizable to other children with UHL.

Introduction

Unilateral hearing loss (UHL) is estimated to occur in 0.83/1,000 newborn children (Prieve et al., 2000). In the National Health and Nutrition Examination Survey (NHANES) III, 3% of school aged children had UHL (Niskar et al., 1998). Whether UHL significantly affects these children from speech-language, educational, and behavioral perspectives has been debated in the literature, along with the continued debate of whether to amplify them and implement other interventions. An early study by Bess and Tharpe (1984) observed that children with UHL may not perform as well as their normal hearing peers in school, with higher rates of grade failures and receiving special assistance. The results of that

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investigation have been supported by multiple other studies (Oyler, Oyler, & Matkin, 1988; Brookhouser, Worthington, & Kelly, 1991; Culbertson & Gilbert, 1986). In contrast, Hallmo, Moller, Lind and Tonning (1986) reported that UHL in childhood “attracts little attention from either patient or parents,” and that “these children experience few communicational or educational problems.” Stein (1983) showed children with UHL had good opinions of themselves; however, parents and teachers reported that these children had frequent behavior problems and below average verbal skills. Two studies by Most (2004 and 2006) observed that children with UHL and or bilateral minimal hearing losses had lower educational performance than those with more severe hearing loss. These conflicting reports are consistent with Lieu’s (2004) systematic review regarding the impact UHL has on the development of speech and language and educational outcomes of children with UHL. Lieu reported that overall, school age children with varying degrees of UHL had higher rates of repeating grades, additional need for educational assistance and apparent behavior issues, although with considerable variation of outcomes among studies. Despite the growing body of research linking UHL with educational or behavioral problems at school, no known studies have directly investigated the impact of UHL on emotional, psychological, social, or physical well-being.

Quality of life has been defined as “an 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” (World Health Organization, 1995). Specifically, health-related quality of life (HRQOL) refers to the degree to which one’s physical, emotional and social well-being is affected by a medical condition. In addition to measuring disease status, measurement of HRQOL has become an important health outcome for clinical trials, clinical practice, health services research and evaluation; HRQOL instruments for children describe the impact of disease and treatment in terms of physical, psychological, social and school functioning domains (Varni, Burwinkle, Seid, & Skarr, 2003). Studies in children with chronic illnesses, such as sickle cell disease and obesity, have shown them to have poorer HRQOL when compared with typically developing peers (Palermo, Schwartz, Drotar, & McGowan, 2002; Schwimmer, Burwinkle, & Varni, 2003).

HRQOL has been evaluated in studies of adults with hearing loss. One study showed that adults with hearing loss have significantly poorer general health and social functioning scores than adults with normal hearing (Parving, Parving, Erlendsson, & Christensen, 2001). Overall, the adult HRQOL domains of social functioning, self-esteem, and physical functioning have improved with interventions such as cochlear implantation or hearing aid usage (Cohen, Labadie, Dietrich, & Haynes, 2004). Most recently, hearing aid usage was found to improve adult HRQOL for patients with sensorineural hearing loss in a systematic review of the literature by an American Academy of Audiology Task Force on HRQOL (Chisolm et al., 2007).

A few studies have described how UHL has affected HRQOL in adults. Giolas and Wark (1967) reported that adult patients with UHL experienced annoyance, embarrassment, confusion and helplessness due to difficulties from extraneous noise and distance. One study investigated the long term effect of UHL on adults ages of 30–55 years as compared to a normal hearing cohort, and found that a significantly greater proportion of participants with normal hearing considered listening to and playing music as a hobby than participants with UHL (Colletti, Fiorino, Carner, & Rizzi, 1988). Newman, Jacobson, Hug & Sandridge (1997) used the Hearing Handicap Inventory for Adults (HHIA), a hearing-specific HRQOL instrument, to measure perceived hearing handicap in 63 adults with UHL or mild hearing loss. Notably, three-quarters of participants with both UHL and mild bilateral hearing loss scored within the ‘handicap’ range (defined as score >16 on a 0–100 scale, with 0 indicating no handicap) on the HHIA, which quantifies the emotional and social impact that adults

perceive to be consequences of their hearing loss. This supports the idea that the degree of difficulty or handicap a patient experiences cannot be solely determined by the degree of hearing loss on an audiogram.

HRQOL in children with bilateral hearing loss, but not UHL, has been addressed in published studies. In an Australian study of 7–8 year old children with bilateral congenital hearing loss, ranging from mild to profound, HRQOL was documented using the Child Health Questionnaire (CHQ), a parent-report measure that assesses physical and psychosocial functioning in children (Wake, Hughes, Collins, & Poulakis, 2004). The authors found that children with hearing loss scored significantly more poorly than the normative sample on 6 of 12 domain scales and on the Psychosocial Summary score; unexpectedly, children with milder hearing losses tended to have poorer physical and psychosocial functioning scores compared to children with more severe-profound hearing losses (Wake et al., 2004). The authors speculated that what may seem a mild condition to clinicians may actually be a significant issue to a child's well-being. Alternatively, these results could be attributed in part to selection bias—the possibility that patients with mild hearing loss in their study was not representative of all children with mild hearing loss, and may have other special needs, such as learning disabilities, which directly influenced their willingness to participate in the research study. Researchers from the UK also documented that significantly increased proportions of children aged 7–9 years with bilateral permanent childhood hearing loss had suboptimal levels of function and HRQOL when compared to children with normal hearing (Petrou et al., 2007). A separate study of Australian children with slight/mild sensorineural hearing loss was reported by Wake et al. (2006) using the PedsQL, another instrument that measures both child self-reported and proxy (parent) reported HRQOL. This study found no significance between HRQOL in children with slight/mild bilateral sensorineural hearing loss and children without hearing loss; however, this study omitted children with UHL.

Because UHL has affected the HRQOL of adults and because children with bilateral hearing loss have been found to have poorer HRQOL than peers with normal hearing, we sought to understand whether UHL affects the HRQOL of children. In addition to their auditory abilities, does UHL affect the whole life of children more comprehensively? Do individuals pursue interests or hobbies that do not require binaural hearing? Are children with UHL more likely to experience difficulty in specific settings, such as school, social or sports activities? Without further information on the effects of UHL, clinicians may overlook the need to evaluate these patients beyond the audiogram and school performance. In this article, we report the results of a pilot study to gather information about the experiences of children with UHL, and to compare outcomes on a generic pediatric HRQOL measure between samples of children with normal hearing, UHL and bilateral hearing loss.

Purpose

The objective of this pilot study was to investigate the HRQOL of children with UHL between the ages of 6–17 years. Based on currently published literature, we hypothesized that children with UHL would report poorer HRQOL compared with their normal hearing peers, and that parents would report their children with UHL to have poorer HRQOL than children with normal hearing. The study was completed in two stages. Stage one was a focus group to obtain descriptions of perceptions of UHL. Stage two was a quantitative study to measure the HRQOL among the three groups of children (normal hearing children, children with UHL and children with bilateral hearing loss), and to measure the perceptions of the three groups of children compared to the perceptions of their parents.

Methodology & Design

Study Population

IRB approval for this study was obtained from the Human Research Protection Office (HRPO) of Washington University School of Medicine, St. Louis. Children between the ages of 6–17 years who had been seen for pediatric otolaryngology services or had participated in the collaborators' research were the source populations for the study. Eligible participants included children of normal cognitive abilities (as reported by parents) with normal hearing (also per parental report), UHL, and bilateral hearing loss and the parents of these children. Hearing status of children with unilateral and bilateral hearing was known through participation in other research studies.

Qualitative Methodology

Participants—A qualitative study was used to elicit the opinions and views of children and their parents on areas of concern which currently may be unknown regarding UHL. Focus group participants were recruited from an ongoing research study (NIH grant K23 DC006638 to Dr. Lieu). Recruitment letters were sent to 25 eligible families of children and adolescents 8–17 years of age with UHL. Eight families responded; these families were sent consent forms and a list of questions. These questions were sent to prepare participants about possible topics to be discussed during the focus group (see Appendices A and B). Of the eight families who responded, six agreed to participate. Two families cancelled the day of the focus group due to inclement weather. The children's focus group consisted of a 12 year old male and two females, ages 13 and 15 years. The parent focus group consisted of four mothers: the three mothers of the children who participated, and a mother of an 8 year old female. Written informed consent was obtained from all participants. The participants were compensated for their time. We did not attempt other focus groups due to inability to coordinate another time with willing participants and moderators before funding of this study ran out.

Procedure—The focus groups were held in quiet rooms with chairs placed in a circle for optimal participation. Discussions were documented through note-taking and audio recording. Discussion content was preceded by open-ended questions such as, "What activities do you like to do in your free time?" Each focus group session included two moderators. One moderator led discussion while the other took notes, made observations and added comments to keep discussions active. The moderators included all three investigators and an additional AuD student. The discussion content, physical setting, and conduct of the focus groups were adapted from guidelines in *Qualitative Research & Evaluation Methods* (Patton, 2001).

The sessions began with both children and parents in one room for an explanation of the study and an icebreaker activity. To optimize group discussion the focus groups were then divided into a parent group and a child group. The child/adolescent focus group started with a hands-on activity, in which they were asked to find pictures from magazines to describe themselves (Hogan, 2001). This was a valuable way to elicit information from the children. After initial reservation, all three children/adolescents contributed to the session. In contrast, the parents quickly began exchanging anecdotes, concerns, and strong feelings about how they have been treated and what they had experienced.

Each discussion was limited to two hours with one break. During the focus group sessions, participants were encouraged to talk to each other, ask questions, exchange experiences and comment on each other's remarks.

Analysis—Both focus group sessions were audio-taped and manually transcribed in Microsoft Word (Redmond, Washington). Figure 1 shows schematically how the data from the discussion narrative were categorized, analyzed and coded. First, each investigator individually reviewed the focus group narrative and identified broad themes into which the narrative content could be organized. Statements relevant to perceptions, barriers, or experiences of the children and the parents were identified as possibly belonging to these broad themes. Next, the investigators collectively classified the list of statements into broad themes or categories that emerged from the focus group narratives. The categories included school, social, emotional, physical and difficult situations. An additional category differentiated between issues discussed by parents versus the children. The general perceptions and specific quotations from the focus group participants were then listed under each category. In addition to perceptions, comments regarding how hearing loss affected the behavior of children or adolescents with UHL, their peers, and professionals were also included in each category.

Quantitative Methodology

Participants—Children ages 6–17 years and their parents were recruited from the patient and research participant populations of the Department of Otolaryngology at Washington University School of Medicine. The participants included children with UHL, bilateral hearing loss, normal hearing, and parent-reported normal cognitive functioning. Introductory letters and 284 inventories were sent to 142 families. For the populations combined, 170 (60%) inventories were received after one mailing (85 self-reports and 85 proxy-reports from parents/guardians).

Measures—The Quality of Life study described in this paper was carried out using the Pediatric Quality of Life Inventory Version 4.0 (PedsQL) (Varni, Seid, & Rode, 1999). This standardized instrument documents an individual's perceived overall HRQOL, and was chosen for its brevity, ease of use, and reliability and validity in multiple age groups and various health conditions. The PedsQL was used to measure the HRQOL in participants with normal hearing, UHL and bilateral hearing loss. It is comprised of 23 questions encompassing subscales of physical function (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items) (Varni et al., 1999). The PedsQL was designed to be used across pediatric populations, with separate PedsQL self-report and proxy-report inventories for the following age groups: 5–7 years old, 8–12 years old, and 13–18 years old. Children aged 7 years and younger were administered a parent-assisted inventory. Children and adolescents 8–17 years completed the child self-report inventory independently, and all parents completed a proxy-report inventory. Self and proxy inventories have parallel questions differing only by age appropriate language. Instructions are on the front of the inventory where participants are directed to answer how much of a problem each item has been during the past month. The child self-report and proxy-report versions of the PedsQL for children 8–12 years of age are available online for review (<http://www.pedsql.org/index.html>, accessed 10/21/09). A five-point Likert response scale is used for children 8–18 years and for proxy-reports: 0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; and 4 = almost always a problem. The child self-report for children 5–7 years old is reworded for ease of administration to a three-point Likert scale corresponding to a happy, neutral and sad face: 0 = not at all a problem, happy face; 2 = sometimes a problem, neutral face; 4 = a lot of a problem, sad face.

Items are reverse scored and linearly transformed to a 0–100 scale: 0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0. This method is used to estimate severity of each domain; higher scores indicate better HRQOL. Scale scores are computed as the sum of the items divided by the

number of items answered. There are three main scale scores: physical health, psychosocial health and total HRQOL. The physical health summary score is the mean of the items answered under the physical functioning subscale. The psychosocial health summary score is the mean of the emotional, social and school functioning subscale items. The total HRQOL score is the mean value of all the items answered.

Procedure—Eligible families were mailed introductory letters and inventories. Data were collected from July 2006–March 2007. Return of the completed inventories was considered confirmation of informed consent by the HRPO at Washington University School of Medicine, St. Louis. To maintain confidentiality all surveys were mailed back and contained no personal health information.

Analysis

Data were entered into a Microsoft Excel spreadsheet (Redmond, WA) and read into SAS Version 8.2 (Cary, NC) for statistical analysis. A one-way analysis of variance (ANOVA) was used to determine if there were significant differences in scores on the PedsQL domains between the three hearing populations—normal hearing, unilateral hearing loss, and bilateral hearing loss. Overall, a two-tailed p value of 0.05 or less was assumed to represent a statistically significant result. The Levene's test of homogeneity was used to determine whether within-group variances were significantly different. When significant heterogeneity was found, the Welch's ANOVA test was used. The differences in means between hearing population scores were examined using the Tukey HSD post hoc test of significance and with 95% confidence intervals (Altman, 2005). Confidence intervals provide not only a measure of precision for making statistical inferences, but also allow for a discussion of the clinical significance of these same estimates.

Results

Qualitative Results

The participants of child/adolescent focus group showed some reticence with sharing experiences, feelings, and personal anecdotes initially. Open-ended questions asking the participants to describe how the pictures from the magazines represented parts of themselves helped them to share their activities, opinions, feelings, problems, and solutions to their perceived problems. Whenever possible, the moderators pursued lines of discussion that the participants themselves volunteered. In contrast, the parents displayed eagerness to share their opinions, experiences, and feelings. Many of the questions on the focus group guide were not discussed because the parents directed their discussion toward topics that most concerned them.

The content analysis revealed children and adolescents with UHL felt they could do the same things as their normal hearing friends. In describing their life from the hands-on collage project they described themselves as “normal kids.”

The children shared experiences of when UHL affected their daily life in school, with friends and with family. Participant A described her experience with assistive listening devices and the UHL in school, “When I was younger [having unilateral hearing loss] used to affect me a lot more than it does now.” This theme of change and adjustment repeated itself throughout both adolescent and adult discussion groups.

The hands-on activity allowed descriptive accounts of how participants feel about their hearing loss. Participant A's collage describes how she has adjusted to her hearing loss and how she has learned to appreciate her hearing loss now that she is older (Figure 2).

The analysis of the adult discussion group also revealed a pattern of adaptation; with time, situations improved for children with UHL. This adaptation was a major theme of the adult focus group session as it applied to all areas of their children's lives.

During discussions the mothers recounted their experiences of initial UHL diagnosis. Mother *AM* gave a vivid explanation of her experience.

I went back in a month and got the MRI done and they checked her hearing again, at that time it was a different audiologist...and she just starts talking like I already know this, 'A has a profound loss, she's deaf in that one ear.' I went hysterical. I think part of the reason why I was so upset by it was the way it was presented to me. It was cold, very cold and very confusing....we did the MRI....and then the machine broke. We had to wait in that cold room... (Mother *AM*)

This description revealed the potential communication issues between professionals and laypeople. At the initial diagnosis of a hearing loss, information beyond "your child has a hearing loss" was not remembered.

These communication issues were seen in the academic setting as well as the health field. Adult participants depicted experiences at their child's school where they had to educate the classroom teachers about UHL, amplification devices, and learning strategies for an individual with UHL. Mothers described other people as being "flippant" about the UHL.

"He does have an IEP [Individualized education plan] that stipulates these things. Until I actually go in and sit down with them and explain the situation, I don't think they really know enough and I think they have so much going on and so many kids to deal with that it's not necessarily going to be their focus—making sure my child can hear." (Mother *BM*)

The focus group participants agreed that, as the years went by, teachers were able to pass on helpful information about the best and worst situations for these children. "There have been a lot of changes from early grade school to now," said Mother *BM*. These type of statements exemplified ways in which parents learned how to help their children. Because teachers were busy with all the children in the classroom, parents had to educate the teachers and advocate for their children by relaying this experiential knowledge.

Stories by the parents of adolescents in the focus groups portrayed their children's social interactions as being mainly one-on-one with peers. Parents also described their children as having only a few close friends. Mother *CM* noted her child's typical social activity was having a friend spend the night, not having large slumber parties with groups of girls.

The children talked about what situations they find to be the most difficult for them. They agreed that when someone would sit on the side with their hearing loss, UHL participants usually found themselves in the most "uncomfortable, annoying and difficult" situations. In particular, participant *B* noted that when he is in a noisy environment, he has to "concentrate really hard to listen." Participants agreed that when they are with friends they frequently pretend to understand what is being said. This happens most often when they are on the bus, in the cafeteria, or in other loud places. This area of difficulty was also discussed in the adult focus group. Mother *DM* explained that her son frequently misunderstands conversations:

He hears you talking, but what you are saying might not be what they're hearing. He's just not hearing the same thing. You know one example is they were playing baseball and talking about *pop flies*. His interpretation of this was they were talking about *potpies* which are two entirely different things. (Mother *DM*)

Both focus group sessions covered the point in time when several of the children noticed they were different from other children. The eldest adolescent explained, "...when I was younger I used to cry about it because I felt like I missed out on things." Mother *DM* explained her son was oblivious to his hearing loss until the middle of second grade; at that point her son began playing more sports such as soccer and baseball. In these situations it is more difficult to understand what the coaches or other players are saying from a distance; this is when her son began to notice he was different.

The adult focus group concluded with participants commenting on what they wanted to know about their child's hearing loss and what they would recommend for parents of newly identified children with UHL. Becoming educated about the hearing loss was the most prominent comment from the mothers. They also stressed a need to obtain a second opinion upon initial diagnosis of the UHL and to investigate the cause of the UHL. The mothers' questions included, "What can my child hear?" and "What can he not hear?" They also wanted to know specific information about the mechanics of the ear that cause hearing loss. Suggestions made to parents of newly diagnosed children with UHL included the importance of staying positive and the importance of reassuring families their children will adapt to his/her environment. Lastly, parents stressed the importance of professionals being compassionate about the hearing loss, because parents of children with UHL may experience similar shock and grieving as parents of children with bilateral hearing loss.

In summary, the results from the focus group confirmed a wide array of experiences. The issues discussed by both adults and children were alike. Children with UHL experience barriers due to their hearing loss; however, these children learn to adapt to the hearing loss. The content analysis revealed that both groups had similar perceptions of UHL but used different words and expressions, and attached different levels of importance to these perceptions.

Quantitative Results

A description of participant characteristics is shown in Table 2. The mean age for the 85 child participants was 10.4 years (SD 2.8 years). The participants included 24 children with normal hearing, 32 children with unilateral hearing loss, and 29 children with bilateral hearing loss, with no significant differences in age, gender or race between groups.

PedsQL findings for the hearing impaired populations and the normal hearing participants are shown in Table 3 for the child self-report. No statistically significant differences between groups were seen in the three main PedsQL scales (total, psychosocial and physical). Children with UHL had a significantly larger variance on the social functioning score than children with normal hearing and bilateral hearing loss (Levene's test for homogeneity, $F(2, 82) 3.73, P = 0.028$). This result widened the 95% confidence interval for difference between children with normal hearing and with UHL on this specific score. Table 4 shows the findings for the same three HRQOL scales as reported in the parent proxy-reports. Similar to the self-reported scores, no statistically significant differences were reported by the parents.

We also examined the possible effect of severity of hearing loss on PedsQL scores. Children with UHL were categorized by their ear with hearing loss, while children with bilateral hearing loss were categorized by their worst hearing ear. No child with bilateral hearing loss had severe asymmetry of hearing loss, such that the better ear was more than one category better than their worse ear, and only one child had this degree of asymmetry. As shown in Figure 3, no trends were discernable based on severity of hearing loss.

Common Themes between Qualitative and Quantitative Studies

Physical functioning—The children expressed no physical differences between themselves and their peers during the focus groups. However, parents noticed more differences in their children, as a result of the UHL, as they became older. For example, Mother *CM* noted her child had increased issues when he began participating in more sports such as baseball and soccer in middle school. When the child had a helmet on or if the coach was yelling the child's name, Mother *CM* noticed increased difficulty localizing voices. This was also true if the child was swimming and the better ear was under water. Mother *BM* noted that when her child played volleyball, the background noise in the gymnasium seemed to cover up all voices. These specific examples represent instances when these mothers of children with UHL may have felt that sports or physical activities were more challenging for their children than for other children with normal hearing.

In the PedsQL measure, the statement “Doing chores around the house” was the most poorly scored proxy-reported statements by parents of children with UHL. In contrast, the parents of children with normal hearing and bilateral hearing loss reported the lowest scores for “Having hurts or aches.” For the children with UHL, these results may be associated with difficulty hearing a request to complete a chore or with their perceived lack of attention.

Emotional and social functioning—In focus group discussions, parents perceived their children with UHL as being emotionally “closed up” and shy, yet resilient. In the PedsQL proxy-report by parents of children with UHL, the poorest scores were reported for the statement, “Getting along with other children.” That statement, along with “Getting teased by other children,” were the poorest self-reported scores for children with UHL. The statement “Getting along with other children” was also the lowest proxy-report scores for the children with normal hearing, but for children with bilateral hearing loss, the lowest proxy-report score was for “Other kids not wanting to be his or her friend.” In contrast to the children with UHL, the lowest self-reported score for children with normal hearing and bilateral hearing loss was for the statement “I cannot do things that other kids my age can do.” Additionally, both children with UHL and their parents scored lower on social functioning than children and parents of children with normal hearing and with bilateral hearing loss.

On the PedsQL, there were no significant differences between the groups' emotional and social functioning as reported by the children and adolescents (Table 3). However, limitations in social functioning were mentioned most in stories by the children who participated in the focus groups, and the PedsQL statements “Getting along with other children” and “Getting teased by other children” elicited the poorest scores for children with UHL. The focus group participants described mainly one-on-one interactions and only having a few close friends. The UHL participants also described instances of their friends becoming angry at them for constantly having to switch sides to their better ear or for ignoring when the friend spoke. Furthermore, they felt that their friends mumbled a lot and admitted that they occasionally pretended to understand what their friends are saying.

Socially, having assistive technology was viewed as a hindrance to being “normal.” Participant *A* explained, “I don't use FMs anymore because I don't feel I really need them and the fact that I just want to be seen as a normal person.” The same participant expressed her experience with UHL as having ‘hollow moments,’ where:

...there's not really anything you can hear. A lot of times I stare off into space which doubles not being able to hear so if I'm not paying attention and there is a lot of noise around or if I'm just not expecting anybody to talk to me, I just go completely deaf. (*A*)

School functioning—During focus group discussion, the UHL participants reported frequent academically-related problems with memory and attention. Participant *B* said “Sometimes I listen really good but I have to concentrate really hard to listen to them.” Meanwhile, Participant *A* noted “At school there is a lot of barriers and blocking because you can’t hear what people are saying a lot of the time.” Participant *A* also said:

Something I’ve noticed about my hearing is I’ll hear somebody say something but it won’t click with me until about five seconds later. I’ll say, ‘What?’ and then understand before she says it again and I don’t know why that happens. I guess my hearing thing is slow (*A*).

Although the differences on school functioning were not statistically significant, the 10.8 point gap between children with UHL and children with normal hearing on the PedsQL represents an effect size of 0.79.

In the parent focus group, whether the child was hearing and not paying attention in school was a significant concern. They also commented on teachers’ assumptions that their child was not paying attention in class. “The teachers automatically assume my child isn’t paying attention,” said Mother *CM*. She had to explain to teachers, “It’s not that he’s not paying attention, he didn’t hear you.” Parents felt that teachers were not educated about UHL and it was not their main focus for the classroom.

Discussion

This is the first known study to examine quality of life specifically in children with unilateral hearing loss. We combined qualitative methods (i.e., focus groups) and quantitative measurement of HRQOL (i.e., PedsQL) to gather insight into the experiences of children with UHL and their families, as well as a deeper understanding of which dimensions of HRQOL might be most affected in children with UHL. Because this was a pilot study done with limited resources, we have gleaned preliminary information that requires confirmation and further explication to understand completely.

The results from the focus group sessions revealed that the children with UHL who participated experienced a wide range of difficulties pertaining to psychosocial aspects of HRQOL. They experienced barriers due to their hearing loss just as adults from prior studies experienced barriers with their UHL. Despite these barriers, they reported being “normal” children. The parents expressed improvements in their children’s HRQOL over time, but remained concerned about difficulties in school and misunderstanding conversation. For at least some children, UHL seemed to affect not only their ability to hear, but also the way they interacted with friends and at school. Although UHL did not seem to prevent the pursuit of interests or hobbies, parents of these children noticed difficulties in social situations and in playing sports.

Quantitatively, children and adolescents with UHL did not report scores on any of the PedsQL domains that were statistically significantly different than their peers with normal hearing. Similarly, parents did not report statistically significant differences between children with UHL or bilateral hearing loss and children with normal hearing. These results do not support our hypotheses regarding children’s self-reported HRQOL nor parental proxy-reporting of their children’s HRQOL. Several interpretations of this result are possible. The first is that children with UHL truly do not have any significant HRQOL differences from peers with normal hearing. However, the children with bilateral hearing loss in this study also had no significant HRQOL differences from peers with normal hearing, which is not consistent with previous studies of similar populations (Wake et al., 2004; Petrou et al., 2007). This negative result suggests a second interpretation that the small

sample size of this pilot study has resulted in a false negative error (Type II, or beta error). Along a similar vein, a third possible interpretation is that the HRQOL assessment we used was not sensitive enough to detect hearing-related HRQOL differences. This could explain the negative findings of Wake et al. (2006) in their study of children with slight/mild sensorineural hearing loss. Although the PedsQL is a well-validated and widely used generic HRQOL measure, only a few questions address the social and school/work functioning domains that adult hearing-related HRQOL measures expand upon. Inadequate sensitivity would prevent finding potentially important differences.

Despite no statistically significant results, several differences in scores between children with UHL and normal hearing stand out. On the social and school functioning subscales of the PedsQL (Table 3), children with UHL reported a mean difference of -7.7 on social functioning and -10.8 on school functioning compared with children with normal hearing, for moderate-to-large effect sizes of 0.60 and 0.79 , respectively. Parents of children with UHL also scored their children's social functioning (-8.3) and school functioning (-6.8) to be poorer than normal hearing peers, with moderate effect sizes of 0.65 and 0.39 , respectively. These differences may be clinically important and are in concert with the senior author's anecdotal experience with a large number of children with UHL, both in the research and clinical settings. Interestingly, children and parents of children with bilateral hearing loss reported PedsQL scores that tended to be more similar to children with normal hearing than the participants with UHL. The findings of this pilot study echo those of Most (2004 and 2006) in terms of school functioning, in which children with bilateral hearing loss wearing hearing aids appeared to have fewer problems and areas of concern than children with UHL.

At least two quantitative methods have been used to determine clinical significance. The minimal clinically important difference (MCID) has been defined as "the smallest difference in a score of a domain of interest that patients perceive to be beneficial and that would mandate, in the absence of troublesome side effects and excessive costs, a change in patient's management" (Jaeschke, Singer, & Guyatt, 1989). Varni et al. (2003) determined the MCID for each PedsQL score by calculating the Standard Error Measurement and suggested that a 5.3 point change in the self-report and 5.5 point change in proxy-report Psychosocial Health score, for example, would be clinically meaningful differences. In our study, the differences in mean Psychosocial Health scores between children with normal hearing and unilateral hearing loss were 5.0 points on self-report and 4.4 points on proxy-reports. However, no corresponding MCID has been reported for the Social and School Functioning subscales, and these were the scales where the largest potential differences were found. Another method for estimating clinical significance is to calculate effect sizes, which can be calculated by dividing the difference in means between two groups (e.g., children with normal hearing vs. unilateral hearing loss) by the standard deviation of the reference group (e.g., children with normal hearing), and defined as small (0.20), medium (0.50), and large (0.80) in magnitude (Cohen, 1988). Comparing children with unilateral hearing loss to their peers with normal hearing, we found effect sizes of 0.44 for self-reported and 0.34 for proxy-reported Psychosocial scores; for Social Functioning, effect sizes were 0.60 for self-report and 0.65 for proxy-report. Some of these effect sizes are similar in magnitude to those between children with chronic illness and healthy children (Varni et al., 2003). Findings such as these suggest that HRQOL measures deserve more investigation to determine the effect of hearing loss on children, in addition to the traditional objective (e.g., audiometry) measures.

The only statistically significant finding from the analysis of PedsQL measures is that children with UHL had a larger variance on the social functioning score when compared with children with either normal hearing or bilateral hearing loss. Due to multiple

comparisons, this finding of heteroskedasticity might be spurious; however, if true this result may help explain the conflicting results of previous studies comparing children with normal hearing and UHL (Lieu, 2004). Earlier studies have involved small samples of children who may represent one end of a spectrum; depending on which end of the spectrum was sampled, differences may or may not have been identified. In addition, a large variance suggests that multiple unmeasured factors may interact with UHL to produce more variability in social functioning scores than for children with normal hearing or bilateral hearing loss.

The main limitations of this study were the low rate of participation and the small sample sizes for both parts of our study. A higher participation rate may have elicited different or additional areas of concern for both child and adult during the focus group sessions. Volunteer or self-selection bias can affect study results when those who choose to participate are not representative of the larger target group from which they come (Kelsey, Whittemore, Evans, & Thompson, 1996, p. 312). Researchers have found that volunteers in studies tend to be either the “worried well” or the most severely affected. The population base for this research was mainly from children and families currently participating in other ongoing studies. Some of the parents who chose to participate with their child may have done so because either they noted problems with their child, or wished to rule-out problems. Without further study, we cannot determine how the participants differed from non-participants, or how well or poorly they represent the entire population of children with unilateral or bilateral hearing loss. The small sample sizes for the quantitative evaluation of HRQOL using the PedsQL is one possible cause of not finding statistical significance. The wide 95% confidence intervals reveal a lack of precision in our point estimates, and we had inadequate statistical power to identify small to medium effect sizes. To exemplify, in order to find a statistically significant medium effect size (0.50) between children with normal hearing and UHL in Psychosocial score, using a two-tailed alpha level of 0.05 and 80% power, 63 children with normal hearing and 63 children with UHL would need to participate. To find a statistically significant small effect size (0.20) for the same score, 392 participants would need to be recruited for each group. However, as a pilot study, the results from this research can provide estimates for expected effect sizes for future studies of HRQOL in children with hearing loss. The other possible explanation for not finding statistical significance is that the PedsQL, a generic measure of pediatric HRQOL, is not sensitive to hearing-related issues of quality of life. Because no validated hearing-related HRQOL exists for children at this time, we were unable to confirm or test this explanation.

Other limitations hampered our ability to find differences in HRQOL. We did not include a structured questionnaire to investigate the receipt of interventions, such as school services or technology (e.g., FM systems). It is possible that children who have received interventions or services might perceive a difference in HRQOL from those who have not. Many children with UHL may have tried using FM systems or have received Individualized Educational Plans (Lieu, Tye-Murray, Karzon, & Piccirillo, 2010), but it is not apparent how receipt of services or interventions might affect a child’s perception of HRQOL. Although services and intervention might improve the child’s functional ability to cope with the disadvantages of UHL, they may contribute to the child’s perception of not being “normal.” We also did not include functional assessments from teachers, audiologists, parents, or the children themselves, such as the SIFTER (Screening Instrument for Targeting Educational Risk) or CHILd (Children’s Home Inventory of Listening Difficulties) (available online at <http://www.kandersonaudconsulting.com/>, accessed 8/12/09). While assessment of auditory function is important, the intent of this pilot study was to obtain the children’s and parents’ perceptions of quality of life. HRQOL is a more global measure of the impact that UHL might have on children, and has not been evaluated in this population in prior studies.

Not surprisingly, proxy-report data from the caregivers differed somewhat from self-report data from the children themselves. Imperfect agreement between self-report and proxy-report has been previously documented in reports of healthy and chronically ill children (Achenbach, McConaughy & Howell, 1987). One explanation might be that parents have higher expectations for their children than children have of themselves. The differences between child and parent reports illustrate the importance of investigating both child and parent or caregiver perceptions of the individual child's HRQOL. Such discrepancies may explain why a parent may push for an intervention, whereas the child may be resistant to doing anything that might make them seem different from his/her peers. Conversely, discrepancies can reveal to professionals and parents that a child may perceive more problems than he/she has been communicating, and open the possibility of recommending an intervention.

Future studies of HRQOL in children with hearing loss will need to survey larger groups of children, not only to meet sample size requirements to find small to medium effect sizes, but also to investigate whether severity of hearing loss, specific interventions (e.g., hearing aids), etiology, or other hearing-related covariates are associated with HRQOL. Development of a hearing-related HRQOL outcome measure specifically for children would also be beneficial for future studies. Because the PedsQL is a generic HRQOL inventory, it is relatively insensitive to domains of HRQOL that are more closely related to hearing loss; therefore, we were unable to draw conclusions about the relationship among HRQOL and hearing-related domains. A specific hearing-related HRQOL outcome measure may assist professionals in evaluating the effects of hearing loss on children's daily lives. For instance, a hearing-related HRQOL measure may reveal particular listening conditions (e.g., cafeteria or gym) that are especially bothersome to a child; determine whether a child or parent limits involvement with activities or sports (e.g., opts for solo sports rather than team sports) due to hearing; or uncover self-esteem issues related to hearing loss. However, a validated, hearing-related, self-reported HRQOL measure for children and adolescents is not currently available.

Conclusion

This pilot study suggests that quality of life should not be overlooked when counseling parents of children with UHL. We have shown that UHL may qualitatively affect the HRQOL of some children to different degrees, in various environments (such as social and academic environments), and should not be assumed to have a trivial or no effect on their quality of life. Therefore, further research on this topic is warranted. Future research should also determine whether patients with UHL experience similar handicaps as patients with bilateral hearing loss, and if so, whether they may benefit from interventions that help patients with bilateral hearing loss.

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Appendix A

Focus Group Guide for Children and Adolescents with UHL

1. What grade was your most/least favorite in school so far?
 - a. Why? More/less friends, easier/harder teacher
2. You are starting a new school tomorrow. What do you tell your teacher about yourself?
3. Lots of kids hang out with friends at the mall, go to the movies or to parties together on the weekend. What do you do on the weekends?
 - a. Are these group activities or individual activities? Large groups or small groups, why?
4. Describe your typical day at school
 - a. Where do you sit? Who do you sit next to? Where is the teacher? Are you always in the same room? Do you have a hard time hearing/understanding in class?
 - b. if you had the power to change things about your class, what would be different?
5. Imagine I am your neighbor and I was just diagnosed with a hearing loss like yours. What would you tell me?
6. UHL makes it hard to know where a sound is coming from. When in a noisy cafeteria or outside on the playground it is even more difficult to talk with your friends.

- a. What other situations are difficult with a UHL?
 - i. Movies, basketball court, at the zoo
- b. How do you feel when in these situations?
- c. Do you feel different when in these situations with your parents? With your classmates on a fieldtrip? When you are alone?
- 7. Imagine you and your mom are going to a back to school pool party this afternoon. There is a DJ playing inside, other kids screaming and playing in the pool and a group of people talking by the BBQ pit. What would you do to be more comfortable/to hear better?
- 8. if you could take a class on hearing loss what would you want to learn?
- 9. What do teachers expect of you compared to your classmates?
- 10. What does having a UHL feel like?
- 11. What questions did I not ask but you feel I should have asked?

Appendix B

Focus Group Guide for Parents of Children/Adolescents with UHL

- 1. Question to think about past compared to present
 - a. Over the years have you noticed *differences* in your child in different classrooms at school?
 - b. What were those differences? Examples: grades better/worse, behavior better/worse, etc.
 - c. What made one year more or less successful than another year? Examples: child had more/fewer friends, the teacher, began using an FM system or hearing aids
- 2. Some parents say their child is self-conscious or embarrassed by their hearing loss. Other parents say their child has adapted well to the hearing loss. How would you describe your child's *feelings* about the UHL?
 - a. This can be role-played by having the parent describe the feelings to his new teacher for the upcoming school year.
 - b. Parents in Lieu's study describe lots of frustration
- 3. Lots of kids hang out with friends at the mall, go to the movies or to parties together on the weekend. What does your child do on the weekends? Are these group activities or individual *activities*? Large groups or small groups, why?
 - a. Parents describe kids with UHL as not very sociable, quiet, shy, etc.
- 4. What services are available to a child with a UHL?
 - a. What have you *experienced* in getting these services placed for your child?
 - b. When did your child begin receiving services?
 - c. Why did your child begin receiving services?
 - i. Proactive: suggested by audiologist, MD

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Figure 1.

Classification system used to code content of focus group sessions. Statements which were relevant to perceptions and barriers of unilateral hearing loss were identified. These statements were labeled by speaker, parent or child. The statement was then assigned a category where it best correlates. The statements were then used to describe the results of the focus group.

Figure 2.

Collage and description by one unilateral hearing loss focus group participant.

- a. "The world is a lot prettier when you don't have all these sounds bombarding you constantly."
- b. "You appreciate the smaller things better when you're not distracted by meaningless noise all the time."
- c. "Represents missing out on some things but it's still pretty."
- d. "Represents having half of something but it's still good."
- e. "All these different people and different sounds and they all come together."
- f. "At school there are a lot of barriers and blocking because you can't hear what people are saying."

Figure 3.

Self-reported PedsQL scores by hearing loss severity. Pure tone averages at 500, 1000, 2000, and 4000 Hz were categorized as follows: mild < 40 dB ($n=7$), moderate = 40–69 dB ($n=21$), severe = 70–89 dB ($n=5$), and profound ≥ 90 dB ($n=27$). There were 25 children with normal hearing.

Table 1Characteristics of focus group participants ($n=7$)

Participant	Gender	Age *	Severity of hearing loss *
Child 1	Female	15 years	Profound
Child 2	Male	12 years	Severe
Child 3	Female	13 years	Profound
Parent 1	Female	15 years	Profound
Parent 2	Female	12 years	Severe
Parent 3	Female	13 years	Profound
Parent 4	Female	8 years	Profound

* Age and severity of hearing loss are the ages and severity of hearing loss of the child with unilateral hearing loss, not the parent.

Table 2

Demographic characteristics of study participants for the quantitative quality of life study.

1	Normal Hearing (n=24)	UHL (n=32)	BHL (n=29)	P value
Age, mean (SD)	9.8 (3.5)	11.0 (2.9)	10.1 (2.0)	0.28
Gender				0.64
Males	12 (50%)	20 (62%)	16 (55%)	
Females	12 (50%)	12 (38%)	13 (45%)	
Race				0.93
Black	2 (8%)	2 (6%)	2 (7%)	
White	20 (83%)	27 (84%)	24 (83%)	
Asian	1 (4%)	0 (0%)	1 (3%)	
Other	1 (4%)	3 (9%)	2 (7%)	
* Hearing Severity				0.01
Mild	--	3 (9%)	4 (14%)	
Moderate	--	5 (16%)	16 (55%)	
Severe	--	3 (9%)	2 (7%)	
Profound	--	20 (62%)	7 (24%)	
* Hearing Laterality				
Right UHL	--	17 (53%)	--	
Left UHL	--	14 (44%)	--	

UHL, Unilateral hearing loss; BHL, Bilateral hearing loss

* Severity and laterality data missing for one UHL participant.

Table 3

Comparison of self-reported PedsQL scores for children with normal hearing (n=24), unilateral hearing loss (n=32) and bilateral hearing loss (n=29).

PedsQL™ score	NH [†] mean (SD) [*]	UHL [‡] mean (SD) [*]	BHL [§] mean (SD) [*]	Differences NH-UHL [95% CI] [¶]	I value	Df	P value
Total QOL	81.0 (8.9)	77.3 (15.3)	81.2 (11.1)	-3.6 [-11.1, 3.8]	1.06	2	0.3519
Physical Score	84.5 (9.5)	83.4 (13.2)	88.9 (13.9)	-1.2 [-9.2, 6.9]	1.58	2	0.2118
Psychosocial Score	79.1 (11.4)	74.1 (15.3)	77.1 (12.3)	-5.0 [-13.5, 3.6]	1.01	2	0.3697
Emotional Functioning	71.9 (17.6)	75.5 (17.0)	74.4 (18.1)	3.6 [-7.7, 14.9]	0.29	2	0.7456
Social Functioning	84.6 (12.8)	76.9 (20.2)	83.1 (11.4)	-7.7 [-17.8, 2.4]	2.00	2	0.1419
School Functioning	80.8 (13.6)	70.0 (21.9)	73.8 (15.3)	-10.8 [-22.2, 0.6]	2.59	2	0.0808

^{*}SD, standard deviation

[†]NH, normal hearing

[‡]UHL, unilateral hearing loss

[§]BHL, bilateral hearing loss

[¶]95% CI, 95% confidence interval

Table 4

Comparison of proxy-reported (parent/guardian) PedsQL scores for children with normal hearing (n=24), unilateral hearing loss

PedsQL™ score	NH [†] mean (SD) [*]	UHL [‡] mean (SD) [*]	BHL [§] mean (SD) [*]	Differences NH-UHL [95% CI] [¶]	F value	df	P value
Total QOL	81.7 (14.1)	77.6 (17.1)	79.6 (14.4)	-4.1 [-14.0, 5.8]	0.49	2	0.6172
Physical Score	84.6 (18.5)	81.1 (21.6)	90.6 (15.8)	-3.6 [-15.8, 8.6]	1.96	2	0.1471
Psychosocial Score	80.2 (12.9)	75.8 (16.1)	73.7 (16.2)	-4.4 [-14.2, 5.5]	1.21	2	0.3028
Emotional Functioning	75.4 (14.5)	77.2 (17.5)	72.1 (21.5)	1.8 [-10.0, 13.5]	0.61	2	0.5448
Social Functioning	87.5 (12.8)	79.2 (17.3)	80.2 (18.5)	-8.3 [-19.0, 2.4]	1.94	2	0.1506
School Functioning	77.7 (17.3)	70.9 (19.1)	68.9 (16.9)	-6.8 [-18.3, 4.7]	1.73	2	0.1844

(n=32) and bilateral hearing loss (n=29).

^{*}SD, standard deviation

[†]NH, normal hearing

[‡]UHL, unilateral hearing loss

[§]BHL, bilateral hearing loss

[¶]95% CI, 95% confidence interval