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Quality of life in children with unilateral hearing loss: a pilot study

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**QUALITY OF LIFE IN CHILDREN WITH UNILATERAL HEARING
LOSS: A PILOT STUDY**

by

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**A Capstone Project
submitted in partial fulfillment of the
requirements for the degree of:**

Doctor of Audiology

**Washington University School of Medicine
Program in Audiology and Communication Sciences**

May 16, 2008

Approved by:

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Abstract: The purpose of this investigation was to determine the impact of unilateral hearing loss (UHL) on the quality of life of children. Focus group sessions were held for parents and children or adolescents with unilateral hearing loss to discuss their perceptions. Parents and children or adolescents completed the Pediatric Quality of Life Inventory. Findings were presented depicting which domains of quality of life are most affected.

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May 16, 2008

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Table of Contents

	Page
Acknowledgments	ii
List of Figures	4
List of Tables	4
Summary	5
Introduction	7
Purpose	10
Methodology & Design	11
Qualitative Methodology	11
Quantitative Methodology	13
Results	15
Qualitative Results	15
Quantitative Results	19
Common Themes between Qualitative and Quantitative Results	20
Discussion	23
Conclusion	26
References	27
Appendix A: Focus Group Guide for Children and Adolescents with UHL	36
Appendix B: Focus Group Guide for Parents of Children/Adolescents with UHL	38
Appendix C: PedsQL™ 4.0 Generic Core Scales Child Self-Report Item Content	40

List of Figures

Figure 1. Classification system used to code content of focus group sessions.

Figure 2. Collage and description by a UHL focus group participant.

Figure 3. Mean PedsQL™ Scores for normal hearing, unilateral hearing loss and bilateral hearing loss children aged 6-17 years.

Figure 4. Mean PedsQL™ Scores for normal hearing, unilateral hearing loss and bilateral hearing loss children aged 6-17 years.

List of Tables

Table 1. Participant demographics for the quantitative quality of life study.

Table 2. PedsQL™ mean scores, range and standard deviations (SD) across functioning for normal hearing (WNL), unilateral hearing loss (UHL) and bilateral hearing loss (BIL) child self-report and parent proxy-reports.

Summary

Objectives

The objective was to look at quality of life (QOL) of children with unilateral hearing loss (UHL) between the ages of 6-17. We investigated what difficulties children with UHL experience related to QOL indicators and hypothesized these indicators were significantly different than those expressed by normal hearing peers and peers with bilateral hearing loss.

Rationale

Little is known about the daily problems experienced by children with UHL compared to peers with normal hearing or with bilateral hearing loss. Few studies address QOL in children with bilateral hearing loss; no research addresses how UHL affects children's every day activities. Early studies of adults with UHL reported a mild to moderate handicap on the Hearing Handicap Inventory for Adults (HHIA) (Newman, Jacobson, Hug & Sandridge, 1997). This shows adults with UHL experience some degree of communication and psychosocial problems as compared to normal hearing adults. Another adult QOL study using the SF-36 questionnaire showed those with hearing loss have significantly poorer general health and social functioning scores than normal hearing adults (Parving, 2001). Most recently, hearing aid usage was found to improve adult QOL for patients with sensorineural hearing loss in a systematic review of the literature by an American Academy of Audiology task force on health-related QOL (Chisolm et al., 2007).

Design

We conducted a qualitative study to elicit information on areas of concern clinicians may be currently unaware of regarding UHL; families of children and adolescents with UHL participated in separate focus group sessions. Participants discussed experiences they perceive to be related to the UHL. A moderator guided participants through these sessions.

We utilized the Pediatric Quality of Life Inventory™ (PedsQL™) in a comparative study (Varni, Seid, & Rode, 1999). This standardized instrument measured health-related QOL in participants with normal hearing, unilateral and bilateral hearing loss. Twenty three questions were answered regarding physical, emotional, social and academic functioning. The children and adolescents completed the child self-report inventory. Their parents completed a proxy-report inventory for their child.

Results

Ten individuals attended two focus group sessions in August 2006. Data was transcribed and extracted by the author and the advisors to note all barriers discussed by participants. A list of problems children with UHL experience was compiled. The list was analyzed to categorize issues into content areas, with implications discussed toward real-world listening experiences. Seventy five participants completed the QOL inventories. A one-way ANOVA was used to analyze data.

Conclusion

Focus group results showed children with UHL felt they are “normal kids;” their parents felt they have adapted to their hearing loss but not without hurdles. Quantitatively, children with UHL reported lower total QOL and psychosocial functioning than children with normal hearing. This difference is less apparent in parental reports; however, none of the differences were statistically significant. Future studies should be continued to determine intervention effects on QOL of children with UHL.

Introduction

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 permanent sensorineural UHL (Niskar et al., 1988). There are mixed reports of how UHL affects these children along with greater debate of whether to amplify them and what interventions should be implemented, if any. 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. This study has since been supported in multiple other studies (Bess & Tharpe, 1984; Brookhouser, Worthington, & Kelly, 1991; Culbertson & Gilbert, 1986). Hallmo, Moller, Lind & Tonning (1986) investigated UHL in children specifically to investigate etiology of hearing loss. They concluded that UHL in children does not affect the child until they become school age. They discussed the need to ease parents' concerns about progression of hearing loss, and only then do they suggest annual re-evaluations. Stein (1983) showed children with UHL have good opinions of themselves; it is their parents and teachers who report the children have frequent behavior problems. It is important to note few studies directly investigate the impact of UHL on emotional and behavioral well-being, a child's participation in daily activities or even their social functioning.

It is also not known how children with UHL compensate for their hearing loss. Studies of adult patients with UHL report experiences of annoyance and embarrassment (Giolas & Wark, 1967). Individuals with UHL have difficulties localizing, limited binaural summation and lessened head shadow effects. However, adults experience hearing *loss* whereas children are often born with hearing impairment. How does this impact these individuals' perceptions of UHL? Another remaining question is whether these individuals pursue interests or hobbies that do not require binaural hearing? Without further information on the affects of UHL clinicians

may be overlooking the need to evaluate these patients further. Audiometry alone cannot quantify the expected experiences or the mental and physical health status of an individual with UHL.

Health-related QOL assessments describe the impact of diseases and treatment outcomes in terms of physical, psychological, social and school domains (Varni, Burwinkle, Seid, & Skarr, 2003). Studies indicated children at risk for disabilities have poorer QOL when compared to typically developing peers (Palmero, Schwartz, Drotar, & McGowan, 2002; Schwimmer, Burwinkle, & Varni, 2003). Results of QOL measures may show a need for professionals to implement interventions for certain populations such as children with hearing loss.

Several studies address QOL in children with bilateral hearing loss (Wake, Hughes, Collins, & Poulakis, 2004; Wake et al., 2006). In a study of 7-8 year old children with bilateral congenital hearing loss, ranging from mild to profound hearing loss, health-related QOL was documented using the Child Health Questionnaire (CHQ), a parent-reported QOL measure. The CHQ is a generic health-related QOL measure to assess physical and psychosocial functioning in children. The authors found that milder hearing losses related to worse physical and psychosocial functioning scores compared to children with more severe-profound hearing losses (Wake et al., 2004). Primarily, what may seem as a mild condition to clinicians may actually be a significant issue to a child's well-being. The authors also attributed these results to the possibility of the findings being due to selection bias—the number of mild hearing loss patients was not as large as the number of severe hearing loss participants. These mild patients may have other special needs, such as learning disabilities, which directly influenced their willingness to participate in the research study. An additional study of children with slight/mild sensorineural hearing loss was reported by Wake et al. (2006) using the PedsQL™. This study found no

significance between QOL in children with slight/mild bilateral sensorineural hearing loss and children without hearing loss; however, this study omitted children with UHL.

Several reports exist on adults' perceptions of UHL. One study investigated the long term effect of UHL on adults between the ages of 30-55 years as compared to their normal hearing cohorts (Colletti, Fiorino, Carner, & Rizzi, 1988). A significant difference was reported in the reported hobbies of the normal hearing group as compared to the UHL group. More normal hearing subjects viewed listening to and playing music as a hobby than UHL subjects (Colletti et al., 1988). The Hearing Handicap Inventory for Adults (HHIA) is a specific health-related QOL measure for adults. This inventory quantifies perceived emotional and social situations that are consequences of hearing loss. Three quarters of UHL subjects reported some degree of communication and psychosocial issue and scored within the 'handicap' range on the HHIA (Newman, Jacobson, Hug, & Sandridge, 1997). This supports the idea that degree of difference experienced by patients cannot be solely determined by an audiogram. Another adult QOL study showed those with hearing loss have significantly poorer general health and social functioning scores than normal hearing adults (Parving et al., 2001). Overall the adult QOL domains of social functioning, self-esteem, and physical functioning improve due to interventions such as cochlear implantation or hearing aid usage (Cohen, Labadie, Dietrich, & Haynes, 2004). Most recently, hearing aid usage was found to improve adult QOL for patients with sensorineural hearing loss in a thorough review of the literature by an American Academy of Audiology Task Force on health-related QOL (Chisolm et al., 2007). It is unknown if hearing impaired children's perceived QOL changes due to intervention.

One age-appropriate inventory for children that has some similarities to the HHIA is the Glasgow Children's Benefit Inventory. The Glasgow Children's Benefit Inventory is a retrospectively applied health-related QOL measure; it has been shown to assess the benefit of

intervention in pediatric otolaryngology, but further study on reliability and validity has not been completed, making it an inadequate means of assessing UHL effects (Kubba, Swan, & Gatehouse, 2004). A hearing health-related QOL assessment for children would aid clinical decision making and assist in developing, monitoring and evaluating interventions for children with UHL and other degrees or configurations of hearing loss.

Health-related QOL is an important aspect to investigate in order to understand the needs of children with UHL. This article describes a study designed to determine specific areas in which children with UHL experience difficulty; such settings may be in school, in their social activities, and in their family life. Studies evaluating QOL have been used increasingly to assess treatment outcomes. This article will describe the outcomes of a QOL measure in a sample of children with normal hearing, UHL and bilateral hearing loss.

Purpose

The objective of this study was to better understand the QOL of children with UHL between the ages of 6-17 years. We investigated what difficulties children with UHL experience related to QOL indicators and hypothesized these experiences were significantly different than those expressed by normal hearing peers and peers with bilateral hearing loss.

Based on the literature review, we formulated the following hypotheses: 1. children and adolescents with UHL would report a lower QOL than normal hearing peers but higher QOL than peers with bilateral hearing loss; and 2. parents of children with UHL would report their child has the same QOL score as children with normal hearing.

The study was completed in two stages. Stage one was a focus group to obtain subjective descriptions of perceptions of UHL. Stage two was a quantitative study to measure the QOL

among the three groups of children (normal hearing children, children with UHL and children with bilateral hearing loss) and the three groups of children compared to their parents.

Methodology & Design

Research

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 population for the study. Eligible subjects included children of normal cognitive abilities with normal hearing, UHL, and bilateral hearing loss and the parents of these children.

Qualitative Methodology

A qualitative study was used to elicit the opinions and views of children and their parents on areas of concern which clinicians may currently be unaware of regarding UHL.

Participants

Focus group participants were recruited from an ongoing research study (by Dr. Judith E. C. Lieu). Recruitment letters were sent to eligible families of children/adolescents aged 8-17 years.

Procedure

Families that expressed interest in the study were sent consent forms and a list of questions to prepare participants about possible topics to be discussed. The question sheet sent

for the children/adolescents is available in Appendix A and the question sheet for the parents is available in Appendix B. Written informed consent was obtained from all participants.

The content to be discussed and the organization of the focus groups were conducted according to *Qualitative Research & Evaluation Methods* (Patton, 2001). The focus groups were held in quiet rooms where the chairs were set in a circle so as to include everyone in conversation. 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?” Two moderators ran each focus group session. One moderator led discussion while the other took notes, made observations and added comments to keep discussions active.

The sessions began with all participants in one room for an icebreaker activity and an explanation of the aim of the study. To optimize group discussion the focus groups were separated by parents and children. After the introduction the children went to a neighboring room where they would feel more comfortable sharing with each other. Their focus group started with a hands-on activity; they were asked to find pictures from magazines to describe themselves. This was a valuable way to begin eliciting information from the children. After initial reservation in the child and adolescent focus group everyone contributed to the session.

Each discussion was limited to two hours. A break during the discussion with refreshments was available at the halfway point. In each focus group session participants were encouraged to talk to each other, ask questions, exchange experiences and to comment on each other’s remarks. Participants were compensated for focus group participation with \$15 gift certificates. Overall, the sessions went smoothly with lively discussions.

Analysis

Both focus group sessions were audio-taped and transcribed in Microsoft Word. Focus group content was then analyzed by each contributor. Figure 1 shows a flow chart of how the data was categorized, analyzed and how the statements were coded before the information was interpreted. First, a list of generalizations was compiled by the researchers. Statements relevant to perceptions, barriers, or experiences of the adolescent with UHL or their parent were identified. Next, the researchers met to classify the list of statements into categories that emerged from the focus group transcriptions. The categories included: school, social, emotional, physical and difficult situations. There was also a category to differentiate between issues mentioned by parents and issues brought up in discussion by the adolescents. The perceptions perceived about each topic were then listed. Comments relating to the hearing loss associated with behaviors of children or adolescents with UHL, their peers, and professionals were also included in each category.

Quantitative Methodology

Participants

Participants in the quantitative section of this study included children ages 6-17 years and their parents. Subjects were recruited from the advisors' patient and research subject populations. Inclusion criteria were families of children ages 6-17 years with normal cognitive functioning. Introductory letters and 284 inventories were sent to 142 families.

Measures

Eligible families were sent the Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™) to determine QOL for different populations (Varni et al., 1999). This standardized

instrument documents an individual's perceived overall QOL. We used it to measure the health-related QOL in participants with normal hearing, UHL and bilateral hearing loss. The PedsQL™ 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. There is a separate PedsQL™ for the following age groups: children 6-7 years old, children 8-12 years old, and adolescents 13-18 years old. Children aged 7 years and younger were administered a parent-assisted inventory. Children and adolescents 8-17 years complete the child self-report inventory; all parents complete 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. An example of the PedsQL™ for children 8-12 years of age is available in Appendix C.

A five-point Likert 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; 4 = almost always a problem; and 5 = always a problem (Varni et al., 1999). The child self-report for children 6-7 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 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 QOL. 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 QOL. 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 QOL score is the mean value of all the items answered.

Procedure

Eligible families were mailed introductory letters and inventories. Data was 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 without personal health information on them.

Analysis

Data were entered into a Microsoft Excel database and read into SAS Version 8.2 for statistical analysis. A one-way analysis of variance (ANOVA) was used to determine if there were significant differences between hearing populations. Overall, a p value of 0.05 or less was assumed to represent a statistically significant result. The difference in means between hearing population scores were examined using the Tukey HSD post hoc test of significance.

Results

Qualitative Results

Focus group recruitment letters were sent to 25 eligible families of children and adolescents aged 8-17 years with UHL. Eight families responded; these families were sent consent forms and a list of questions to prepare participants about possible topics to be discussed.

Four families arrived to participate for the focus group; two families cancelled the day of the focus group due to inclement weather. The children's focus group consisted of three

children/adolescents 10-14 years of age. The parent focus group consisted of four mothers of children aged 8-14 years.

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 it 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 confirms the knowledge that at the initial diagnosis of a hearing loss information beyond “your child has a hearing loss” is not remembered. It also expresses the communication issues between professionals and laypeople.

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*. This is helpful since teachers are busy with all the children in the classroom and it reminds parents to take the time to educate the teachers and advocate for their child.

Stories by the parents of adolescents in the focus groups portrayed interactions as being mainly one on one interactions and only having 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 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 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 *popflies*. 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 mother’s 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 child will adapt to his/her environment. Lastly, parents stressed the importance of being compassionate about the 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 mentioned similar perceptions of UHL but in various words and importance.

Quantitative Results

For the populations combined 170 (59.9%) inventories were received after one mailing (85 self-reports and 85 proxy-reports). A breakdown of participant ages and populations is shown in Table 1. The mean age for the 85 child subjects was 11.0 years.

Although no statistically significant differences between groups were found, UHL subjects scored more poorly on child self-reports and parent proxy-reports for several QOL scales than children with normal hearing and with bilateral hearing loss. PedsQL™ findings for the hearing impaired populations and the normal hearing subjects are available in Figure 3 for the child self-report. Children with UHL scored worse than the normal hearing children and the bilateral hearing impaired children in all three main QOL scales (total, psychosocial and physical). Figure 4 shows the findings for the same three QOL scales as reported in the parent proxy-reports. Parents of children with UHL reported their child's QOL to be lower than normal hearing children in all three main QOL scales. The UHL parents also reported their child's QOL to be worse than children with bilateral hearing loss in the total and physical scales but reported UHL children to have better psychosocial functioning than children with bilateral hearing loss.

UHL children scored themselves more poorly than normal hearing and bilateral hearing loss peers in social and school functioning. They scored higher than the other populations in the emotional functioning subscale. Their parents also scored their child's QOL to be worse than normal hearing and bilateral hearing loss peers in the social functioning domain but better in the emotional functioning domain. It is noted that parents of children with bilateral hearing loss reported their child's school functioning to be worse than parents of both normal hearing children and children with UHL reported. These findings are shown in Table 2.

Children with UHL had a larger range of QOL scores than children with normal hearing in all scales of the PedsQL™ except for the emotional functioning domain. The self-reported range of emotional functioning for children with UHL was the same as the self-reported range of emotional functioning of children with normal hearing. Children with UHL had larger self-reported ranges of QOL than children with bilateral hearing loss in all scales except the physical domain. The physical QOL range for children with UHL was smaller than the self-reported physical QOL range for children with bilateral 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, their parents discussed noticing more differences in their child, as a result of the UHL, as they became older. For example, Mother *MC* 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 *MC* noticed increased difficulty localizing voices. This was also true if the child was swimming and the good ear was under water. Mother *MB* noted when her child played

volleyball the background noise in the gymnasium seemed to cover up all voices. These specific examples portray instances when a child with UHL may feel that sports or physical activities are more challenging than not.

In the QOL measure the fourth health and activities statement, “It is hard for me to lift something heavy” was the most poorly scored self-reported statement in the physical category for all groups of children. Statements “Doing chores around the house” and “Having hurts or aches” were the most poorly scored proxy-reported statements by parents of children with UHL and bilateral hearing loss. For the hearing impaired children these results may be associated with inability of children to clearly hear a request to complete a chore or with their perceived lack of attention.

Emotional Functioning

Parents of all three populations reported their children as feeling angry often on the PedsQL™. There were no significant differences between the groups’ emotional functioning as reported by the children/adolescents.

Social Functioning

In focus group discussions parents perceive the child with UHL as being emotionally “closed up” and shy, yet resilient. In the PedsQL™ proxy-report by parents of children with UHL the worst scores were reported for the statement, “Getting along with other children”. That statement along with “Getting teased by other children” was the poorest score for children with UHL. 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.

Limitations in social functioning were mentioned most in stories by children participating in focus groups. Participants portrayed the UHL as mainly having one on one interactions and only having a few close friends. The UHL participants also described instances of their friends getting angry at them for constantly having to switch sides to their good ear or their friend thought they were ignoring them when the friend spoke. The UHL participant explained they felt their friends mumble a lot and they occasionally pretend 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)

These statements show children with UHL feel differently than their normal hearing peers as was seen in the quantitative results.

School Functioning

All participants and their parents reported “forgetting things” as the lowest scored question in the PedsQL™. UHL participants scored lower on school functioning than did normal hearing and bilateral hearing loss peers. Academically during focus group discussion the UHL participants reported frequent 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).

These comments are associated with how children/adolescents and parents reported school functioning. In the parent focus group the topic was discussed through questioning if the child was hearing and not paying attention. While parents brought up this question, they also commented on teachers’ assumptions that the child is not paying attention in class. “The teachers automatically assume my child isn’t paying attention,” said Mother *MC*. She has to substantiate her child’s actions by explaining, “It’s not that he’s not paying attention, he didn’t hear you.” With this, parents expressed the importance of advocating to teachers for their child’s sake. Parents feel teachers are not educated about UHL and it is not their main focus for the classroom.

Discussion

This is the first study to examine QOL in children with UHL. Using a combination of qualitative methods and a quantitative QOL measure provided insight to the experiences of children and families with UHL. The combination also allowed greater depth of investigating the dimensions of QOL that are affected in children with UHL.

Both qualitative and quantitative methodologies examining QOL consistently show children with UHL experience a wide range of difficulties pertaining to psychosocial aspects of QOL. Children with UHL experience barriers due to their hearing loss just as adults experience

barriers with their UHL. During focus group sessions adolescents reported being “normal” children; however, children and adolescents with UHL have lower total QOL and psychosocial scores compared to their normal hearing peers.

Although the differences in QOL between normal hearing children, UHL children and bilateral hearing loss children are small, the scores are similar to the differences reported by other authors between children with chronic illness and healthy children (Varni et al., 2003). Children with chronic health conditions experience lower physical, emotional, social and school functioning than healthy children. This trend is also seen in a study comparing chronically ill, acutely ill and healthy children where, although not statistically significant, chronically ill children score lower in all domains on the PedsQL™ (Varni, Seid, & Kurtin, 2001). Findings such as these demonstrate the need for both objective (e.g. audiometry) and subjective (e.g. PedsQL™) measures to determine the effect of illnesses or disabilities.

One limitation of this study was the participation rate for the focus group sessions. Several cancellations were received on the morning of the focus group due to inclement weather. A higher participation rate may have elicited different areas of concern for both child and adult during the focus group sessions.

Another limitation is that the results of this study are not statistically significant; this may be due in part to our small sample size. While our sample size was small the differences found in this study are similar to ones reported in larger studies, with similar reported standard deviations. A higher response rate may have been achievable with direct phone calls or repeat mailings to families. Selection bias may be another reason why our results were not statistically significant. 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 they noted problems with their child.

It is not surprising that the proxy-report data from the caregivers varies from self-report data. Imperfect agreement between self-report and proxy-report has been previously documented in reports of healthy and chronically ill children (Achenbach et al., 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 suggest the importance of investigating both groups' (child and parent or caregiver) perceptions of the individual child's QOL.

Analyzing larger groups of children by severity of hearing loss may also be beneficial in future studies. Future studies are also needed to better understand the correlation between hearing loss and health-related QOL in children. Since the PedsQL™ is a generic QOL inventory, we were not able to make conclusions about the relationship among health-related QOL and specific domains that may be directly affected by hearing loss.

Development of a hearing-related QOL outcome measure which is more sensitive to hearing-related issues compared to the generic QOL measure used in this study would be beneficial for future studies. A specific hearing-related QOL outcome measure may be able to assist professionals in evaluating the effects of hearing loss on children's daily lives. Issues to concentrate on include what listening conditions are detrimental for children's performance, determining the typical emotional well-being of these children and determining what social situations may negatively affect a child with hearing loss most frequently.

Further investigation of what interventions children with UHL are receiving should be considered. Determining if certain interventions correlate to the range of QOL of these children may help in suggesting appropriate interventions for newly diagnosed children with UHL. Clinicians should address the need for possible interventions since milder hearing losses may affect QOL as much as bilateral hearing losses do. Audiologists have advocated fitting for

bilateral hearing aids in the belief that two hearing ears are better than one; similarly children with UHL should not be ignored.

Conclusion

The primary finding of the present study was that children with UHL demonstrated overall lower and a wider range of QOL scores compared to normal hearing peers and their peers with bilateral hearing loss. Evidence has been provided to show that UHL affects children to different degrees, implying that further research on this topic is warranted.

Future research should also determine if UHL patients experience the same disabilities that bilateral hearing loss patients experience. This should include what situations are the most difficult for these populations as well as determining if interventions that help bilateral hearing loss patients will assist UHL patients as well. Additional research should investigate if QOL increases with intervention or other variables such as aging.

This pilot study demonstrates QOL is an issue which should not be overlooked when counseling parents of children with UHL. This study serves as a starting point for research in this area.

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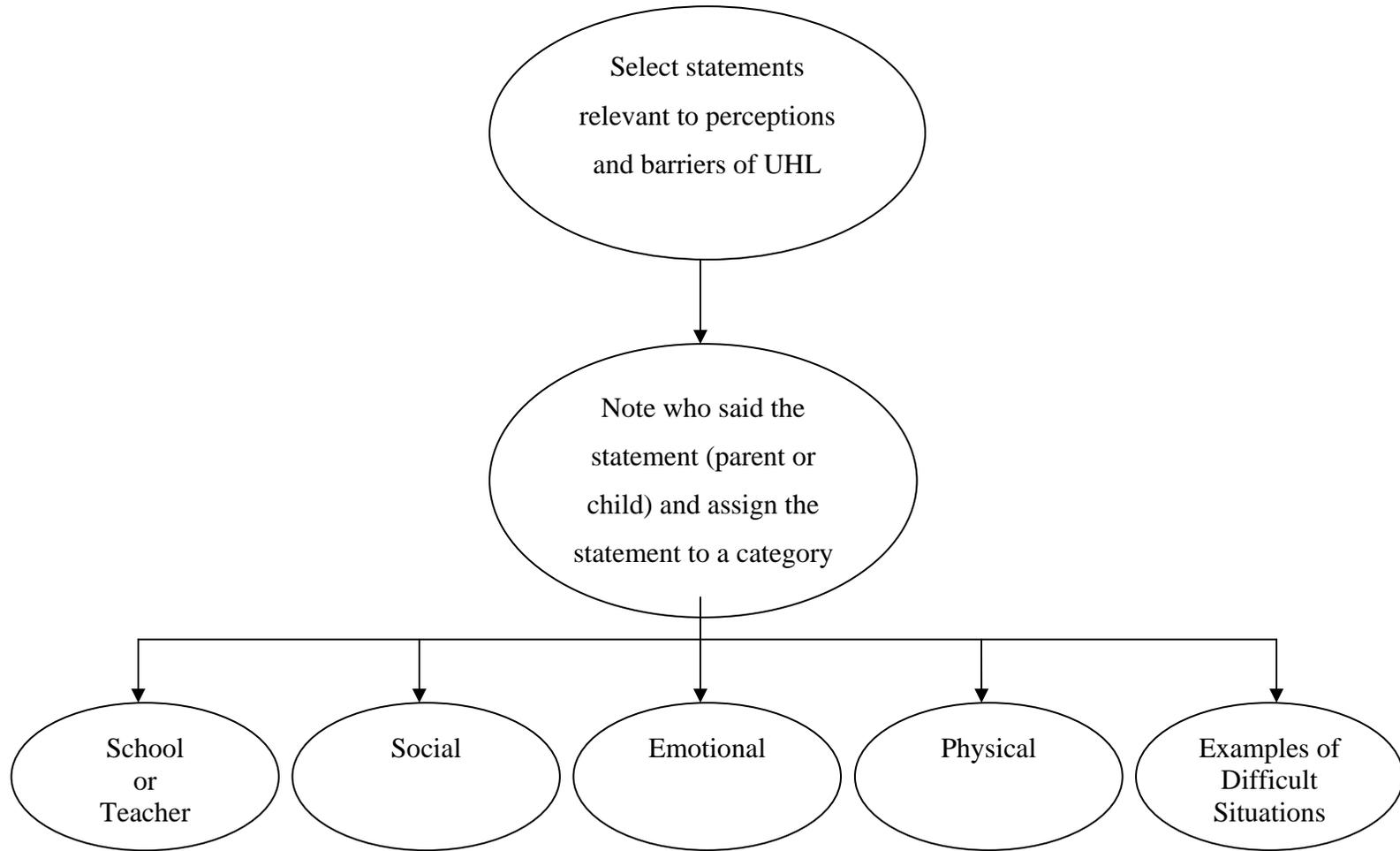


Figure 1.

Classification system used to code content of focus group sessions.



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.”

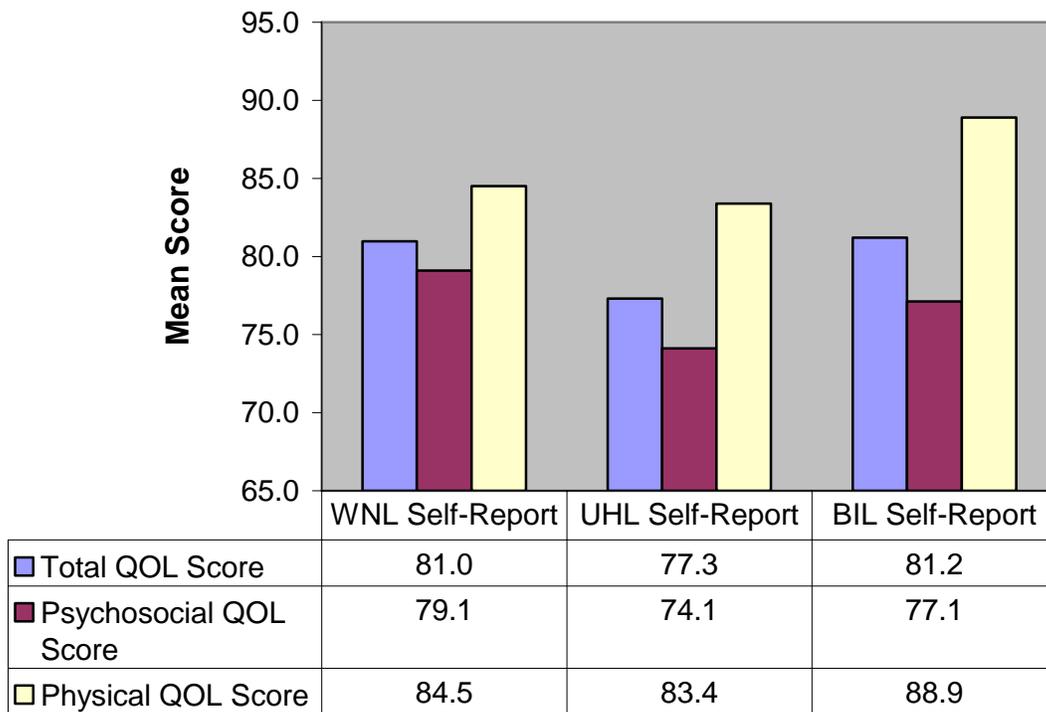


Figure 3.

Mean PedsQL™ Scores for normal hearing, unilateral hearing loss and bilateral hearing loss children aged 6-17 years.

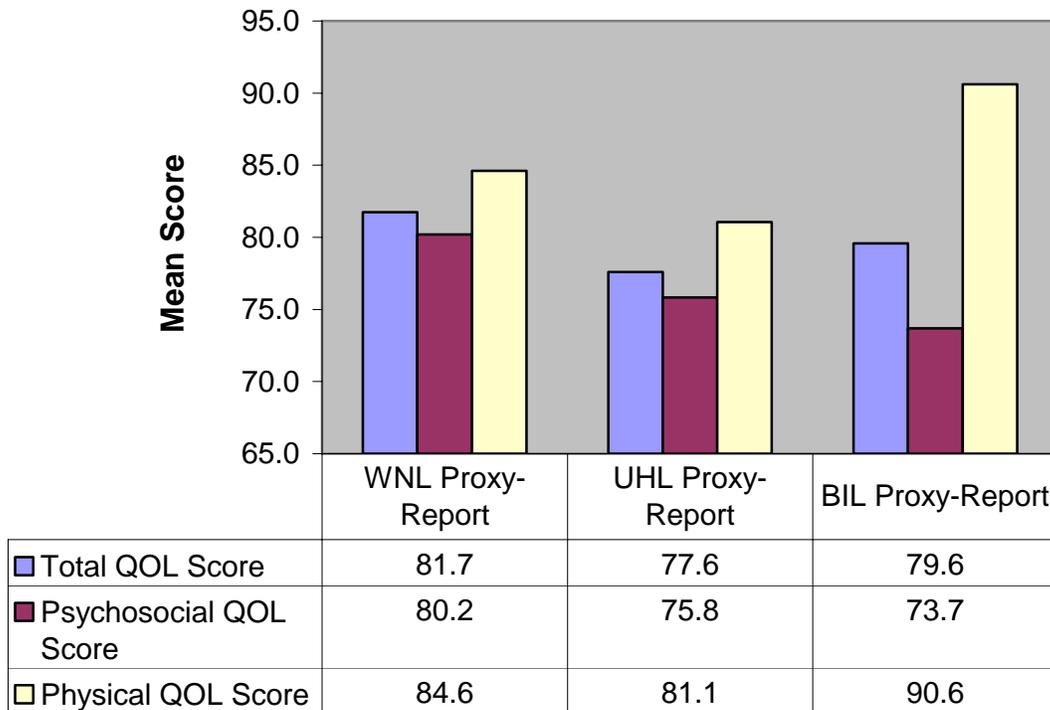


Figure 4.

Mean PedsQL™ Scores for normal hearing, unilateral hearing loss and bilateral hearing loss children aged 6-17 years.

Table 1.

Participant demographics for the quantitative quality of life study.

	Normal Hearing (n = 24)	Unilateral Hearing Loss (n = 32)*	Bilateral Hearing Loss (n = 29)
	Males = 12 Females = 12	Males = 20 Females = 12	Males = 16 Females = 13
Mean Age (years)	9.8	11.0	10.1
Hearing Classification (by worse ear) *Severity data missing for one UHL participant		Mild 3 (9.4%) Moderate 5 (15.6%) Severe 3 (9.4%) Profound 20 (62.5%) R UHL 17 (53.1%) L UHL 14 (43.7%)	Mild 4 (13.8%) Moderate 16 (55.2%) Severe 2 (6.9%) Profound 7 (24.1%)

Table 2.

PedsQL™ mean scores, range, and standard deviations across functioning for normal hearing, unilateral hearing loss, and bilateral hearing loss child self-report and parent proxy-reports.

Normal Hearing Self-Report					Normal Hearing Proxy-Report				
	Mean	Range		Standard Deviation		Mean	Range		Standard Deviation
Total QOL	81.0	67.1	95.7	8.9	Total QOL	81.7	34.8	98.9	14.1
Physical Score	84.5	62.5	100.0	9.5	Physical Score	84.6	25.0	100.0	18.5
PsychosocialScore	79.1	58.3	98.3	11.4	PsychosocialScore	80.2	40.0	100.0	12.9
Emotional Functioning	71.9	40.0	100.0	17.6	Emotional Functioning	75.4	35.0	100.0	14.5
Social Functioning	84.6	55.0	100.0	12.8	Social Functioning	87.5	50.0	100.0	12.8
School Functioning	80.8	50.0	100.0	13.6	School Functioning	77.7	35.0	100.0	17.3

Unilateral Hearing Loss Self-Report					Unilateral Hearing Loss Proxy-Report				
	Mean	Range		Standard Deviation		Mean	Range		Standard Deviation
Total QOL	77.3	42.4	98.9	15.3	Total QOL	77.6	23.9	98.9	17.1
Physical Score	83.4	43.8	100.0	13.2	Physical Score	81.1	15.6	100.0	21.6
PsychosocialScore	74.1	38.3	98.3	15.3	PsychosocialScore	75.8	28.3	100.0	16.1
Emotional Functioning	75.5	40.0	100.0	17.0	Emotional Functioning	77.2	25.0	100.0	17.5
Social Functioning	76.9	20.0	100.0	20.2	Social Functioning	79.2	35.0	100.0	17.3
School Functioning	70.0	0.0	100.0	21.9	School Functioning	70.9	15.0	100.0	19.1

Bilateral Hearing Loss Self-Report					Bilateral Hearing Loss Proxy-Report				
	Mean	Range		Standard Deviation		Mean	Range		Standard Deviation
Total QOL	81.2	44.6	100.0	11.1	Total QOL	79.6	39.1	97.8	14.4
Physical Score	88.9	31.3	100.0	13.9	Physical Score	90.6	28.1	100.0	15.8
PsychosocialScore	77.1	51.7	100.0	12.3	PsychosocialScore	73.7	30.0	100.0	16.2
Emotional Functioning	74.4	45.0	100.0	18.1	Emotional Functioning	72.1	25.0	100.0	21.5
Social Functioning	83.1	60.0	100.0	11.4	Social Functioning	80.2	20.0	100.0	18.5
School Functioning	73.8	40.0	100.0	15.3	School Functioning	68.9	45.0	100.0	16.9

Note. Quality of life scores range from 0-100, higher scores indicate higher reported quality of life.

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 HAs
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

- ii. Reactive: bad grades, decreased attention,
 - d. If you had the power to change things about ____, what would be different?
- 5. Imagine you were sitting in the doctor's office waiting room. I am sitting next to you and am waiting for my child to return from having his hearing tested which confirms a profound UHL. What would you tell me?
- 6. UHL makes locating the origin of a sound difficult. When in a noisy cafeteria or outside on the playground communication is affected.
 - a. What other *situations* are difficult for your child with UHL?
 - i. Movies, basketball court, at the zoo
 - ii. What about situations at home? Mom's calling child from another room, in the car going to dinner with the family, etc.?
 - b. What does your child do when in these situations?
 - i. Talk loud, withdraw, mix-up the conversation, etc.
- 7. If you could take a class on hearing loss with your child what would you want to learn?
- 8. What do teachers expect of your child compared to his/her classmates?
 - a. Are children being given special attention or treated equally?
- 9. What do professionals tell you about your child's hearing loss?
 - a. What do they say you should expect/encounter?
- 10. What questions did I not ask but you feel I should have asked?

Appendix C.

PedsQL™ 4.0 Generic Core Scales Child Self-Report Item Content.

PedsQLTM
Pediatric Quality of Life
Inventory

ID#

Date: _____

Version 4.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than one	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by	0	1	2	3	4
6. It is hard for me to do chores around the	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age	0	1	2	3	4
5. It is hard to keep up when I play with other	0	1	2	3	4

ABOUT SCHOOL <i>(problems with...)</i>	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

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