

2008

Quality of life measure for adolescents and children with hearing loss

Amy M. Streufert

Follow this and additional works at: http://digitalcommons.wustl.edu/pacs_capstones



Part of the [Medicine and Health Sciences Commons](#)

Recommended Citation

Streufert, Amy M., "Quality of life measure for adolescents and children with hearing loss" (2008). *Independent Studies and Capstones*. Paper 437. Program in Audiology and Communication Sciences, Washington University School of Medicine.
http://digitalcommons.wustl.edu/pacs_capstones/437

This Thesis is brought to you for free and open access by the Program in Audiology and Communication Sciences at Digital Commons@Becker. It has been accepted for inclusion in Independent Studies and Capstones by an authorized administrator of Digital Commons@Becker. For more information, please contact engeszer@wustl.edu.

**QUALITY OF LIFE MEASURE FOR ADOLESCENTS AND CHILDREN
WITH HEARING LOSS**

by

Amy M. Streufert, B.S.

**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 21, 2010

**Approved by:
Judith E.C. Lieu, M.D., Capstone Project Advisor
Roanne Karzon, Ph.D., Second Reader**

Abstract: The purpose of this investigation was to determine the impact of hearing loss on the quality of life of adolescents and children. Focus group sessions were held for parents and children or adolescents with hearing loss to discuss their perceptions. Quality of life questionnaires were developed for adolescents and children with hearing loss.

Copyright by
Amy M. Streufert, B.S.

May 2010

Acknowledgements

I would like to thank Judith Lieu, M.D. and Roanne Karzon, Ph.D. for their guidance and encouragement in helping me complete this Capstone Project. I would also like to thank the Valente Scholarship Award for their support of this project.

Table of Contents

Acknowledgements.....	2
Summary	2
Objectives	2
Rationale	2
Design	4
Results.....	6
Conclusion	6
Introduction.....	8
Purpose.....	15
Methodology & Design.....	15
Research.....	15
Procedure	16
Analysis	16
Results.....	18
Discussion	22
Future Direction	23
Conclusion	24
References.....	25
Appendix A.....	29
Appendix B.....	30
Appendix C.....	34
Appendix D.....	36
Figure 1. Classification system used to code content of focus group sessions	32
Figure 2. Collage and description by focus group participants.....	33

Summary

Objectives

This study was a qualitative study to investigate the impact of hearing loss on the quality of life of children and adolescents aged 7-17 years. The long-term goal of this study was to create a hearing-specific quality of life measurement for children and adolescents with hearing loss. The primary aim was to gather information concerning the experiences children and adolescents with hearing loss have and appreciate how hearing loss affects their life. We attempted to gain information regarding which domains of quality of life are influenced by hearing loss through the use of focus group sessions. The information gathered will aid in creation of quality of life measurements specific for hearing loss. With these measurements we will be able to evaluate the hearing-specific quality of life of children with hearing loss as compared to their normal hearing peers.

Rationale

Hearing tests do not provide a complete picture of the impact of an individual's hearing loss. While hearing tests can provide quantifiable information regarding the status of an individual's hearing loss, they cannot provide information regarding the effect of the hearing loss on a person's everyday function, or the handicap imposed by the hearing loss (Ventry & Weinstein, 1982). Over the years, considerable emphasis has been placed on implementing screening services for hearing loss in children, including universal newborn hearing screening (UNHS). However, the intervention and treatment issues for children and families given the diagnosis of hearing loss have been given far less attention. Developing valuable intervention and treatment options are important because a detection system is only as beneficial as the intervention that is implemented following diagnosis. Appropriate management for children

following detection is vital and yet the system of care and intervention process is not well defined (Fitzpatrick et al., 2007).

Quality of life (QOL) refers to an individual's perceived physical and mental well-being (Parmet et al., 2002). Many factors that influence and contribute to a person's quality of life exist. A health-related quality of life (HRQOL) is concerned with those factors which influence a person's quality of life that can be affected by illness and their treatment. For example, a person's quality of life may be adversely affected by increased dependence on others due to pain brought on by an illness (Parmet et al., 2002).

Numerous studies have revealed that adults with hearing loss have poorer mental health, physical and social functioning, and overall quality of life (Strawbridge et al, 2000; Dalton et al, 2003; Chisholm et al., 2007). However, few studies have compared quality of life in hearing-impaired children to their peers with normal hearing. A pilot study by Borton, Mauze, and Lieu (AAA annual meeting, 2007) suggested that differences in quality of life between normal hearing children and those with hearing loss may be similar to those reported between children with chronic illness and healthy children (Varni et al., 2003).

The purpose of creating a quality of life measure is to assess the physical, emotional, and social dimensions of hearing loss. The advantage of using a generic health-related quality of life (HRQOL) questionnaire is that it allows for rating the quality of life of individuals and making comparisons across illnesses. Generic HRQOL questionnaires are not intended for a specific health condition but are nonspecific; they may lack validity or sensitivity to specialized subgroups, such as children with hearing loss (Sung et. al., 2003). No specific questions, for example, are aimed at hearing impairment in children (Chia et. al., 2007). Currently, no hearing-specific QOL measure for children exists.

After reviewing the existing adult QOL instruments for hearing loss, the Hearing Handicap Inventory for Adults (HHIA) was chosen as a platform for a new questionnaire for children (Ventry & Weinstein, 1982). The Hearing Handicap Inventory for Adults (HHIA) was chosen due “to its brevity, ease of administration/interpretation, excellent internal consistency reliability, and high test-retest reliability” (Newman & Weinstein, 1988; Newman et al., 1990). The HHIA has also been established as an appropriate measure to assess the emotional consequences and the social and situational effects of hearing impairment on adults (Weinstein, Spiter, & Ventry, 1986, Newman et. al, 1990). However, it lacks the physical effects of hearing loss that are related to a quality of life measure and is not geared towards a younger person’s daily life activities (Chia et. al., 2007).

To have a questionnaire for the child to fill out and not solely a parent-proxy report is also important. It has been well documented that information provided by proxy-respondents is not equivalent to that reported by the patient and thus should not be substituted for child reports (Achenback, McConaughy, & Howell, 1987; Varni, Limbers, & Burwinkle 2007).

Methods and Design

IRB approval for this study was obtained from the Human Research Protection Office (HRPO) of Washington University School of Medicine, St. Louis. Eligible subjects include children and adolescents ages 7-17 years with normal cognition and normal hearing, unilateral hearing loss, or bilateral hearing loss and their parents. The children and adolescents were recruited from St. Louis Children’s Hospital and Special School District of St. Louis County. Audiologists from these locations identified individuals who qualified to participate for the researcher. The eligible individuals were then contacted by the researcher, who had the

prospective participants sign an informed consent to participate in the focus group and to allow access to their audiological records.

Qualitative Methodology

The first part of the study involved contacting families of children and adolescents with hearing loss and asking them to take part in focus group sessions. Focus groups are useful for eliciting perceptions and experiences of an issue not well known or understood (Balch and Mertens, 1999). Our intent was to gain information regarding which domains of quality of life are influenced by hearing loss through the use of focus group sessions. The information packet contained guided questions to orient the participants toward the topics to be discussed.

A total of 19 individuals attended focus groups to assess how those with hearing loss feel their quality of life is affected by their hearing loss. Sessions were documented through audio recording as well as note-taking. Open-ended questions were used to encourage discussion. Two moderators were in the room with one leading the discussion and the other taking notes and making observations.

The raw data of a qualitative study are the discussion and narrative content from the participants. Interpretation and analysis of this data involves making sense of what has been recorded, looking for patterns, integrating what different people have said, and putting together information that was said in one place with what was said in a different place (Patton, 2002). The audio tapes from the focus group sessions were transcribed in Microsoft Word. Following transcription, content analysis was performed. Analysis involved identifying components, coding, and categorizing the components. During analysis, a distinction was made as to whether the statement was elicited from a child/adolescent or an adult. The individual perception was then listed under the appropriate category.

Following analysis of the data modified questionnaires were created following the format of the HHIA. The HHIA is comprised of two subscales looking at the emotional consequences and the social and situational effects of hearing impairment (Newman et al., 1990). The modified version kept these same areas and added the physical domain, related to adolescent and children's daily living. This modified version was created subsequent to the analysis of the data collected from the focus groups. This was reviewed by audiologists, faculty, and peers. Following comments and critiques a revised draft was made. This draft will then be given to a small sample of children and adolescents with hearing loss in a field-test. Following this initial review a final version will be developed.

Results

Eleven individuals attended the focus group session in November 2007. Eight individuals attended the focus group session in March 2008. Data were transcribed the transcript was used to extract the barriers discussed by participants and to create a list of problems children with hearing loss. The list was analyzed to categorize issues into content areas, with implications discussed toward real-world listening experiences. Audiologists, parents, and peers reviewed the initial questionnaire.

Conclusion

Focus group results indicate that children with hearing loss are affected differently than adults and the currently available adult inventories are not appropriate for children or adolescents. Parents' specific concerns included social and physical functioning. Following the analysis of the sessions, hearing related QOL measures for children and adolescents were created and reviewed by audiologists, parents, and peers. Self-reporting techniques are recognized as valuable assessment tools for adults. Although results from this study are preliminary, similar

assessments tools for adolescents and children appear to be valuable for assessing interventions and (re)habilitation.

Introduction

The Department of Health and Human Services (Centers for Disease Control and Prevention) state that more than 12,000 babies are born with some form of hearing loss in the United States each year (2007). According to Niskar et al. (1998), approximately 15% of US children have some form of hearing loss. With these children being identified at increasingly younger ages, intervention needs to be monitored over the years as they grow and their listening needs change.

Over the years, considerable emphasis has been placed on implementing screening services for hearing loss in children, including universal newborn hearing screening (UNHS). However, intervention and treatment issues for children with hearing loss and their families have been given far less attention. This hinders the care and treatment of these children because a detection system is only as beneficial as the intervention that is implemented following diagnosis. Appropriate management of care a child receives following detection is vital and yet the system of care and intervention process is not well defined (Fitzpatrick et al., 2007). With services evolving over the years, keeping abreast of how the children are performing, not only audiological but also overall is important. Hearing loss causes a broad impact on a child's development and it is unclear whether clinical measures such as pure tone thresholds and measures of speech reception threshold and discrimination correlate with functioning in school and social environments (Lin & Niparko, 2006). Children with hearing loss have various professionals (e.g. teachers, speech pathologists, occupational therapists) who work with them both in school and outside of the school environment. These different professionals may all have different perceptions of the child's performance. The child's social, emotional, and physical abilities cannot be predicted from clinical audiological tests (Purdy et al., 2002; Ventry & Weinstein, 1982).

Sensorineural hearing loss in children, as well as adults, is a chronic condition for which medical or surgical treatment is not commonly available. However, audiological treatment with amplification through hearing aids and/or other assistive devices is possible. The goal of intervention is to improve the individual's communication and auditory perception as well as minimize restrictions and impairment brought on by the hearing loss (Chisholm et al., 2007; Kiessling et al., 2003). Typically, the effects of intervention are objectively measured in children and adolescents through sound field and/or real-ear measurements. Understanding how the child's overall quality of life is affected by the assistive device(s) and determining whether treatment has been optimized is important.

Available listening questionnaires for school-aged children include: Screening Instrument for Targeting Educational Risk (SIFTER), Hearing Performance Inventory for Children (HPIC), Listening Inventories for Education (LIFE), Children's Auditory Behavior in Everyday Life (ABEL), Abbreviated Profile of Hearing Aid Benefit (APHAB) for Children, Meaningful Auditory Integration Scale (MAIS). These questionnaires however, do not encompass what we are seeking in a quality of life measurement. The ABEL and MAIS questionnaires look only at parental perceptions of their children's auditory behavior. The SIFTER, LIFE, and HPIC inventories are designed specifically for classroom listening and are not intended for parental evaluation of auditory behavior outside of school. The children's APHAB covers a range of listening environments but is designed to assess hearing aid benefit. The HPIC, LIFE, and APHAB for children questionnaires are intended to determine whether specific behaviors have been achieved rather than comparing the child with their peers. Quality of life assessment involves the perception of the individual and not just their functional status. Although there are functional assessments available, none look specifically at the quality of life.

According to the Journal of the American Medical Association (Parmet et al., 2002), quality of life (QOL) refers to an individual's perceived physical and mental well-being. Many factors that influence and contribute to a person's quality of life exist. A health-related quality of life (HRQOL) questionnaire includes factors which influence a person's quality of life that can be affected by illness and their treatments. For example, a person's quality of life may be adversely affected by increased dependence on others due to pain brought on by an illness (Parmet et al., 2002).

Studies looking at children's overall well-being are often performed with general samples of school-age students. While such studies are pivotal, various authors contend that enhanced life quality should be considered the primary goal of *every* youth, including those with disabilities (Gilman et al. 2004; Brown et al., 1999; Green and Reid, 1999; Griffin and Huebner, 2000). Studies focused on hearing impaired children have found that they have more behavioral and social problems than their normal hearing peers (Davis & Hind, 1999; Eldik et al., 2004). Studies using health-related quality of life (HRQOL) measurements have shown that children with adverse health conditions score more poorly than their normally developing peers (Waters et al., 2003; Wake, Salmon, & Reedihough, 2003). A study by Gilman et al. (2004) revealed that deaf/hard of hearing youth reported overall lower life satisfaction scores across multiple domains compared to their normal hearing peers. Most studies addressing the effects of hearing loss are on adults. The results with adults have revealed psychosocial effects associated with hearing impairment, even in the case of mild hearing loss. These effects include a decreased quality of life and well-being, poorer mood and depression, social isolation, and poorer physical functioning (Chia et al., 2007). The elderly also report their perceived effects of hearing impairment as severe handicaps, even in those individuals with only mild to moderate hearing

losses (Mulrow et al., 1990). However, these results should not be generalized to children and adolescents.

The quality of life of both the younger and older populations with hearing loss needs to be addressed. Assessment of the quality of life of those with hearing loss is often subjective and not easily quantifiable. However, an assessment scale that quantifies the self-perceived disability is also an objective tool that allows for quantifying the efficacy of intervention (Newman and Weinstein, 1988).

One way to assess the quality of life is through health-related quality of life (HRQOL) measurements. Such measurements are comprised of the physical, emotional, and social dimensions of a condition (Chia et al., 2007). These measurements can be used to examine how a particular condition is affecting a person's life and how the well-being of that individual compares to those with and without the condition (Wake et al., 2004).

One available generic health questionnaire is the Child Health Questionnaire (CHQ). This questionnaire emphasizes subjective perspectives that concentrate on aspects of health important to all children: physical, emotional, social, and family themes (Wake et al., 2003). The CHQ utilizes 14-concept health status and well-being concepts as well as physical and psychosocial scores (Bukstein et al., 2000). The questionnaire was developed specifically for children and contains 12 scales, including those which evaluate the effects of a child's health on their behavior and self esteem as well as effects on family functioning.

The Pediatric Quality of Life InventoryTM Version 4.0 (PedsQLTM) is another instrument used to document the individual's perceived overall QOL (Varni et al., 1999). The PedsQLTM is comprised of 23 questions encompassing subscales of physical, emotional, social, and school functioning. There are separate PedsQLTM forms for different pediatric age groups. These

include one for each of the following: children 6-7 years old, 8-12 years old, and adolescents 13-18 years old. The PedsQL™ children 7 years and younger includes a parent-assisted inventory. Children and adolescents 8-17 years complete the child self-report inventory and all parents complete a proxy-report inventory. The self and proxy inventories have parallel questions differing only by age appropriate language. The three main scale scores are 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. While these are widely used generic HRQOL measures, they are just that-generic and non-specific for our population of interest, those with hearing loss.

The advantage of using a generic health-related questionnaire is that such instruments have the ability to rate the quality of life of an individual and compare it across illnesses. These generic questionnaires also typically include normative data and this allows for comparison of the effects of one condition against a range of other medical conditions (Spieth and Harris, 1996). HRQOL questionnaires are not intended for a specific health condition but rather are nonspecific; they may lack validity or sensitivity to specialized subgroups, such as children with hearing loss (Sung et al., 2003). For example, they may have no specific questions aimed at hearing impairment (Chia et al., 2007). In a review by Chisholm et al (2007) studies using disease-specific instruments (such as the Hearing Handicap Inventory for the Elderly) for HRQOL outcome measures showed strong reductions in the emotional and social impacts of hearing loss for adult participants (as a result of hearing aid use) contrary to the results of those utilizing a generic instruments which did not show such robust outcomes. Similar results were reported by Mulrow et al. (1990) who reported that disease-specific instruments were better at

detecting adverse effects of hearing impairment in the elderly than generic functional status measurements. Disease-specific measures are also more likely to provide information that is clinically relevant and be included into clinical protocols more than generic measures (Spieth and Harris, 1996). One goal of assessing the quality of life of a child with hearing loss is to determine whether or not (further) intervention is necessary. There are no currently available tools are for this evaluation.

The Pediatric Quality of Life Inventory (PedsQL) is an example of a HRQOL instrument which contains a separate form for the parents to complete on the child's behalf. It has been shown for both children and adults that results of proxy-respondents (those filled out by a parent or significant other on the patient's behalf) are not equal to results of the patient (Achenbach, McConaughy, & Howell, 1987; Sprangers & Aaronson, 1992). Studies have also shown that a poor correlation between parent and child scores, specifically for mental, social, and emotional functioning domains, exists when utilizing HRQOL assessment tools (Lin & Niparko, 2006, Hays et al., 2006). Additionally, evidence supports the reliability and validity of pediatric patient's ability to self-report their HRQOL when assessed with an age-appropriate measurement (Varni et al., *Literature Review*, 2007). Although patient reported measures should be considered the predominant method for assessing HRQOL in pediatrics, a complementary parent proxy-report should also be considered. A parent proxy-report proves to be a useful tool for children who are too young, too cognitively impaired, too ill or fatigued to complete a valid HRQOL measure (Hays et al., 2006; Varni, Limbers, & Burwinkle, 2007). Additionally, a child's health care is often influenced predominantly by the parent's perceived HRQOL rather than the child's perspectives (Varni, Limbers, & Burwinkle, 2007; Janicke, Finney, & Riley,

2001). Therefore, it may be beneficial to have both the parent's and the child's perspectives to provide the whole picture and to help guide the audiologist and parent.

Ronen and colleagues (1998) have emphasized that measurement tools are more likely to be valid if the HRQOL questions are derived from a sample of the population in which the tool is to be used. However, to date no specific HRQOL questionnaires have been created specifically for the children and adolescent populations with hearing loss. It is logical to involve those with hearing loss, in addition to their parents, as a foundation for information.

A proposed method for creating more disease specific questionnaires is to take advantage of the lengthier scales and utilize them as "item pools" from which to draw relevant questions. This is advantageous in that it provides well-tested questions that are clearly written and providing information that may be comparable to the standardized questionnaires (Deyo & Patrick, 1989).

After reviewing the existing adult QOL instruments for hearing loss, the Hearing Handicap Inventory for Adults (HHIA) was chosen as the platform for the new questionnaire. The HHIA was chosen due "to its brevity, ease of administration/interpretation, excellent internal consistency reliability, and high test-retest reliability" (Newman & Weinstein, 1988). The HHIA has been established as an appropriate measure to assess the emotional consequences and the social and situational effects of hearing impairment on adults (Weinstein, Spiter, & Ventry, 1986, Newman et. al, 1990). However, it lacks the physical effects of hearing loss that are related to a quality of life measure and it is not geared towards a younger person's daily life activities (Chia et. al., 2007).

In order to grasp a valid understanding of the issues related to a certain population and the questions to be formed from those issues, it is essential to derive information from a sample

of the population in which the tool is to be used. Qualitative research using the children themselves as respondents has only recently been utilized (Ronen et al., 2001). As stated previously, with quality of life assessment the focus is on the self-perceived functioning and wellbeing of the individual. Therefore we found it only logical to involve children and adolescents with hearing loss, and their parents, as pivotal sources of information. Focus groups were used to elicit information from the populations of interest. Focus groups are useful for eliciting perceptions and experiences of an issue not well known or understood. Through focus groups, ideas are often generated through the sharing and expanding of ideas that may not have surfaced through individual interviews (Balch and Mertens, 1999).

Purpose

The objective of this study was to create quality of life (QOL) measurements for children and adolescents with hearing loss. Studies concerning hearing impaired children have found that they present more behavioral and social problems than their normal hearing peers (Davis & Hind, 1999). However, there is currently no available quality of life assessment tool specifically available for children or adolescents with hearing loss. Through investigating what difficulties children and adolescents with hearing loss experience related to QOL categories, we will be able to generate a list of significant topics and create such questionnaires.

Based on literature review, we formulated the following hypotheses:

1. Children and adolescents with hearing loss will report daily issues that differ from adults with hearing loss; and
2. A valid and reliable instrument for children and adolescents with hearing loss can be created to assess hearing-related quality of life.

The study was designed to be carried out in two stages. The first stage included the use of focus groups to obtain subjective perceptions of hearing loss for the two age groups: children (7-12) and adolescents (over 12-17). The second stage included the creation of QOL questionnaires for children and adolescents.

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. Eligible subjects include children and adolescents ages 7-17 years with normal cognition and normal hearing, unilateral or bilateral hearing loss; and the parents of those subjects. The goal in setting these inclusion criteria was to involve children and adolescents with hearing loss who would resemble those for whom the questionnaire was being developed. The children and adolescents were recruited from St. Louis Children's Hospital and Special School District of St. Louis County. Audiologists from these locations identified individuals who qualified to participate for the researcher. A total of 32 possible subjects from St. Louis Children's Hospital and 28 possible subjects from Special School District of St. Louis County were identified by audiologists. The eligible individuals were then contacted by the researcher. A total of 18 parents who were interested in participating contacted the researcher for more information. A follow-up phone call was made to the families resulting in the parents of 8 children and 6 adolescents agreeing to participate. The researcher had the prospective participants sign an informed consent to participate in the focus group and to allow access to view their audiological records.

A qualitative study design was utilized to gain subjective information regarding the feelings, opinions, and thoughts of children with hearing loss, adolescents with hearing loss, and their parents on issues that affect the quality of life of those with hearing loss.

Procedure

Phone calls were made to eligible families and information packets were sent to those who were interested in participating. These packets included questions/topics that would be discussed at the focus group, a brief schedule of events for the session, directions, consent forms, and a letter explaining the study and appropriate contact information. The questions for children/adolescents are provided in Appendix A and the questions for parents is provided in Appendix B. Written consent was obtained from all participants the day of the focus group.

The focus groups were held in quiet rooms with snacks and drinks available outside the classrooms for participants. The participants sat in a circle to encourage participation and include everyone in the discussion. Sessions were documented through audio recording as well as note-taking. Open-ended questions were used to encourage discussion. Two moderators were in the room with one leading the discussion and the other taking notes and making observations.

The sessions began with an introduction of the moderators and the study followed by an ice breaker activity with all participants. To encourage honest and open discussion, parents and children were separated into two separate focus groups. The parents began open discussion immediately while the children started with a hands-on activity. This activity consisted of the children finding pictures from magazines for the following statements: “Find some pictures that describe you”, “What are some places where you notice your hearing loss the most?”, and “Find pictures that show how your hearing loss makes you feel.” These statements were written on the

board for continued reference. This allowed the children to be active and share their feelings comfortably.

The sessions were limited to two hours. Halfway through the discussion, a break was given with snacks and refreshments available. Participants were compensated for involvement in the study with \$10 gift cards.

Analysis

The raw data of a qualitative study are the discussion and narrative content from the participants. Interpretation and analysis of this data involves making sense of what has been recorded, looking for patterns, integrating what different people have said, and putting together information that was said in one place with what was said in a different place (Patton, 2002). The audio tapes from the focus group sessions were transcribed in Microsoft Word. Following transcription, analysis of the content was performed. The flow chart of how the transcribed data were categorized, analyzed, and coded is provided in Figure 1. Analysis involved identifying components, coding, and categorizing these components. A total of 5 categories were identified: school, emotional, physical, social, and well-being/future. During analysis, a distinction was made as to whether the statement was elicited from a child/adolescent or an adult. The individual perception was then listed under the appropriate category.

Following the analysis of the focus groups new measurements were created. The new questionnaires are based on the Hearing Handicap Inventory for Adults. The HHIA is a 25-item self-assessment scale composed of two subscales: emotional and social/situational. The scoring system consists of a yes which is awarded 4 points, sometimes is 2 points, and no is 0 points. Possible scores range from 0, which suggests no perceived handicap, to 100, which indicates significant perceived handicap. The new questionnaires are in similar format; however, they also

include questions about the physical domain in addition to the emotional and social/situational subscales. This allows for a more complete quality of life assessment.

Results

A total of 19 individuals attended the focus group sessions. Data were transcribed and extracted to note all barriers discussed by participants. The list of problems children and adolescents with hearing loss experience was compiled with a total of 5 categories identified: school/education, emotional, physical, social, and well-being/future.

A collage of pictures that were found by the children and adolescents was compiled and comments recorded. This can be viewed in Figure 2.

School/Education

Children and adolescents stated that classes that were less structured, larger, and with a lot of students talking were harder for them. Classes in which the teachers were soft-spoken are also more difficult. A female adolescent with bilateral hearing loss stated that “the younger teachers they try pointing at things and talking directly at you in class and you’re a little embarrassed; it’s like I don’t like that kind of attention.” They stated that most of their teachers don’t really know how to act towards them or ways to help them without singling them out.

Emotional

Emotional aspects of hearing loss included being embarrassed by hearing aids and becoming annoyed by people constantly asking them about their hearing aids. They also discussed how annoying it becomes when others try too hard to “help” them hear. An adolescent with bilateral hearing loss stated “sometimes I feel lonely because I don’t have other kids my age that have hearing loss”. Most children and adolescents stated that they preferred having other students with hearing loss in their school or as friends. The majority of the adolescents stated

that they felt their hearing loss concerned them more or bothered them more when they were younger and they have accepted it more as they have grown up.

Physical

Physical issues that were discussed included avoiding certain environments such as the movies or loud restaurants and choosing more quiet environments when possible. One boy stated that his parents won't let him ride his bike alone. Most agreed that hearing aids are a "pain" when playing sports. One teenage girl with hearing loss stated that she took her hearing aids out when running in races and felt it was an advantage to not have any distractions.

Social

Going to the beach or a pool was one social dilemma for participants. They stressed the difficulty of either going swimming and not hearing friends or sitting on the side outside the water with their hearing aids on to hear their peers. They also discussed being in big groups; one adolescent girl with hearing loss explained being frustrated when "my friend pulls me from the group and tells me what's going on." The child participants all agreed that word or listening games and activities in class where hearing plays a big role are hard and frustrating for them. Most participants stated that they liked having friends with hearing loss and other kids in their schools with hearing loss and hearing aids. They appreciate having someone who understands and can relate to that part of their life, their hearing loss.

Well-being/Future

Most participants were not too worried about their future careers or have already thought about how they would adapt for the professions that they had chosen. A few stated some apprehension about college. The immediate future issues were more of a concern than thinking about careers and other more distant matters.

A few also stated that they try to avoid people whom they have trouble hearing or understanding. They also agreed that some people treat them differently and it could become annoying when people try to be nice or change how they act towards them once they find out they have hearing loss. One child with bilateral hearing loss stated that it makes her uncomfortable when a person changes the way they act and especially frustrating when they over-enunciate. They also discussed how they have worries that their friends do not have, such as “like when the battery [for the hearing aid] runs out in the middle of class or something and it’s so hard cause then you have to try to like try to excuse yourself to go to your locker or the bathroom” and “sometimes during class [the hearing aid] starts buzzing and you have to turn it off.” These are issues that do not concern the average student with normal hearing.

Parents stated that it was harder for their children to make friends and they really had to push them. They recognized that many of the children did not have friends until school. The parents stated their concerns for their children, whether it is difficulty playing sports without their hearing aids or being able to get a job because of their hearing loss. Social issues were a common theme among both the children and adolescent parent groups. One parent explained that their boy with bilateral hearing loss “doesn’t get social, he talks too much...he’s afraid he’s going to miss what the other person is gonna say,...[so] he’ll keep talking and talking.” One father of two teenagers with bilateral hearing loss viewed himself as a “buffer” for his children to the hearing world and worries about what they would miss without their parents. While some concerns were concerns that all parents share, such as letting them go out with friends alone or getting them a cell phone, other issues are clearly unique to parents of children with hearing loss. Hearing aid equipment is also an issue--one father described the equipment as a “black hole,” because they (the parents) do not understand it or what their children get out of it. Difficulty

with sports was a topic that the children, adolescents, and parents discussed. All the groups agreed that the children had more difficulty with their peers hearing both the other players and especially the coaches and parents on the side-lines.

Focus group results indicated that children and adolescents with hearing loss are affected differently than adults and the currently available adult inventories are not appropriate for children or adolescents. Parents' specific concerns included social and physical functioning.

Following the analysis of the sessions, hearing-related QOL measures were created for children ages 7-12 years and adolescents ages 12-17 years. These can be viewed in appendices 3 and 4. The questionnaires were then reviewed by audiologists and colleagues in the St. Louis area.

Discussion

This study was the initial endeavor to elicit QOL information directly from children and adolescents. The use of focus groups as a qualitative method to achieve this proved to be an effective technique. We demonstrated that focus groups with children and adolescents are a reasonable and appropriate method to explore how children and adolescents with hearing loss perceive their quality of life. The focus groups allowed participants to share their thoughts candidly.

Focus group results indicate that children and adolescents with hearing loss are affected differently than adults. Therefore, currently available adult inventories are not appropriate for children or adolescents. In contrast to adults who are concerned with self-sufficiency and depression or mood, children and adolescents are more concerned with domains such as school, sports, and fitting-in with their peers (Chia et al., 2007). The results from the focus groups support previous findings that children with hearing loss experience more social problems than

their normal hearing peers (Davis & Hind, 1999; Eldik et al., 2004). Although this may be true for some children with hearing loss, as we found in our qualitative study, it is not something that can be assumed true for *all* children with hearing loss. It can also not be assumed that these individuals are receiving maximum support.

The primary aim of this study was to develop a clinical tool that improves the quality of life for children and adolescents with hearing loss. The credibility of the study was supported by the use of focus groups; this methodology was consistent with the research questions and the study objectives. The findings of this study were presented in a way to be utilized for further research and in the creation of new assessment instruments for the target populations.

In qualitative research, like any research methodology, limitations exist. The personnel running the focus groups were not all professionally skilled moderators and the children and adolescent focus groups were not always run efficiently. The children would sometimes go off on unrelated tangents and introduce irrelevant issues.

Limitations of the study also existed due to difficulty with participant recruitment and possible selection bias. A few participants were unable to come the day of the focus groups due to transportation issues or parents working multiple jobs. A higher response rate may have been achieved with weekday sessions or repeated mailings. The involvement of those unable to come may have brought up other issues and areas of concerns for both the adult and children's groups.

Future Direction

In order to be confident in our instruments' reliability, validity, and responsiveness, they need to be tested in the same setting and same population with a comparable competing scale (Deyo & Patrick, 1989). With this knowledge, the next steps will involve the need to test the new instruments and ensure their reliability and validity before being implemented. In addition,

for such instruments to be useful for clinicians, the measures will need to be as short and concise as possible while preserving the validity and functionality (Deyo & Patrick, 1989). Thus, the questionnaire will likely go through alterations and testing before being an effective method of assessing the quality of life in children and adolescents.

Conclusion

Hearing loss is a condition that affects both the young and older populations' quality of life in various ways. In contrast to adults who are concerned with self-sufficiency and depression or mood, children and adolescents are more concerned with domains such as school, sports, and fitting-in with their peers. Without appropriate assessment of the quality of life for children and adolescents, it should not be assumed that they are receiving appropriate intervention specific to their needs. With a suitable assessment tool for children and adolescents the clinician would be able to effectively evaluate how that child's quality of life is affected by their hearing loss and what further involvement may be necessary.

References

- Achenbach, T. M., McConaughy, S.H. & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychology Bulletin*, *101*, 213-232.
- Balch, G. I., & Mertens, D. M. (1999). Focus group design and group dynamics: Lessons from the deaf and hard of hearing participants. *American Journal of Evaluation*, *20*(2), 265-277.
- Borton, S., Mauze, Lieu, J. Quality of Life in Children with Unilateral hearing Loss: A Pilot Study. (AAA conference April 2007).
- Brown, W.H., Odom, S.L., Li, S., & Zercher, C. (1999). Ecobehavioral Assessment in Early Childhood Programs: A Portrait of Preschool Inclusion. *Journal of Special Education*, *33*.
- Bukstein, D.A., McGrath, M.M, Buchner, D.A., Landgraf, J., & Goss, T.F. (2000). Evaluation of a short form for measuring health-related quality of life among pediatric asthma patients. *Journal of Allergy Clinical Immunology*, *105*(2 part 1), 245-251.
- Chia, E., Wang, J.J., Rochtchina, E., Cumming, R.R., Newall, P., Mitchell, P. (2007). Hearing Impairment and Health-Related Quality of Life: The Blue Mountains Hearing Study. *Ear and Hearing*. *28*(2), 187-195.
- Chisolm, T.H.; Johnson, C.E.; Jeffrey L. Danhauer, J.L.; Laural J.P.; Portz, L.J.P.; Abrams, H.B.; Lesner, S.; McCarthy, P.A.; Newman, C.W. (2007). A Systematic Review of Health-Related Quality of Life and Hearing Aids: Final Report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. *Journal of American Academy of Audiology* *18* (151-183).
- Dalton D.S.; Cruickshanks K.J.; Klein B.E.; Klein R.; Wiley T.L.; Nonhdahl D.M. (2003) The impact of hearing loss on quality of life in older adults. *Gerontologist*, *43*, 661–668.
- Davis, A., & Hind, S. (1999). The impact of hearing impairment: A global health problem. *International Journal of Pediatric Otorhinolaryngology*, *49*(Suppliment), S51–S54.
- Department of Health and Human Services Center for Disease Control and Prevention. (2007). Retrieved January 19, 2008. *Early Hearing Detection & Intervention Program*. Web site: <http://www.cdc.gov/ncbddd/ehdi/default.htm>.
- Deyo, R.A. & Patrick, D.L. (1989). Barriers to the Use of Health Status Measures in Clinical Investigation, Patient Care, and Policy Research. *Medical Care*, *27*(3) S254-S268.
- Eldik, T.V.; Treffers, D.A.; Veerman, J.W.; Verhulst, F.C. (2004). Mental Health Problems of Deaf Dutch Children As Indicated by Parents' Responses to the Child Behavior Checklist. *American Annals of the Deaf*, *148*(5), 390-395.

- Fitzpatrick, E., Coyle, D.E., Durieux-Smith, A., Graham, I.D., Angus, D.E., Gaboury, I. (2007) Partents' Preferences for Services for Children with Hearing Loss: A Conjoint Analysis Study. *Ear and Hearing* 28, 842-849.
- Gilman, R., Easterbrooks, S.R., Frey, M. (2004). A Preliminary Study of Multidimensional Life Satisfaction Among Deaf/Hard of Hearing Youth Across Environmental Settings. *Social Indicators Research*, 66, 143-164.
- Griffin, M.D., Huebner, E.S. (2000). Multidimensional Life Satisfaction Reports of Middle School Students with Serious Emotional Disturbance. *Journal of Psychoeducational Assessment*, 18(2), 111-124.
- Green, C.W., and Reid, D.H. (1999). A Behavioral Approach to Identifying Sources of Happiness and Unhappiness Among Individuals With Profound Multiple Disabilities. *Behavior Modification*, 23(2), 280-293.
- Hays, R.M., Valentine, J., Haynes, G., Geyer, J.R., Villareale, N., McKinstry, B., Varnie, J.W., Churchill, S.S. (2006). The Seattle Pediatric Palliative Care Project: Effects on Family Satisfaction and Health-Related Quality of Life. *Journal of Palliative Medicine*, 9(3), 716-728.
- Janicke, D.M., Finney, J.W., Riley, A.W. (2001). Children's Health Care Use A Prospective Investigation of Factors Related to Care-Seeking. *Medical Care*, 39(9), 990-1001.
- Kiessling J., Pichora-Fuller, M.K., Gatehouse, S., Stephens, D., Arlinger, S., Chisolm, T., Davis, A.C., Erber, N.P., Hickson, L., Holmes, A., Rosenhall, U., & von Wedel, H. (2003). Candidature for and delivery of audiological services: special needs of older people. *International Journal of Auidology*, 42(Suppliment), 2S92-101.
- Lin, F.R. & Niparko, J.K. (2006). Measuring health-related quality of life after pediatric cochlear implantation: A systematic review. *International Journal of Pediatric Otorhinolaryngology*, 70, 1695-1706.
- Mulrow, C.D., Aguilar, C., Endicott, J.E., Velez, R., Tuley, M.R., Charlip, W.S., Hill, J.A. (1990). Association between hearing impairment and the quality of life of elderly individuals. *Journal of American Geriatrics Society*, 38(1), 45-50.
- Newman, C.W., Weinstein, B.E. (1988). The Hearing Handicap Inventory for the Elderly as a Measure of Hearing Aid Benefit. *Ear and Hearing*. 9(2), 81-85.
- Newman, C. W., Weinstein, B. E., Jacobson, G. P., & Hug, G. A. (1990). The hearing handicap inventory for adults: Psychometric adequacy and audiometric correlates. *Ear and Hearing*, 11, 430-433.

- Niskar, A.S.; Kieszak, S.M.; Holmes, A.; Esteban, E.; Rubin, C.; Brody, D.J. (1998). Prevalence of Hearing Loss Among Children 6 to 19 Years of Age The Third National Health and Nutrition Examination Survey. *Journal of the American Medical Association*, 279(14): 1071-1075.
- Patton, Michael Quinn. (2002). *Qualitative Research & Evaluation Methods 3rd Edition*. Thousand Oaks: Sage Publications.
- Parmet, S.; Lynn, C.; Glass, R.M. (2002). Quality of Life. *The Journal of the American Medical Association*, 288 (23), 3070.
- Purdy, S.C., Farrington, D.R., Moran, C.A., Chard, L.L., Hodgson, S.A. (2002). A Parental Questionnaire to Evaluate Children's Auditory Behavior in Everyday Life (ABEL). *American Journal of Audiology*, 11, 72-82.
- Ronen, G.M., Rosenbaum, P., Law, M., Streiner, D.L. (2001). Health-related quality of life in childhood disorders: A modified focus group technique to involve children. *Quality of Life Research*, 10, 71-79.
- Spieth, L.E., & Harris, C.V. (1996). Assessment of Health-Related Quality of Life in Children and Adolescents: An Integrative Review. *Journal of Pediatric Psychology*, 21(2), 175-193.
- Sprangers, M.A. & Aaronson, N.K. (1992). The Role of Health Care Providers and Significant Others in Evaluating the Quality of Life of Patients with Chronic Disease: A Review. *Journal of Clinical Epidemiology*, 24(7), 743-60.
- Strawbridge, W.J.; Wallhagen, M.I.; Shema, S.J.; Kaplan, G.A. (2000) Negative consequences of hearing impairment in old age: a longitudinal analysis. *Gerontologist*, 40, 320–326.
- Sung, L, Greenburg, ML, Doyle, JJ, Young, NL, Ingber, S, Rubenstein, J, Wong, J, Samanta, T, McLimont, M, Feldman, BM. (2003). Construct validation of the Health Utilities Index and the Child Health Questionnaire in children undergoing cancer chemotherapy. *British Journal of Cancer*, 88, 1185-1190.
- Varni, J. W., Burwinkle, T. M., Seid, M., & Skarr, D. (2003). The PedsQL™ 4.0: as a Pediatric Population Health Measure: Feasibility, Reliability, and Validity. *Ambulatory Pediatrics*, 3(6), 329-341.
- Varni, J.W., Limbers, C., Burwinkle, T.M. (2007). Literature Review: Health-Related Quality of Life Measurement in Pediatric Oncology: Hearing the Voices of the Children. *Journal of Pediatric Psychology*, 1-13.
- Varni, J.W., Limbers, C., Burwinkle, T.M. (2007). Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, 5(2).

- Varni JW, Seid M, Rode CA. The PedsQL: Measurement model for the pediatric quality of life inventory. *Medical Care*. 1999; 37(2):126-139.
- Ventry, I.M.; Weinstein, B.E. (1982). The Hearing Handicap Inventory for the Elderly: a New Tool. Article. *Ear & Hearing*. 3(3),128-134.
- Wake M, Hughes EK, Collins CM, Poulakis Z. (2004). Parent-reported health-related quality of life in children with congenital hearing loss: a population study. *Ambulatory Pediatrics*, 4:411-417.
- Wake, M., Salmone, I. Reddihough, D. (2003). Health status of Australian children with mild to severe cerebral palsy: cross-sectional survey using the Child Health Questionnaire. *Developmental Medicine & Child Neurology*, 45, 194-199.
- Waters, E.B., Wake, M.A., Hesketh, K.D., Ashley, D.M., & Smibert, E. (2003). Health-Related Quality of Life of Children with Acute Lymphoblastic Leukaemia: Comparisons and Correlations Between Parent and Clinician Reports. *International Journal of Cancer*, 103, 514-518.
- Weinstein, B. E., Spiter, J.B., Ventry, I.M. (1986). Test-Retest Reliability of the Hearing Handicap Inventory for the Elderly. *Ear and Hearing*. 7(5), 295-299.

Appendix A.

Focus Group Questions for Adolescents with Hearing Loss:

Areas of Life affected by Hearing Loss

1. What ways/situations/examples are there that your hearing loss affects what you do, how you feel, or what you might do differently from kids without hearing loss?
2. What are some situations where your hearing aids are absolutely necessary; where you might have extreme difficulty without them?
3. If you wear hearing aids, are you uncomfortable if people ask you about them?
4. How do you think dating will be affected by your hearing loss? Will you plan where you go out to eat more carefully/the activity of the date (movies vs. concert vs. mini golf)
5. Do you have a hard time in the cafeteria or when you're out to eat with friends or family?
6. Are you less likely to participate in certain activities because of your hearing loss?
Sports, parties, classroom participation
7. What classes do you have the most trouble hearing in? Why?
 - a. Spelling, English, Math, Science...anyone in band? Choir? Are those harder/easier than other classes?
 - b. Are you comfortable raising your hand if you know the answer?
8. What do you plan on doing after high school/college? Do you think your hearing loss will influence what career/profession you go into?
9. What questions did I not ask that you feel I should have asked?

Appendix B.

Focus Group Guide for Parents of Children/Adolescents with Hearing Loss

How they feel their child handles their hearing loss

1. Do you or does anyone in your family have hearing loss?
2. What are some situations where your child has more difficulties due to their hearing loss?
Social activities, restaurants
3. Does the hearing loss limit what your child can do, i.e. are there physical functioning limitations? Examples:
 - a. Are you less likely to let your child ride their bike by themselves due to their hearing loss?
 - b. Are you more proactive of your child with hearing loss? (Then maybe other “normal” hearing siblings?)
4. Are there certain school classes/activities that your child has stated they have trouble participating in due to their hearing loss? Cafeteria, sports/gym
5. Do you think your child’s future profession is limited? Does your child ever express concern about not being able to do certain things because they have a hearing loss?
6. What concerns you the most about your child’s hearing loss? (Is it a big concern or are there other things you worry more about with your child-if they have a learning disability, etc....where does the hearing loss rate in the scheme of things?)
7. Where do you notice your child improves the most with use of their hearing aid(s)? Are there certain instances where you don’t think your child could participate if they did not have hearing aid(s)? sports, classroom, hanging out with friends (social life)

8. What other ways/situations/examples are there in that your child's hearing loss affects what they do or what they might do differently from kids without hearing loss?
9. What questions did I not ask that you feel I should have asked?

HHIA

1. What were your initial impressions of the questionnaire?
2. Do you think your child would be able to answer the questions?

Understandable/able to answer how they hear WITHOUT hearing aid(s)/able to answer with just YES/SOMETIMES/NO
3. Which questions do you think would not apply to your child? Why?
4. Are there any questions/issues that were not addressed by the questionnaire but you thought should be? Any questions you would like to see on a questionnaire geared towards adolescents/children?

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

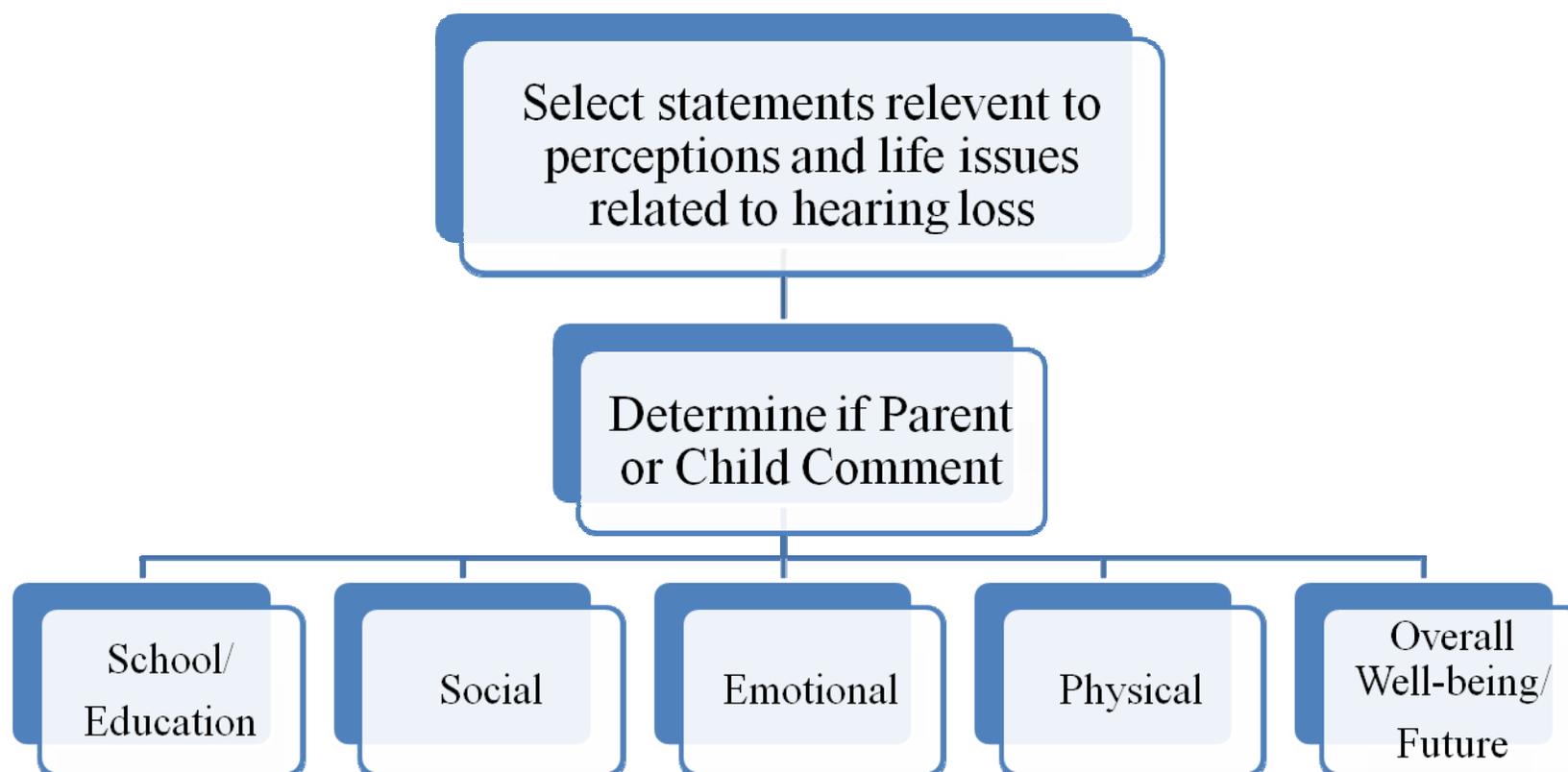


Figure 2. Collage and description by focus group participants



- A. "It's hard to play sports together because I have to take my hearing aids off" -13 year old boy with bilateral hearing loss
- B. "Sometimes I feel like a robot because the hearing aids are electronic and people always ask what they are" -9 year old boy with bilateral hearing loss
- C. "Sometimes I feel disappointed"-10 year old boy with unilateral hearing loss
- D. "Math class is hard because other kids are loud" -13 year old girl with bilateral hearing loss
- E. "I feel frustrated in different situations-in school with teachers, with friends" -14 year old girl with bilateral hearing loss
- F. "Sometimes I'm confused" -14 year old girl with bilateral hearing loss
- G. "Sometimes I have to work extra hard to hear what's going on" -13 year old boy with unilateral hearing loss
- H. "I'm happy being me" -9 year old boy with bilateral hearing loss

Hearing Related QOL Measurement for Children

Instructions:

The purpose of this scale is to find how your hearing is affecting you. Answer YES, SOMETIMES, or NO for each question. If you use a hearing aid, please answer the way you hear with the hearing aid.

Check the appropriate boxes:

- I wear **ONE** hearing aid (circle **LEFT** or **RIGHT**)
- I wear **TWO** hearing aids
- I use an **FM** system in class

AGE: _____

GENDER: *Male* or *Female* (circle)

		YES	SOME-TIMES	NO
1.	Do you talk on the phone less often because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Do you feel shy when meeting new people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Does your hearing loss make you feel different from everyone else?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Does your hearing loss annoy you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Do you to get annoyed when talking to members of your family because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Do you have problems at a pool or the beach because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Do you raise your hand or answer questions less in school because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Do you have trouble hearing when someone whispers to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Do you feel different from others because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Do you have problems when playing with friends or relatives because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Do you have trouble with movies or TV because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Does your hearing cause you to be nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Do you to play with friends or relatives less often than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Do you to have problems with family members because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Does your hearing cause you problems in gym class (Physical Education, PE)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Do you have problems at restaurants because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Do you have problems with your hearing that make you angry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Do you play with less people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Do you not play with certain people outside of school because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		YES	SOME-TIMES	NO
20.	Does your hearing cause you problems when in the cafeteria (lunch room) with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Do you have a harder time hearing than your friends at parties?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	Do you worry about your hearing loss getting worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	Do you do play less sports or activities than your friends because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24.	Does your hearing cause you to listen to an IPOD, MP3 player, or other music less often than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25.	Do you feel uncomfortable when talking to friends because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26.	Do you feel left out when you are with a group of people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27.	Do your parents not let you do certain things because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28.	Do you have trouble hearing friends or coaches during sports due to your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29.	Do you pay attention less in class because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30.	Do you think you have a harder time hearing than your friends in noisy places (restaurants, ball games, field trips, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31.	Do you think you would do better in gym class (physical education, PE) if you could hear better?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32.	Do you have a hard time hearing your friends at recess?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33.	Do you have a hard time hearing your friends when playing outside?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34.	If you can't hear someone, do you have a hard time asking them to speak louder or repeat what they said?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35.	Do you go to parties less because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hearing Related QOL Measurement for Adolescents

Instructions:

The purpose of this scale is to find how your hearing is affecting you. Answer YES, SOMETIMES, or NO for each question. If you use a hearing aid, please answer the way you hear with the hearing aid.

Check the appropriate boxes:

- I wear **ONE** hearing aid (circle **LEFT** or **RIGHT**)
 I wear **TWO** hearing aids
 I use an **FM** system in class

AGE: _____

GENDER: *Male* or *Female* (circle)

		YES	SOME-TIMES	NO
1.	Do you talk on the phone less because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Do you feel shy when meeting new people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Does your hearing loss make you feel different from everyone else?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Does your hearing loss annoy you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Do you to get annoyed when talking to members of your family because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Do you have problems at a pool or the beach because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Do you raise your hand or answer questions less in school because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Do you have trouble hearing when someone whispers to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Do you feel different from others because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Do you have problems when interacting with friends because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Do you have trouble with movies or TV because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Does your hearing cause you to be nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Do you to interact with friends less than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Do you have problems when interacting with family (parents, brothers, sisters) because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Do you to have problems with family members because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Do you to interact with family (parents, brothers, sisters) less than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Does your hearing cause you problems in gym class (Physical Education, PE)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Do you have problems at restaurants because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix D

		YES	SOME- TIMES	Streufert NO
19.	Do you have problems with your hearing that make you angry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	Do you interact with fewer people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Do you not play with certain people outside of school because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	Does your hearing cause you problems when in the cafeteria (lunch room) with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	Do you worry about your hearing loss getting worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24.	Do you do participate less in sports or activities than your friends because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25.	Does your hearing cause you to listen to an IPOD, MP3 player, or other music less than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26.	Do you feel uncomfortable when talking to friends because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27.	Do you feel left out when you are with a group of people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28.	Do your parents not let you do certain things because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29.	Do you have trouble hearing friends or coaches during sports due to your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30.	Do you pay attention less in class because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31.	Do you think you have a harder time hearing than your friends in noisy places (restaurants, ball games, concerts, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32.	Do you think you would do better in gym class (physical education, PE) if you could hear better?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33.	Do you have a hard time hearing in the car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34.	Do you have a hard time hearing your friends when outdoors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35.	When you can't hear someone, do you have a hard time asking them to speak louder or repeat what they said?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36.	Do you think that others talk about you behind your back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37.	Do you get frustrated when you respond incorrectly to a statement or question?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38.	Do you have a hard time when meeting new people because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39.	Do you have a hard time learning people's names due to your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		YES	SOME-TIMES	NO
40.	Do you go to parties less than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41.	Does your hearing cause you to be nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42.	Do you to interact with extended family (grandparents, aunts, uncles, cousins) less than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43.	Do you date less than you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44.	Do you go to movies less then you would like because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45.	Do you have problems when interacting with extended family (grandparents, aunts, uncles, cousins) because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46.	When you can't hear a teacher or coach, do you have a hard time asking them to speak louder or repeat what they said?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47.	Do you attend school social events less because of your hearing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>