

CROSS-CULTURAL COMPARISON OF PARENTAL PERSPECTIVES OF HEALTH-RELATED QUALITY OF LIFE IN CHILDREN WITH COCHLEAR IMPLANTS

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## DEDICATION

Dr. Silver, thank you for supporting my genuine interest in cochlear implants and helping cultivate a fantastic committee who understands my passion for this niche. I am especially grateful for the support, guidance and encouragement you've consistently shown me. Your never-ending kindness and patience inspire me, and thank you for being my biggest advocate in this endeavor. Dr. Warner-Czyz, this project is such a wonderful contribution to the field because of you! A special thank you for all the time you've spent listening to my ideas and helping guide this project. Not only have you taught me so much, but you've inspired my career path. For that, I am forever grateful! Dr. Tobey, thank you for your constant support, expertise and enthusiasm for this project. I greatly appreciate your input! Dr. Loy, thank you so much for willingly sharing your valuable data from your CI summer camps with me. Thank you to my supportive family and encouraging friends, for always believing in me and in this project. To the memory of my dad, I know you would have been so proud of my thesis!

Lastly, to my patient who struggled to find his place in a hearing world after receiving a cochlear implant, this project is wholeheartedly dedicated to you and all of the other boys and girls just like you.

CROSS-CULTURAL COMPARISON OF PARENTAL PERSPECTIVES OF HEALTH-  
RELATED QUALITY OF LIFE IN CHILDREN WITH COCHLEAR IMPLANTS

by

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## Abstract

**BACKGROUND:** Assessing health-related quality of life (HRQoL) is a useful way to quantify benefits that cochlear implants (CI) provide children with hearing loss. Since children often are too young or lack communication skills to convey their HRQoL, parents serve as a reliable proxy. This study examines parent report of HRQoL (categorized in eight domains) and demographic variables in children with CI. Lastly, this study compares parent HRQoL ratings in the United States (US) to parent ratings in the Netherlands, Finland and the United Kingdom (UK).

**SUBJECTS:** Parents of 33 children with CIs participated in the US component of this study.

**METHOD:** An analysis of variance was used to measure differences among HRQoL domains.

Correlations between HRQoL and demographic variables, and correlations among HRQoL domains were assessed using Spearman and point bi-serial correlations. Cross-cultural differences in HRQoL domain scores were computed using one sample t-tests.

**RESULTS:** In this US sample, education and effects of CI domains were rated least positively. Cross-culturally, US parents rated HRQoL more positively than parents in the Netherlands, generally less positively than parents in Finland and aligned most closely with parents in the UK.

**DISCUSSION:** Limited access to CI-related accommodations and varying parent expectations likely explain the differences in low ratings of education and effects of implantation in the US, as well as the differences seen cross-culturally. Providing useful CI accommodations at school and preparing parents for realistic outcomes could greatly benefit children with CI and their families.

*Keywords:* Health-related quality of life, pediatric cochlear implants, parent proxy, cross-cultural.

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CROSS-CULTURAL COMPARISON OF PARENTAL PERSPECTIVES

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LIST OF ABBREVIATIONS

CHQ – *Child Health Questionnaire*

CI – Cochlear implant

dB HL – Decibels hearing level

FDA – Food and Drug Administration

HA – Hearing aid

HL – Hearing loss

HRQoL – Health-related quality of life

NIDCD – National Institute on Deafness and Other Communication Disorders

QoL – Quality of life

UK – United Kingdom

US – United States

## CHAPTER ONE

### Introduction

Language serves as a primary communication tool between individuals of all ages, beginning in infancy across all cultures and communities. Communication fosters relationships and promotes a sense of uniqueness among individuals. Therefore, conditions that hinder acquisition of communication, such as hearing loss (HL), may negatively impact an individual's psychological and social well-being (Reilly et al., 2006). Individuals with HL often experience difficulties developing language due to inadequate ability to hear and understand conversational speech. These difficulties can cause a shift in relational dynamics, reducing the bond, security and understanding that verbal communication can offer (Maxon & Brackett, 1992). The negative impact of limited communication due to HL can extend beyond family dynamics to include issues such as social and developmental maladjustment and psychological distress (Barker et al., 2009).

Auditory assistive devices such as cochlear implants (CI) afford children with severe to profound HL the opportunity to develop auditory and communication skills similar to that of their hearing peers, especially when HL is detected early and CIs are received early (Sharma & Dorman, 2006). CIs positively influence not only communication performance, but also psychosocial well-being (Sach & Whyne, 2005). Because of the potential impact of CI use on psychosocial outcomes, exploring a child's range of emotions associated with his or her CI can be a useful way to ensure the most positive outcome for the child. Studies that examine general life satisfaction among children with CI often utilize the construct of health-related quality of life (HRQoL) via parent assessment (proxy). Parents generally report high levels of satisfaction with

CI use in several areas specific to their child's psychosocial development and cochlear implantation (Archbold, Sach, O'Neill, Lutman, & Gregory, 2008).

A number of studies worldwide assess parental perspectives of HRQoL among their children with CI, but no studies to date have compared these results cross-culturally (Archbold et al., 2008; Huttunen et al., 2009). Examination of cross-cultural outcomes allow both clinicians and researchers insight into HRQoL on a global level, which may generate more CI services, aid in anticipating potential outcomes and provide insight into the role that CIs play in childhood psychosocial development. Cross-cultural HRQoL research among children with CIs is a notable endeavor that can provide several opportunities to ensure the greatest satisfaction in all areas of a child life.

## CHAPTER TWO

### Review of the Literature

A child's overall well-being can be seen in several areas of his or her life. Identifying and measuring domains of well-being allows researchers to assess HRQoL in efforts to further understand a child's behavior, relationships and overall happiness. Understanding domains in which children with CI succeed or struggle can provide opportunities for healthcare providers, teachers and family members to support children with CI in the most meaningful way. Decision making can be challenging for parents contemplating cochlear implantation on their child's behalf. Understanding HL and the benefits of CI on auditory skills and psychosocial functioning can be a useful way for parents to provide the most beneficial opportunities for their children with HL.

### Hearing and Hearing Loss

Sensorineural HL can affect individuals of all ages, from newborn infants to older adults (American Speech-Language Hearing Association, 2011). HL can be congenital (i.e., present at birth) or acquired (Bess & Tharpe, 1986). Acquired HL is described relative to completeness of the acquisition of language: Prelingual, perilingual, or post-lingual (Tye-Murray, 2009). Prelingual HL refers to HL prior to development of spoken language skills, generally before two years of age (Tye-Murray, 2009). Perilingual HL describes HL onset in the midst of language acquisition (Tye-Murray, 2009). Postlingual HL occurs after development of speech and language (Tye-Murray, 2009). While there is no specific age where the perilingual stage ends and the postlingual stage begins, research approximates it to be 5 years of age. However, these estimates vary individually (Tye-Murray, 2009).

### **Normal Hearing Sensitivity**

Understanding the process of typical hearing, as it relates to the auditory system, provides a foundation for understanding differences associated with HL. The ear consists of three main parts: the outer ear, the middle ear and the inner ear. Sound enters through the outer ear that includes the pinna, the visible outer cartilage-filled portion of the ear, and the external auditory canal (Audiology Awareness Campaign, 2010). The external auditory canal extends from the pinna to the concave-shaped tympanic membrane (i.e., eardrum) which marks the beginning of the middle ear. In addition to the eardrum, the middle ear consists of an air-filled space that houses three tiny bones called the ossicles (i.e., malleus, incus, and stapes). The ossicles are grouped together and connect the eardrum to the oval window to the inner ear. The central part of the eardrum is connected to the malleus which transmits sound vibrations to the incus and stapes when sound passes through (Audiology Awareness Campaign, 2010). As the stapes moves from the vibration, it pushes the oval window in and out. This action is passed onto the cochlea, which is a fluid-filled snail-like structure that contains the receptor organ for hearing known as the Organ of Corti (Animated Dissection of Anatomy for Medicine, 2012).

The cochlea marks the beginning of the auditory portion of the inner ear. The cochlea is housed in the temporal bone of the skull and divided into three fluid filled membranous canals known as the scala vestibuli, scala media, and scala tympani. The scala vestibuli and scala tympani are filled with perilymphatic fluid while the scala media is filled with endolymphatic fluid. The scala media is located between the scala vestibuli and scala tympani and is separated from them by the basilar membrane and vestibular membrane (Salt, 2010).

When the stapes moves in and out of the oval window, it sets perilymphatic fluid into motion. The fluid's pressure vibrates the basilar membrane, which houses the Organ of Corti. The Organ of Corti is lined with rows of inner and outer hair cells that convert hydraulic motion from movement of the perilymphatic and endolymphatic fluids into electro-chemical signals that stimulate the auditory nerve. The auditory nerve then transmits the signals to higher auditory pathways leading to the auditory cortex in the temporal lobes of the brain where the signals are heard as sound (Audiology Awareness Campaign, 2010). However, in some cases the auditory system does not always function as intended or expected, as described in the following section.

### **Hearing Loss**

Sensorineural HL encompasses loss of auditory function in the sensory portion of the ear (i.e., cochlea or inner ear), the neural portion of the ear (i.e., auditory nerve) or both (Audiology Awareness Campaign, 2010). HL in the neural region indicates pathology related to the auditory nerve itself. For example, it includes conditions such as auditory neuropathy/auditory dyssynchrony, a disorder in which sound travels from the outer ear to the inner ear properly, but transmission signals from the inner ear to the auditory nerve and brain are impaired due to genetics, trauma or disease (National Institutes of Health, 2003). Loss of hearing in the sensory region often indicates damage to the cochlea's hair cells, which can result from a variety of etiologies such as excessive noise exposure, viruses, genetic factors, syndromes, and presbycusis (age-related HL) (Bess & Tharpe, 1986). An individual with sensory HL may have difficulties understanding speech even at suprathreshold levels (i.e., intensity levels that are loud enough for that individual to hear).

Characterization of HL depends on type, configuration, and degree of HL. Type of HL refers to the portion of the auditory system causing the deficit. Problems in the outer or middle ear create difficulties conducting sound through the auditory system and therefore are called *conductive HL*. In contrast, conditions of the inner ear – the sensory organ – or auditory nerve cause a *sensorineural HL*. HL that includes both conductive and sensorineural components is called a *mixed HL*. Degree of HL characterizes intensity of sound needed for a sound to be audible to a listener. Sound intensity, measured in decibels hearing level (dB HL), typically ranges from 0 dB HL (very soft) to 120 dB HL (very loud) (Gallaudet University, 2012). Degree of HL is grouped in five main categories: Mild (26-40 dB HL), moderate (41-55 dB HL), moderately severe (56-70 dB HL), severe (71-90 dB HL) and profound (91+ dB HL) HL (Gallaudet University, 2012).

The hair cells in the cochlea act similarly to the keys of a piano, with each auditory region responding to a specific set of frequencies between 20 and 20,000 Hz (National Institutes of Health, 2012). Much like playing a piano with missing keys, sound can be misinterpreted when the cochlea's hair cells are damaged or missing. Although sound can be amplified on a piano by playing louder, the distorted sound remains the same due to the loss of various piano keys. This analogy is useful when considering assistive technology to assist in recreating or restoring sound in the cochlea.

### **Assistive Technology: CI**

Assistive technology aims to make speech and environmental sounds perceptible to individuals with HL. Two common types of assistive devices for HL – hearing aids (HA) and CI

– provide access to sound for many individuals with sensorineural HL. However, the devices accomplish this task in different ways, as described below.

HAs are comprised of a microphone, amplifier, transducer and battery power source, and can be worn on the body, behind the ear, or in the ear (Maxon & Brackett, 1996). Sound that travels through the ear is amplified by the HA to maximize access to conversational speech for the individual user. Much like playing music at a louder volume through missing piano keys, the amplification of sound is not always most accurate to the listener since the sound still travels through the damaged sensorineural system. For some individuals with severe to profound sensorineural HL, in which the sound of a lawnmower is barely audible or entirely inaudible, HAs may provide inadequate access to sound. Inability to hear conversational speech is particularly detrimental to children because of its negative impact on attainment of the auditory milestones that underlie speech and language development (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). For children with severe to profound HL, CIs may offer a better opportunity than HAs to gain auditory access to speech and optimize communication outcomes.

A CI is an electronic auditory prosthesis designed to provide hearing sensations to an individual with severe to profound HL by electrically stimulating nerves inside the inner ear (Food and Drug Administration, 2009). The external portion of the device consists of a microphone, speech processor and coil. The microphone of the CI collects acoustic sound and converts it into an electrical signal. The speech processor, a computer-like device which can be worn at ear level (like a HA) or on the body, analyzes and codes the electrical variations for intensity, frequency, and duration to make the sound perceptible to the implant wearer (Maxon & Brackett, 1992). The coded signal is transmitted to the coil, which transdermally transmits the

signal via radio frequency waves to the internal receiver/stimulator, implanted on a flat or recessed portion of the skull.

The receiver/stimulator converts the radiofrequency waves to an electric signal, which it sends to the electrode array that is surgically inserted into the cochlea (Loizou, 1998). The electrode array consists of at least one extra cochlear electrode, which serves as electrical ground, and 12-24 intracochlear electrodes. The intracochlear electrodes are surgically inserted into the scala tympani through a round window or cochleostomy. These electrodes directly stimulate the spiral ganglion cells, which transmit the signal to the auditory nerve and the higher auditory pathways. In contrast to the first CIs, which used only one channel and one electrode, contemporary devices contain multiple electrodes and multiple channels (i.e., a multichannel CI). Multichannel implants use an array of electrodes that stimulate a variety of frequencies across the cochlea in efforts to afford a more accurate representation of sound (Loizou, 1998).

### **History of CI**

The idea of CIs originated in the 18<sup>th</sup> century, when Alessandro Volta applied an electrical current to metal rods inserted in his ears and realized that certain voltages produced something perceived as “a boom within the head” (Niparko, 2009). Continued experimentation in Europe in the 18<sup>th</sup> and 19<sup>th</sup> centuries, plus availability of battery-supplied electric currents, lead to the first CI prototype in which Djournon and Eyries (1957) placed a wire on the auditory nerve of a patient undergoing surgery for facial nerve paralysis. The patient developed limited recognition of common vocabulary and improved speech reading capabilities, supporting continued research of electrical devices. Exploration of more efficient ways to administer electrical stimulation to the inner ear lead to House’s (1976) creation of a single electrode

implant. The single electrode array, in combination with a speech processor that interfaced with the implant, became the first device to be commercially marketed (House, 1976). From 1972 to the mid-1980s, more than 1,000 individuals received the first commercially marketed single electrode implant (Niparko, 2009).

### **CI Criteria and Prevalence Rates among Children**

CI prerequisite criteria have significantly changed since their initial presence among the general population. Initially, the United States Food and Drug Administration (FDA) only approved adults to receive CIs (Food and Drug Administration, 2009). Device success in adults with post-lingual HL (>18 years of age) sparked changes in the approved age at implantation, which began to include younger children and individuals with earlier onset of HL. For example, the FDA-approved age at cochlear implantation lowered to 2 years chronological age in 1980 and to 1 year chronological age in 2000 for children with prelingual HL (Food and Drug Administration, 2009). Several hundred children received a single electrode implant by the mid 1980s. Multiple channel devices were introduced to the public in 1984, but FDA approval of clinical use of the multichannel CI for children with profound HL who are unable to hear with any other assistive device did not occur until 1990 (Maxon & Brackett, 1992). Criteria continue to expand, currently including individuals with greater amounts of residual hearing, higher levels of preoperative speech skills, and individuals with abnormal cochleae (Sampaio, Araujo, & Oliviera, 2011).

CI prevalence has increased throughout the past decades, from approximately 500 children in 1991 to over 28,400 in 2010 (National Institute on Deafness and Other Communication Disorders, 2011). Expectations have increased as well. More than half of

children with CI in the early 1990s were placed in classrooms or schools for children with HL (Maxon & Brackett, 1992). Children with CI within the past decade have been enrolled in mainstream classrooms, illustrating the evolution of children with CI in educational settings (American Speech-Language Hearing Association, 2011). As CI prevalence rates continue to increase and candidacy criteria relaxes with age at implantation and degree of HL, we can expect a larger proportion of children with significant HL to receive CIs in the future (Bradham & Jones, 2008; National Institute on Deafness and Other Communication Disorders, 2011).

### **Impacts of Cochlear Implantation on Communication Performance**

Benefits of CI are highlighted in several studies that measure specific elements of communication such as speech perception, speech production, language acquisition, and speech intelligibility (Nikolopoulos, Archbold, & O'Donoghue, 1999; Tobey et al., 2000). CIs aid development of oral skills and contribute to the formation of sounds, perception, and language as children with HL grow and develop language skills (Tobey et al., 2000). Access to speech and environmental sounds via CIs leads to improvements in speech perception skills from sound awareness to sound pattern recognition, which underlies language learning. Improved speech production and language skills with CI leads to improved speech intelligibility, the accuracy with which an average listener can understand a spoken word or phrase, relative to pre-CI performance (Archbold et al., 2000). Appropriate use of social language, high levels of speech intelligibility and reliance on speech indicate greater success as an oral communicator after implantation (Connor, Hieber, Arts, & Zwolan, 2000; Kent, 1993). Success in oral communication provides the framework for establishment of conversational abilities and sound repertoires (Tobey et al., 2000). In general, children with severe to profound HL improve speech

perception, speech production, and language acquisition skills with CI experience (Niparko, 2009).

However, variability exists in communication outcomes. Some children meet or exceed expectations of typical hearing peers whereas others are delayed in perception and production capabilities (Holt & Kirk, 2005; Robbins, Svirsky, & Kirk, 1997). A multitude of factors contribute to variability in performance, including demographic, audiologic, and CI-related variables. Demographic variables that impact communication outcomes include chronological age, age at implantation, duration of CI use, configuration/number of implants, socioeconomic status and cognitive delay (Huber, 2005). Additionally, audiologic factors such as degree of HL (i.e., amount of residual hearing), duration of HL, and age of HL detection affect outcomes. Finally, CI-related factors such as number of inserted electrodes and speech processing strategy may explain difference in outcomes (O'Donoghue, Nikolopoulos, & Archbold, 2000).

### **Demographic Variables and Their Impact on Cochlear Implantation**

Several demographic variables are associated with successful communication performance in children with CI. Earlier detection of HL, earlier age at cochlear implantation and longer duration of CI use tend to correlate with more positive communication outcomes (McConkey Robbins, Koch, Osberger, Zimmerman-Phillips, & Kishon-Rabin, 2004; Staller, Dowell, Beiter, & Brimacombe, 1991). Exposure to stimulation (sound) is integral within the first 3.5 years due to the plasticity of auditory pathways in the brain (Sharma & Dorman, 2006). Hearing sound during this period enables children with HL to develop skills that match auditory development of their hearing peers (Sharma & Dorman, 2006). Since the brain is best able to absorb language in these formative years, many researchers suggest that early cochlear

implantation in chronologically younger children is a catalyst for successful speech, language, and oral communication among children with HL (Govaerts et al., 2006; Miyamoto et al., 1997; National Institutes of Health, 2012; Sharma & Dorman, 2006). Lastly, bilateral CI (two CIs) or bimodal (one CI and one HA) input additionally suggest more effective communication skills, highlighting further examination of the importance of CI configuration (Ching, Psarros, Hill, Dillon, & Incerti, 2001).

CI benefits in communication outcomes are seen pervasively throughout literature. However, benefits of CI are not limited to communication but extend their impact to psychosocial functioning, educational success, overall well-being and satisfaction with CI. Studies that examine children's psychosocial wellness generally utilize the construct of quality of life (QoL).

### **Quality of Life**

Initially, researchers and clinicians defined "success" with a CI as improvements in speech perception, speech production, and language scores in children. As children using CI have excelled beyond expectations, researchers have begun to explore benefits of CI beyond communication benefits. CIs have the potential to produce overall positive psychosocial outcome for children with HL at home, in school and in social settings once initial difficulties are addressed and rectified (Sach & Whyne, 2005). Viewing CI use through the lens of QoL helps identify specific domains of psychological, social and academic development that benefit from cochlear implantation in efforts to illustrate more well-rounded benefits for children with CI.

### **Characteristics of QoL**

The World Health Organization Quality of Life Group (1998) defines QoL as a broad multi-dimensional construct that includes subjective evaluations of contentment or satisfaction with one's life and activities of daily living. In pediatric populations, school and home life are emphasized as the primary environments in which to measure a variety of psychosocial domains. Physical, mental and social well-being represent domains that encompass the overall QoL in a child's daily life (Centers for Disease Control and Prevention, 2011). Health-related QoL (HRQoL) assesses the impact of health on well-being and satisfaction across a variety of domains (Centers for Disease Control and Prevention, 2011). More specifically, physical and mental health includes the assessment of social supports, health risks and conditions, functional status and socioeconomic status (Centers for Disease Control and Prevention, 2011).

HRQoL assessment can bolster attempts to alleviate discomfort, provide proper treatment, administer ethical clinical trials, and promote a sense of universality among members of the same health-related peer group. Furthermore, assessment of HRQoL enables health agencies to address public policy in a meaningful way by quantifying a specific population's subjective well-being. Social service agencies and other public health care providers can revise public policies for the betterment of a medical population (Kindig, Booske, & Remington, 2010). For example, HRQoL assessment among children with intellectual and developmental disabilities provided the catalyst for change in communities (Brown, 1999). Community-based service providers for this population made significant accommodations in community learning centers by focusing efforts to implement programming for interdependent and independent skills training, as these were areas that showed a marked need for improvement (Brown, 1999).

HRQoL assessment aids in shifting focus from a medical model of diagnosis and treatment to a biopsychosocial model of integrating the biological, psychological and social constructs surrounding HRQoL.

Research examining HRQoL in children with CIs has increased since 2006, when only 10 published articles explored this population (Lin & Niparko, 2006). Initial attempts to measure HRQoL in children with CIs focus on the marked increase of perception after cochlear implantation (Geers, Brenner, & Davidson, 2003; Hammill & Newcomer, 1997). More recent research highlights HRQoL in its own right using *ad hoc* and validated questionnaires to assess HRQoL domains (Fortunato-Tavares, Befi-Lopes, Ferreira Bento, & Furquim de Andrade, 2012; Huber, 2005; Loy, Warner-Czyz, Tong, Tobey, & Roland, 2010; Schorr, Roth, & Fox, 2009; Warner-Czyz, Loy, Roland, Tong, & Tobey, 2009; Warner-Czyz, Loy, Tobey, Nakonezny, & Roland, 2011). Questionnaires that assess HRQoL vary in their implementation. Some instruments assess general HRQoL issues whereas others are tailored to a specific condition (i.e., generic vs. condition-specific instruments). Furthermore, some questionnaires have both a self-report version, in which the child answers his or her own questions as they pertain to their HRQoL, as well as a parent proxy version, where parents rate HRQoL as they feel it relates to their child (i.e., self-report vs. parent proxy). The following section details these methodological variables – generic vs. condition-specific and self-report vs. parent proxy – to provide a foundation to understand fully research of HRQoL in children using CIs.

### **Methodological Variables in QoL Assessment**

*Generic vs. condition-specific instruments.* Research in HRQoL assessment use generic measures, condition-specific instruments, or both. Generic HRQoL instruments assess physical,

psychological and social well-being and self-esteem independent of a medical condition. Generic HRQoL instruments allow comparison of HRQoL ratings across various diseases, interventions or conditions – including comparison to normal, healthy populations (e.g., children using CIs vs. children using HAs vs. children with normal hearing). However, a drawback of generic measures of HRQoL is the insensitivity to smaller changes specific to a treatment, condition, or certain population (Lin & Niparko, 2006).

Several existing validated measures assess generic HRQoL in children, including but not limited to the *PedsQL* (Varni, Seid, & Rode, 1999), the *Child Health Questionnaire (CHQ)* (Landgraf, Abetz, & Ware, 1996), and the *KINDL<sup>R</sup>* (Ravens-Sieberer & Bullinger, 1998). All three of these generic HRQoL measures (a) include both a self-report and a parent-proxy report module, and (b) address multidimensional domains such as physical, emotional, social, and school functioning. Some of the surveys include additional psychosocial domains (*KINDL<sup>R</sup>*: Self-esteem and family; *CHQ*: Family, self-esteem, mental health). Other differences among these three generic HRQoL instruments include number of items per questionnaire (*PedsQL*: 23; *KINDL<sup>R</sup>*: 12 or 24, depending on version; *CHQ*: 28 or 50, depending on version), and appropriate chronological age range (*PedsQL* = 2-18 years; *KINDL*: 4-16 years; *CHQ* = 5-18 years).

On the other hand, condition-specific instruments can be much more sensitive to positive and negative consequences of a particular treatment or condition (Bjornson & McLaughlin, 2001). Validated condition-specific questionnaires are common for chronic conditions such as cancer and diabetes but sparse for other conditions such as HL and cochlear implantation, although a few exist. *The Hearing Environments and Reflection on Quality of Life (HEAR-QL)* is

a validated condition-specific questionnaire that assesses self-report of HRQoL issues among children with HL (Umansky, Jeffe, & Lieu, 2011). *Children with Cochlear Implants: Parental Perspectives (Parental Perspectives)* is a validated parent proxy condition-specific questionnaire covering two overarching domains of the process of cochlear implantation: Decision making and outcomes of cochlear implantation (Archbold et al., 2008). Both the *HEAR-QL* and the *Parental Perspectives* questionnaires narrow the scope of HRQoL for specific domains most likely experienced by children with HL or CIs, respectively.

***Self-report vs. parent proxy.*** HRQoL assessment should measure a child's beliefs, emotions and perceptions as accurately as possible. However, sometimes self-report information cannot be used when children are too ill or fatigued to represent an accurate description of their HRQoL, or when children cannot express their feelings or rate progress due to underdeveloped communication skills (Hays et al., 2006). Several studies support the usefulness of proxy reports, or reports from another individual close to the target individual. Because parents often serve as the closest proxy to a child, they can answer effectively various questions about HRQoL as it relates to their child's well-being (Dodson et al., 2008; Varni, Limbers, & Burwinkle, 2007).

Parent proxies additionally show a well-rounded overview of the child's well-being (Varni et al., 2007). Studies that examine HRQoL in pediatric palliative care and studies researching children's public policy both suggest the effectiveness and significance of parent proxies and their influence in reforming health care utilization, examining certain risk factors and improving quality of care (Hays et al., 2006; Janicke, Finney, & Riley, 2001). However, parent and child assessment of QoL do not match always. Parents tend to provide more reliable responses for observable behaviors such as physical symptoms and function, and in family

relational domains (e.g. inter-family dynamics and sibling relationships) (Eiser, 1997; Eiser & Jenney, 2007). Conversely, parents provide less reliable ratings for cognitive and emotional attributes, including judgments, peer relationships and future worries (Eiser, 1997; Eiser & Jenney, 2007). Children tend to self-report more accurate descriptions of internal thought and dialogue in reference to peer relationships, sociability and emotions (Eiser, 1997). Differences between parent and child reports may reflect developmental stage, reference framework, and/or the emergence of independence (Eiser, 2001). Some studies of HRQoL in pediatric CI users solely assess self-reports, some focus on parent reports, and some include both self-report and parental proxies. Eiser and Jenney (2007) herald the inclusion of multi-informant perspectives to provide a well-rounded picture of a child's QoL.

### **Impact of Cochlear Implantation on HRQoL**

Research on HRQoL in children with CIs varies with respect to chronological age, HRQoL instruments, methodologies, and respondent. Researchers have examined various child and adolescent age groups in different countries. The following studies will be categorized and described in two overarching groups. The first group of studies compares self-report of HRQoL (including both children with CI and children with normal hearing) while the second group examines parent proxy of HRQoL (including a comparison of children with CI and their parents).

#### **QoL in Children Using CI: Children Using CI vs. Children with Normal Hearing**

A handful of studies have compared generic HRQoL in children using CIs and normal hearing peers between 6 and 20 years chronological age (Chmiel, Sutton, & Jenkins, 2000;

Huber, 2005; Loy et al., 2010; Schorr et al., 2009; Warner-Czyz et al., 2009). Children using CI perceive that the device(s) afford improvements in several domains, particularly general functioning, self-reliance, social relations and education. The majority of self-report HRQoL studies report similar or more positive ratings of HRQoL among children with CI compared to their normal hearing peers. However, results are tempered by chronological age.

Initial studies exploring self-report of HRQoL in children with CI focus on children older than 7 years of age due to their maturity and cognitive ability to answer questions independently (Topolski, Edwards, & Patrick, 2004). Studies in both Austria and the United States (US) use the KINDL<sup>R</sup> (Ravens-Sieberer & Bullinger, 1998), a HRQoL self-report and parent proxy assessment, to assess HRQoL among children with CI and their normal hearing peers (Huber, 2005; Loy et al., 2010). Six dimensions of physical well-being, emotional well-being, self-esteem, family, friends and everyday functioning are assessed, with four questions in each domain. Each of the KINDL<sup>R</sup>'s domains can be easily examined between various peer groups regardless of age, gender and disease.

The Austrian and US studies both include children and adolescents stratified into age groups (8-11/12 years and 12/13-16 years) with two sets of children per age group (CI and normal hearing) (Huber, 2005; Loy et al., 2010). Older Austrian children using CI rate HRQoL less positively in all domains than hearing peers while the older group of American children using CI reported similar levels of HRQoL in well-being, self-esteem, friends and family to their hearing peers and rank less positively in education (Huber, 2005; Loy et al., 2010). Younger Austrian children with CI rate each domain (well-being, self-esteem, family, friends and education) less positively than those of their hearing peers (Huber, 2005). Conversely, younger

children in the US with CI rate each domain more positively than their hearing peers showing overall inconsistency between the two countries (Loy et al., 2010).

Studies examining HRQoL among American children ages 4-7 with at least one CI answered questions via an interview version of the KINDL<sup>R</sup> appropriate for younger children (i.e., Kiddy KINDL<sup>R</sup>) (Ravens-Sieberer & Bullinger, 1998; Warner-Czyz et al. 2009; Warner-Czyz et al., 2011). Younger children in the US with CI rate overall HRQoL more positively than normal hearing peers in well-being, family, friends, and education (Warner-Czyz et al., 2009). Additionally, US findings highlight that the younger the age of the child with CI, the more likely they are to rate a more positive HRQoL, particularly with shorter durations of CI experience (Warner-Czyz et al., 2011).

These results are consistent with patterns in global development. Younger children are often less aware of societal and peer pressures since they are more likely to identify with the implant as an accepted self-identity (Oswalt, 2008). Younger children are also less likely to view implantation as a barrier that hinders them from hearing peers (Oswalt, 2008). More positive levels of HRQoL could relate to family encouragement and normalization via school accommodation and audiological rehabilitation (Oswalt, 2008). Overall, children with CI rate their HRQoL similarly to, if not more positively than, their hearing peers. Cultural differences, school resources or family involvement could be linked with these results, although no specific study information depicts the reasoning behind these differences. Earlier implantation and the younger the child's age are found to correlate with more positive levels of HRQoL (Warner-Czyz et al., 2009; Warner-Czyz et al., 2011). Closer analysis of results across studies reveal that children who have better speech perception, speech production, language acquisition, and longer

CI use rate more positively in overall HRQoL scores (Huber, 2006; Loy et al., 2010; Schorr et al., 2009).

### **QoL in Children Using CI: Self-Report vs. Parent Proxy**

Comparison of parent and child ratings of QoL affords a cross-check on outcomes within a family unit. The literature exploring HRQoL in pediatric CI users suggests parents and children tend to agree on observable behaviors such as physical well-being and function, but that ratings diverge on subjective domains such as cognitive and emotional attributes (Eiser, 1997; Eiser & Jenney, 2007). Whether HRQoL ratings converge or diverge, parents and children provide different perspectives, both of which are important to a comprehensive understanding of HRQoL in children who use CI. The following studies examine children using CI's self report and their parent's perspectives on HRQoL.

Children with CI and their parents show overall consistencies in their reporting of HRQoL, although differences exist in domain-specific ratings of general functioning, social relations, hearing/safety, education and communication. American children with CI (8-16 years) and Austrian children with CI rate overall HRQoL similarly to parents (Loy et al., 2010; Huber, 2005). Austrian children (8-11 years), however, rate HRQoL less positively than parents (Huber, 2005). Domain-specific differences emerge as American children (8-16 years) and Austrian children (8-11 years) rate general functioning less positively than their parents (Chmiel et al., 2000; Huber, 2005). In contrast, adolescents in the UK rate general functioning and the effects of implantation more positively than parents (Wheeler, Archbold, Gregory, & Skipp, 2007).

American parents rate more positive HRQoL in communication (Schorr et al., 2009). Specifically, parents rate improvements in speech perception, speech production, and the ability

to hear environmental sounds clearly. American children, however, report difficulty hearing loud environmental sounds (Chmiel et al., 2000; Schorr et al., 2009). American children additionally report that a source of stress often involves disagreement with parents over when to use the CI, which could explain this disparity if children only use the CI when prompted by parents (Schorr et al., 2009).

Ratings of social relations and making new friends also differ among parents and children with CIs. American children rank social relations and making new friends more positively than their parents, suggesting that parents underestimate their child's ability to develop and maintain peer relationships (Chmiel et al., 2000; Loy et al., 2010). Lastly, parents differ from their children with CI in education. American adolescents rate education positively overall, but less positively than their parents (Loy et al., 2010; Wheeler et al., 2007). These findings suggest that parents and children have varied definitions of what constitutes educational success. For example, adolescents with CI could attribute educational success with sociability in school or stress level while parents rate HRQoL based on grades and feedback from teachers.

Parents generally rate communication more positively than children and children rate sociability (i.e., meeting and making new friends) more positively than parents. Both parents and children found that implantation was useful, and many children reported satisfaction with a parent's decision to implant. The main discrepancies were found in education and younger children reporting opposing ratings to their parents, which could be attributed to communication barriers (Huber, 2005). Cross-cultural differences and parenting styles among various countries are also useful to examine. Countries that are more collectivistic or individualistic in nature

could explain variability in responses. Parenting styles in across countries could also characterize the similarities or disparities between parent and child.

### **Parent Proxy of HRQoL in Children with CI.**

Studies around the world examine only parental perspectives of HRQoL among children using CI (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Archbold, et al., 2008; Damen, Krabbe, Archbold, & Mylanus, 2007; Huttunen et al., 2009; Incesulu, Vural & Erkam, 2003; Sach & Whynes, 2005). Parents in the UK rate their child with CI's general functioning, social relations and communication positively (Sach & Whynes, 2005). Parents in the UK also feel that cochlear implantation positively affected their children's well-being and self-reliance, which contributes an inclination become more involved in social groups and clubs (Archbold et al., 2002; Sach & Whynes, 2005). While most of the feedback was positive, UK parents' negative experiences include feelings of helplessness in the absence of the implant and feeling that their child's disability was highlighted (Sach & Whynes, 2005).

A few studies worldwide have used Archbold et al.'s (2008) *Parental Perspectives* questionnaire that assesses CI condition-specific domains. Parents in the UK report highest ratings in communication, followed by social relations and education (Archbold et al., 2008). A study in Finland using the same questionnaire found that parents express the most satisfaction with their children's increased communication, social relations, and improved self-reliance (Huttunen et al., 2009). Parents in the Netherlands rated overall HRQoL less positive, but reported marked improvements in supporting the child (Damen et al., 2007). Turkish parents of children who had CIs for at least 1 year respond similarly, finding the decision for implantation

to be stressful, but recognizing benefits of improved communication, social relations and self-reliance on their children's HRQoL (Incesulu et al., 2003).

Parent proxy studies agree that higher ratings of overall HRQoL are associated with improvements in communication, self-reliance and social relations. However, cultural affiliations could explain why differences arise when specific domains are considered. For example, parents in the US rate education more positively than parents in the UK (Archbold et al., 2008; Warner-Czyz et al., 2009). Similarities are seen as well, as parents in Finland and the UK both feel that supporting their children became a more challenging task post-CI (Huttunen et al., 2009; Sach & Whynes, 2005). All countries felt that overall general functioning was significantly improved in that children were able to respond when spoken to, and could understand verbal cues in situations where lip-reading was impossible. Researchers in the US, however, found that although children found more ease in general functioning, they still felt that the implant could not cater to every need (Schorr et al., 2009).

While studies that assess HRQoL among children with CIs have been conducted in several countries around the world, no studies to date compare results cross-culturally. Similarities and disparities in parental perspectives among various countries could indicate cultural differences in several domains. Cultural implications could be attributed to lifestyle, parenting, or access to implant-specific resources.

### **Usefulness of CI Cross-Cultural Comparison**

Cross-cultural comparison offers insight into cultural dynamics that can influence a child's functioning and satisfaction levels. Differences in cross-cultural HRQoL can be indicative of cultural perspective and acceptance of CI and HL, parenting style, or socio-

economic status. Studies that compare countries often view countries through the lens of individualism and collectivism (Black, Mrasek, & Ballinger, 2003; Groce, 1999). For example, countries that are collectivistic in nature could rate domains such as social relations and communication more positively while individualistic countries might rate self-reliance more positively. Understanding cultural affiliation in each country can be a useful indicator of the dynamics that influence behavior among children with CI.

While cross-cultural comparisons originated as an experimental branch of research, these studies have become more mainstream due to the impact they carry (Groce, 1999). Cross-cultural insight into where a child with CI struggles or succeeds enables health care professionals, researchers and clinicians to deliver the most meaningful services to children with CI and their parents. Specific to pediatric cochlear implantation, cross-cultural insight to HRQoL could be useful when providing services to children of another country or culture who are acclimating to new culture. Awareness of HRQoL domains that rate less positively can encourage appropriate programming and services in efforts to bolster HRQoL in particular domains. Parents can be better equipped to anticipate potential psychosocial outcomes their children could face at socially, academically and psychologically at school and home. Proactive preparation could ease CI-specific transitional difficulties and hopefully decrease distressing situations for children with CI. In efforts to generate greater life satisfaction for children with CI, the worldwide gap between children with normal hearing and children with HL and CI could become less noticeable over time.

### Summary

Communication fosters relationships and builds a foundation between family members, specifically between children and their parents. The dynamic of this relationship often shifts when a child is born with, or acquires, HL – particularly with a significant HL. Children with severe to profound sensorineural HL can be candidates for a CI, an auditory prosthesis that can provide auditory access to sound, albeit with a compromised signal.

A child's speech, language skills and speech intelligibility improve after cochlear implantation (Archbold, et al., 2000; Connor et al., 2000; Kent, 1993; Nikolopoulos et al., 1999; Tobey et al., 2000). Demographic variables such as earlier age of implantation, longer duration of CI use, younger chronological age and earlier age of HL detection also increases the likelihood of implant success (Loy et al., 2010). Bilateral CI and bimodal input can also contribute to better communication success (Ching et al., 2001). In addition to communication benefits, CIs are an integral part of psychosocial development among children with sensorineural HL (Chmiel et al., 2000). Assessing a child's HRQoL is a beneficial way to understand the importance and usefulness of a CI as it applies to a child on an individual and community level.

HRQoL assessment has played a significant role in public health development, reforming policies and providing adequate health care services (Brown, 1999). In pediatric populations, parent proxies are believed to provide an accurate representation of a child's HRQoL should the child be either too young or too compromised by ill health to present an accurate descriptor of his or her own HRQoL. Parent proxies often carry more weight than children's self-report when reforming public policy, highlighting the gravity of this research (Hays et al., 2006; Janicke et al., 2001).

Several researchers around the world have evaluated HRQoL in children with CI using the child's self-report and the parent's proxy report. Studies exploring the effects of pediatric cochlear implantation on HRQoL in children via parent proxy support overall benefits of the auditory prostheses on general well-being (Loy et al., 2010; Warner-Czyz et al., 2009). Results vary on certain demographic characteristics, such as chronological age, age at implantation, duration of CI use, configuration/number of implants and age of HL detection. Younger children, children who received CIs early, and children whose HL was detected early report more positive HRQoL overall (Loy et al., 2010; Warner-Czyz et al., 2009). Children with longer experience of CI also reported more positive HRQoL than children with shorter CI experience (Huber, 2005). Lastly, use of bilateral CIs or bimodal input enhances communication outcomes in children relative to unilateral input (one CI) (Ching et al., 2001). Improved communication outcomes via bilateral or bimodal input may positively impact HRQoL ratings in children.

In addition to differences according to demographic variables, results show cross-cultural differences on domain-specific ratings of HRQoL. For example, US findings show that parents rate their children's HRQoL more positively in physical and emotional well-being, school and everyday functioning, and less positively in self-esteem, family and friends (Warner-Czyz et al., 2009). Dutch parents rate HRQoL most positively in supporting the child (Damen et al., 2007). Parents in the UK rate HRQoL very positively in communication, psychosocial development and self-reliance and less positively in education and supporting the child (Archbold et al., 2008; Sach & Whynes, 2005). Finnish parents rate HRQoL most positively in communication, well-being, general functioning and social relations while rating well-being, education, effects of implantation and supporting the child less positively (Huttunen et al., 2009). Thus, self-reliance,

education and social relations receive more positive ratings in some countries versus others, suggesting the possibility of cultural implications in assessment of HRQoL in children using CI. However, no published studies to date compare HRQoL across different cultures and countries.

This study assessed parental perspectives of condition-specific HRQoL in children using CI in the US and compared results to published data from the UK, the Netherlands, and Finland. Archbold et al.'s (2008) questionnaire, *Children with Cochlear Implants: Parental Perspectives*, a HRQoL instrument that examines domains specific to CI, was administered to a sample of American parents of children using CI. Data assessing parents of children with CI in the US were analyzed in several ways. First, differences in mean ratings were examined across eight HRQoL domains (i.e., communication, general functioning, well-being, self-reliance, social relations, education, effects of implantation, and supporting the child). Second, potential relationships among domains (e.g. well-being and self-reliance) were explored. Third, demographic variables such as chronological age, age at cochlear implantation, duration of CI use, and device configuration (i.e., number of devices: unilateral vs. bilateral input) were compared to HRQoL ratings to uncover potential associations. Finally, parent responses from the US sample were compared to parent responses in a Dutch sample (Damen et al., 2007), a UK sample (Archbold et al., 2008) and parent responses in a Finnish group (Huttunen et al., 2009) to assess cross-cultural similarities and differences in CI specific domains.

### **Hypotheses**

The overarching goal of this project was to analyze American parental perspectives of HRQoL among their children with CI and to compare these responses to British, Finnish and

Dutch parental perspectives of CI-specific HRQoL to gain a global perspective. This goal will be accomplished via four basic points, outlined below:

### **Hypothesis 1**

In the US, parent ratings for education, well-being, and general functioning will be significantly more positive than ratings for self-reliance and social relations. Parent ratings for effects of implantation and supporting the child will be less positive than communication.

**Rationale 1.** Previous HRQoL data assessing children with CI using a different psychosocial instrument in the US report more positive ratings for education, well-being and general functioning and less positive ratings for self-reliance and social relations (Warner-Czyz et al., 2009). Less positive ratings for effects of implantation and disagreement between American parents over when to use the CI are seen, but positive ratings in communication are also reported (Schorr et al., 2009)

### **Hypothesis 2**

In the US, parent ratings for communication and education will be positively correlated with ratings for well-being and social relations.

**Rationale 2.** Strong relationships among HRQoL domains on this questionnaire have been found (Huttunen et al., 2009). Previous HRQoL domain comparisons show that children have greater self-esteem/reliance when they can communicate effectively at home and school (Huttunen et al., 2009).

**Hypothesis 3**

In the US, parent ratings for HRQoL will be associated with demographic variables of chronological age, age at cochlear implantation, duration of CI use and configuration/number of implants.

**Hypothesis 3a**

For all HRQoL domains, parent ratings will be negatively correlated with chronological age of the child, with higher HRQoL scores associated with younger age at time of rating.

**Hypothesis 3b**

For the domains of communication, well-being, social relations, self-reliance, and effects of implantation, parent ratings will be negatively correlated with age at cochlear implantation, with higher HRQoL scores associated with younger age of implantation.

**Hypothesis 3c**

For the domains of communication, well-being, social relations, self-reliance, and effects of implantation, parent ratings will be positively correlated with duration of CI use, with higher HRQoL scores associated with longer CI use.

**Hypothesis 3d**

For the domains of communication and general functioning, parent ratings of children of HRQoL will be positively correlated with CI configuration with higher HRQoL associated with bilateral compared with unilateral input.

**Rationale 3.** Younger chronological age, younger age at cochlear implantation, earlier detection of HL and longer use of CI are associated with more positive HRQoL among children in different countries (Huber, 2005; Huttunen et al., 2009; Loy et al., 2010; Warner-Czyz et al.,

2009). Although few studies assess HRQoL among children with bilateral CI or bimodal input versus unilateral CI, studies suggest more effective communication skills among children with bilateral CI and bimodal input, which could result in more positive HRQoL (Ching et al., 2001).

#### **Hypothesis 4**

Differences will be found between US parent ratings for HRQoL and parent ratings for HRQoL in the Netherlands, UK and Finland.

#### **Hypothesis 4a**

Parent ratings for education and supporting the child will be significantly more positive in the US than ratings for education and supporting the child in the Netherlands, UK, and Finland.

#### **Hypothesis 4b**

Parent ratings for well-being and social relations will be similar in the US and the Netherlands.

#### **Hypothesis 4c**

Parent ratings for self-reliance, well-being and social relations will be significantly more positive in the UK compared with the US.

#### **Hypothesis 4d**

Parent ratings for communication will be significantly more positive in the US compared with Finland.

**Rationale 4.** In the US, Netherlands, UK and Finland, parents rate communication and general functioning most positively (Archbold et al., 2008; Damen et al., 2007; Huttunen et al., 2009; Loy et al., 2010; Warner-Czyz et al., 2009). Specifically, US parents assign most positive

HRQoL ratings to the domains of education, self-reliance and supporting the child (Loy et al., 2010; Warner-Czyz et al., 2009). The domain receiving the most positive HRQoL ratings in the UK is self-reliance; furthermore, well-being and social relations were rated very positively (Archbold et al., 2002; Archbold et al., 2008). Finnish parents rated all HRQoL domains very positively, especially social relations and well-being (Huttunen et al., 2009).

## CHAPTER THREE

### Method

#### Participants

Participants in the US sample were recruited from CI summer camps in 2007 and 2008. Thirty-three families of children with severe to profound sensorineural HL using CI (17 boys, 15 girls, one family did not complete demographic data) enrolled in the study. All children received a CI by 8 years of age, had at least 3 years of device experience, and spoke English. Children with diagnosed or suspected cognitive, visual, or developmental delay were excluded from the study. Participation was not limited by CI manufacturer or configuration (unilateral or bilateral) because published studies report no difference in early outcomes among devices or configurations in children (Davis, Tobey, Moore, & MacNeilage, 2004).

Parents in the US provided demographic information for 32 of the 33 children (Table 1). Chronological ages of children using CI ranged from 4 to 18 years ( $M = 9.85$  years,  $SD = 3.30$ ). Mean age at first CI activation was 2.47 years ( $SD = 1.85$ , range = 4 months to 8 years). Twenty-five participants (78%) received a second CI at the mean age of 4.89 years ( $SD = 3.24$ , range = 9 months to 13 years). Average duration of CI use was 7.47 years ( $SD = 2.80$ , range = 1 year to 12 years).

Authors of the studies published in the Netherlands, UK and Finland also provided demographic information for their samples (Archbold et al., 2008; Damen et al., 2007; Huttunen, et al., 2009) (Table 1). Chronological age, age at CI activation, duration of CI use and CI configuration (variables assessed in the US cohort) were not provided for all countries, however. Parents from the Netherlands provided data on 130 children with CI with a mean chronological

age of 8 years (range = 1 – 18 years), average age of 4 years at CI activation, (range = 7 months – 14 years) and average CI use of 4 years (Damen et al., 2007). In the UK sample, 101 parents of children participated in the study (Archbold et al., 2008). Average age at CI activation for children in the UK was 4.7 years (range of 1.3 to 12.4 years) (Archbold et al., 2008). Thirty-six parents in Finland participated in Huttunen et al.'s 2009 study. In this sample, chronological ages of children averaged 5 years ( $SD = 2$  years, range = 5 months – 2 years) and average age at CI activation was 3 years, 5 months ( $SD = 2$  years, range = 1 – 12 years). Average duration of CI use was 2 years (Huttunen et al., 2009).

### **Materials**

The CI-specific HRQoL questionnaire used in this study was Archbold et al.'s (2008) validated parental proxy assessment, *Children with CIs: Parental Perspectives*. The authors developed the questionnaire based on parental experiences as described in their own words through an open-ended questionnaire or interview (Archbold et al., 2002). Archbold et al. (2002) then analyzed these subjective open-ended views into content-driven topics that highlight the domains parents find most relevant. The resulting questionnaire includes 74 items covering two overarching domains of the process of implantation: Decision-making (26 items) and outcomes of implantation (48 items). Outcomes of implantation are further subcategorized into domains, including communication (6 items), general functioning (6 items), well-being (5 items), self-reliance (4 items), social relations (7 items), education (7 items), effects of implantation (7 items), and supporting the child (6 items) (Archbold et al., 2008). Several studies evaluate HRQoL in children who use CI using this parental perspectives questionnaire (Damen et al., 2007; Fortunato-Tavares et al., 2012; Huttunen et al., 2009; Incesulu et al., 2003) and have

documented its validity and reliability (Nunes, Pretzlik, & Ilicak, 2005; O'Neill, Lutman, Archbold, Gregory, & Nikolopoulos, 2004).

The 74 items in the questionnaire are dispersed throughout the questionnaire so as to not group statements according to theme. Statements are numbered consecutively as they appear in the questionnaire and parents rate their responses to the statements on a 5-point Likert scale that ranges from strongly agree to strongly disagree. The following values were assigned to each categorical response to allow quantitative evaluation of responses: strongly agree (5), agree (4), neutral (3), disagree (2) and strongly disagree (1). The questionnaire's items are balanced for negativity and positivity, with 46 statements phrased in a positive format (e.g., *Now s/he is talkative and engages others in conversation*) and 28 statements in a negative format (e.g., *S/he is unable to cope with mainstream schooling*) (Archbold et al., 2008). Scoring of negative statements was reversed so that a higher score will indicate a more positive response.

### **Procedure**

Families participating in the study were recruited from the Colorado Neurological Institute's Cochlear Kids Camp in Estes Park, Colorado, and the Crystal Charity Ball Cochlear Implant Summer Listening Camp in Dallas, Texas. Data were collected directly from these camps in 2007 and 2008, as well as through telephone, email, and mail contact.

Parents answered the *Children with Cochlear Implants: Parental Perspectives* questionnaire independently either at camp or at their home. Parents also provided background demographic information about their child's HL (i.e., chronological age of the child, age at implantation, duration of CI use, and configuration of CI).

Data for the Dutch, British and Finnish samples were obtained through published studies by Damen et al. (2007), Archbold et al. (2008) and Huttunen et al. (2009), respectively. The author had no direct contact with the participants from those samples. To test the hypotheses, significance was set at  $< 0.01$  to reduce the likelihood of Type 1 error. Results significant at the  $< 0.05$  level will be reported, however.

The University of Texas at Dallas Institutional Review Board approved this project (IRB 07-24). All parents who participated in this study voluntarily provided responses. No participants received compensation for their input.

## CHAPTER FOUR

### Results

#### Descriptive Statistics

##### Parental Perspectives Questionnaire

Each parent rated HRQoL for the 8 domains outlined in Archbold et al.'s (2008) *Parental Perspectives* questionnaire (Appendix). Throughout the data, non-responses were classified as missing values. Domains for analysis included communication, general functioning, self-reliance, well-being, social relations, education, effects of implantation and supporting the child. Parents rated their agreement with the statement by answering from 1-5 on a Likert scale, with a higher score indicating more positive HRQoL ratings (i.e., greater levels of satisfaction). Throughout the questionnaire, negative statements were reversed for scoring purposes. After all statements were evaluated and reversed accordingly, HRQoL domain statements were averaged to produce a domain mean.

As shown in Table 2 and Figure 1, parents in the US rated communication, ( $M = 3.93$ ,  $SD = 0.62$ , range = 2-5) general functioning ( $M = 3.86$ ,  $SD = 0.47$ , range 3-4.83) and social relations ( $M = 3.85$ ,  $SD = .38$ , range = 3.14-4.57) most positively. Self-reliance ( $M = 3.71$ ,  $SD = 0.77$ , range 2.25-5), well-being ( $M = 3.65$ ,  $SD = 0.62$ , range = 2.6-5) and supporting the child ( $M = 3.74$ ,  $SD = 0.56$ , range 2.33-4.67) also received positive ratings. Education ( $M = 3.32$ ,  $SD = 0.50$ , range = 2.43-4.29) and effects of implantation ( $M = 3.11$ ,  $SD = 0.70$ , range = 1.71-4.14) received the least positive ratings of all the HRQoL domains.

### Results of Hypothesis Testing

#### Hypothesis 1: HRQoL domain comparison

In the US, parent ratings for education, well-being, and general functioning will be significantly more positive than ratings for self-reliance and social relations. Parent ratings for effects of implantation and supporting the child will be less positive than communication.

A repeated measures one-way ANOVA revealed a significant main effect for domain on HRQoL ratings,  $F(4, 150) = 12.67, p < .001$  with Greenhouse-Geisser correction. Least Significant Difference post hoc tests for multiple comparisons were used to calculate statistical differences among domains (Table 3). Post hoc testing revealed that education received significantly less positive ratings than self-reliance ( $M = .392, SE = .135, p = .007$ ) and social relations ( $M = .524, SE = .102, p < .001$ ). Well-being and general functioning were not significantly lower than either self-reliance ( $M = -.066, SE = .082, p = .428$ ) ( $M = .144, SE = .121, p = .244$ ) or social relations ( $M = -.198, SE = .104, p = .066$ ) ( $M = .012, SE = .086, p = .893$ ). Effects of implantation received significantly less positive ratings than communication ( $M = .824, SE = .119, p < .001$ ), but supporting the child did not receive less positive ratings than communication ( $M = .192, SE = .123, p = .129$ ). Effects of implantation and education had the highest number of significant inter-domain differences. Effects of implantation was significantly less positive than communication ( $M = -.824, SE = .119, p < .001$ ), general functioning ( $M = -.750, SE = .129, p < .001$ ), self-reliance ( $M = -.606, SE = .113, p < .001$ ), well-being ( $M = -.540, SE = .102, p < .001$ ), social relations ( $M = -.738, SE = .137, p < .001$ ), and supporting the child ( $M = -.632, SE = .101, p < .001$ ). Education was also significantly less positive than communication ( $M = -.610, SE = .098, p < .001$ ), general functioning ( $M = -.536, SE = .108, p$

<.001), self-reliance ( $M = -.392, SE = .135, p = .007$ ), social relations, ( $M = -.524, SE = .102, p < .001$ ), and supporting the child ( $M = -.418, SE = .134, p = .004$ ). These differences, excluding education compared with self-reliance and supporting the child, were the most significant differences found. Additionally, well-being and effects of implantation ( $M = .540, SE = .102, p < .001$ ) also presented a strong difference. No other differences were significant.

Hypothesis 1 was partially supported because the domain of effects of implantation was rated significantly less positive than communication. However, ratings for education, well-being and general functioning did not exceed ratings for self-reliance and social relations. Additionally, supporting the child was not significantly less positive than communication.

### **Hypothesis 2: Associations within HRQoL domains**

In the US, parent ratings for communication and education will be positively correlated with ratings for well-being and social relations.

Spearman correlation coefficients were computed to assess the relationships among HRQoL domains (Table 4). Self-reliance, communication and well-being each achieved significant associations with the most number of HRQoL domains. Parent ratings of communication positively correlated with self-reliance,  $r(31) = .493, p = .004$ ; general functioning,  $r(31) = .445, p = .010$ ; well-being,  $r(31) = .432, p = .012$ ; social relations,  $r(31) = .468, p = .006$ ; education,  $r(31) = .549, p < .001$ ; and effects of implantation,  $r(31) = .410, p = .018$ . Self-reliance positively correlated with overall communication; general functioning,  $r(31) = .507, p = .003$ ; well-being,  $r(31) = .798, p < .001$ ; effects of implantation,  $r(31) = .618, p < .001$ ; and supporting the child,  $r(31) = .532, p < .001$ . Well-being positively correlated with self-reliance, general functioning,  $r(31) = .589, p < .001$ ; social relations,  $r(31) = .400, p = .021$ ;

effects of implantation,  $r(31) = .646, p < .001$ ; and supporting the child,  $r(31) = .504, p = .003$ . A positive correlation also was found between effects of implantation and supporting the child,  $r(31) = .499, p = .003$ . Strongest correlations ( $p < .001$ ) were found with well-being when associated with general functioning, self-reliance and effects of implantation. Self-reliance and effects of implantation ( $p < .001$ ) were also strongly correlated, as were communication and education ( $p < .001$ ).

Hypothesis 2 was partially supported because communication was significantly positively correlated with social relations, but was not fully supported as there were no significant correlations with communication and well-being, education and well-being or education and social relations.

### **Hypothesis 3: Associations between HRQoL domains and demographic variables**

Hypothesis 3 predicted that parent ratings for HRQoL will be associated with demographic variables of chronological age (Hypothesis 3a), age at cochlear implantation (Hypothesis 3b), duration of CI use (Hypothesis 3c), and configuration/number of implants (Hypothesis 3d).

#### **Hypothesis 3a**

For all HRQoL domains, parent ratings will be correlated negatively with chronological age of the child, with higher HRQoL scores associated with younger age at time of rating.

Spearman correlation coefficients revealed no statistically significant negative correlations between chronological age and any of the eight HRQoL domains (Table 5). However, trends were found in self-reliance,  $r(30) = .389, p = .028$ , and effects of implantation,  $r(30) = .408, p = .021$ , in that parents of older children gave ratings of more positive self-

reliance and greater satisfaction with effects of implantation. Since no significant correlations were found, Hypothesis 3a was not supported.

### **Hypothesis 3b**

For the domains of communication, well-being, social relations, self-reliance, and effects of implantation, parent ratings will be negatively correlated with age at cochlear implantation, with higher HRQoL scores associated with younger age of implantation.

As shown in Table 5, Spearman correlation coefficients revealed no statistically significant negative relationships between age at CI activation and any of the HRQoL domains. Overall, Hypothesis 3b was not supported as no significant correlations were found.

### **Hypothesis 3c**

For the domains of communication, well-being, social relations, self-reliance, and effects of implantation, parent ratings will be positively correlated with duration of CI use, with higher HRQoL scores associated with longer CI use.

As shown in Table 5, Spearman correlation coefficients revealed no statistically significant correlations. However, a trend was found between duration of CI use and self-reliance,  $r(32) = .423, p = .016$ , such that longer CI use correlated with greater self-reliance and independence among children with CI.

Hypothesis 3c was not supported as duration of CI use did not positively correlate with communication, well-being, social relations, self-reliance and effects of implantation.

**Hypothesis 3d**

For the domains of communication and general functioning, parent ratings of children of HRQoL will be positively correlated with CI configuration with higher HRQoL associated with bilateral compared with unilateral input.

As shown in Table 6, point bi-serial correlations found no significant relationships between CI configuration and HRQoL. A trend showing more positive self-reliance with second CI activation was found,  $r(23) = .457, p = .022$ , such that greater independence is observed in children with bilateral CIs. However, because no significance was found, Hypothesis 3d was not supported.

**Hypothesis 4: Cross-cultural comparison**

Hypothesis 4 predicted differences in HRQoL domains between the US, the Netherlands, UK and Finland, as outlined in Hypotheses 4a-4d. Tables 7, 8 and 9 detail mean comparisons between the US and the Netherlands, UK, and Finland, respectively.

**Hypothesis 4a**

Parent ratings for education and supporting the child will be significantly more positive in the US than ratings for education and supporting the child in the Netherlands, UK, and Finland.

As shown in Table 7, one sample t-tests found that parents in the US rated education,  $t(32) = 12.20, p < .001$ , and supporting the child,  $t(32) = 8.88, p < .001$ , more positively than parents in the Netherlands. Parents in the UK, however, rated education higher than parents in the US,  $t(32) = -4.14, p < .001$ , but no significant difference was found in supporting the child (Table 8). Results from comparison with the Finnish group mirrored those from the UK: Parents

in Finland rated education significantly more positively than parents in the US,  $t(32) = -5.53, p < .001$ , but no significant differences were found in supporting the child (Table 9).

Hypothesis 4a was partly supported as parents ratings of education and supporting the child were higher in the US than the Netherlands, but was not fully supported as parents in the US did not rate education and supporting the child higher than parents in the UK or Finland.

#### **Hypothesis 4b**

Parent ratings for well-being and social relations will be similar in the US and the Netherlands.

Parents in the US rated both well-being,  $t(32) = 11.41, p < .001$ , and social relations  $t(32) = 24.84, p < .001$ , higher than parents in the Netherlands, as shown in Table 7. Additionally, parents in the Netherlands rated all other domains significantly less positively than parents in the US: Communication  $t(32) = 17.3, p < .001$ , general functioning  $t(32) = 17.28, p < .001$ , self-reliance  $t(32) = 8.71, p < .001$ , education  $t(32) = 12.2, p < .001$ , effects of implantation  $t(32) = 6.58, p < .001$  and supporting the child  $t(32) = 8.88, p < .001$ .

Hypothesis 4b was not supported as significant differences were found between parents in the US and the Netherlands.

#### **Hypothesis 4c**

Parent ratings for self-reliance, well-being and social relations will be significantly more positive in the UK compared with the US.

As shown in Table 8, a one sample t-test comparing parents in the US with parents in the UK did not find significant differences for self-reliance,  $t(32) = -1.39, p = .175$ , well-being,  $t(32) = -.01, p = .989$  or social relations  $t(32) = -2.02, p = .052$ . Other significant findings were found,

however. As mentioned above in Hypothesis 4a, Parents in the UK rated education significantly higher than parents in the US. Additionally, parents in the UK rated effects of implantation  $t(32) = -3.06, p = .004$ , significantly more positively than parents in the US.

Because no significant differences were found in self-reliance, well-being or social relations, Hypothesis 4c was not supported.

#### **Hypothesis 4d**

Parent ratings for communication will be significantly more positive in the US compared with Finland.

As shown in Table 9, one sample t-tests found that parents in Finland rated HRQoL in communication  $t(32) = -3.39, p = .002$ , more positively. In addition to a significant difference in education as depicted in Hypothesis 4a, additional significant findings showed that parents in Finland rated general functioning  $t(32) = -5.38, p < .001$ , self-reliance  $t(32) = -4.38, p < .001$ , social relations  $t(32) = -6.88, p < .001$  and effects of implantation  $t(32) = -4.87, p < .001$  more positively than parents in the US.

Since parents in the US did not rate communication more positively than parents in Finland, Hypothesis 4d was not supported.

## CHAPTER FIVE

### Discussion

#### Rating Differences among HRQoL Domains

Hypothesis 1 was partially supported in that ratings for communication exceeded that of effects of implantation, but not supporting the child. The communication domain received the highest numerical score for this sample of parents, but the difference between the communication score and scores for most other domains was not significant.

#### Communication Domain

When parents in this study were asked to rate HRQoL in communication, satisfaction in speech and language was strongly endorsed. For example, parents consistently indicated the high quality of their child's speech production. Parents positively rated "his/her use of spoken language has developed greatly" and negatively rated "the quality of her/his speech gives me cause for concern" (Archbold et al., 2002). Results indicate that effective communication with a CI largely influences positive HRQoL in children with CI as they are able to connect with the world around them.

Positive ratings of communication were expected for two reasons. First, numerous reports provide evidence of improved speech perception, speech production, and language outcomes with CI use (Archbold et al., 2000; Connor et al., 2000; Kent, 1993; Niparko, 2000). Second, improved communication often accompanies positive quality of life (Christiansen & Leigh, 2004; Loy et al., 2010; Schorr et al., 2009; Warner-Czyz et al., 2009). Although communication received the highest mean score of all HRQoL domains, it did not differ significantly from the remaining domains. Characteristics of the sample could provide insight into this lack of

significance. Participants of this study completed these HRQoL questionnaires at CI summer camps that focus on empowering, educating and uniting parents and children with CIs. Because of their involvement with the camp, parents in this study likely focused on the well-being of their children with CIs and took active steps to improve HRQoL when possible. Lack of a significant difference in communication because of equally high scores in other domains (i.e., general functioning, social relations) could be because parents' objective is to bolster HRQoL in domains other than just communication, focusing on the holistic well-being of their child. Additionally, families attending these camps are generally of middle to higher socioeconomic status, suggesting greater ability to finance CI-related costs. Ability to attend CI family camps, invest in private tutoring, and greater access to health care could explain higher HRQoL in social relations and general functioning.

The other component of Hypothesis 1 predicted that ratings for education, well-being and general functioning would exceed ratings for self-reliance and social relations. These differences were not found. In fact, parents rated self-reliance and social relations significantly higher than education, suggesting that improvement in the educational setting is not as salient for these American parents as is the ability of their children to function independently and build relationships with their peers. Furthermore, education and effects of implantation were rated significantly lower than all other domains, with the exception of well-being and education, which did not significantly differ. Results suggest that parents feel that their children are not progressing as steadily in academics and are not adapting well to the effects of implantation.

**Education Domain**

Very modest ratings in education are specific to this study. Parents positively rated education statements such as “s/he is unable to cope with mainstream schooling” and “I am concerned about her/his future school placement.” Additionally, they negatively rated “s/he is keeping up well with children of her own age at school” and “the local school and support services adequately meet all our needs concerning the use of her/his implant at school.” These findings counteract the intention of protective laws for CI users. Children with CIs are supported by the Individuals with Disabilities Educational Act, (IDEA) requiring children to receive an individualized educational plan (IEP) in the least restrictive educational environment (United States Department of Education, 2012). Least restrictive environments describe mainstreamed general classrooms where most children in this study are placed.

Although children are entitled to receive CI-specific services, funding disparities often are seen across states (Federal Education Budget Project, 2012). Because of differences in state-specific economic resources and willingness of state officials to fund these resources, some states cannot provide specific accommodations (i.e., American Sign Language interpreters, tutoring, treatment team consultation, etc.) for children with CI (Federal Education Budget Project, 2012). Consequently, wealthier states provide greater access to resources while states with financial deficits struggle (Federal Education Budget Project, 2012). For children with CI who potentially live in areas with greater financial strain, inability to access appropriate services could be an indicator of less positive HRQoL if children do not receive the most optimal educational experience. A limitation of this study is that we did not collect data on educational background

(e.g. school accommodations, special classroom placement, CI support at school), which could have provided more details about the educational setting.

While inconsistency in state-wide academic funding could explain negative ratings in education, academic and CI expectations could provide further insight into this disparity. It is possible that parent expectations were not fully met. Research suggests that parental involvement and expectation positively correlate with academic success (Soman, Kan, & Tharpe, 2012). Parents in this study do exhibit parent involvement as evidenced by their enrollment in family CI summer camps. Expectations were not addressed, however. Parents in this study could anticipate quicker adaptation to mainstream schooling. If children do not progress at the rate expected, parents could view this as lack of academic success. When considering CI-related factors at school, CI school accommodations encourage daily functional checks within the first few months of implantation (Tye-Murray, 1993). Children are often unable to assess optimal functionality and generally require the assistance of an adult who has a basic understanding of the CI (“Meeting the Educational Needs”, 2007; Tye-Murray, 1993). Children likely miss school for doctor’s appointments, potentially causing them to fall behind with schoolwork, possibly further illustrating parent’s low ratings in education.

### **Effects of Implantation Domain**

Very modest ratings in effects of implantation were prominent in this sample, and similar ratings were seen in other studies. Parents in this study positively rated statements such as “I worry that s/he will blame me for my decision for him/her to have an implant” and “I am concerned that my deaf child will be rejected by the Deaf community because of the implant”. Previous studies found that parents reported difficulty in choosing between a hearing-only and

deaf-only classroom, as choosing a classroom could indicate inclinations towards a deafness identity (Christiansen & Leigh, 2004). Statements endorsed in this questionnaire along with previous research suggest that deafness and identity could play a role in HRQoL. Psychosocially, children generally begin to formulate roles and identity in early adolescence, potentially explaining parents' urgency to choose appropriately for this group of children, whose mean age of 9-10 years slowly approaches this developmental stage (Erikson, 1985). The responsibility of aligning with a hearing or Deaf community on their child's behalf at a crucial age could explain low scores of parents in this cohort.

Deaf communities (denoted with a capital "D") include Deaf individuals who celebrate Deafness as an identity (National Association of the Deaf, 2012). Use of American Sign Language (ASL) along with shared beliefs, knowledge and practices are specific to those in the Deaf community as they identify as a cultural group. Deaf communities differ from individuals with hearing loss in that Deaf communities embrace deafness and generally do not support the use of assistive technology to provide hearing (National Association of the Deaf, 2012). Because of these differences in communities, parents could feel pressure that choosing a classroom could inadvertently label their child in one group or another. Interestingly, in a study that assessed children with CI's inclinations towards Deaf or hearing peers, results were mixed. Results indicated that children endorsed a dual identity, in that they felt equally comfortable with hearing and Deaf peers (Spencer, Tomblin, & Gantz, 2012). Although identifying with a group might not be as stressful for children, negative ratings in effects of implantation suggest that parents feel overwhelmed by the responsibility of choosing an identity for their children who are unable to do so, and, as a consequence, may not be satisfied with the outcome.

### **Associations among HRQoL Domains**

Hypothesis 2 was supported partially because communication and social relations were significantly correlated, but no other predicted relationships were supported. Results suggest that parents felt their children were able to formulate meaningful relationships and participate independently in social settings as a result of improved communication skills. Communication also positively correlated with general functioning, self-reliance and education, illustrating that improvements in communication strongly influence overall well-being, independence and academic success. In addition to communication, self-reliance correlated with well-being, effects of implantation, general functioning and supporting the child, highlighting the importance of independence and its influence on several overarching domains of HRQoL. Overall well-being positively correlated with general functioning, effects of implantation, and supporting the child.

No other American study to date has assessed the relationship among HRQoL domains. An interesting finding specific to this study shows that HRQoL domains often are interconnected; positivity in one domain can directly influence the positivity in another. This could be encouraging for parents who feel they can support their child in one particular area, but struggle to provide well-rounded support (Sach & Whynes, 2005). For example, some parents can provide support in communication by adhering to doctor's visits and mapping adjustments, but feel less adequate in aiding social skills. Since communication and social relations are positively correlated, efforts to support communication abilities could be beneficial to social well-being, as well.

### **Associations between HRQoL Domains and Demographic Variables**

Hypothesis 3 predicted that higher ratings of HRQoL would correlate with younger chronological age, younger age at implantation, longer CI use and bilateral input. No significant correlations were found, but trends in self-reliance were noted. For example, parents endorsed statements such as “s/he is as independent as most other children of her age” and “a significant change has been improvement in her/his confidence” and negatively rated “I can seldom leave her/him to do something on own”. Higher ratings of self-reliance coincided with older chronological age, bilateral CIs, and longer durations of device use. Chronologically older children with CIs potentially have richer CI experience than their younger peers, and are able to independently function in most settings because of their prolonged familiarity with CIs. Additionally, children with bilateral CIs have greater localization of sound, so they are likely to be more independent as they are better equipped to hear environmental sounds which help keep them safe. It is possible that trends in self-reliance reflect the value of independence in an individualistic culture like the US (Harms, 2007). Cultural research that assessed parents of children with normal hearing found that parents value self-reliance in their children. They felt that self-reliance was an indicator of future success, which most likely aligns with the views of parents in this study (Taylor, 2010).

Two studies have assessed the relationship between demographics and HRQoL in children with CI. Younger age at implantation and younger chronological age have been linked to more positive ratings of HRQoL (Schorr et al., 2009; Warner-Czyz et al., 2009). However, results in duration of CI use diverge. Schorr et al. (2009) found that longer duration of CI use correlated with more positive HRQoL while Warner-Czyz et al. (2009) reported more positive

HRQoL with shorter CI use. However, a narrow range of ages in the sample could explain Warner-Czyz et al.'s findings: Participant age spanned from 4 to 7 years and all received their devices by an average of 2.5 years (Warner-Czyz et al., 2009). In this study, lack of significance between HRQoL and demographic variables could be attributed to the homogeneity of this population, reflected in low standard deviations for all demographics variables of interest (approximately 1-3 years). Because of limited variability, a wide range of perspectives were simply unavailable, therefore failing to demonstrate a relationship between HRQoL ratings and demographic variables. Assessing demographics and HRQoL in a broader sample with greater variance could characterize potential influences of chronological age, duration of CI and configuration of CI more accurately. In this situation, correlations might be found.

### **Rating Differences across Cultures**

No other study to date has compared parent ratings of HRQoL cross-culturally to determine similarities and differences across different communities of pediatric CI recipients. Results from this study suggest that ratings of HRQoL differ significantly among cultures.

#### **The US and the Netherlands**

Hypothesis 4a was partially supported because ratings of education and supporting the child were higher in the US than the Netherlands (Damen et al., 2007). Hypothesis 4b was not fully supported because well-being and social relations were higher in the US than the Netherlands, contrary to the prediction that no differences would exist. In fact, parents in the US rated HRQoL significantly more positively than parents in the Netherlands in all eight domains (i.e., communication, general functioning, well-being, social relations, self-reliance, education, effects of implantation, and supporting the child).

Several factors could explain such significant differences between the US and the Netherlands. Differences in sample demographics, costs of CI-related expenses and multilingualism in the Netherlands could potentially play a role in differences between these countries. When examining characteristics of their samples, previous research predicts demographics that correlate with greater success and more positive HRQoL. For example, researchers in the Netherlands found that shorter duration of deafness (pre-CI) and greater residual hearing are indicators of success and satisfaction with CI (van Dijk et al, 1999). Younger chronological age is also a predictor of more positive HRQoL (Schorr et al., 2009; Warner-Czyz, et al., 2009). Data from Dutch children included in Damen et al.'s (2007) study varied in age at implantation (<1 – 14.3 years) and duration of deafness (<1 – 14.3 years). Because Damen et al. did not report standard deviations, distribution of these demographic variables is unclear. In comparison, mean age of US children in this study was 9.85 ( $SD = 3.3$ ) and mean age at 1<sup>st</sup> CI activation was 2.47 years ( $SD = 1.85$ ). If children in this American sample were considerably younger than children in the Dutch sample when they received a CI, their communication skills could be further advanced (Schorr et al., 2009). Because more positive HRQoL is often attributed to effective communication skills, demographic variables could be a factor in the HRQoL differences between the Netherlands and the US.

Further explanations for low scores in the group of Dutch families could relate to differences in CI-related costs between the Netherlands and the US. Netherlands-based studies found that cost of CI related expenses (e.g. pre- and post-implantation visits, surgery, rehabilitation, post-operative check-ups) result in relatively higher costs than CI expenses in other countries (Severens, Brokx, & van den Broek, 1997). Conversely, cost-analysis studies for

the US found that costs for implantation appear to be a reasonable investment for American families (Cheng et al., 2000). Although these studies both were published over a decade ago, results illustrate considerable differences in CI-related costs and could underlie the discrepancy in scores between the US and Netherlands. Because of the financial demands, parents in the Netherlands could feel more pressured to earn the income to provide for families, adding stress to their lives and pressure on relationships within the family. As a result of high costs, Dutch parents potentially are unable to provide finances for extra-curricular activities, school tutors or other activities that could bolster HRQoL of their children with CI. Additionally, they may be less satisfied with the outcome.

In addition to the financial demands of the CI, multilingualism could affect HRQoL in Dutch children with a CI. Many children in the Netherlands are bilingual or multilingual as Dutch, English, French and Frisian (a coastal Netherlands language) are prominent languages in the Netherlands. A recent study examined language development in bilingual versus monolingual children with CI in the Netherlands and found that bilingual children exhibit more difficulties with language development (Wiefferink, 2012). Communication difficulties that children in the Netherlands potentially experience could be the reason for such negative ratings in communication. Since this study found that communication is correlated with many other domains, negative overall HRQoL could be attributed to difficulties with CI use and multilingualism.

### **The US and the UK**

Hypothesis 4c was not supported and Hypothesis 4a was not fully supported: No differences existed between ratings for self-reliance, well-being and social relations.

Additionally, US ratings for education and supporting the child were not more positive than ratings in the UK. In fact, education, as well as effects of implantation, was rated more positively by parents in the UK than the US. Several studies regarding educational services and CI exist in the UK, and could explain the disparity in satisfaction with education between the US and UK. Researchers in the UK continually stress the importance of an ongoing dialogue between CI centers and parents and teachers, the caretakers who play influential roles in a child's everyday life (Archbold, 2008; Archbold & O'Donoghue, 2007). Consequentially, CI centers have created programming to educate teachers on deafness and CI, and these programs are prevalent in the UK, as are CI centers and hospitals (Archbold & O'Donoghue, 2007). Parents and teachers in the UK could be more adequately prepared to respond to their child's CI needs than parents and teachers in the US since there are widespread CI resources and accommodations available. Greater access to CI accommodations could explain high ratings of effects of implantation among parents in the UK. While research in the US does discuss the importance of teachers being mindful of the effects of CI, no organization has published reports of community awareness as widespread as the UK ("Meeting the Educational Needs," 2007).

### **The US and Finland**

Hypothesis 4d was not supported and Hypothesis 4a was not fully supported as ratings for communication and education were less positive in the US than Finland. Additionally, parents in Finland rated education more positively than parents in the US (Huttunen et al., 2009). Parents in Finland also rated effects of implantation, social relations, self-reliance and general functioning more positively than parents in the US.

Since few studies have researched HRQoL in children with CI in Finland, analyzing general quality of life in Finland could provide insight into the differences between Finland and the US. Huttunen & Valimaa (2012) found that parents rated high satisfaction in speech and language after their children received CIs. Additionally, parents in Finland reported greater independence and more sociability within the family after implantation. Since education and effects of implantation were rated considerably less positive than all other HRQoL domains in the US sample, it can be expected that these two domains are lower in the US than Finland. As previously mentioned, parent expectations, and pressure to associate with Deaf or hearing communities could explain low ratings in the US. However, Finland's ratings exceeded US ratings in three very positively rated US domains: social relations, general functioning, and self-reliance. Parental expectations and overall quality of life (QoL) in Finland could potentially explain this phenomenon.

Huttunen et al. (2009) affirms the influential role that parental expectation has on HRQoL report. It is possible that parents in Finland simply have more realistic expectations of their children with CIs. The environment in which these families reside could play an integral role. Specifically, Finland has been continually ranked highly in reports of generic country-wide QoL. For example, the Organisation for Economic Co-operation and Development (OECD) reported that Finland's overall life satisfaction, education system and health care system ranked significantly high and more positively than most other countries (OECD, 2012). Finland, in fact, has been labeled "The World's Best Country" for its overall positive quality of life, academic achievement and economic security (Newsweek, 2010). It is very likely that the positive environment in which these families live positively affects QoL of the parents. In turn, parents

could be more likely to rate their children's HRQoL more positively, potentially explaining the consistently positive HRQoL ratings seen in Finland as compared to this US sample.

### **Conclusion**

American parents of children using CI rate HRQoL very positively, regardless of the child's age at implantation, duration of CI use, chronological age and bilateral input. The most highly rated domains were communication, general functioning and social relations, with communication numerically most positive. Surprisingly, education and effects of implantation received the least positive ratings, perhaps due to lack of educational CI resources, or pressure to associate with hearing or Deaf communities. Results found that HRQoL domains often are correlated (e.g., positivity in communication indicates positivity in social relations). Comparison to outcomes from other countries revealed that US parent reports of HRQoL are significantly less positive than parents in Finland and more positive than parents in the Netherlands. US aligned most closely with the UK, with the exception of education and effects of implantation, which were more positive in the UK.

This study is not without limitations. First, a broader sample with greater variability could have produced significant correlations between HRQoL and demographic variables. Second, information detailing educational accommodations was not collected, as this could have provided greater insight into less positive scores for education in the US. Several strengths of this study do exist, however. No other US study has utilized a CI-specific questionnaire to assess parental perspectives of HRQoL among children with CI. Additionally, since the questionnaire used has been validated and published, cross-cultural comparisons were drawn by comparing results between countries that used the same instrument.

Cross-cultural comparisons provide global views of HRQoL in children with CI. Differing results indicate that parents in different countries have varying expectations of their child's progress with CI use. Factors such as access to CI centers, health care and parent education could influence parent expectation and satisfaction post-implantation. These findings suggest that clinicians need to consider cultural values and community support when setting realistic expectations of CI outcomes for families. It is important for children with CIs and their families to be empowered, educated and given appropriate resources, accommodations and preparation for CI use. As a result, utilization of available resources in all communities and cultures will likely optimize CI use and bolster HRQoL in children with CI.

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Table 1

*Demographic characteristics of children in the US, Netherlands UK and Finland using CI (in years)*

Demographic (in years)	United States <sup>a</sup> ( <i>n</i> = 33)	Netherlands ( <i>n</i> = 130)	United Kingdom ( <i>n</i> = 101)	Finland ( <i>n</i> = 36)
	M (SD) Range	M (SD) Range	M (SD) Range	M (SD) Range
Chronologic age	9.85 (3.30) 4 – 18	8 (--) 1-18	--	5 (2) <1-2
Age at 1 <sup>st</sup> CI activation	2.47 (1.85) <1 – 8	4 (--) <1-14	4.7 (--) <1-12	3 (2) 1-12
Age at 2 <sup>nd</sup> CI activation	4.89 (3.24) <sup>b</sup> <1 – 13	--	--	--
Duration of CI experience	7.47 (2.80) 1 - 12	4 (--)	--	2 (--)

*Note.* CI = Cochlear implant. Data for the Netherlands comes from Damen et al. (2007). Demographic information for the UK group comes from Archbold et al. (2008). Demographic characteristics for the Finnish group were drawn from Huttunen et al. (2009).

<sup>a</sup>Demographic information for the United States group only was available for 32 children.

<sup>b</sup>*n* = 25

Table 2

*Descriptive statistics for HRQoL domains (n = 33)*

	<i>M</i>	<i>SD</i>	Range
Communication	3.93	0.62	2-5
General functioning	3.86	0.47	3-4.83
Self-reliance	3.71	0.77	2.25-5
Well-being	3.65	0.62	2.6-5
Social relations	3.85	0.38	3.14-4.57
Education	3.32	0.50	2.43-4.29
Effects of implantation	3.11	0.70	1.71-4.14
Supporting the child	3.74	0.56	2.33-4.67

Table 3

*Differences between means for HRQoL domains*

HRQoL domain	Compared with	<i>MD</i>	<i>SE</i>	<i>p</i> <sup>a</sup>
Communication	General functioning	.075	.104	.479
	Self-reliance	.219	.139	.125
	Well-being	.285	.122	.027
	Social relations	.086	.106	.422
	Education	.610*	.098	<.001
	Effects of implantation	.824*	.119	<.001
	Supporting the child	.192	.123	.129
General functioning	Communication	-.075	.104	.479
	Self-reliance	.144	.121	.244
	Well-being	.210	.091	.028
	Social relations	.012	.086	.893
	Education	.536*	.108	<.001
	Effects of implantation	.750*	.129	<.001
	Supporting the child	.117	.113	.309
Self-reliance	Communication	-.219	.139	.125
	General functioning	-.144	.121	.244

	Well-being	.066	.082	.428
	Social relations	-.132	.131	.320
<hr/>				
HRQoL domain	Compared with	<i>MD</i>	<i>SE</i>	<i>p</i> <sup>a</sup>
<hr/>				
(Self-reliance)	Education	.392*	.135	.007
	Effects of implantation	.606*	.113	<.001
	Supporting the child	-.027	.103	.797
<hr/>				
Well-being	Communication	-.285	.122	.027
	General functioning	-.210	.091	.028
	Self-reliance	-.066	.082	.428
	Social relations	-.198	.104	.066
	Education	.326	.130	.017
	Effects of implantation	.540*	.102	<.001
	Supporting the child	-.093	.101	.364
<hr/>				
Social Relations	Communication	-.086	.106	.422
	General functioning	-.012	.086	.893
	Self-reliance	.132	.131	.320
	Well-being	.198	.104	.066
	Education	.524*	.102	<.001
	Effects of implantation	.738*	.137	<.001

	Supporting the child	.105	.098	.288
Education	Communication	-.610*	.098	<.001
	General functioning	-.536*	.108	<.001
HRQoL domain	Compared with	<i>MD</i>	<i>SE</i>	<i>p</i> <sup>a</sup>
(Education)	Self-reliance	-.392*	.135	.007
	Well-being	-.326	.130	.017
	Social relations	-.524*	.102	<.001
	Effects of implantation	.214	.124	.093
	Supporting the child	-.418*	.134	.004
Effects of implantation	Communication	-.824*	.119	<.001
	General functioning	-.750*	.129	<.001
	Self-reliance	-.606*	.113	<.001
	Well-being	-.540*	.102	<.001
	Social relations	-.738*	.137	<.001
	Education	-.214	.124	.093
	Supporting the child	-.632*	.101	<.001
Supporting the child	Communication	-.192	.123	.129
	General functioning	-.117	.113	.309

Self-reliance	.027	.103	.797
Well-being	.093	.101	.364
Social relations	-.105	.098	.288
Education	.418*	.134	.004
Effects of implantation	.632*	.101	<.001

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*Note.* Based on estimated marginal means. a. Adjustment for multiple comparisons: Least Significant Difference (equivalent to no adjustments). *MD* = Mean difference, *SE* = Standard error.

\*  $p < .01$

Table 4

*Correlations among HRQoL domains (n = 33)*

	1	2	3	4	5	6	7	8
1. Communication	--	<b>.445**</b> .010	<b>.493**</b> .004	<b>.432*</b> .012	<b>.468**</b> .006	<b>.549**</b> <.001	<b>.410*</b> .018	.316 .073
2. General functioning			<b>.507**</b> .003	<b>.589**</b> <.001	<b>.354*</b> .043	.176 .328	.258 .148	.217 .225
3. Self-reliance				<b>.798**</b> <.001	.294 .097	.308 .081	<b>.618**</b> <.001	<b>.532**</b> .001
4. Well-being					<b>.400*</b> .021	.158 .381	<b>.646**</b> <.001	<b>.504**</b> .003
5. Social relations						.140 .439	.025 .891	<b>.381*</b> .029
6. Education							.328 .062	-.081 .655
7. Effects of implantation								<b>.499**</b> .003
8. Supporting the child								--

*Note.* 1. Communication, 2. General functioning, 3. Self-reliance, 4. Well-being, 5. Social relations, 6. Education, 7. Effects of implantation, 8. Supporting the child.

\*\*  $p < .01$

\*  $p < .05$

Table 5

*Correlations between chronological age, age at CI activation, duration of CI experience and HRQoL domains (n = 32)*

	1	2	3	4	5	6	7	8
Chronological Age	<b>.126<sup>a</sup></b> .492 <sup>b</sup>	<b>.063</b> .730	<b>.389*</b> .028	<b>.222</b> .222	<b>-.256</b> .157	<b>-.033</b> .858	<b>.408*</b> .021	<b>.180</b> .324
Age at 1 <sup>st</sup> CI activation	<b>.201</b> .270	<b>.050</b> .787	<b>.137</b> .455	<b>.198</b> .277	<b>.108</b> .557	<b>.074</b> .687	<b>.308</b> .087	<b>.037</b> .843
Age at 2 <sup>nd</sup> CI activation	<b>.370</b> .069	<b>.315</b> .125	<b>.457*</b> .022	<b>.338</b> .098	<b>-.110</b> .601	<b>.304</b> .140	<b>.317</b> .123	<b>.086</b> .684
Duration of CI experience	<b>.081</b> .658	<b>-.038</b> .837	<b>.423*</b> .016	<b>.196</b> .283	<b>-.288</b> .110	<b>-.059</b> .747	<b>.282</b> .118	<b>.216</b> .235

*Note.* 1. Communication, 2. General functioning, 3. Self-reliance, 4. Well-being, 5. Social relations, 6. Education, 7. Effects of implantation, 8. Supporting the child.

\* $p < .05$ . <sup>a</sup>Spearman correlation coefficient. <sup>b</sup> $p$  value.

Table 6

*CI configuration and HRQoL domains (n = 28)*

	1	2	3	4	5	6	7	8
CI configuration	<b>.148<sub>a</sub></b> .453 <sub>b</sub>	<b>.049</b> .805	<b>-.065</b> .742	<b>-.174</b> .375	<b>.114</b> .564	<b>.070</b> .722	<b>-.259</b> .183	<b>.130</b> .508

*Note.* 1. Communication, 2. General functioning, 3. Self-reliance, 4. Well-being, 5. Social relations, 6. Education, 7. Effects of implantation, 8. Supporting the child.

<sup>a</sup>Spearman correlation coefficient. <sup>b</sup>*p* value.

Table 7

*Mean comparison between US and the Netherlands*

HRQoL domain	Netherlands			
	<i>MD</i>	t	df	<i>p</i>
Communication	1.873	17.30	32	<.001
General functioning	1.419	17.28	32	<.001
Self-reliance	1.165	8.71	32	<.001
Well-being	1.228	11.41	32	<.001
Social relations	1.637	24.84	32	<.001
Education	1.053	12.20	32	<.001
Effects of implantation	.799	6.58	32	<.001
Supporting the child	.871	8.88	32	<.001

*Note.* t = t score, df = degrees of freedom, *p* = *p* value, *MD* = mean difference. Scores indicate the US scores when compared to the Netherlands.

Table 8

*Mean comparison between US and the UK*

HRQoL domain	UK			
	<i>MD</i>	t	df	<i>p</i>
Communication	.003	.03	32	.976
General functioning	-.071	-.87	32	.391
Self-reliance	-.185	-1.39	32	.175
Well-being	-.002	-.01	32	.989
Social relations	-.133	-2.02	32	.052
Education	-.357	-4.14	32	<.001
Effects of implantation	-.371	-3.06	32	.004
Supporting the child	.241	2.46	32	.019

*Note.* t = t score, df = degrees of freedom, *p* = *p* value, *MD* = mean difference. Scores indicate the US scores when compared to the UK.

Table 9

*Mean comparison between US and Finland*

HRQoL domain	Finland			
	<i>MD</i>	t	df	<i>p</i>
Communication	-.367	-3.39	32	.002
General functioning	-.441	-5.38	32	<.001
Self-reliance	-.585	-4.38	32	<.001
Well-being	-.252	-2.34	32	.026
Social relations	-.453	-6.88	32	<.001
Education	-.477	-5.53	32	<.001
Effects of implantation	-.591	-4.87	32	<.001
Supporting the child	-.059	-.60	32	.555

*Note.* t = t score, df = degrees of freedom, *p* = *p* value, *MD* = mean difference. Scores indicate the US scores when compared to Finland.

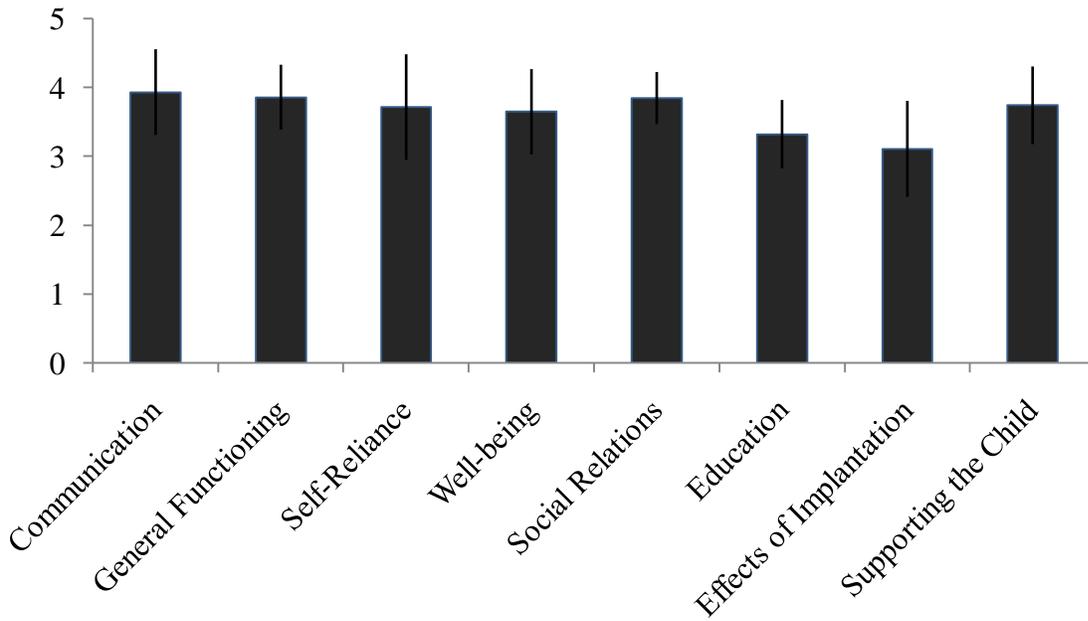


Figure 1. Means and standard deviations for HRQoL domains (n = 33).

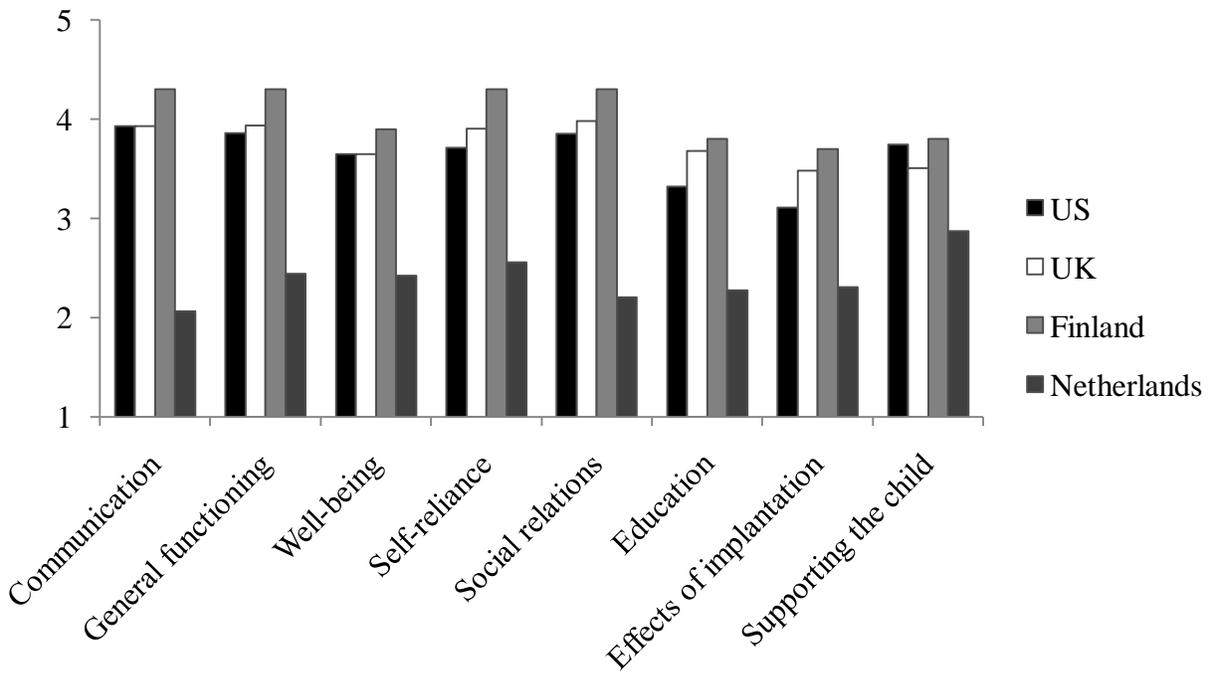


Figure 2. Cross-cultural mean comparison

## Appendix

*Children with Cochlear Implants: Parental Perspectives Questionnaire*

# Children with cochlear implants: parental perspectives

Devised by Sue Archibold and Mark Lutman.  
Development support by The Royal National Institute for Deaf People.

Child's name

### We would like your help in completing this questionnaire.

We recognise that you are in the best position to describe what cochlear implants have meant to your child and family.

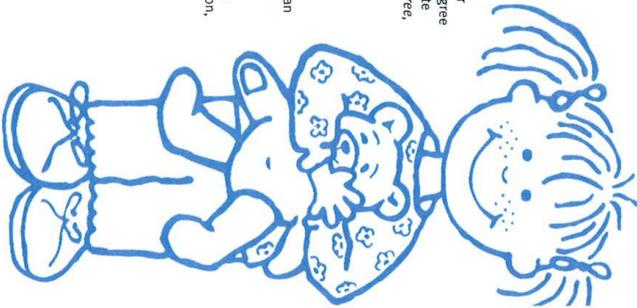
This questionnaire is aimed at parents at least one year after implantation. It consists of statements with which you can agree or disagree. You are asked to tick one of five boxes to indicate your opinion: *strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, *strongly disagree*.

The statements are based on interviews with parents who have a child with a cochlear implant.

Please give your initial response to the statements rather than dwelling on each one for a long time.

Please tick only one box per statement and do not leave any unanswered. If any statement does not apply to your situation, for example if there are no brothers or sisters, please write 'N/A' (meaning not applicable) so that we know you haven't overlooked it.

Thank you very much for taking the time to complete the questionnaire.



### Parents' views and experiences

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. Communication is difficult even with people she knows well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Immediately after implantation her ability to communicate was poorer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The help I give her has become more productive now she has her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Before implantation she obtained no benefit at all from her hearing aids.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. She does not have a close relationship with her grandparents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. She is totally reliant on her implant all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. She knows when I want her attention because she can hear me call.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I worry that the implant will break down.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. She is unable to cope with mainstream schooling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. It has been a problem getting someone to look after the family when we go to the Implant Centre.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Progress during the first few months seemed very slow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I can seldom leave her to do something on her own.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. The programme at the Implant Centre should emphasise speaking and listening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I worry that she will blame me for my decision for her to have an implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. She has needed more help from me since she received her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. She still shows signs of frustration in her behaviour.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am concerned that my child will be rejected by the Deaf Community because of the implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. The quality of her speech gives me cause for concern.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. A lot of help at first means a child needs less help later.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Parents' views and experiences

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
20. I get more time to myself because of her increased independence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Only experienced teams should carry out cochlear implantation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. The costs of travel to the Implant Centre are a problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. She is keeping up well with children of her own age at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Signing support is helpful for a considerable time after implantation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I wish to participate in meetings with other families who have an implanted child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Progress after implantation has exceeded my expectations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. We can now chat even when she cannot see my face (for example in the car or in the dark).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Making the decision to proceed with implantation was the most difficult part for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. It was a difficult time waiting for the results of the assessments before implantation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. She was socially isolated before getting her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. The local school and support services adequately meet all our needs concerning the use of her implant at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. A significant change has been improvement in her confidence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. She was very dependent on us before the implantation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. We feel the need for advice from the Implant Centre concerning her future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. She can now amuse herself listening to music or watching TV or playing games.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. We are reliant on the Implant Centre for technical advice about her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I am concerned about her future school placement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Parents' views and experiences

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
38. The process of implantation was no more intrusive than expected.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. She does not make friends easily outside the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. It is essential that she is encouraged to wear the processor all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. She is sociable within the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. A positive attitude is a great help towards successful use of the implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Regular tuning and checking of the implant system are essential.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. At least one visit per year by Implant Centre staff to home/school is essential.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. She shares in family situations more than before implantation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Before proceeding with implantation, parents should obtain as much information and advice as possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. She is as independent as most other children of her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Parents should have a choice in the use of sign language at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. It was useful to meet another family with an implanted child before deciding on an implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. I am happy about her progress at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. I can now let her play outside as she is aware of the sound of traffic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. The most important factor in choosing an implant device is its reliability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. She is still unable to cope in new situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. I am confident that long-term electrical stimulation will not be a problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. The whole process of implantation is still stressful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. I expected her to learn to talk once she had her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Parents' views and experiences**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
57. I worry that ultimately she may be neither part of the deaf nor the hearing world.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. It was important to me that my child could hear sounds from traffic for safety reasons.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. Her behaviour has improved since she had her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. I believe now that my child will have reasonable prospects for employment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. She has become argumentative since getting her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. A parent of a child with an implant needs to be patient as benefits may take time to show.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. It has been hard to take time off work for the appointments at the Implant Centre.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. She is less frustrated than before she had the implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. She takes part in family relationships on an equal footing with other members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. I find it easier to communicate with her by speaking than by signing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. I give the same amount of help as before her implant.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. I chose implantation for my child so she would have a chance to become part of the hearing world.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. She is totally reliant on her implant at school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. She continues to be a happy child and good fun to be with.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. Her use of spoken language has developed greatly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. Now she is talkative and engages others in conversation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. Other children in the family resented the time and attention taken up by the implant. (Tick here <input type="checkbox"/> if no other children.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. Her relationship with brothers and sisters has improved. (Tick here <input type="checkbox"/> if no other children.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you very much for taking the time to complete this questionnaire

0735



Child's date of birth Your name <i>(person filling in form)</i> Your relationship with child <i>(father, guardian etc)</i> Month and year of implantation Today's date ID number <i>(office use only)</i>
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Please use this space to make comments about issues not covered in the questionnaire.

Please return your completed questionnaire to:

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**BIOGRAPHICAL SKETCH**

Roshini Ruth Kumar  
Roshini.R.Kumar@gmail.com

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**EDUCATION/TRAINING** *(Begin with baccalaureate or other initial professional education,*

INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	YEAR(s)	FIELD OF STUDY
Baylor University	B.A.	2006	Psychology, Studio Art
The University of Texas	M.R.C.	2012	Rehabilitation Counseling
Southwestern School of Health Professions			Psychology

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**Positions and Employment**

2007-present Milieu Therapist – Children’s Medical Center Dallas

**Clinical Experience**

2007-present Milieu Therapist – Children’s Medical Center Dallas

2009-2010 Intensive Bipolar Outpatient Program Coordinator – Children’s Medical Center Dallas

2010-2011 Student Counselor – UT Southwestern Medical Center

2010-2011 Pediatric Neuropsychology Intern – UT Southwestern Medical Center

2011 Adult Neuropsychology Intern – Texas Health Resources