

Published in final edited form as:

*Int J Pediatr Otorhinolaryngol.* 2009 October ; 73(10): 1423–1429. doi:10.1016/j.ijporl.2009.07.009.

## Parent versus child assessment of quality of life in children using cochlear implants

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### Abstract

**Objective**—Children with hearing loss who use cochlear implants have lower quality of life (QoL) in social situations and lower self-esteem than hearing peers. The child's QoL has been assessed primarily by asking the parent rather than asking the child. This poses a problem because parents have difficulty judging less observable aspects like self-esteem and socio-emotional functioning, the domains most affected by hearing loss.

**Methods**—This case-control study evaluated QoL in 50 preschoolers using a cochlear implant and their parents with the Kiddy KINDL<sup>R</sup>, an established QoL measure. Children's responses were compared to a hearing control group and correlated with demographic variables. We used a questionnaire for parents and a face-to-face interview with children. T-tests were used to compare (a) paired parent-child ratings and (b) children with cochlear implants versus normal hearing. Spearman rank correlations were used to compare QoL with demographic variables.

**Results**—Children using cochlear implants rated overall QoL significantly more positively than their parents ( $M_D = 4.22, p=.03$ ). Child rating of QoL did not differ significantly by auditory status (cochlear implant (82.8) vs. hearing (80.8),  $p=0.42$ ). Overall QoL correlated inversely with cochlear implant experience and chronologic age, but did not correlate with implantation age.

**Conclusions**—Preschool children using cochlear implants can assess adequately their own QoL, but parents afford valuable complementary perspective on the child's socio-emotional and physical well-being. Preschool children using cochlear implants rate overall QoL measures similar to hearing peers. A constellation of QoL measures should be collected to yield a better understanding of general QoL as well as specific domains centered on hearing loss.

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#### Conflicts of interest

Dr. Roland serves on the medical advisory committee for Med El Corporation, Advanced Bionics Corporation, and Cochlear Corporation. In addition, he has received travel grant from the Med-El Corporation. Dr. Loy received a travel grant to support data collection from the Med-El Corporation. Drs. Warner-Czyz and Tobey do not have any sponsorship or funding arrangements relating to their research that would pose a conflict of interest.

## Keywords

cochlear implant; quality of life; hearing loss; children; normal hearing

## Introduction

Children with severe or profound sensorineural hearing loss experience well-documented improvements in communication skills after receiving a cochlear implant, but the broader impact of cochlear implantation on a child's physical, emotional, and social functioning receives little attention<sup>2-9</sup>. Health-related Quality of Life (QoL), a uniquely personal perception of physical, mental, and social well-being in diverse situations and developmental activities<sup>10-12</sup>, provides a mechanism to evaluate the multidimensional impact of a health-related condition such as hearing loss or cochlear implantation on a child's daily life<sup>10-12</sup>. The dearth of studies addressing the impact of cochlear implantation on QoL<sup>2-9, 13-15</sup> is surprising in light of the documentation of lower QoL – particularly with respect to social participation, self-esteem, and school acceptance – for children with lesser degrees of hearing loss<sup>16-20</sup>. Difficulties in these domains may be exacerbated further in individuals with severe or profound hearing loss, resulting in slower emotional adjustment,<sup>21</sup> fewer relationships and social activities<sup>22</sup> and feelings of isolation and depression<sup>23</sup>. Although some studies represent a pediatric cochlear implant user's overall well-being in a single value<sup>5, 13-15</sup>, only eleven studies to date yield quantifiable outcomes in QoL domains in children using cochlear implants<sup>2-4, 6-9, 24-27</sup>.

QoL in children using cochlear implants relies consistently on parental perceptions of their child's quality of life<sup>6, 7, 9, 24, 25, 28</sup>. Parents rate the QoL of their children who use a cochlear implant as moderately positive: a rating also associated with higher auditory perception skills, better communication outcomes, longer duration of cochlear implant use, and earlier age at implantation<sup>6, 7, 24</sup>. However, asking parents rather than asking children about health-related QoL unveils discrepancies in parent versus child ratings of a child's communicative and functional capacities<sup>29-34</sup>. Parents adeptly judge objective aspects of a child's behavior such as physical function but show less aptitude on less observable aspects such as self-esteem, emotional or social functioning,<sup>35, 36</sup> the domains likely to be most affected by hearing loss. Moreover, self-report of QoL maintains consistency with the definition of health-related QoL as an individual's self-perception.<sup>10, 11</sup> Six studies to date query children with cochlear implants about QoL<sup>2-4, 8, 26, 27</sup>, but only two studies ask both parents and children to complete complementary surveys<sup>2, 3</sup> to allow investigation of independent perspectives within parent-child dyads<sup>1, 7, 37, 38</sup>.

Chmiel et al.<sup>3</sup> administered a self-constructed instrument focused on benefits and problems associated with cochlear implant use with questions derived from the parent responses reported by Kelsay and Tyler<sup>9</sup> to 11 parent-child dyads. Participant age at time of testing ranged from 6 to 20 years ( $M = 11$  years). Parents independently completed a 54-item questionnaire and cochlear implant recipients younger than 12 years of age completed an 18-item questionnaire presented in interview format. Parents reported improved communication as the greatest benefit of their child's cochlear implant, followed by the child's sense of safety, self-esteem, language skills, and family relationships<sup>3</sup>. Children using cochlear implants responded similarly, but they rated making new friends more positively than parents; peer acceptance less positively than parents; and overall problems less positively than parents<sup>3</sup>. Chmiel's<sup>3</sup> self-constructed measure included questions about QoL that have not been tested for reliability or validity in pediatric cochlear implant users, which creates difficulty in generalization of results.

Huber<sup>2</sup> used an established instrument, the KINDL<sup>R39</sup>, to compare health-related QoL in 44, 8- to 16-year-old cochlear implant users to their parents and to hearing children of comparable ages. Results indicate children with cochlear implants in the 8- to 11-year-old group rate overall QoL significantly less positively than parental proxies, but adolescents with cochlear implants between the ages of 12 and 16 years achieve similar subscale and overall QoL levels compared to their parents<sup>2</sup>. The KINDL<sup>R39</sup> appears to be a reliable and valid measure evaluating general health-related QoL in cochlear implant users at least 8 years of age when child responses are compared to parental responses. However, it remains unclear if these measures are equally reliable and valid for cochlear implanted children younger than 8 years of age.

Although emerging evidence suggests children reliably describe themselves as young as 7 years of age<sup>35, 41</sup> and possibly younger<sup>42-46</sup>, only three studies<sup>3, 4, 8</sup> have queried cochlear implant users younger than 8 years regarding QoL issues. Schorr, Roth, and Fox<sup>8</sup> collected self-reported QoL measures in 37 cochlear implant users between the ages of 5 and 14 years ( $M = 9$  years). Two other studies<sup>3, 4</sup> included children younger than 8 years. However, the broad age range and limited sample size of children younger than 8 years complicate application of results to younger children who may experience different QoL than chronologically older peers due to differences in cognitive, emotional, and social development.

We highlight gaps in the QoL literature of children with cochlear implants with respect to parent versus child reports; and age at testing (i.e., children older vs. younger than 8 years of age). Previous studies of pediatric cochlear implant users, however, appear to agree regarding the relationship between QoL ratings and demographic variables such as age at identification of hearing loss, age at implantation, and duration of cochlear implant experience. Studies consistently show a direct relationship of QoL with duration of implant use<sup>2</sup> and communication outcomes<sup>2, 7</sup> and an inverse relationship with age at implantation.<sup>2, 6, 7</sup> and age at first amplification<sup>8</sup>. That is, more positive QoL scores are associated with younger age at intervention, longer duration of cochlear implant experience, and higher speech perception and speech production test scores. However, the relationship of these variables remains unexamined within a cohort of pediatric cochlear implant users younger than 8 years of age.

A paucity of information also exists about comparisons between pediatric cochlear implant users and their normal hearing peers. Huber<sup>2</sup> reports 8- to 11-year-old children who use a cochlear implant rate specific psychosocial domains and overall QoL significantly less positively than age-matched children with normal hearing. A reliable group difference is not evident for the 12- to 16-year-old cochlear implant users, who achieved similar subscale and overall QoL levels with normal hearing peers. Huber's<sup>2</sup> evaluation of QoL in children with cochlear implants versus children with normal hearing raises questions regarding the reliability of QoL differences related to chronologic age and maturation level of the children and highlights the uncertainty of QoL ratings by younger cochlear implant users compared with normal hearing peers.

In this report, we explore multidimensional aspects of health-related QoL in 50, four to seven year-old children who use cochlear implants via child and parental (proxy) assessments. We also examine QoL relative to important demographic variables such as age at identification of hearing loss, age at implantation, duration of cochlear implant use, and chronologic age at time of testing. Finally, we compare the CI data to normal hearing peers. We expect congruence between parent-child ratings on overall QoL but differences between parent-child ratings on less observable domains. We hypothesize that a child's QoL derives from his or her developmental level and anticipate no difference in overall QoL between

children with cochlear implants and children with normal hearing of the same chronologic age. Finally, we hypothesize that health-related QoL is negatively associated with age at identification of hearing loss and age at implantation and is positively associated with duration of cochlear implant use.

## Methods

A case-control study was used to assess health-related QoL in preschool children who use cochlear implants. Comparisons were made between (1) parent vs. child assessment of health-related QoL in preschool children using cochlear implants; and (2) child assessment of health-related QoL in preschoolers using cochlear implants vs. preschoolers with normal hearing.

## Participants

**Children using Cochlear Implants**—Sixty-eight families with children between four and seven years of age who used a cochlear implant were contacted as a means of eliciting participation in the study. Fifty families responded positively for their child to participate. Forty-five of the fifty families also contributed parental assessments. Inclusion criteria for the children were (1) documented severe-profound hearing loss defined as a pure-tone average (0.5, 1, 2, and 4 kHz) greater than 75 dB HL (NHANES III, 1988–1994) prior to cochlear implantation; and (2) use of at least one cochlear implant device. Children were not excluded based on age at identification of hearing loss, etiology of hearing loss, age at cochlear implant activation, duration of cochlear implant experience, type of cochlear implant device (i.e., manufacturer or speech processing strategy), number of cochlear implants (i.e., unilateral vs. bilateral), or mode of communication (i.e., oral vs. oral + sign) in order to form the sample of preschool children using cochlear implants. The only exclusion criterion was the inability to complete the questionnaire as presented in interview format. Children were recruited from the Crystal Charity Ball Cochlear Implant Summer Listening Camp in Dallas, Texas ( $n = 28$ ), and the Colorado Neurological Institute's Cochlear Kids Camp in Estes Park, Colorado ( $n = 22$ ) between June 2007 and August 2008.

Fifty children who used a cochlear implant completed the health-related QoL questionnaire for a response rate of 73.5%. The mean age (with standard deviations in parentheses) of identification of deafness in the children was 0.79 (0.96) years and spanned from birth through 3 years of age. Age at implant activation ranged from 7 months to almost 7 years with a mean of 2.52 (1.49) years. Duration of cochlear implant experience averaged 3.27 (1.69) years, ranging from less than 6 months to 5 years, 7 months. The mean age at test of the children who used a cochlear implant was 5.77 (1.13) years. Age at interview was distributed among the age groups: 4 years (16%); 5 years (28%); 6 years (20%); and 7 years (36%). Demographic characteristics of the children using cochlear implants are described in Table 1. Participants included an essentially equal distribution of boys and girls. The majority of children had an unknown etiology of hearing loss (52%) and used an oral communication mode (62%). School placement was distributed among private and public, mainstream and special needs settings.

**Control Group 1: Parents of Children using Cochlear Implants**—The first control group consisted of one parent of each of the children enrolled in the cochlear implant group. The parent control group included mothers and fathers of a child using a cochlear implant. All parents served as the full-time caregivers for their children. Forty-five parents completed the health-related QoL questionnaire for a response rate of 66.2%.

**Control Group 2: Children with Normal Hearing**—Participants in the second control group included children with normal hearing between four and seven years of age. Inclusion criteria were normal hearing sensitivity as reported by the child’s parent. Participants in the normal hearing group were recruited via friends, family members, and acquaintances of the research team. The normal hearing group of children consisted of 25 preschool children with a mean age of 4.88 years (0.78) at the time of interview. Age at interview was distributed among the three younger age groups: 4 years (36%); 5 years (40%); and 6 years (24%). Normal hearing participants included 52% boys (n = 13) and 48% girls (n = 12). The Institutional Review Board at the University of Texas Southwestern Medical Center and at the University of Texas at Dallas approved this project with written, informed consent was obtained from each participant.

## Materials

The KINDL<sup>R 39</sup> is an established generic health-related QoL measure designed for children between the ages of 4 and 16 years [<http://www.kindl.org/>]. Three versions of the questionnaires exist to accommodate different cognitive, social, and developmental levels. This study used the Kiddy KINDL<sup>R 39</sup> interview version for children with additional questions for parents, a metric appropriate for 4- to 7-year-old children. The Kiddy KINDL<sup>R 39</sup> consists of 6 multi-dimensional subscales: emotional well-being, family, friends, physical well-being, school, and social well-being. These six subscales sum to an overall index score. Each score is transformed to a 100-point scale, with 0 denoting minimal QoL and 100 denoting maximal QoL.

We administered the child self-report version of the Kiddy KINDL<sup>R 39</sup> in a face-to-face interview format. The first or second author interviewed all of the children. Child response categories spanned three levels on a Likert scale: never, sometimes, and very often. We presented the response categories to the child after each question. For example, we asked the child “In the past week, did you play with friends?” (Question 1 on the friends scale). If the child answered no, we would verify by restructuring the question: “You did not play with any friends this week?” If the child answered no again, we marked the “never” category. If the child answered yes when we asked the question, we clarified the response level by asking “Did you play with friends a lot or just sometimes?” If the child responded “sometimes,” we marked the “sometimes” category. If the child answered “a lot,” we marked the “very often” category. Although the 12 items addressed each of the six HRQoL domains, the limited number of items per domain on the child self-report version prevents calculation of individual subscale scores. Therefore, the child self-report versions yielded only a total health-related QoL score.

The parents’ version of the Kiddy KINDL<sup>R 39</sup> contained 24 items in six dimensions plus 22 items designed to supplement the limited information provided by the child self-report questionnaire. Parent response categories included five points on a Likert scale: never, seldom, sometimes, often, and all of the time. We instructed parents to complete the questionnaire independently of the child and the investigators to ensure the answers reflected the parent’s assessment of the child’s well-being.

The KINDL<sup>R 39</sup> was selected based on (1) psychometric properties such as reliability, convergent validity, factorial validity, and sensitivity; (2) ease of administration; (3) use of direct observation with no interpretation of results; and (4) the presence of significant results obtained by other researchers across a variety of medical conditions including asthma<sup>47, 48</sup>, obesity<sup>49, 50</sup>, and diabetes<sup>42</sup>. Additionally, the KINDL<sup>R’s 39</sup> profile approach to health-related QoL applied to parent and child assessment for children 4 to 7 years of age. Other widely used metrics such as the Child Health Questionnaire<sup>51</sup> also employ a profile



approach, but fail to have complementary parent and child forms appropriate for children younger than 10 years of age.

### Statistical Analysis

Summary statistics were calculated for all variables of interest. Paired t-tests were used to test the primary hypothesis that parent and child assessments of the child's total QoL reliably differed. Transformed subscale scores were computed for both child and parent assessments to examine trends. These individual subscale scores were not submitted for statistical analysis due to the limited number of items per subscale in the child version of the KINDL<sup>R</sup> 39. Tests for sphericity, normality of the distribution, and homogeneity were used to meet the required assumptions of using the parametric t-test. Pearson correlations tested the hypothesis that children's overall health-related QoL was positively associated with duration of cochlear implant experience and chronologic age and negatively associated with age at identification and age at implantation. Pearson correlations also were used to evaluate associations among auditory history variables. Two-sample t-tests tested the secondary hypothesis that self-assessment of health-related QoL was not different between children using cochlear implants vs. children of comparable ages with normal hearing. Data were analyzed using SAS 9.1 for Windows (SAS Institute, Inc., Cary, North Carolina). P-values less than .05 were considered statistically significant.

## Results

### Parent vs. child assessment of QoL

A paired t-test was conducted to compare overall quality of life as rated by children with cochlear implants and their parents in 45 parent-child pairs. Children with cochlear implants rated their overall QoL significantly more positively than their parents did ( $M_{Difference} = 4.22$ ,  $SD_{Difference} = 12.45$ ,  $t(44) = 2.46$ ,  $p = .03$ ). Table 2 details subscale scores for all participants. Child ratings of quality of life were included to illustrate trends even though statistical analysis could not be completed as described in the methods section. Subscale evaluation of parental responses reveal parents rated their child's QoL positively for the following subscales: emotional well-being ( $M = 82.5$ ,  $SD = 13.5$ ), school ( $M = 81.7$ ,  $SD = 16.1$ ), and physical well-being ( $M = 77.1$ ,  $SD = 16.6$ ). Parents rated family ( $M = 74.7$ ,  $SD = 12.9$ ), self-esteem ( $M = 73.9$ ,  $SD = 14.7$ ), and friends ( $M = 74.7$ ,  $SD = 14.2$ ) subscales least positively. Parents assigned a moderate value to their child's QoL on the additional subscale that included questions about the child's temperament and activity level ( $M = 78.7$ ,  $SD = 10.7$ ).

### Association between QoL and auditory history variables

Pearson correlations were computed to investigate associations between the children's transformed scores for overall QoL and auditory history variables such as age of identification of hearing loss, age at activation of the cochlear implant, duration of cochlear implant experience, and chronologic age at time of testing (Table 3). A significant inverse correlation was detected between the overall QoL rating by the child and duration of CI experience ( $r = -.28$ ,  $p = 0.045$ ), suggesting that children with a shorter duration of experience with the cochlear implant assigned more positive ratings of their overall QoL relative to children with a longer duration of experience with the cochlear implant. Additionally, a significant inverse correlation was detected between the child's assessment of overall QoL and chronologic age ( $r = -.29$ ,  $p = .045$ ) indicating that younger children in the 4- to 7-year-old group rated their overall QoL more positively than their chronologically older peers in the 4- to 7-year-old group.

Significant correlations also existed among the auditory history variables. Duration of cochlear implant experience showed a significant positive correlation with chronologic age ( $r = .40, p = 0.005$ ) and significant negative correlations with age at implant activation ( $r = -.78, p < .0001$ ) and age at identification of hearing loss ( $r = -.41, p = 0.008$ ). Age at identification of hearing loss correlated positively with age at implant activation ( $r = .38, p = 0.016$ ). That is, children whose hearing losses were identified earlier were implanted earlier and had less cochlear implant experience than children who were identified and implanted later. Older children tended to have more cochlear implant experience than younger children.

### Children with cochlear implants vs. children with normal hearing

Two sample t-tests were conducted to investigate the secondary hypothesis that that self-assessment of health-related QoL would not differ between children using cochlear implants vs. children with normal hearing (Table 2). Overall QoL rating for the CI group ( $M = 82.8, SD = 9.7$ ) did not differ significantly from the NH group of preschool children ( $M = 80.8, SD = 10.3$ ) ( $t(45.3) = 0.81, p = .42$ ).

### Discussion

Children rate their overall QoL significantly more positively than their parents. Total QoL showed a significant inverse association with duration of cochlear implant experience and chronologic age at time of testing. No significant correlations existed between the total QoL score and age at identification of hearing loss or age at cochlear implantation. Child assessment of QoL did not differ significantly between children with cochlear implants and children with normal hearing.

Only two other studies to date collected independent assessment of QoL from parents and children after cochlear implantation<sup>2, 3</sup>. Our parent-child comparisons revealed that 4 to 7 year old children rated QoL more positively than their parents did. This result contrasts with Huber's<sup>2</sup> findings of less positive ratings by 8- to 11-year-olds and equivalent ratings by 12- to 16-year-old cochlear implant users compared to their parents.

Several explanations may account for this difference. One alternative focuses on the integration of the cochlear implant into the child's daily life. The younger children in this study underwent activation of their implants at a younger chronologic age compared to the 8- to 11- year-old pre-adolescents ( $M = 4.5$  years) and 12- to 16-year-old adolescents ( $M = 7.5$  years) studied by Huber<sup>2</sup>. Duration of cochlear implant experience for our group was less than that of the pre-adolescent ( $M = 6.2$  years) or adolescent ( $M = 6.9$  years) groups studied by Huber<sup>2</sup>. However, the proportion of lifetime experience with the implant may offer a more telling story. The children in our group have spent approximately 60% of their life using the cochlear implant, with the initial 40% of non-implant use occurring during infancy. Huber's<sup>2</sup> pre-adolescents approach this proportion (58%) but the adolescents do not (48%). Thus, our younger cohort began toddlerhood with the cochlear implant and primarily knows life with some type of auditory intervention. In contrast, the older cohorts in Huber<sup>2</sup> may have residual memories of feeling different or isolated as a toddler or school-aged child because of hearing loss or hearing aids. Thus, earlier identification of and intervention for the hearing loss may have afforded a quicker, more complete assimilation to the hearing loss and cochlear implant for the children in the younger group.

The concept of assimilation of the cochlear implant into the child's everyday activities feeds into a second alternative centered on the development of self and the sensitivity to peer influence based on chronologic age. Young children, such as the participants in our study, have developed a categorical self in which they view themselves dichotomously: boy vs. girl

or blue-eyed vs. brown-eyed<sup>52</sup>. These children likely viewed the cochlear implant as part of themselves rather than something that distinguished them from normal hearing counterparts. The lack of critical comparison to peers teemed with considerable amount of encouragement from parents and teachers in early childhood leads to high levels of self-esteem in young children<sup>52</sup>. Children's self-concepts become more complex as they mature, with school-aged children transitioning from an egocentric subjective self-image to an objective self-image<sup>53</sup>. Middle childhood (i.e., 7 to 11 years of age) is characterized by constant critical evaluation and self-consciousness of physical, social, emotional, and behavioral characteristics<sup>54</sup>. Constant self-doubt and peer comparison often result in lower self-esteem in 7- to 13-year-olds compared to younger and older children<sup>55, 56</sup>. The importance of self-esteem and self-awareness in middle childhood is compounded by the increased influence of peers with respect to time, opinions, reinforcement, and acceptance. Huber's<sup>2</sup> 8- to 16-year-old cohort includes children engaged in the peer-centered phase of middle childhood, which may have decreased the subscale scores for friends and self-esteem, thereby decreasing the overall QoL score. Thus, the children's self-concept and susceptibility to peer influence may explain the difference between our young group and Huber's<sup>2</sup> older group of pediatric cochlear implant users.

Comparison of parent and child assessment led to discrepancies not only in the total QoL index, but also on specific domains. Our findings converged with those of Chmiel and colleagues<sup>3</sup> in that the children rated some aspects of their own QoL (e.g. making new friends) more positively than the parent's ratings of their child's QoL. This trend was particularly true for the self-esteem, family, and friends subscales, in which the average child rating exceeded the average parent rating by 10 points. These differences in QoL assessment within parent-child dyads echo discrepancies found across chronic conditions<sup>29–34</sup>. Parents proficiently assess objective domains such as physical well-being but ineffectively rate subjective domains such as self-esteem, family, and peer interactions<sup>35–36</sup>. Previous studies have suggested that these very areas – self-esteem, social participation and acceptance - are negatively impacted by any degree of hearing loss in children<sup>16–19, 21–23, 57</sup>. Thus, these findings bolster the need to elicit QoL information from both parent and child perspectives.

Correlation results suggest that more positive ratings of overall QoL were associated with children with a shorter duration of cochlear implant experience and children of a younger chronologic age. Additionally, younger children tended to have less cochlear implant experience than their chronologically older peers. One potential explanation for the difference in overall quality of life relative to duration of CI experience and chronologic age is the language abilities of the children at the time of interview. That is, the younger children may have a less complete understanding of the KINDL<sup>R</sup> questions compared to older children in the study.

This study has implications for the evaluation of QoL in young children using cochlear implants. We do not need to rely solely on the parents to gain information about how the child feels in different situations. A young child can contribute important information complementary to the parent's assessment and perhaps more accurate with respect to domains in which the parent does not have first-hand knowledge or observation.

Our study does have limitations. Huber<sup>2</sup> correlated health-related QoL ratings not only with age at implantation and duration of deafness, but also with speech perception outcomes. Our study did not address the communication performance abilities of these children. It is possible that the more successful cochlear implant users with higher speech perception, speech production, and language capacities rate their QoL higher than those children at lower performance levels. However, examination of studies that have compared QoL to



communication outcomes are inconclusive with some documenting a positive association between QoL and speech perception scores<sup>2, 5</sup> and others reporting no significant associations<sup>27</sup>. Nonetheless, the child's communication outcomes may also influence the parent's assessment of the child's QoL such that parents may be more likely to assign a higher rating of QoL for a child with higher communication performance abilities than for a child who struggles with speech perception or production skills. Results of the current study point out that the impact of cochlear implantation extends beyond the communication realm to include other domains of QoL such as self-esteem and friends. A second limitation of this study is the lack of convergent validity with another QoL measure such as the Children's Health Questionnaire<sup>51</sup> used for children and adolescents with a variety of chronic conditions including cancer, diabetes, epilepsy, juvenile rheumatoid arthritis, and sickle cell disease<sup>58</sup>. Such a comparison would be difficult because the existing QoL measures for children younger than 8 years rely solely on parent responses and do not have a child version of the questionnaires. A third limitation of this study is the lack of comparison of overall quality of life by children with normal hearing and their parents. Inclusion of the difference between child and parent ratings for both the cochlear implant and the normal hearing group would afford not only absolute differences or similarities within parent-child dyads, but also relative differences based on auditory status. Unfortunately, data from parents of children with normal hearing were not collected for this study.

This study has three primary strengths. First, our study included 4- to 7-year-old children at similar cognitive, emotional, and social developmental levels. By narrowing our chronologic age range, we were able to equalize maturational effects across children in the group, thereby circumventing potential confounding of the broad age ranges used in previous studies<sup>3, 8</sup>. Second, this study used a general health-related QoL measure, similar to Huber<sup>2</sup>, to allow for comparison not only to parents of children with cochlear implants, but also to normal hearing counterparts and children with other medical conditions. Third, this study emphasized the child's assessment of his or her own QoL. This is the first study comparing self-reported QoL in children who use cochlear implants and children with normal hearing. One of the goals of cochlear implantation is "normalization" of daily function. Expansion of this normalization from a specific definition of communication performance to a global definition of well-being highlights the far-reaching impact of the cochlear implant on a child's experiences.

In conclusion, parents and children offer distinct and crucial information regarding the influence of cochlear implantation on a child's physical, social and emotional well-being assessed via a QoL measure. Preschool children using cochlear implants can attain overall QoL measures similar to their normal hearing peers. However, future studies should incorporate open-ended questions to gain more information on individual domains to allow more in depth comparison between the two groups of children. Additionally, future studies should include subscales informing both general domains of QoL and specific domains related to hearing loss and cochlear implants. A combination of general and specific domains in QoL assessment will provide powerful information as to the broader influence of cochlear implantation on children with hearing loss who receive cochlear implants.

## Acknowledgments

Funding for this project was supported in part by Grant Number 1 UL1 RR024982-01, titled, "North and Central Texas Clinical and Translational Science Initiative" (Milton Packer, M.D., PI) from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. The Med El Corporation also sponsored travel to Colorado for data collection. Portions of this manuscript have been presented at the 10<sup>th</sup> International Conference on Cochlear Implants and other Implantable Auditory Technologies in San Diego, California (2008, April) and AudiologyNOW in Dallas, Texas (2009, April).

We appreciate thoughtful comments on the overall project from Ira Bernstein, and valuable feedback on earlier versions of this manuscript provided by John Nelson, Charles Quinn, and Mike Singer. We gratefully acknowledge the support of the Crystal Charity Ball Cochlear Implant Summer Listening Camp in Dallas, Texas; the Colorado Neurological Institute's Cochlear Kids Camp in Estes Park, Colorado; and Children's House Montessori School in Allen, Texas, all of whom allowed us to interview children enrolled in their programs. Finally and most importantly, we thank the children and families who participated in this project.

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**Table 1**

Characteristics of Participants in the Cochlear Implant Group.

Variable	Number	%
<b>Gender</b>		
Males	28	56
Females	22	44
<b>Etiology of Hearing Loss<sup>a</sup></b>		
Unknown	26	52
Connexin 26	6	12
Cytomegalovirus	4	8
Enlarged vestibular aqueduct	4	8
Other	10	20
<b>Communication Mode<sup>b</sup></b>		
Oral communication	31	62
Unknown	12	24
Total communication	7	14
<b>School Environment<sup>c</sup></b>		
Mainstream public	20	40
Unknown	14	24
Special needs	6	12
Other	12	24

<sup>a</sup>Information on etiology of hearing loss was provided by the medical records (n = 16) or by the parents (n = 34).

<sup>b</sup>Communication mode was defined by the parents.

<sup>c</sup>In the educational environment section, the "Other" category includes School for the Deaf (n = 4), Mainstream Private (n = 3), Mainstream Special Needs (n = 2), Children not in school (n = 2), and Home schooling (n = 1).



**Table 2**  
Parent and Child assessment of Quality of Life in children using Cochlear Implants

Variable	Children with CI (n = 50)		Parents of Children with CI (n = 45)		Children with NH (n = 25)	
	M	SD	M	SD	M	SD
Physical Well-being	71.5	27.2	77.2	16.4	74.0	19.7
Emotional Well-being	85.0	19.6	82.8	13.5	76.0	18.4
Self-esteem	85.0	18.2	74.9	12.7	72.0	25.3
Family	87.5	15.4	73.9	14.6	90.0	14.4
Friends	84.0	15.8	75.1	14.3	90.0	12.5
Everyday functioning/school	84.0	25.6	81.4	16.0	83.0	28.6
General	-	-	78.6	10.5	-	-
Total	82.8	9.7	78.1	9.6	80.8	10.4

<sup>a</sup>Multi-dimensional quality of life (QoL) was assessed via the Kiddy KINDL R<sup>39</sup>. Children completed 12 items evenly distributed among 6 subscales (e.g. physical well-being, emotional well-being, self-esteem, family, friends, and everyday functioning/school). Parents completed 4 items per subscale plus an additional 22 questions as part of a General subscale that provided information about the child's temperament and behavior patterns. The subscales of Kiddy KINDL R<sup>39</sup> sum to an overall index score. Each score is transformed to a 100 point scale, with 0 representing minimal quality of life and 100 representing maximal quality of life. Statistical analysis of parent versus child assessment of quality of life only could be conducted for overall quality of life due to the low number of items completed by the children in individual subscales. Thus, inclusion of individual subscales for children are included solely to demonstrate trends in the data.

**Table 3**

Relationship between total QoL score, age at identification of hearing loss, age at implant activation, duration of cochlear implant experience with quality of life ratings by preschool children.

	Total QoL Score	Age at Identification of Hearing Loss	Age at Implant Activation	Duration of Implant Use	Chronologic Age at Testing
Total QoL Score	-	-0.05	0.07	-0.29*	-0.29*
Age at Identification of Hearing Loss	-	-	0.38*	-0.41**	-0.01
Age at Implant Activation	-	-	-	-0.76***	0.24
Duration of Implant Use	-	-	-	-	0.40**
Chronologic Age at Testing	-	-	-	-	-

\*  $p < .05$ .

\*\*  $p < .01$ .

\*\*\*  $p < .0001$ .