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The children speak: An examination of the quality of life of pediatric cochlear implant users

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Abstract

Objective—To examine the results of health-related quality of life questionnaire scores from profoundly deaf children fitted with at least one cochlear implant and compare responses to normal hearing age mates and to their parents.

Study design—Cross sectional study utilizing a generic quality of life questionnaire designed to be completed by both parents and children independently of each other.

Setting—Questionnaires completed at various summer camps designed for children with cochlear implants in Texas and Colorado.

Subjects and Methods—Eighty-eight families from 16 states were divided in to two subgroups by age of cochlear implantation: an 8–11 year old group and one 12–16 year old group. The KINDL^R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents was distributed and participants completed the questionnaire independently from their participating family member.

Results—CI users in both age groups scored similarly to their normal hearing peers and their parents. Younger CI users scored their family domain lower than their normal hearing peers. Teen CI users scored the school domain lower than their parents. Among CI participants, earlier implantation and longer cochlear implant use resulted in higher Quality of Life scores.

Conclusion—Children with cochlear implants experience similar quality of life as normal hearing peers. Parents are reliable reporters on the status of their child's overall quality of life.

Introduction

The complex transition from early childhood to preadolescence and adolescence often is compounded when a child has a hearing loss since they are at risk for increased social and

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emotional challenges.^{1, 2} Psychosocial dimensions of self-esteem, family and social-emotional adjustment in deaf children before the availability of cochlear implants (CI) are evident in the literature.³ Deaf children feel less socially accepted, experience more difficulty in making friends, and demonstrate greater adjustment problems than their hearing-peers.^{4–8} Meadow and Trybus assert emotional adjustment problems of deaf children are three to six times larger than that of the hearing population.⁵ Altshuler and colleagues report that deaf students also are significantly more impulsive.⁶ Fifty percent of deaf children remain concerned with lack of friendship and social acceptance compared with 16 percent of normally hearing (NH) children. ⁷ Deaf children experience difficulty in social interaction and acceptance to a greater degree than NH children.^{8–9}

The advent of the multi-channel CI in the pediatric population brought with it the promise of improved speech perception and production and language development, in many cases to age appropriate levels. Its proven success in these areas now leads to questions beyond speech and language performance to questions of psychosocial behaviors and adjustment. ¹⁰

Lin and Niparko's systematic review of health related QoL studies involving CI children found only ten studies where participants were less than 18 years, where a questionnaire in English was used, and where the psychosocial domains of physical, mental, and social health were utilized.¹¹ Three additional studies included parent or parent and child responses but fell outside other criteria of the review. $^{12-14}$ Most studies relied solely on a proxy respondent, usually a parent. Many investigations assume a proxy is an appropriate and reliable respondent for children. Clearly, a child's primary caregiver has valuable insight into the psychosocial dimensions of the child's life. Nevertheless, proxy reports do not directly reflect a child's point of view. QoL, as a subjective measure, should be obtained from the recipient's perspective whenever possible.^{15, 16} Only four studies were located where the CI child's perspective was sought.^{12–14, 17} Children, ages 5–14, indicated an overall mean score of 26.59 (out of a possible score of 35) indicating significant improvement in QoL because of their CI.¹² Length of use of the implant was positively correlated to the score and age at implantation was negatively correlated to the QoL score. CI users, ages 3–12 years, and their parents report their expectations were met with the implant (81%), 88% would have the procedure again, and 94% would recommend the procedure to others. ¹³ High levels of satisfaction and contentment with the CI are equated by the authors to represent a higher QoL than that prior to implantation.

Two studies sought parent and child responses.^{14, 17} In one, parent and child groups reported substantial QoL benefits from the implants, and children and parents reported remarkably similar benefits for implant use.¹⁴ The second study examined parent-child pairs composed of groups of 8–12 and 13–16 year old CI recipients.¹⁷ Results indicated that the younger group's scores were significantly lower than their parents' scores and lower than their normal hearing peers. Older CI children scored similarly to their parents and hearing peers on all sub-scales and total overall scores. Both age groups showed a positive correlation with duration of deafness and a negative correlation with age at implantation.

This study examines if deaf children with CI demonstrate similar psychosocial issues as typical hearing peers based on their own responses, and if their parents are reliable reporters regarding their child's health related QoL. We hypothesized that CI children qualitatively demonstrate similar overall quality of life scores as their typical hearing age mates but qualitatively different responses in psychosocial domains where deaf children traditionally have difficulty such as social situations and feelings of success in school. Additionally, we hypothesized that parents qualitatively demonstrate observational skills sufficient to perceive clearly and sensitively their child's emotional and social state of well being in domains but qualitatively different responses in domains where there is little chance for observation such as the school setting.

Methods

A cross sectional study design compares ratings of QoL in CI children to their parents and to their normal hearing age mates. Families participating in the study (n = 88) representing 16 American states were recruited from cochlear implant summer camps in Estes Park, Colorado and Dallas, Texas in 2007 and 2008, as well as through phone and mail contact. Inclusion criteria for the CI participants included documented severe-profound hearing loss and use of at least one cochlear implant device. Parent respondents are the primary caregiver of the child. The only exclusion criterion is the inability to complete the questionnaire independently. All participants use English as the primary language of the family.

Parent-child dyads are categorized by the child's chronologic age to yield two sub- groups: 8–11 year olds (n = 50) and 12–16 year olds (n = 34). An additional four children in the 8–11 year old group completed forms with no matching parent questionnaire (parents did not return). Age groups are pre-determined by the QoL questionnaire. Parents and children were independently assessed and scored. Scores of each parent are compared to their child's scores in one analysis, and a second analysis compared the CI child's scores to an age appropriate comparison group of NH children. The majority of CI responders in both age groups were female, have no known cause of hearing loss, used spoken language as the primary mode of communication and were mainstreamed in a public classroom (Table 1).

The NH comparison group, recruited by the authors of the assessment questionnaire described below, consisted of 1501 pupils in the fourth and eighth grade. Average age at completion of the questionnaire for fourth graders (n=918) was 9.7 years. The eighth grade teenagers (n=583) had an average age of 14.1 years. The overall sample consisted of 48.3 percent girls and 51.7 percent boys. Further interpretation of data from the NH comparison group was not possible due to its historical nature.

This study was approved by the University of Texas Southwestern Medical Center Institutional Review Board (#122006-040).

Materials

The KINDL^R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents revised version is an established generic health-related QoL questionnaire suitable for children between the ages of 4 and 16 years.¹⁸ The Kid KINDL^R (8–11 year olds), the Kiddo KINDL^R (12–16 year olds) and a corresponding parental questionnaire serve as assessment tools. Each measure consists of 24 questions equally distributed among six multidimensional sub-scales: physical well-being, psychological well-being, self-esteem, family, friends, functioning in school (Table 2). The sub-scale scores are combined for an overall total score, transformed to a 100 point scale, with 0 representing minimal QoL and 100 representing maximal QoL. The KINDL^R format is a 5 point Likert scale: never, seldom, sometimes, often, all the time. Questions refer to current events, for example, "During the past week, I enjoyed my lessons." Child and parent versions of the questionnaire contain identical items but differ by point of view (i.e., "I enjoyed my lessons" versus "My child enjoyed his or her lessons.") All respondents completed questionnaires independent of other family members.

Statistical Analysis

Summary statistics based on transformed sub-scale and overall scores were calculated for all variables. Two sample t-tests were used to evaluate the primary hypothesis that CI children rate their QoL similarly to NH children of comparable chronologic age. Paired t-tests were conducted to assess the secondary hypothesis comparing parent and child responses. The *p*-values were corrected for multiple comparisons, which increases the Type I error (i.e., findings

of false significance), by using the Hochberg step up adjustment for multiplicity. Spearman rank-order correlation analyses were used to examine the relationship between total QoL score and CI participants' demographics. *P*-values less than .05 were considered statistically significant. All analyses were performed using SAS Version 9.2 (SAS Institute Inc., Cary, NC, USA).

Results

8-11 year old sub-group

The average age (with standard deviations in parentheses) of the CI children in this group at the time of the study was 9.1 (1.1) years. Mean age at onset of deafness was 1.11 (1.35) years. Age at implantation was 3.37 (2.13) years, and duration of use was 5.71 (2.19) years.

Table 3 displays mean scores on the KINDL^R for individual sub-scales and the combined total. After adjustment for multiple comparisons, children in the CI group (M=72.57, SD=15.52) rated their family QoL less positively than their NH peers(M=83.98, SD=13.02).

Comparisons of parent and CI children via paired t-tests revealed similar scores across all subscales and the overall total score (Table 4).

Spearman's rank correlations (Table 5) investigated relationships between transformed subscale scores and variables relating to age at onset of deafness, age at cochlear implantation, and duration of CI use. The emotional sub-scale scores (r=0.26, p=0.06) and the self-esteem sub-scale scores (r=0.26, p=0.07) relative to the age at onset of deafness approached significance. These results indicate that children in the 8–11 year old group with older ages at onset of deafness tended to report more positive QoL scores in emotional well-being and selfesteem domains.

12-16 year old sub- group

The mean chronological age of the adolescents in the 12-16 year old group at the time of the study was 13.7 (1.4) years. The mean age at identification of hearing loss was 1.18 (1.01) years. Mean age at implantation was 5.83 (4.02) years with a mean duration of CI use of 7.87 (3.44) years.

Student's t-tests revealed that the adolescents with CI and NH scored similarly in all QoL subscale domains and on the total QoL score (Table 6). However, CI adolescents tended to rate their QoL less positively than their NH peers on the friends sub-scale (CI: M=68.35, SD=22.99; NH: M=78.25, SD=12.71) and the school sub-scale (CI: M=55.24, SD=20.48; NH: M=64.36, SD=13.64). Table 7 shows paired t-tests comparisons within parent and child dyads. Parents (M=68.20, SD=15.52) rated their child's success at school significantly higher than their child rated it (M=56.07, SD= 19.85).

Spearman's rank correlations investigated significant correlations between the six QoL variables and the variables of age at identification of hearing loss, age at implantation, and duration of CI use (Table 8). A moderately strong negative correlation was detected in the total QoL score and the age of CI activation (r=-0.43, p=0.01) suggesting that adolescents with a younger age at CI activation rated their QoL more positively than adolescents with an older age at CI activation. A moderately strong positive correlation existed between the total QoL score and the duration of CI use (r=0.39, p=0.02) such that adolescents with a longer duration of CI experience assign more positive ratings to their overall QoL than adolescents with a shorter duration of use.

Results between CI age groups

Pairwise t-test showed that the younger CI children rated their overall QoL significantly higher (M=75.31, SD=9.22) than the CI teenage group (M=70.37, SD=12.38) (p=0.0354).

Discussion

Child and adolescent evaluation of overall QoL did not differ between the CI and NH groups. However, examination of individual subscales revealed that 8–11 year old CI children rate their QoL with family less positively than NH peers. Chronologically younger CI recipients rated overall QoL more positively than the older 12–16 year old CI group. Parents and CI children of both age groups concur on overall QoL, but parents of 12–16 year old CI children overestimate their adolescent's success in school relative to the child's self-assessment. Overall QoL showed a significant inverse association with age at implantation and a significant positive correlation with duration of CI use in the 12–16 year old group.

Both CI age groups rated QoL similarly to their NH peers, indicating the CI do not appear to negatively impact QoL beyond adjustment to life as a whole. This observation converges with previous comparisons of self-esteem and general QoL in CI and NH adolescents.^{17, 19, 20} In contrast, Huber's group of 8–11 year olds assigned a significantly less positive overall QoL than the NH group.

8-11 year old sub-group

The 8–11 year old group rated the family sub-scale lower than the NH group. Children, to some degree, know the financial and emotional burdens the CI can have on the family, and this knowledge may factor in to the lower rating the CI child gives to his or her perception of place in the family versus the NH child.

Another key finding is the 8–11 year old CI users rated overall QoL more positively than the older group. This difference may relate to pressures of adolescence not yet realized by the younger children. Although self-consciousness and lower self-esteem are common in middle childhood, these issues are compounded by peer pressure, self-image, and self-identity in early adolescence.² However, higher QoL in younger children compared to the adolescents on the same QoL instrument differs from Huber.¹⁷ Several explanations for this difference exist. It may be related to sample size (44 vs. 88) or cultural differences (Austrian vs. American). Another option centers on differences in auditory history variables between the two studies. Compared to Huber's participants, our 8-11 year old group underwent CI activation at a younger age (3.37 vs. 4.5 years) and had less experience with the CI (5.7 vs. 6.2 years). It is possible that earlier exposure to sound via the CI allowed the children in our study to integrate audition into their everyday activities such that they do not foster residual memories of isolation or segregation because of their hearing loss. An alternative relates to differences in the children's chronologic age. Our participants were chronologically younger than Huber's (9.1 vs. 10.7 years). The age discrepancy could reflect differences in psychosocial development in the transition from middle childhood, in which children tend to be closely attached to their parents, to early adolescence in which children have more conflicts with parents and rely on peer relationships to develop self-identity. Perhaps more children in Huber's study than ours have transitioned to early adolescence. Further investigation will be needed to address these issues.

12-16 year old sub-group

Examination of individual subscales for the 12–16 year old group revealed that the school subscale was rated more positively by parents than adolescents, suggesting that 12–16 year olds do not feel as successful in school as the parents believe them to be. This contrasts Huber's

finding of equivalence on all subscales in the 13–16 year old group. The parent-child difference might expose a difference in how the school environment is viewed in the United States versus Austria. Adolescents might have a broader perspective of school as a social dynamic beyond academics, thereby incorporating social difficulties at school or with friends often reported by deaf adolescents into their rating of QoL.^{4, 9} However, difficulties in school appear to stem from the typical angst of adolescence, as indicated by equivalent ratings on the self-esteem and school subscales in CI and NH adolescents.

Significant correlations for the 12–16 year olds suggest success in school is greater in those who were implanted earliest and had the most experience with the implant. Early implantation offers better opportunity for age appropriate auditory development thereby making it potentially easier to feel successful in school. However, our group of 12–16 year olds, with lower school scores than their hearing mates, was implanted relatively late compared to CI recipients of today. For the CI adolescent, having a normal regard for one's self (i.e., similar self-esteem subscale score to NH peers) and experiencing feelings of success in school and other social situations are not axiomatic. ^{19–20}

A limitation of the study is that the majority of participants were queried during vacation time, arguably not a typical situation. Additionally, the questionnaire used was a generic instrument designed for use with a variety of chronic illnesses, and therefore informs us only generally about feelings directly related to deafness and cochlear implantation. Finally, we have no accompanying data as regards levels of speech and language development of the CI participants. To address these limitations future studies should collect data during the school year or, at the least, outside of vacation time. They should incorporate not only a generic QoL instrument but also a condition-specific measure focusing on hearing loss and cochlear implantation. Levels of speech and language development for both CI and NH participants need to be collected in order to provide broader, more accurate comparisons.

Conclusions

CI children rate themselves and their success in several psychosocial domains and how their feelings compare with same aged hearing children. All CI users rated their overall QoL on a par with the NH comparisons. When parent responses were compared to their child's, parents proved to be reliable reporters in areas where they could observe and participate. The younger CI sub-group rated their overall QoL as better than the older CI sub-group.

For profoundly deaf children who regularly use a cochlear implant, feelings about life overall are no better or worse than their hearing peers; while individual areas of difficulty may be different the aggregate scores remain the same. These findings indicate that cochlear implantation seems to have a positive affect on certain psychosocial domains, and that cochlear implants don't seem to create greater psychosocial problems over all for their users.

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Demographics of the 8–11 year old cochlear implant users (n=52)¹ and the 12–16 year old CI users (n=34)

Variable	Age 8–11 years Frequency (%)	Age 12–16 years Frequency (%	
Gender			
Boys	23 (44%)	11 (32%)	
Girls	29 (56%)	23 (68%)	
Etiology of Hearing Loss			
Unknown	28 (54%)	21 (62%)	
Connexin 26	2 (4%)	0 (0%)	
Cytomegalovirus	2 (4%)	1 (3%)	
Enlarged vestibular aqueduct	4 (8%)	2 (6%)	
Ototoxicity	5 (9%)	0 (0%)	
Meningitis	5 (9%)	4 (12%)	
Waardenberg	3 (6%)	0 (0%)	
Other	3 (6%)	6 (18%)	
Communication Mode			
Oral communication	45 (86%)	24 (71%)	
Cued speech	1 (2%)	0 (0%)	
Total communication	6 (12%)	10 (29%)	
School Environment			
Mainstream	37 (71%)	24 (71%)	
Homeschool	2 (4%)	4 (12%)	
Mainstream/Special needs	9 (17%)	2 (6%)	
Deaf school	4 (8%)	4 (12%)	

 $^{I}\mathrm{Demographic}$ Information was not available for two participants

Explanation of the six subscale domains

Subscale Domains Explanation		Sample Question	
Physical Well-being	How they felt about their physical health.	During the past week did you feel strong and full of energy?	
Emotional Well-being	How they felt in general.	During the past week did you have fun and laugh a lot?	
Self-Esteem	How they felt about themselves.	During the past week did you have a lot of good ideas?	
Family	How they felt about their family.	During the past week did you get along well with your parents?	
Friends	How they felt about their friends.	During the past week did you feel different from other children?	
School	How they felt about their school.	During the last week in which you were in school did you feel that doing your homework was easy?	

Subscale and overall quality of life ratings by 8-11 year olds using CI and children with NH

Variable	Children with CI (n=54) Mean (std)	Children with NH (n=918) Mean (std)	Raw p-Value ²	Hochberg p-value ³
Physical Well-being	79.75 (15.35)	75.59 (13.62)	0.0284*	0.1162
Emotional Well-being	83.22 (14.56)	83 (11.01)	0.4572	0.4572
Self-Esteem	71.41 (17.74)	66.6 (18.44)	0.0291*	0.1162
Family	72.57 (15.52)	83.98 (13.02)	<0.0001*	0.0000
Friends	74.77 (16.38)	78.16 (13.29)	0.0705	0.2114
School	70.37 (16.96)	73.19 (12.61)	0.1172	0.2344
Total ⁴	75.35 (9.22)	76.75 (8.65)	0.1400	

²Unadjusted p value

 ${}^{\mathcal{S}}_{\text{Hochberg's adjusted } p}$ value

⁴Total score is the linear combination of all subscales, therefore, no multiplicity adjustment is done on overall total

Subscale and overall quality of life paired t-test results for 8–11 year olds using CI and their parents (n=50)

Variable	Mean (Std) ⁵	Paired t-test p-value ⁶	Hochberg p-value ⁷
Physical	-0.88 (14.73)	0.6762	0.8678
Emotional	-0.38 (15.84)	0.8678	0.8678
Self-esteem	1.5 (19.95)	0.5973	0.8678
Family	1.75 (16.94)	0.4686	0.8678
Friends	5.13 (18.07)	0.0504	0.2519
School	-5.5 (18.11)	0.0367^{*}	0.2202
Total ⁸	0.27 (9.68)	0.8440	

 5 Difference of the means of children using CI and their parents

 6 Unadjusted p value

⁷Hochberg's adjusted p value

 8 Total score is the linear combination of all subscales, therefore, no multiplicity adjustment is done on overall total

Spearman Correlation Coefficients⁹ for ages 8–11 measuring 6 sub-scales and total QoL scores with three variables

Variable Age in years	Age at onset Corr (p-value) M=1.1(sd1.35)	Age at HU Corr (p-value) M=3.7(sd=2.13)	Duration of use Corr (p-value) M=5.7(sd=2.19)
Emotional	0.26 (0.06)	0.20 (0.16)	-0.07 (0.61)
Family	0.07 (0.60)	0.07 (0.62)	0.02 (0.89)
Friends	-0.08 (0.58)	0.04 (0.77)	0.01 (0.97)
Physical	0.15 (0.30)	0.19 (0.18)	-0.16 (0.27)
School	0.15 (0.30)	0.01 (0.97)	-0.00 (0.99)
Self-esteem	0.26 (0.07)	0.11 (0.43)	-0.19 (0.17)
Total	0.23 (0.10)	0.17 (0.22)	-0.10 (0.47)

 ${}^{9}_{p}$ -values are presented without multiplicity adjustment

Subscale and overall quality of life ratings by 12–16 year olds using CI and NH teens.

Variable	Children with CI (n=34) Mean (std)	Children with NH (n=583) Mean (std)	Raw p-Value ¹⁰	Hochberg p-value ¹¹
Physical Well-being	70.56 (23.67)	72.86 (15.31)	0.2989	0.3087
Emotional Well-being	76.21 (16.09)	79.45 (12.34)	0.1389	0.3087
Self-Esteem	69.15 (21.47)	60.79 (19.21)	0.0207*	0.0828
Family	78.83 (12.98)	77.6 (17.36)	0.3087	0.3087
Friends	68.35 (22.99)	78.25 (12.71)	0.0119*	0.0595
School	55.24 (20.48)	64.36 (13.64)	0.0101*	0.0595
Total ¹²	69.72 (12.62)	72.2 (9.42)	0.1445	

10Unadjusted p value

¹¹Hochberg's adjusted *p* value

 12 Total score is the linear combination of all subscales, therefore, no multiplicity adjustment is done on overall total

Subscale and overall Quality of Life paired t-tests results for 12-16 year olds using CI and their parents (n=34)

Variable	Mean (Std) ¹³	Paired t-test p-value ¹⁴	Hochberg p-value ¹⁵
Physical	-1.29 (18.26)	0.6837	0.6837
Emotional	2.39 (14.43)	0.3414	0.6837
Self-esteem	-2.02 (18.25)	0.5228	0.6837
Family	2.76 (16.08)	0.3246	0.6837
Friends	4.6 (21.78)	0.2272	0.6837
School	-12.13 (17.87)	0.0004^{*}	0.0023*
Total ¹⁶	-0.95 (12.02)	0.648	

 13 Difference of the means of children using CI and their parents

¹⁴Unadjusted p value

¹⁵Hochberg's adjusted p value

 16 Total score is the linear combination of all subscales, therefore, no multiplicity adjustment is done on overall total

Spearman Correlation Coefficients¹⁷ for ages 12–16 measuring 6 sub-scales and total QoL scores with three variables

Variable Age in years	Age at onset Corr (p-value) M=1.2(sd=1.0)	Age at HU Corr (p-value) M=5.7(sd=3.9)	Duration of use Corr (p-value) M=7.9(sd=3.4)
Emotional	0.28 (0.11)	-0.24 (0.17)	0.20 (0.26)
Family	0.11 (0.55)	-0.19 (0.27)	0.21 (0.24)
Friends	0.22 (0.22)	0.21 (0.23)	-0.28 (0.10)
Physical	0.30 (0.08)	-0.13 (0.47)	-0.05 (0.77)
School	0.26 (0.14)	-0.20 (0.26)	0.14 (0.42)
Self-esteem	0.20 (0.26)	0.19 (0.29)	-0.19 (0.29)
Total	0.14 (0.43)	-0.43 (0.01)*	$0.39 (0.02)^{*}$

17 p-values are presented without multiplicity adjustment

* p<0.05