

ORIGINAL RESEARCH–PEDIATRIC OTOLARYNGOLOGY

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

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Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

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 (CI) and to compare their responses with those of normal-hearing mates of similar age and 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 CIs in Texas and Colorado.

SUBJECTS AND METHODS: Eighty-eight families from 16 states were divided into two subgroups by age of cochlear implantation: an eight- to 11-year-old group and a 12- to 16-year-old group. The KINDL-R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents was distributed, and CI participants completed the questionnaire independently of 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 compared with their normal-hearing peers. Teen CI users scored the school domain lower compared with their parents. Among CI participants, earlier implantation and longer CI use resulted in higher quality-of-life scores.

CONCLUSION: Children with CIs experience quality of life similar to that of normal-hearing peers. Parents are reliable reporters on the status of their child's overall quality of life.

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The complex transition from early childhood to preadolescence and adolescence often is compounded when a child has a hearing loss because they are at risk for increased social and emotional challenges.^{1,2} Psychosocial dimensions of self-esteem, family, and social-emotional adjustment in deaf children before the availability of cochlear implants (CIs) 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 Trybus⁵ assert that emotional adjustment problems of deaf children are three to six times larger than that of the hearing population. Altschuler and colleagues⁶ report that deaf students also are significantly more impulsive. Fifty percent of deaf children remain concerned with lack of friendship and social acceptance compared with 16 percent of normal-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 multichannel CI in the pediatric population brought with it the promise of improved speech perception, speech 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's¹¹ systematic review of health-related quality-of-life (QOL) studies involving CI children found only 10 studies in which participants were younger than 18 years, a questionnaire in English was used, and the psychosocial domains of physical, mental, and social health were utilized. 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} We found only four studies that sought the CI child's perspective.^{12–14,17} Children, ages five to 14 years, 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 with the score, and age at implantation was negatively

Received August 12, 2009; revised October 9, 2009; accepted October 27, 2009.

correlated with the QOL score. CI users, ages three to 12 years, and their parents report their expectations were met with the implant (81%), 88 percent would have the procedure again, and 94 percent 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 two groups of CI recipients, eight- to 12-year-olds and 13- to 16-year-olds.¹⁷ Results indicated that the younger group's scores were significantly lower than their parents' scores and lower than their NH peers. Older CI children scored similarly to their parents and hearing peers on all subscales 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, on the basis of their own responses, psychosocial issues similar to those of typical-hearing peers, and if their parents are reliable reporters regarding their child's health-related QOL. We hypothesized that CI children qualitatively demonstrate overall QOL scores similar to those of their typical-hearing age mates but qualitatively different responses in psychosocial domains in which 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 that allow direct observation but provide qualitatively different responses in domains for which there is little chance for observation, such as the school setting.

Methods

A cross-sectional study design compared ratings of QOL in CI children with those of their parents and their NH age mates. Families participating in the study (n = 88) representing 16 American states were recruited from CI 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 CI device. Parent respondents were the primary caregiver of the child. The only exclusion criterion was the inability to complete the questionnaire independently. All participants used English as the primary language of the family.

Parent–child dyads were categorized by the child's chronological age to yield two subgroups: eight- to 11-year-olds (n = 50) and 12- to 16-year-olds (n = 34). An additional four children in the eight- to 11-year-old group completed forms with no matching parent questionnaire (parents did not return questionnaire). Age groups were predetermined

by the QOL questionnaire. Parents and children were independently assessed and scored. Scores of each parent were compared with their child's scores in one analysis, and a second analysis compared the CI child's scores with an age-appropriate comparison group of NH children. The majority of CI responders in both age groups were female, had 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 in subsequent text, consisted of 1501 pupils in the fourth and eighth grades. 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 owing 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 ver-

Table 1
Demographics of the eight- to 11-year-old cochlear implant (CI) users (n = 52)* and the 12- to 16-year-old CI users (n = 34)

Variable	Frequency (%)	
	Age 8-11 years	Age 12-16 years
Sex		
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%)
Home school	2 (4%)	4 (12%)
Mainstream/special needs	9 (17%)	2 (6%)
Deaf school	4 (8%)	4 (12%)

*Demographic information was not available for two participants.

Table 2
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?

sion, is an established generic health-related QOL questionnaire suitable for children between the ages of four and 16 years.¹⁸ The Kid KINDL-R (8- to 11-year-olds), the Kiddo KINDL-R (12- to 16-year-olds), and a corresponding parental questionnaire served as assessment tools. Each measure consists of 24 questions equally distributed among six multidimensional subscales: physical well-being, psychological well-being, self-esteem, family, friends, and functioning in school (Table 2). The subscale scores are combined for an overall total score and transformed to a 100-point scale, with 0 representing minimal QOL and 100 representing maximal QOL. The KINDL-R format is a five-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” vs “My child enjoyed his or her lessons”). All respondents completed questionnaires independently of other family members.

Statistical Analysis

Summary statistics based on transformed subscale 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 chronological 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 0.05 were considered statistically significant. All analyses were performed with SAS version 9.2 (SAS Institute, Cary, NC).

Results

Eight- to 11-Year-Old Subgroup

The average age (with SD 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 subscales 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 compared with 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 rank correlations (Table 5) investigated relationships between transformed subscale scores and variables related to age at onset of deafness, age at cochlear implantation, and duration of CI use. The emotional subscale scores ($r = 0.26$, $P = 0.06$) and the self-esteem subscale scores ($r = 0.26$, $P = 0.07$) relative to the age at onset of deafness approached significance. These results indicate that, in the eight- to 11-year-old group, children who were older at onset of deafness tended to report more positive QOL scores in emotional well-being and self-esteem domains.

Twelve- to 16-Year-Old Subgroup

The mean chronological age of the adolescents in the 12- to 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 *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 subscale (CI: $M = 68.35$, $SD 22.99$; NH:

Table 3
Subscale and overall QOL ratings by CI user and NH eight- to 11-year-olds

Variable	Children with CI (n = 54) Mean (SD)	Children with NH (n = 918) Mean (SD)	Raw P value*	Hochberg P value†
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§	75.35 (9.22)	76.75 (8.65)	0.1400	

CI, cochlear implant; NH, normal hearing; QOL, quality of life.

*Unadjusted P value.

†Hochberg's adjusted P value.

‡P < 0.05.

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

M = 78.25, SD 12.71) and the school subscale (CI: M = 55.24, SD 20.48; NH: M = 64.36, SD 13.64). Table 7 shows paired *t* test 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 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 ex-

isted 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 assigned more positive ratings to their overall QOL compared with adolescents with a shorter duration of use.

Results between CI Age Groups

A pair-wise *t* test showed that the younger CI children rated their overall QOL significantly higher (M = 75.31, SD 9.22) compared with 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 eight- to 11-year-old CI children rated their QOL with family less positively compared with NH peers. Chronologically younger CI recipients rated overall QOL more positively versus the older 12- to 16-year-old CI group. Parents and CI children of both age groups concurred on overall QOL, but parents of 12- to 16-year-old CI children overestimated 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- to 16-year-old group.

Both CI age groups rated QOL similarly to their NH peers, indicating that CIs 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 eight- to 11-year-olds assigned a significantly less positive overall QOL compared with the NH group.

Table 4
Subscale and overall QOL of life paired *t* test results for eight- to 11-year-olds using CI and their parents (n = 50)

Variable	Mean (SD)*	Paired <i>t</i> test P value†	Hochberg P value‡
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	0.27 (9.68)	0.8440	

CI, cochlear implant; QOL, quality of life.

*Difference of the means of children using CI and their parents.

†Unadjusted P value.

‡Hochberg's adjusted P value.

§P < 0.05.

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

Table 5
Spearman correlation coefficients* for ages eight to 11 years measuring six subscales and total QOL scores with three variables

Variable	Age at onset (yrs) Corr (<i>P</i> value) M = 1.1 (SD 1.35)	Age at HU (yrs) Corr (<i>P</i> value) M = 3.7 (SD 2.13)	Duration of use Corr (<i>P</i> 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)

Corr, correlation coefficient; HU, hook up; QOL, quality of life.

**P* values are presented without multiplicity adjustment.

Eight- to 11-Year-Old Subgroup

The eight- to 11-year-old group rated the family subscale lower compared with 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 into 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 that the eight- to 11-year-old CI users rated overall QOL more positively versus 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 with the adolescents on the same QOL instrument differs from Huber's result.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 with Huber's participants, our eight- to 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 chronological 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 had transitioned to early adolescence. Further investigation will be needed to address these issues.

Table 6
Subscale and overall QOL ratings by 12- to 16-year-olds using CI and NH teens

Variable	Children with CI (n = 34) Mean (SD)	Children with NH (n = 583) Mean (SD)	Raw <i>P</i> value*	Hochberg <i>P</i> value†
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§	69.72 (12.62)	72.2 (9.42)	0.1445	

CI, cochlear implant; NH, normal hearing; QOL, quality of life.

*Unadjusted *P* value.

†Hochberg's adjusted *P* value.

‡*P* < 0.05.

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

Table 7
Subscale and overall QOL paired *t* tests results for 12- to 16-year-olds using CI and their parents (n = 34)

Variable	Mean (SD)*	Paired <i>t</i> test <i>P</i> value†	Hochberg <i>P</i> value‡
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	−0.95 (12.02)	0.648	

CI, cochlear implant; QOL, quality of life.

*Difference of the means of children using CI and their parents.

†Unadjusted *P* value.

‡Hochberg's adjusted *P* value.

§*P* < 0.05.

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

Twelve- to 16-Year-Old Subgroup

Examination of individual subscales for the 12- to 16-year-old group revealed that the school subscale was rated more positively by parents versus adolescents, suggesting that 12- to 16-year-olds do not feel as successful in school as the parents believe them to be. This contrasts with Huber's finding of equivalence on all subscales in the 13- to 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 the 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- to 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- to 16-year-olds, with lower school scores than their hearing mates, was implanted relatively late compared with CI recipients of today. For the CI adolescent, having a normal regard for one's self (i.e., self-esteem subscale score similar to that of 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 related to levels of speech and language development of the CI participants. To address these limitations, investigators in 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 to provide broader, more accurate comparisons.

Conclusions

CI children rated themselves and their success in several psychosocial domains, and their feelings were compared with those of same-age hearing children. All CI users rated their overall QOL on a par with the NH comparisons. When parent responses were compared with their child's, parents proved to be reliable reporters in areas in which they could

Table 8
Spearman correlation coefficients* for 12- to 16-year-olds measuring six subscales and total QOL scores with three variables

Variable	Age at onset (yrs) Corr (<i>P</i> value) M = 1.2 (SD 1.0)	Age at HU (yrs) Corr (<i>P</i> value) M = 5.7 (SD 3.9)	Duration of use Corr (<i>P</i> 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)†

Corr, correlation coefficient; HU, hook up; QOL, quality of life.

**P* values are presented without multiplicity adjustment.

†*P* < 0.05.

observe and participate. The younger CI subgroup rated their overall QOL as better than that of the older CI subgroup.

For profoundly deaf children who regularly used a CI, feelings about life overall were no better or worse than their hearing peers; while individual areas of difficulty may have differed, the aggregate scores remained the same. These findings indicate that cochlear implantation seems to have a positive effect on certain psychosocial domains, and that cochlear implants do not seem to create greater psychosocial problems overall for their users.

Acknowledgments

We gratefully acknowledge the support of the Crystal Charity Ball Cochlear Implant Summer Listening Camp in Dallas, TX, and the Colorado Neurological Institute's Cochlear Kids Camp in Estes Park, CO, both of whom allowed us to recruit families attending their programs.

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Portions of this manuscript were presented at the 10th International Conference on Cochlear Implants and Other Implantable Auditory Technologies, San Diego, CA, April 2008; AudiologyNOW, Dallas, TX, April 2009; and the 11th Symposium on Cochlear Implants in Children, Seattle, WA, June 2009.

Author Contributions

Betty Loy, development of research protocol, data collection, primary writer of manuscript; **Andrea Warner-Czyz**, data collection, assistance with protocol, consultation on manuscript, data analysis and interpretation, editing; **Liyue Tong**, biostatistics, editing of statistical section of the manuscript; **Emily Tobey**, consultation on manuscript, data analysis and interpretation, editing; **Peter Roland**, consultation on manuscript, data analysis and interpretation, editing.

Disclosures

Competing interests: **Betty Loy**, Med-El: travel and partial salary support paid in 2008 (<\$9000); **Andrea Warner-Czyz**, Clinical Sciences Scholar with funding from NIH grant number 1 UL1 RR024982-01: provided part of salary; **Peter Roland**, Med-El: corporation advisory board member.

Sponsorships: Partial funding provided by Med-El Corporation (funding for travel to and from data collection sites) and NIH grant number 1 UL1 RR024982-01 titled "North and Central Texas Clinical and Translational Science Initiative" (Milton Packer, MD, PI) from the National Center for Research Resources, a component of the NIH, and NIH Roadmap for Medical Research (Clinical Scholarship program for new researchers).

Neither sponsor had a role in creating the research project, collecting or interpreting data, or writing or editing this manuscript.

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