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Original Article

Health-Related Quality of Life Evaluation in Children with Cochlear Implants

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BACKGROUND: To compare the quality of life scores of children with monoaural cochlear implants (CIs) aged 4-16 with those of normally hearing (NH) children and parents' reports.

METHODS: The KINDL-R questionnaire that measures health-related quality of life (HRQoL) was delivered to 72 children aged 4-16 years and their parents. The children were divided into 3 subgroups of 4-7, 8-11, and 12-16 years and asked to report their quality of life from their own perspectives. The parents were divided into 2 subgroups for 4-7 aged and 8-16 aged children and were asked to report their child's quality of life status from their perspectives. The QoL scores of children with CI in the 3 subgroups were compared with the scores of their parents and NH peers.

RESULTS: The total scores of children with CIs in all subgroups were significantly worse than NH peers. The total scores of parents and children with CIs in all subgroups revealed no statistically significant differences. In the correlation analysis, the age of implantation was negatively correlated with the total score both in 8-11 (ρ: −0.777) and 12-16 year subgroups (ρ: −0.591). Similarly, the implant usage duration was positively correlated with the total score in all age groups.

CONCLUSION: Children with CI experience worse QoL status than their NH peers. The possible causes of the lower QoL scores following cochlear implantation must be investigated. Reports from parents on their children's QoL status are reliable.

KEYWORDS: Children with cochlear implants, parents, quality of life

INTRODUCTION

Cochlear implants (CIs) are devices developed for patients with bilateral severe and profound sensorineural hearing loss who do not benefit from hearing aids.[1-3] They convert mechanical sound energy into electrical signals and transfer it directly to the cochlea, allowing sound perception. In this respect, CIs have been a huge technological breakthrough, enabling hearing-impaired children to experience sound.[4,5]

The goal of CI surgery, which aims to restore a function that has never existed or was subsequently lost, should not only be the success of the surgical procedure but also a successful surgery followed by the normalization of the personal well-being provided by this function. From this point of view, not only objective measures, such as speech perception, but also subjective measures, such as quality of life (QoL), are required to assess the success of the whole procedure.[6]

Literature reveals that the effectiveness of the CI is primarily assessed using postoperative objective hearing and speech perception tests. Studies have reported that patients benefit from CIs, and this may create a perception that patients with CIs should have a

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good QoL. However, when the literature is examined, it is seen that there are studies showing low QoL in children using CI. On the other hand, some studies report that the QoL scores of children using CI are not different from those of children with NH. In conclusion, it is a fact that the number of studies focusing on QoL in patients who have undergone CI surgery is quite limited, and their results vary widely.[7-10]

Assessing the QoL of these patients is possible by using the generic health-related QoL (HRQoL) test, a scale providing health information regardless of medical condition.[11] Generic HRQoL instruments have advantages because they have multidimensional scales used to compare different groups, such as children with normal hearing and children with CIs of different ages.[11]

This study aimed to evaluate the QoL of children using monoaural CIs rather than their hearing outcomes and compare the QoL between children with monoaural CIs and NH children aged 4-16 years. Furthermore, the cochlear implanted children's self-reports were compared with the parents' reports on their children's QoL.

METHODS

This study was conducted in accordance with the Declaration of Helsinki and approved by the ethics committee with the approval number 11/20 at Dışkapı Research and Training Hospital, a tertiary reference center, on November 11, 2013. The study was conducted retrospectively. The patients' medical records and their demographic and clinical data were collected. All patients and their families were provided with information regarding the study. They agreed to participate in the research and provided written informed consent for their medical records to be reviewed.

For the study group, patients between 4 and 16 years old who used monaural CIs because of bilateral severe sensorineural hearing loss, had been using the CIs regularly for at least 1 year, who had complete medical data, and did not have any other chronic, physical, or mental disease were included. Those with missing medical data, chronic disease, physical or mental disability, as well as bilateral CI and bimodal hearing, were excluded from the study. All the patients were monaural CI users who underwent surgery for congenital or progressive bilateral severe and profound sensorineural hearing loss. During the surgery for each patient, the functionality of each electrode was confirmed through telemetry once the implant was inserted. At the time of the operation, all the patients were at least 12 months, had a difference of less than 4 years between the age of receptive and/or expressive language and chronological age or had a receptive and/or expressive language of 4 years or older, or had a post-lingual hearing loss. All patients had used binaural hearing aids for a period of at least 3 months prior to surgery.

MAIN POINTS

- Successful results are achieved with cochlear implant surgery in the treatment of advanced and profound hearing loss.
- Hearing and speech perception tests are mostly used as measures of success in the literature.
- The good results of these tests may create the perception that the quality of life (QoL) of the patients has improved, but different results have been reported in the literature on this subject.
- In our study, total QoL scores were found to be low. While such advanced surgery can be performed successfully, the low postoperative QoL scores are thought-provoking, and the possible reasons for this should be investigated.

Children with CIs who were aged 4-16 years were divided into 3 subgroups: aged 4-7, 8-11, and 12-16 years. Children aged 4-7 years answered the questionnaire as an interview, while others answered the questionnaire by themselves. The parents were divided into 2 subgroups: parents of children aged 4-7 and 8-16 years. The parents answered their questionnaires from their own perspective to evaluate their child's QoL status.

For the comparison group with NH, the analysis results of 918 healthy children aged 8-11 years and 583 healthy children aged 12-16 years, collected by the main producers of the questionnaire, were used.[8,12] However, for the comparison group of children with NH aged 4-7 years, the results of a dialog survey administered to healthy children attending the nursery, with the permission of their parents and under parental observation, were used.

The measured QoL scores of children with CIs in all subgroups were compared with the scores of their parents and their counterparts with NH.

Generic Health-Related Quality of Life Measure

The KINDL-R questionnaire is a widely used generic HRQoL questionnaire designed for measuring the QoL status of children and adolescents.[12] The valid and reliable local language translation of KINDL-R was used.[13] The KINDL-R has different documents for children and parents, such as Kid-KINDL-R, Kiddo KINDL-R, and Kiddy KINDL-R for children aged 8-11, 12-16, and 4-7 years, respectively. The parental questionnaires were designed in 2 different forms for parents with children aged 8-16 and 4-7 years. The questionnaire for 4-7 year-old children was conducted as an interview. The children rate the questionnaire according to their life experiences thinking just about the past week; thus, documents for children provide self-assessment measures. The parents answer the parental questionnaire to evaluate their child's QoL status from their own perspective; hence, the document provides external assessment measures of the child's HRQoL.[11]

Although different pediatric HRQoL measures exist, the authors selected the KINDL-R for its validity and reliability in the current study's local language and its easy applicability to various pediatric ages with the availability of a parent stand-in.[11]

With this questionnaire, the perception of QoL is evaluated in 6 different subscales: physical well-being, emotional well-being, self-esteem, family, friends, and school.

In the questionnaire for the 4-7-year-old age group, 2 different sentences are given in each of these 6 subscales, and the child is asked to state their opinion about these sentences by choosing one of the options: "very often," "sometimes," and "never." In all other child and parent questionaries, 4 different sentences are given in each subscale, and the child/parent is asked to state their opinion about the judgment in these sentences by selecting 1 of the options:

"always," "often," "sometimes," "rarely," and "never," considering only what their child experienced in the previous week. In the questionnaire for parents of children aged 4-7 years, additional information is asked with 22 sentences, in addition to the 4 sentences in these 6 subscales.

For the 8-16 year-old children and parent groups, the total and subscale scores were calculated from the questionnaire responses, then these responses were transformed to a score range from 0 to 100. However, only the total score was calculated for the questionnaires of the 4-7 year-old children and parent groups. The scores were calculated according to the rules of the authors. A score of 100 indicates the highest QoL, whereas 0 indicates the worst.

Statistical Analysis

The Statistical Package for Social Sciences for Windows version 22.0 (IBM SPSS Corp.; Armonk, NY, USA) program was used to evaluate the data of this study. Descriptive statistics were expressed as mean ± SD, frequency distribution, and percentage. The Kolmogorov–Smirnov/Shapiro–Wilk test was used to evaluate normally distributed variables. Moreover, the chi-square test was used to evaluate categorical variables. The Mann–Whitney *U* test and Wilcoxon signed-rank test were used for data analysis of continuous variables. The relationship between variables was evaluated using the Spearman correlation test. Statistical significance was determined at $P < .05$.

RESULTS

Seventy-two children who used monoaural CIs for at least one year were included in the study. Table 1 shows their age and sex distribution.

Results of 4-7-Year-Old Children

In this age group, the mean age at implantation was 2.91 years, and the mean duration with CI was 1.91 years. The QoL scores of children with normal hearing were significantly better than those of their counterparts with CIs ($P = .006$; Table 2).

When the results of the questionnaire were applied to the parents of 4-7 year-old children with CIs, the total QoL scores between parents' opinions and the children's results were not significantly different ($P = .17$; Table 3).

Results of 8-11-Year-Old Children

In this age group, the mean age at implantation was 5.80 years, and the mean duration with CI was 3.40 years. The total QoL scores of children with normal hearing were significantly better than their counterparts with CIs ($P = .006$; Table 2). Regarding the subscale scores, the emotional well-being, family, and school scores of children with normal hearing were statistically significantly higher than those of children with CIs ($P = .006$, .006, and .04 respectively), whereas other subscales showed no significant difference.

When the questionnaire results were applied to the parents of 8-11-year-old children with CIs, the total scores, as well as the subscale scores, between the children and parent responses were not significantly different ($P = .91$; Table 3).

Results of 12-16-Year-Old Children

In this age group, the mean age at implantation was 9 years, and the mean duration of cochlear implantation was 5 years. The total QoL scores of children with normal hearing were significantly better than their counterparts with CIs ($P = .006$; Table 2).

The subscale scores of emotional well-being and friends items were lower in children with CIs ($P = .007$ and .001, respectively) than those in children with normal hearing, whereas no significant difference was found for other subscales.

When the questionnaire results were applied to the parents of 12-16-year-old children with CIs, the total scores between the children and parents were not significantly different ($P = .70$; Table 3). Moreover, the emotional well-being score in children with CIs (70.73 ± 13.69) was significantly better than that in the parent groups (63.92 ± 19.75; $P = .047$), whereas no significant differences were found in other subscales.

Effect of Implantation Age and Duration of Implant Use on Quality of Life

Based on the results of the correlation analysis to understand whether the QoL score is related to the age of implantation and duration of implant use, the age of implantation was negatively correlated with the total score both in the 8-11 (ρ: −0.777) and 12-16 year-old age groups (ρ: −0.591). Similarly, the duration of implant use was positively correlated with the total score in the 4-7, 8-11, and 12-16 year-old age groups (ρ: 0.394, 0.620, and 0.490, respectively; Table 4).

DISCUSSION

In addition to successful intraoperative intervention and restoration of hearing, the goal of cochlear implantation is to help patients achieve holistic well-being comparable to their normal-hearing peers, as assessed by QoL questionnaires. However, objective evaluation of QoL in CI patients remains limited, and existing studies report divergent results that can be attributed to various factors such as methodological differences and contextual components.[4,6,8,9,11,14]

In the current study, the QoL of 72 children aged 4-16 years with severe bilateral hearing loss who had been using monoaural CIs for at least 1 year was evaluated. These children were compared with their normal-hearing peers using the KINDL-R, a generic QoL questionnaire. The results indicated that the total QoL scores of the CI group were significantly lower across all age groups (4-7, 8-11, and 12-16 years). However, some subscale scores such as self-esteem, physical well-being, and family relationships in the older age groups (8-11 and 12-16 years), showed no significant differences between the groups, which is promising as it suggests that the QoL in children with CIs can be improved.

Table 1. Demographic Characteristics of Children with CIs

	4-7 Year-Old Age Group	8-11 Year-Old Age Group	12-16 Year-Old Age Group
n (%)	34 (47.2%)	16 (22.2%)	22 (30.6%)
Sex (M/F)	12/22	11/5	6/16

f, female; m, male; n, number of patients.

Table 2. Comparison of Questionnaire Results Applied to Children with Cochlear Implants and Normal Hearing

	Cochlear Implanted	Normal Hearing	*P*
4-7 year-old children's total scores (mean ± SD)	72.10 ± 17.55	82.70 ± 12.33	.006
8-11 year-old children's total scores (mean ± SD)	69.33 ± 9.22	76.75 ± 8.65	.006
12-16 year-old children's total scores (mean ± SD)	65.43 ± 10.29	72.2 ± 9.42	.006

**P*-values indicate comparison with the Mann–Whitney *U* test.

Table 3. Comparison of Questionnaire Results applied to Children with Cochlear Implants and Their Parents

Cochlear Implanted Children Total Scores (Mean ± SD)	Parents' Total Scores (Mean ± SD)	*P*
(4-7 years old) 72.10 ± 17.55	71.85 ± 10.29	.17
(8-11 years old) 69.33 ± 9.22	69.14 ± 11.1	.91
(12-16 years old) 65.43 ± 10.29	66.05 ± 12.45	.70

**P*-values indicate comparison with the Wilcoxon signed-rank tests.

Table 4. Correlation of the QoL Score with the Age of Implantation and Duration of Implant Use

n = 72		Total Score	Age of Implantation	Duration of Implant Use
4-7 years old		*r*	*r*	*r*
	Total score	1		
	Age of implantation	0.073	1	
	Duration of implant use	0.394*	−0.723**	1
8-11 years old	Total score	1		
	Age of implantation	−0.777**	1	
	Duration of implant use	0.620*	−0.880**	1
12-16 years old	Total score	1		
	Age of implantation	−0.591**	1	
	Duration of implant use	0.490*	−0.923**	1

r, Spearman correlation coefficient.
*$P < .05$. **$P < .01$.

Previous studies using the KINDL-R scale have reported varying outcomes. Huber[9] found that total QoL scores for 8-12-year-old children with CIs were significantly lower than those of their normal-hearing peers, while no significant differences were observed among adolescents aged 13-16 years. Conversely, Loy et al[8] reported no significant QoL differences for CI users aged 8-11 and 12-16 years compared to normal-hearing peers, though this study was conducted in a CI-specific summer camp, which may have positively influenced responses. Similarly, Pereira et al[6] found no significant QoL differences between CI users and normal-hearing children, possibly due to earlier implantation age and longer follow-up in their cohort. Percy-Smith et al[7], using a different questionnaire, reported that children with CIs had self-esteem and social well-being scores comparable to or better than their normal-hearing peers. These discrepancies may be influenced by differences in social environments, questionnaire types, sociocultural and socioeconomic factors, or access to postoperative rehabilitation and education programs.[15-19]

In this study, although total scores were lower in the CI group, some subscale scores (e.g., self-esteem, physical well-being) showed no significant differences in older age groups, highlighting potential areas of resilience. For the 8-11 age group, self-esteem, friends, and physical well-being scores showed no significant differences between the CI and NH groups. Similarly, for the 12-16 age group, no significant differences were observed in self-esteem, physical well-being, school, or family scores. These findings align with recent studies suggesting that children with CIs can achieve a QoL comparable to their normal-hearing peers when provided with adequate support.

For example, Gundacker et al[20] (2023) found that unilateral CI users achieved QoL scores similar to those of their normal-hearing peers and demonstrated significant improvements in speech comprehension post-implantation, regardless of implantation timing. Similarly, Hoffman et al[21] reported no significant differences in HRQoL between children with CIs and their normal-hearing peers, attributing this to early diagnosis, timely interventions, and favorable socioeconomic factors, which collectively foster optimal development. Their findings highlight the need for interventions addressing not only spoken language but also social-emotional and cognitive development, equipping children with skills for emotional regulation and social interaction. Haukedal et al[22] further emphasized the importance of individual and environmental factors in HRQoL, noting comparable scores between CI and NH children but identifying social and school functioning as areas needing improvement.

These studies suggest that multidimensional support—combining auditory rehabilitation with social-emotional development—can enable children with CIs to achieve a QoL perception similar to their normal-hearing peers. In this study, the similarity of some subscale scores supports this notion, indicating that comprehensive support may bridge the gap in the overall QoL for children with CIs.

This study evaluated the agreement between self-reported and proxy-reported QoL in children with CIs. No significant differences in total QoL scores were found between children with CIs and their parents across all age groups, suggesting that parents can reliably assess their child's QoL. Subscale comparisons revealed no differences in the 8-11 and 12-16 age groups, except for emotional well-being, where 12-16-year-old children scored significantly higher than their parents.

In contrast, Huber[9] reported low parent-child agreement, with higher child scores correlating with lower parent scores, possibly due to communication or coping challenges. Similarly, Haukedal et al[23] found discrepancies, with proxies rating physical health higher than children, emphasizing caution in relying solely on proxy reports when self-reports are available. Loy et al[8] found no significant differences in total or subscale scores between children with CIs and their parents in the 8-11 and 12-16 age groups, except for the school subscale, where children scored higher than their parents.

Although proxy reports were reliable in this study, findings from other studies suggest maintaining caution when interpreting proxy-reported QoL.

In this study, a lower age at implantation was positively correlated with higher total scores in the 8-11 and 12-16 age groups. The lower scores in older children may reflect increased awareness of social challenges related to hearing impairment or the impact of wearing a prominent hearing device during adolescence, a period when appearance is highly valued. Similarly, Loy et al[8] reported significantly better total scores for 8-11-year-olds compared to 12-16-year-olds. Additionally, longer CI use was positively correlated with higher total scores across all age groups in our study. De Giacomo et al[24] similarly concluded that early implantation has a greater positive impact on the lives of hearing-impaired children.

The main limitation of this study is the small sample size, as it included only monaural implant recipients. The exclusion of audiological data and the lack of information on demographic, cultural, and economic characteristics of families, as well as their adaptation to rehabilitation, further limit the findings. The inclusion of different age groups may have affected the homogeneity of results, and direct comparisons with the normal population may not fully account for the unique challenges faced by implant recipients. However, to the best of knowledge, a specific QoL questionnaire for CI users in the study's language was unavailable, requiring the use of a generic QoL questionnaire, which is another limitation. Comparisons with non-implanted hearing-impaired individuals or pre- and post-implantation assessments may offer deeper insights. Future studies should include larger, more homogeneous cohorts to improve validity and generalizability.

CONCLUSION

In conclusion, this study highlights the importance of QoL scores in evaluating outcomes following cochlear implantation. The findings indicate that children with monoaural CIs have significantly lower total QoL scores compared to their normally hearing peers. This disparity, despite the successful completion of a complex surgical procedure requiring substantial expertise, underscores the need for further investigation into its underlying causes.

Encouragingly, the lack of significant differences in certain subscale scores between the 2 groups suggests that targeted interventions have the potential to enhance the QoL of cochlear-implanted children. Comprehensive and well-structured support programs are essential for dealing with these challenges and improving the overall QoL for this population.

Data Availability Statement: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Committee Approval: This study was approved by the Ethics Committee of Dışkapı Research and Training Hospital (approval no.: 11/20; date: November 11, 2013).

Informed Consent: Written informed consent was obtained from the patients and their families who agreed to take part in the study.

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