

Original Article

Parents' View on Quality of Life after Cochlear Implantation in Children with Auditory Neuropathy

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OBJECTIVES: The aim of this study is to evaluate the quality of life in pediatric patients with auditory neuropathy according to the perspective of their parents after cochlear implantation.

MATERIALS and METHODS: The pediatric patients, who underwent cochlear implantation with the diagnosis of auditory neuropathy at İzmir Bozyaka Training and Research Hospital ENT Clinic between January 1997 and May 2017, were included to the study. "Parents' Perspective Questionnaire" developed by Nottingham Pediatric Cochlear Implant Programme was used in the study. The questionnaire was composed of 11 sub-scales and 58 questions in total.

RESULTS: The study included 26 pediatric patients (14 female, 12 male) who used cochlear implant for at least 1 year. The mean age of patients was 10.91 ± 3.85 (4.3-17.3 years old) and implantation age varied between 14 months and 80 months. (median; 35.65 ± 20.03 months). Patients who attended school had more self-confidence, and also those having implant use over 6 years had a better self confidence and social relationship.

CONCLUSION: Cochlear implantation not only improves the ability of hearing but also provides development of speech and language skills and therefore enhancing the patient's quality of life. From the perspective of parents, the use of cochlear implant in the children with auditory neuropathy improves the quality of life in many different ways. The perspective of parents can provide a multidimensional evaluation about the child's progress, therefore, it should be taken into consideration by the staff in implant centers.

KEYWORDS: Auditory neuropathy, cochlear implantation, quality of life, satisfaction, listening skill

INTRODUCTION

Auditory neuropathy spectrum disorder (ANSD), defined over 20 years ago, is not a common disease. There are significant criteria for the diagnosis of ANSD that include intact otoacoustic emissions (OAEs) indicating the normal functioning of the outer hair cells, and the presence of cochlear microphonic (CM) and the absence or dyssynchrony of the waves generated in the auditory-evoked potential/brain response (ABR) ^[1, 2]. The patients with ANSD have a decreased speech discrimination in contrast to puretone audiogram thresholds. Abnormal neural dyssynchronization that occurs as a response to neuronal stimulation is responsible for this situation ^[3].

Although contemporary hearing aids are equipped with advanced technology, they still can not provide enough stimulation to overcome the neural dyssynchronization that takes place in ANSD. Yet, cochlear implantation can meet this demand, and patients with ANSD who were implanted may be expected to show significant improvement in language development and speech perception ^[4].

Pediatric patients with a severe or profound hearing loss experience an extremely significant progress in terms of self-confidence and social relationship after implantation ^[5, 6]. Although numerous audiological test parameters are performed in cochlear implantation centers to evaluate the efficacy of cochlear implantation, they are not solely enough to evaluate the progress of the child in social life. Therefore, questionnaires defining the quality of life and satisfaction of the patients with cochlear implantation have been developed ^[7]. These questionnaires provide a multidimensional assessment related to the quality of life, psychological state and social relationships of patients.

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Not only the life of the children with hearing loss but also the life of their families change drastically after implantation. These changes are directly recognized by parents; therefore, the questionnaires that target parents contribute considerably to the knowledge related to the progress of the child, relationship with other children, education and psychological state of their children [8-12].

In this respect, we aimed to evaluate the quality of life of children with ANSD after cochlear implantation using the Parents' Perspective Questionnaire (PPQ), which is a worldwide accepted tool to evaluate the quality of life after cochlear implantation in pediatric patients. To the best of our knowledge, this study is a kind of study with the largest series of patients which evaluates the quality of life of children with ANSD after cochlear implantation.

MATERIALS AND METHODS

This retrospective study included pediatric patients with ANSD, who underwent cochlear implantation due to bilateral severe to profound hearing lost, between January 1997 and May 2017. The ethical committee of the institution approved the study protocol and informed consent was obtained from all participants. Necessary data for conducting the study were obtained from the cochlear implant center of

the same hospital, where the patients were followed up. Parents were informed comprehensively about the study and then they approved it.

Children were diagnosed with ANSD when they had intact CM and OAEs, and an abnormal ABR. Possible etiologic factors of ANSD such as prematurity, jaundice, kernicterus, neonatal intensive unit hospitalization, genetic syndromes and concomitant neurological diseases were investigated. Children with ANSD were offered cochlear implantation when they demonstrated hearing loss and when they failed to meet speech and language development milestones despite conventional amplification and rehabilitation efforts. All patients were followed up for at least 1 year after implantation.

The PPQ, which was developed by the Nottingham Pediatric Cochlear Implant Program (Nottingham University Hospital, Nottingham, United Kingdom) [8-12] translated to Turkish and validated previously was used in the study [13]. The questionnaire was composed of 11 subscales and 58 questions in total (Figure 1). The replies of the parents to the questions were rated as *strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree*. Questionnaires were either mailed to the parents if they were living in another city, or they were filled out during the visit to the implant center.

Child Name:	Date of first fitting:
Date of birth:	School:
Date of implantation:	Rehabilitation center:
Implant use: continuously while awake hours during day
This form is filled by: mother father both parents parents with teacher	

Choose the best statement suitable for you and your child.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
DECISION FOR IMPLANTATION					
1. The first few weeks before and after implantation were stressful.					
2. It was very difficult to decide about cochlear implantation.					
3. It was very difficult to wait for the evaluation results and surgery after application to the implant center.					
4. Some of our relative was against our decision about implantation.					
5. I am concerned that my child could blame me for this decision in the future.					
6. I decided for implantation because I wanted my child to be a part of the hearing world.					
7. I was so relieved when my child reacted to sound for the first time.					
PROCESS OF IMPLANTATION					
8. It is helpful to meet the other families with implanted children.					
9. The families should get as much information as they could before implantation.					
10. I know that it is important to wear the implant all the time.					
11. During the first few months after implantation, I was worried whether I was doing wrong.					
12. The cost of traveling to the implant center is a burden for me.					
13. It is difficult to take time off from work for our appointment in the implant center.					
14. My other children (if any) are upset because I do not have much time and energy to spend with them.					
15. For a short time after implantation, it can be helpful to use sign language in addition to verbal communication for early progress.					
POSITIVE EFFECT OF THE IMPLANT					
16. My child's progress was very slow in the first months after implantation.					
17. After a few months my child's progress was better than my expectations.					
18. I thought that my child would speak right after the first fitting.					
19. I worry that implant will break down.					
20. Cochlear implant will help my child to find a better job in the future.					
SUPPORT					
21. My child need more help since he received his implant.					
22. My help has become more productive after implantation.					
23. Parents should be patient during rehabilitation.					
24. It is easier to communicate with my child by speaking than by signing.					
25. A lot of help at first means a child needs less help later.					

COMMUNICATION					
26. Although the other people know that my child is hearing impaired, they have difficulty in communication.					
27. I am worried about my child's pronunciation.					
28. I expected that my child would have a better pronunciation after implantation.					
29. After using the implant he has better pronunciation than I expected.					
30. I can talk to my child even when he cannot see me.					
SELF-CONFIDENCE					
31. There is a significant improvement in his confidence.					
32. He was very dependent on us before implantation.					
33. He acts as independent as his peers.					
34. I seldom leave him alone to do something before implantation.					
35. Now I let him do something on his own.					
WELL-BEING AND HAPPINESS					
36. After implantation he became less frustrated.					
37. He still shows signs of frustration in his behaviors.					
38. He is enjoying his toys, TV and music more than before.					
SOCIAL RELATIONSHIPS					
39. He was socially isolated before implantation.					
40. Now he is talkative and he tries to communicate.					
41. Now he is socially active and we want to attend family gatherings.					
42. Now he has better relationship with his brothers and sisters.					
43. Now he has better relationship with his elderly relatives.					
44. Now he can easily make friends.					
EDUCATION					
45. He can keep up well with the other children at school.					
46. He is still unable to cope with mainstream schooling.					
47. I am concerned about his future education.					
48. I need advice from the implant center concerning his future.					
SERVICE OF THE IMPLANT CENTER					
49. The implant center provided sufficient information about the surgery.					
50. The implant center provided sufficient information about the implant use.					
51. The implant center can handle any problem regarding implant.					
52. The implant center and the rehabilitation center should cooperate.					
53. Implant center should give suggestions about my child's future.					
54. The teachers should contact the implant center in order to provide the best for my child.					
GENERAL					
55. He is used to his implant he cannot give up.					
56. I can let my child play outside since he can hear the traffic and other sounds.					
57. He can hear me when I call out to him.					
58. My child has difficulty in getting used to the implant.					

Comments:

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Thank you for taking the time to complete this questionnaire.

Figure 1. Parents' Perspective Questionnaire is composed of 11 subscales and 58 questions in total.

Before beginning the questionnaire, all the necessary information was provided to parents, with a letter that was mailed with the questionnaire, or face-to-face during their visit, and they were encouraged to declare their child's situation before and after the implantation.

In ANSD, where quite variable cochlear implant performances were observed, the data related to the quality of life and satisfaction of patients were evaluated by comparing the subgroups. For a better statistical evaluation of children, PPQ subscales were compared in relation to age at implantation and the duration of implant use.

Statistical Analysis

The Statistical Package for the Social Sciences software version 24 (IBM Corp.; Armonk, NY, USA) was used to perform statistical analysis. All parameters were defined as the mean±standard deviation, median (min-max) and percentage. The Mann Whitney U test was used to compare the differences between groups. Multiple comparisons were conducted with the Bonferonni test. The Kruskal-Wallis test was performed for the analysis of continuous dependent variables. A value of p<0.05 was considered statistically significant.

RESULTS

A total number of cochlear implantations performed in the cochlear implant center from January 1, 1997 to May 1, 2017 was 2110. Among these 2110 patients, 28 pediatric patients with the diagnosis of ANSD were implanted. Two patients were not included into the present study; 1 for not replying the questionnaire and the other due to the short follow-up time, which was shorter than 1 year. Also, the patients that were not using their implants constantly were planned to be excluded from the study.

The average age of 26 patients (14 female and 12 male) at the time of study was 10.91±3.85 (4.3-17.3) years. The age at implantation ranged between 14 months and 80 months (median; 35.65±20.03 months).

The possible etiologies of ANSD in these 26 patients were investigated and determined as follows: 9 patients had a history of consanguineous marriages with no genetic syndromes, 4 had as newborns infections that required hospitalization, 3 had a history of kernicterus, 4 of them were premature and 3 had a history of neonatal intensive care unit hospitalization with various etiologies. There were no obvious reasons for ANSD in the remaining 3 patients. One of the patients with a history of intensive care unit hospitalization had moderate mental retardation and autism.

Before the implantation, 10 of the children had been attending the rehabilitation center for 2 or 3 hours per week, where they received educational support, and 4 children were attending to the rehabilitation program of our implant center. The remaining 12 children did not undergo any special rehabilitation before surgery. All children continued their ongoing education after the implantation and they used their implants constantly. When the study was conducted, 14 of 26 children were attending to primary school, and 6 patients were attending to high school. Six of them were still at preschool age and 5 of these kids were attending in kindergarten with normal hearing kids. Children who attended school were slightly more self-confident than those who did not, but the difference was not statistically significant (p>0.05).

The data of PPQ were analyzed using descriptive analysis. We also analyzed PPQ scores in terms of the duration of use the implantation and the age in the implantation time. There was a statistically significant difference in the subscale of communication in the comparative analysis between the age at implantation and PPQ (p<0.024). (Table 1) No statistically significant difference was found in the other subscales.

When the correlation between the duration of implant use and PPQ was analyzed, we found that the self-confidence (p=0.036) and social relationship (p=0.031) subscales values were significantly different (p<0.05) (Table 2). In terms of the implant usage time, children, those who had used their device for more than 6 years, displayed a better

Table 1. Effect of the age at implantation on Parents' Perspective Questionnaire

	Age at Implantation Mean±Standard deviation med (min-max)			p
	< 24 months	24-48 Months	>48 months	
	Mean±SD	Mean±SD	Mean±SD	
Decision for implantation	17.5±3.78	17.27±5.82	16.8±2.68	0.865
Process of implantation	23.4±5.6	23.55±5.24	22.2±3.96	0.667
Positive effect of implant	13.6±2.99	10.73±3	10.2±2.95	0.079
Support	9.2±2.53	7.36±2.29	9±4.06	0.272
Communication	12.9±2.47	10.64±3.29	11±2.55	0.024
Self - confidence	7.3±3.02	9.64±5.45	8.6±2.07	0.413
Well-being and happiness	7.4±2.27	6.45±1.97	6.6±1.52	0.652
Social relationship	9.4±2.12	11±6.24	7.6±2.19	0.268
Education	10.1±2.88	11.64±3.2	9.6±3.58	0.223
Clinical	9.9±3.03	7.27±2	10±5.15	0.086
General	9.1±0.99	8.27±1.74	8.4±0.89	0.059

* For the calculation of scores, numerical values were rated for each answers ranging from 1 to 5: strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

Table 2. The effect of duration of using the implant on parents' perspective questionnaire

	Duration of Implant Use			p
	1-6 years	6-10 years	>10 years	
	Median (Min.-Max.)	Median (Min.-Max.)	Median (Min.-Max.)	
Decision for implantation	19 (10-23)	17 (15-32)	15 (8-23)	0.499
Process of implantation	24 (9-28)	23.5 (22-28)	28 (16-28)	0.667
Positive Effect of implant	10 (5-18)	12.5 (11-15)	11 (7-18)	0.377
Support	9 (5-14)	8 (5-12)	7 (5-12)	0.698
Communication	10 (4-15)	12 (7-17)	13 (6-14)	0.873
Self - confidence	7 (5-23)	6.5 (5-11)	9 (5-14)	0.036
Well-being and happiness	7 (4-11)	7 (4-9)	7 (4-8)	0.347
Social relationship	7 (6-27)	10 (6-13)	8 (6-17)	0.031
Education	11 (4-13)	11 (4-13)	12 (8-16)	0.049
Clinical	7 (6-17)	9 (6-11)	6 (6-17)	0.621
General	8 (6-13)	9 (8-11)	8 (7-10)	0.073

*For the calculation of scores, numerical values were rated for each of the answers ranging from 1 to 5: strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

1. The first week before and after implantation were stressful.
2. I was so relieved when my child reacted to sound for the first time.
3. He was very dependent on us before implantation.
4. He acts as independent as his peers.
5. I seldom let him alone to do something before implantation.
6. Now I let him do something on his own.
7. He was socially isolated before implantation.
8. Parents stated that their children became more talkative and became more eager to involve in the conversations.

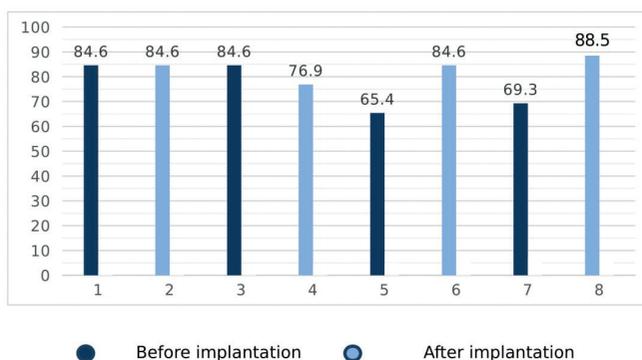


Figure 2. Highlights according to data from the Parents' Perspective Questionnaire.

performance in self-confidence and social relationship compared with children who had used their device for less than 6 years. No correlation between other variables and PPQ was found.

Parents' Perspective Questionnaire

Decision for implantation

Of the parents who answered the questionnaire, 84.6% said they were under extreme stress during the preoperative period and the first week after surgery. Also, 84.6% of these parents stated that they were extremely satisfied when their children responded to their voice for the first time (Figure 2).

Implantation duration

According to the questions related to implantation duration, 92.3% of parents thought it was useful to communicate with the other fam-

ilies who had children with cochlear implants. The same number of parents believed that before the implantation, families should get as much information and advice as possible. All parents said that all of the children were constantly using cochlear implants.

Effect of implantation

As for the effect of implantation; 65.4% of parents believed that their children would have a better position later in business life in the future after undergoing implantation. 69.2% of the parents stated that they were worried about any possible failure of the implant device.

Support

90% of parents thought that their children would not need help when they grow up.

Communication

After the cochlear implant operation, 76.9% of the parents reported that pronunciation of their children was better than they had expected. Before the cochlear implant operation, 92.3% of parents stated that they believed the pronunciation of their children would be better than it used to be after the implantation. After cochlear implant surgery, 80.8% of parents reported that they were able to speak with their children even if they were out of sight.

Self confidence

All parents, except one, reported that the self-confidence of their children increased after implantation. While all parents reported that their children were dependent on them more than their peers, 76.9% of parents reported their children became independent like their peers after implantation. Furthermore: 65.4% of parents did not allow their children to do any work by themselves before implantation, whereas 84.6% of parents allowed them to do it after implantation.

Well-being

While 84.6% of parents stated that their children became calmer compared with the period before implantation, 11.5% of parents

reported that their children were still nervous. 80.1% of parents observed that their children extremely enjoyed listening to music, watching television or playing after implantation.

Social relationships

Most of the parents stated that their children were introvert and socially isolated before implantation; however 92.3% of the parents observed that their children tended to attend family gatherings and activities and became more talkative after implantation (Figure 2). Moreover, 92.3% of the parents reported their children had better relationships with their siblings, family members and friends after implantation (Figure 2).

Education

After the cochlear implant, 80.8% of the parents stated that their children were able to achieve the same success rate at school as other children who had no hearing problems. Also, 69.2% of the parents reported that the children adapted well to the same school like the other normal children.

Service of the implant center

Of the parents, 80.7% considered that they were given comprehensive information by the implant center. 92.3% of the parents believed that, if the device failed, implant center would overcome the trouble.

General

All parents, except one, stated that their children never gave up putting on their device after implantation. Although the child with mental retardation was not using his cochlear implant continuously, he was putting on his device at least 6 hours a day. On the other hand, 88.4% of the parents reported that they allowed their children to spend time in and out because they could already hear.

DISCUSSION

Cochlear implants, which are regarded as the ideal treatment approach for patients with severe to profound sensorineural hearing loss, provide improvement in language and speech skills by overcoming neural dissynchronization of the patients with ANSD^[14]. Therefore, the patients with ANSD could benefit from cochlear implants as much as the other suitable candidates with different etiologies. There are numerous published studies, in which children with ANSD are matched with non-ANSD children in terms of auditory thresholds after the cochlear implant^[15]. In most of these case comparisons, the reported progress of the children was almost similar to non-ANSD children who were matched^[16].

Budenz et al.^[17] compared 26 patients with ANSD to the same number of their peers with non-ANSD and, they reported that there was no significant difference in speech perception scores between the 2 groups after the cochlear implantation. Therefore, significant improvement could be expected in the quality of life of the patients with ANSD after the cochlear implantation.

It is quite important to evaluate the changes in the quality of life after the cochlear implantation for determining the effective treatment in patients with hearing loss. It is a known fact that the attentive parents perfectly reflect the improvement process of the child with the implant and the changes of the quality of life after implantation.

Therefore, Archbold et al.^[8] developed *The Children with Cochlear Implants: Parental Perspectives Questionnaires* for evaluating the quality of life in children with cochlear implants. These questionnaires are so validated and reliable questionnaires that different versions have been used for research and clinical studies in numerous cochlear implant centers worldwide^[18-23].

Damen et al.^[24] in their study including 7 children with Usher syndrome used a hearing-specific quality of life questionnaire (The Nijmegen Cochlear Implant Questionnaire). They reported that the cochlear implantation was more beneficial compared with the former hearing aids.

Most of the studies on the efficiency of cochlear implants have focused on clinical assessments (hearing and speech improvement and auditory thresholds)^[25-27]. However, these measurements remain unsatisfactory for the evaluation of results of the cochlear implants in the patients with ANSD, who have inconsistent auditory thresholds. Evaluating the quality of life and improvement progress of the child after implantation may lead to a better guidance and motivation for the patients.

Unfortunately, the groups involved in the studies measuring the quality of life after cochlear implantation are not only crowded but also the individuals composing the groups are heterogeneous in terms of etiology, comorbidity, and general health as well as containing insufficient number of patients if focused on a specific etiology. Accordingly, it becomes difficult to determine the quality of life and satisfaction of the patients.

Naturally, the parents of children with hearing loss would like their children to become hearing individuals. Nevertheless, they experience difficulty in giving the decision regarding implantation. Incesulu et al.^[13] published their findings on 27 pediatric patients with cochlear implant by using the Parents Perspective Questionnaire. They reported that the decision making was the most challenging period during the cochlear implantation. Similarly, our study has determined that the difficulty of the implant decision lead the parents to research internet or social networks in order to gather information. Moreover, they look forward to having more discussions with other parents who have a child with hearing loss. In this respect, the staff of the cochlear implant center should manage and direct the parents who have difficulty deciding about implantation.

Providing an effective support may not only decrease the anxiety of the parents within the first few weeks in the preoperative period but also it may prevent unrealistic expectations of the parents such as speech understanding and language development in a very short time. Parents are often impatient with their speech understanding and language development. Hence, being impatient may lead them to have worries related to the progress of the child. Yet, the worried parents will be relieved when they notice the advancement of their children in speech and language skills in the course of time.

The important indicators regarding the efficacy of cochlear implantation for the parents are self confidence and social relationships. Almeida et al.^[28] published a study including 15 pediatric patients with a cochlear implant by using the Children with Cochlear Implants: *Parents Perspective Questionnaire*. In the study, they stated that it had

a positive effect on the quality of life and that this effect was more remarkable with regard to self confidence and social relation. In our study, parallel to these results, all parents, except for one, reported that their children increased the self-confidence and became more enthusiastic to get involved in conversations and more talkative in social relations. Additionally, they stated that cochlear implantation proved major contribution to the education and communication abilities.

The results of our study showed that the duration of implant use had positive effects on communication, education, self-confidence and social relationship of children. Furthermore, the parents were more satisfied in terms of self-confidence and social relations development of their children after implantation and, these subscales had significant correlations. Certainly, it is not possible to associate the PPQ with traditional auditory threshold outcomes, however, it can provide valuable information in assessing the development of the child.

An important question is whether the decision making time for the implantation of ANSD patients has an impact on the progress of speech and language development. We analyzed the possible correlation between PPQ and age in implantation to evaluate this question and, as a result, a statistically significant correlation was found between the communication subscale and age in implantation, namely; communication skills were better in patients after implantation. We believe that patients with ANSD should be assessed in detail to avoid unnecessary cochlear implantation, but also, if implantation is necessary, it should not be delayed to prevent an impair on speech and language development.

It is not surprising that parents encourage their children to use the cochlear implant which benefit was proved. However, the cochlear implant is an electronic device and can cause the family to worry about possible damage of the device in the future. Therefore, the parents will continue to demand help from the cochlear implant center regarding the technical support and maintenance of the device. The constant involvement of the parents providing the connection between the child and the cochlear implant center is quite important for the child's progress, as the cochlear implant is a long lasting treatment, which requires patience.

CONCLUSION

Although many different results have been achieved due to various etiologic factors of the hearing loss, cochlear implants, generally provide a positive effect on the quality of life by producing speech understanding and language improvement. In addition, the change observed in the life of a child with a cochlear implant is noticed remarkably by his or her parents. Nonetheless, these parents are usually impatient regarding the progress of the child. Also, they experience a great hesitation when deciding about the implant. In terms of the points mentioned above, the staff in the implant center should overcome many tasks and take responsibility to provide more support for the child and the parents. Questionnaires that evaluate the quality of life after implantation are considered quite useful for guiding the parents.

Ethics Committee Approval: Ethics Committee Approval was received for this study from the Ethics Committee of İzmir Bozyaka Training and Research Hospital (06-12-2016 /02).

Informed Consent: Written informed consent was obtained from patients' parents who participated in this study.

Peer-review: Externally peer-reviewed.

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