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Original Article

Quality of Life in Pediatric Cochlear Implantations

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OBJECTIVE: To evaluate the satisfaction of patients with a cochlear implant using a Parents' Perspective Questionnaire and analyze the significant parameters.

MATERIALS and METHODS: Patients who received a cochlear implant in Çukurova University between March 2002 and November 2012 were included in the study. Parents were asked to answer the Parents' Perspective Questionnaire.

RESULTS: The age ranges of 62 patients were 2–5 years and of 99 patients were 6–11 years and over. In total, 144 parents were satisfied with the cochlear implant. Patients who attended school had more self-confidence, and users of an implant aged over 18 months had better social relations and self-confidence.

CONCLUSION: Cochlear implants' positive effect on the quality of life is a fact, but parents have concerns in the preoperative and postoperative periods. Patients and parents should be informed carefully about cochlear implants. Also, patients' satisfaction is correlated with increasing duration of the implant and age.

KEYWORDS: Cochlear implantation, bilateral sensorineural hearing loss, quality of life scale

INTRODUCTION

Cochlear implantation has become a routine surgical procedure in the management of serious hearing loss. There are 188,000 cochlear implant users worldwide [1]. In Turkey, although there are no certain data, it is estimated that 9000 cochlear implant operations have been performed in the last 20 years.

Most national and international studies emphasize results in speaking and hearing [2-4]. However, the social status, the reading ability and academic success of children, and the listening and speaking ability of adults have been evaluated in recent studies.

There is an increasing interest in complementary studies about the quality of life of pediatric and adult cochlear implant users. In Turkey, cochlear implantation is gradually increasing, and there have only been a few studies about the quality of life in adults; also, there has been no specific study of pediatric patients in this area.

In this study, we aimed to investigate the quality of life in pediatric patients using a Parents' Perspective Questionnaire.

MATERIALS and METHODS

In total, 161 pediatric patients with total prelingual sensorineural hearing loss who underwent cochlear implantation in the Department of Otorhinolaryngology, School of Medicine, Çukurova University between March 2002 and November 2012 were included in this study. The study was performed after approval from the local ethics committee of Çukurova University, Adana, Turkey. Patients were informed about the study and approved the study. The age range of patients was 2–18 years. Prelingual congenital deafness with normal physiatric and neurologic status and normal radiologic findings were selected as the inclusion criteria for this study. All patients were followed up for at least 6 months after implantation, and all of them use their device regularly with systematic education. Parents were asked to answer the Parents' Perspective Questionnaire, which was translated into the Turkish language with proven reliability [5, 6]. This questionnaire was designed with 11 subscales and 58 questions in total (Figure 1). All questions were numbered from 1 to 5: (1, strongly agree; 2, agree; 3, neither agree nor disagree; 4, disagree; and 5, strongly disagree). Missing answers were scored as 0. Also, the validity of the questionnaire was supported by the use of negative questions.

Statistical Analysis

Statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) v 20.0 software (IBM Corporation; Chicago, IL, USA). All data were tested for conformity to normal distribution. An independent samples t-test or one-way analysis of variance was performed for the analysis of normally distributed continuous variables. A Mann–Whitney U-test and a Kruskal–Wallis test were performed

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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. Summary of the results of the questionnaire (The results only show the percentage of parents who stated "strongly agree" and "agree.")

for the analysis of non-normally distributed continuous variables. A chi-square test was used for the analysis of categorical variables. The results were expressed as mean±standard deviation, median (min–max), n, and percentage. A value of $p<0.05$ was accepted as statistically significant.

RESULTS

In this study we posted questionnaires to 300 patients with total prelingual sensorineural hearing loss who underwent cochlear implantation in the Otorhinolaryngology Department, Çukurova University School of Medicine between March 2002 and November 2012. However, only the 161 patients who replied to our questionnaire were included in the study. There were 20 patients between 2 and 3 years old, 42 patients between 4 and 5 years old, 75 patients between 6 and 11 years old, and 24 patients between 12 and 18 years old.

In terms of device usage, 13% of patients used their device for less than 11 h/day, but 87% used theirs for more than 11 h/day. In addition, time since implantation was less than 18 months for 78.89% of patients, whereas this was more than 18 months in 21.11% of patients.

Seventy patients only received special education (43.5%), 13 patients attended kindergartens (8.1%), 63 patients attended primary school (39.1%), and 15 patients attended high school (9.3%).

Twenty-one patients spoke Arabic (13%), 25 patients spoke Kurdish (15.5%), and 115 patients spoke Turkish (71.4%) at home.

On the "Implantation Decision" subscale, 93.1% of parents stated that the preoperative period and first weeks after surgery were extremely stressful. However, 93.2% of parents stated "I relaxed when I realized first response of my child to my voice." According to these data, 90.1% of parents remarked that they needed more information and recommendations before the surgery, 81.3% of parents had problems with transportation to the implantation center, and 78.3% of parents stated that sign language may have been helpful after implantation for verbal communication for a period. On the "Implantation Effect" subscale, 86.9% of parents stated that implantation would be beneficial for their children to find a job in the future. On the "Support" subscale, 94% of parents stated that speaking was easier than sign language during communication. On the "Communication" subscale, 71.5% of parents stated that communication was still a problem with people with normal hearing, even though they were aware of their child's

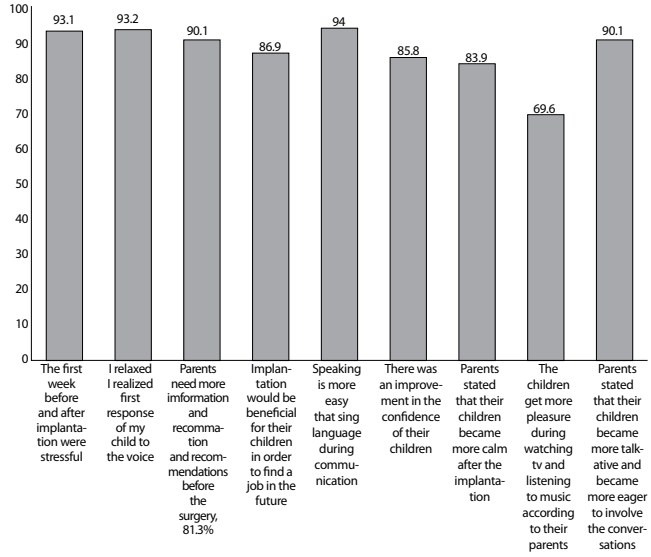

Figure 2. Parents' perspective questionnaire

disability. After implantation, 76.4% of parents stated that the pronunciation of their children improved more than they had estimated. Also, 79.5% of children were able to speak with their parents even if they did not see them. On the "Self Confidence" subscale, 85.8% of parents stated that there was an improvement in the confidence of their children. Also, 84.5% of parents stated that their children became independent to a similar degree to most of their fellows. On the "Feel Good" subscale, 83.9% of parents stated that their children became calmer after implantation, and 69.6% of children got more pleasure while watching TV and listening to music, according to their parents' statement. On the "Social Relationship" subscale, 90.1% of parents stated that their children became more talkative and more eager to get involved in conversations. Also, 85.7% of parents stated that their children became more sociable in familial relations, and 88.2% of children could make friends more easily with non-family members, according to their parents' statement. On the "Education" subscale, 57.2% of parents stated that in spite of using their device, their children still had problems in attending regular schools. Also, 75.1% of parents stated that they were worried about their children's educational life, and 93.8% of parents remarked that the implantation center should give information about the future life of their children. On the "Clinical Support" subscale, 79.5% of parents stated that the preoperative information that was provided at the hospital was sufficient, and 80.2% of parents believed that the implantation center could solve the problems related to the device. Also, 92.2% of parents stated that schoolteachers should contact the implantation center in order for them to react correctly. On the "General" subscale, 89.5% of parents stated that after getting used to the implant, their children could not give it up, and 79.5% of parents stated that they could easily give their children permission to play outside. Also, 86.9% of parents stated that their children could easily hear when they were called (Figure 2). We compared children's school educational status using subscales. Children who attended school were more self-confident than those who did not (p=0.026), but there were no other differences on other subscales. In terms of implant usage time, children who had used their device for more than 18 months displayed better performance in self-confidence (p=0.005), feeling good (p=0.034), social communication (p=0.004), and education (p=0.014), with significant differences compared with children who had used their device for less than 18 months (Table 1).

DISCUSSION

Internationally published studies that relate to quality of life after cochlear implantation are gradually increasing in the literature [7-9]. Cochlear implantation has been performed for more than 20 years, and we estimate that there are approximately 9000 users in Turkey. A study that was published in 2001 and conducted by Incesulu et al. [10] showed that adults with cochlear implants displayed better performance in satisfaction, self-confidence, communication, emotional status, and concentration, with significant differences. The Parents' Perspective Questionnaire, which is used in the Nottingham Paediatric Cochlear Implantation Programme, was adjusted to the Turkish society and used in a study in 2003, in which 27 children with pediatric cochlear implants and their parents were investigated satisfactorily. At the end of the study, the most stressful period was found to be the decision period, and the children showed better social communication and self-confidence after the operation. As a result, this questionnaire should be used in cochlear implantation centers and might give important feedbacks for implantation centers [6].

In this study, 93.1% of parents stated that the perioperative period and first postoperative weeks were very stressful. Also, 93.2% of parents stated that "I relaxed when I saw the first reaction of my child to my voice." Quittner et al. [11] reported that periods of stress continued after the operation at high levels because the demands of the children continued. Some problems gradually increased, such as communication problems and behavior problems in children. Spahna et al. [12] compared persons with normal hearing and users of cochlear devices. Psychological stress and expectations from the treatment were higher in parents of cochlear implant users, using familial psychological parameters. Parents of cochlear implant users participated in the study more than the other group because these families were more involved with the clinics. Parents of cochlear implant users obtained information mostly from the media and Internet about the process. According to this study, cochlear implantation centers should improve patient education.

In the literature, Edwards et al. [13] prepared a questionnaire that consisted of 22 questions and applied this questionnaire to parents of children with cochlear implants. They reported that cochlear implantation had a positive effect on the quality of life, communication abilities, and freedom. Tavares et al. [14] also reported that cochlear implantation had a positive effect on the quality of life by presenting a questionnaire to 10 parents of patients . Thoutenhoofd et al. [15] and Frank et al. [16] concluded that studies on the quality of life have variable parameters such as age at implantation and duration of the cochlear implant that make these studies more heterogeneous, which was described as a handicap in obtaining objective results. They reported that studies conducted among children with similar implant durations and age at implantation may give more effective results. In our study, children with cochlear implants were subdivided into pre-school (ages 2–5 years) and school (ages 6–18 years) groups. Self-confidence and social communication were statistically significantly higher in older children.

Allen et al. [17] reported that cochlear implantation improved language development, and effective results could be achieved at ap-

Table 1. Effect of duration of usage of cochlear implant

	Duration of implant Mean±standard deviation med (min–max)		
	<18 months	>18 months	p
Decision for implantation	10.74±5.59 8.5 (7–29)	9.87±3.96 9.0 (7–27)	0.307
Process of implantation	13.06±5.38 11.0 (8–30)	13.55±6.04 11 (8–35)	0.667
Positive Effect of implant	8.85±3.58 8 (5–22)	8.57±3.66 8 (5–21)	0.693
Communication	9.59±4.16 8 (5–23)	9.22±3.98 8 (5–23)	0.637
Self-confidence	10.12±5.32 8 (5–25)	8.02±3.35 7 (5–19)	0.005
Well-being and happiness	6.53±3.49 5 (3–15)	5.33±2.72 4 (3–15)	0.034
Social relationship	10.79±5.94 9 (6–30)	8.54±3.29 7 (6–24)	0.004
Education	9.15±3.73 8.5 (4–18)	7.60±3.06 7 (4–16)	0.014
Clinical	9.85±4.59 8 (6–21)	9.33±4.41 8 (6–27)	0.545
General	7.44±3.47 6 (4–19)	6.52±3.15 5 (4–15)	0.141
Total	96.12±35.02 86.5 (57–210)	86.46±26.38 80 (56–200)	0.080

For the calculation of scores, numerical values were assigned to each of the answers ranging from 1 to 5: 1, strongly agree; 2, agree; 3, neither agree nor disagree; 4, disagree; and 5, strongly disagree. Missing answers were scored as 0.

proximately 3 years after the operation. However, studies measuring hearing performance reported that effective results were achieved at 18 months. In this study, self-confidence, feeling good, social communication, and education were better in children who had used implants for longer than 18 months, with a significant difference.

Huttunen et al. [18] observed that the most satisfying results were improvements in social relations, communication, and speaking and general functional improvements. This study applied to 36 families, whose children underwent the operation at 2 years of age after a recovery period of 2–3 years. Calderon [19] emphasized that the most important factor in the follow-up and control of children by healthcare providers was their family. Thus, the perspectives of families should be evaluated effectively.

In conclusion, the positive effect of cochlear implants on the quality of life is a fact, but parents have concerns at the preoperative and postoperative periods. Patients and parents should be informed carefully about cochlear implants. Also, the satisfaction of patients is correlated with an increasing duration of the implant and age.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Çukurova University/Adana.

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

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