

# A Comprehensive Analysis Research on Information, Expectations and Satisfaction of Parents of Children with Cochlear Implant

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## Abstract

**Objectives:** The aim of the study was to analyze information, expectations and satisfaction of parents of the children between 1 and 12 years of age who had hearing loss and cochlear implantation (CI) without any additional disability.

**Methods:** 111 parents (mother and father) having children between 1-12 years who did not have any disability other than hearing loss and had cochlear implants were included in the study. "Family-Child General Information Form" and "Information and Expectation Evaluation Questionnaire for Families Having a Child with Cochlear Implant" were used.

**Results:** As a result of our research, main source of information for the parents who use many information resources about cochlear implant was audiologists (63.1%) and ENT doctors (40.5%). It was observed that the specialist who can guide and help in cochlear implantation procedures was audiologists (51.4%) and ENT doctors (38.7%). Also, at the end of the study, satisfaction level of the parents and children about cochlear implant was found high.

**Conclusion:** Although the parents find the information before cochlear implantation sufficient, training about cochlear implant device and more detailed information about the procedure may affect their expectations after the implantation. We believe that our study would help to detect information and expectation states of the parents about cochlear implantation, to understand needs and expectations of the parents better and develop the services provided to the patients and their family during different stages of cochlear implant process.

**Keywords:** Children; Cochlear implant; Parent; Information; Expectations; Satisfaction

## Introduction

When children are diagnosed with loss of hearing, parents tend to enter a process of unexpected and unfamiliar intervention. During this process, the parents deal with various negative emotions such as anxiety, fear, shock, sadness, panic and bereavement [1-3]. Studies have indicated extremely challenging experiences during the implantation and regular use of hearing aid, conduction of auditory-verbal educational activities at home and necessity of cooperation with specialists during this process [2,4-8]. Despite the necessity of getting urgent interventions following diagnosis of hearing loss, parents seem to have difficulties in seeking the appropriate centres and specialists [9,10]. It has also been reported that paediatricians, who are generally the first group contact with the babies, may have an insufficient level of knowledge on informing the parents about hearing loss and Cochlear Implant (CI) applications [11-13]. It is demonstrated in the study that an obligatory and extensive mechanism of addressing issues concerning the nature and characteristics of the disability and the intervention, as well as requirements for the process of intervention is required [14,15].

CI process starts a new phase in which complicated emotions such as anxiety, hope and excitement that are experienced by the parents are described following the diagnosis [7,8,10]. One of the common study findings indicates that when the parents are given the appropriate information about the process involved in every phase, they can meet the requirements of the process more easily [10,16-21]. Some findings indicate that when the stress level of the parents decreases, they can make informed decisions much more easily, giving credit to the process informing the parent [10,16,17,19,20]. Similarly, the results of this research indicate that proper information on the process is extremely crucial because it guides the parents and makes them ready for the experiences in the forthcoming process. Important to note is that certain situations may create difficulties for the parents during the process. These challenges may include; overlapping of the decision-making and candidate evaluation phases, referral of the parents via specialist opinions during the decision-making phase, different opinions of the specialists in referral procedures, the presence of open-ended criteria, complications that may develop during surgery. Other challenges include; programming problems of the device, obligatory attendance to the auditory-verbal education by the parents, the presence of different approaches in auditory-verbal education, possible technical problems of the device. The financial burden of the device due to lack of inadequate allocation of resources by the government

can also affect the different phases of the CI process. Despite all these challenges, the parents seem to prefer surgery to provide a good future for their child [10,20].

The concept “expectation” evaluates the hope and thoughts of the parents concerning how CI application will contribute to the development and future life of their child [8]. The parents define their expectations as one of the most significant factors bringing the advancement of the CI process into a certain state [10]. Researchers emphasize that one of the fundamental responsibilities of the specialists involved in the CI process is to help the parents determine their realistic expectations by effectively informing and offering consultation to them [8,22-24]. When proper guidance is not provided by the specialists, realistic expectations are not formed thus leading the parents to experience a great disappointment [2]. Evidently, the disappointment experienced negatively affects the emotional participation of the parents [2,8,25]. One of the most important factors determining the development of a child with hearing loss is active participation of the parents in auditory-verbal education [13,16,20,26-29]. According to the study results, parents with high but realistic expectations prior to CI participate more intensively in educational activities to support the development of the child [10,26]. They believe that hearing loss is only a medical issue and CI application will resolve this issue causes the parents to have unrealistic expectations. The expectation that a child will hear and speak “normally” after CI application also influences psychological and cognitive processes of the parents [3,8,19,25,26,30]. Studies have revealed that in CI applications, the expectations of parents are fundamental to provide their child with a development which is consistent with that of their normal-hearing peers and to attend a normal school for their education as well as live a self-sufficient life. In addition to having a good and pleasant future for their child, the parents must meet all requirements of the CI process in order to achieve what they want. The first condition for them to achieve this is to have knowledge about characteristics of the CI process, the progression of the phases, their interrelations and their roles during this process [7-10,16,21,31-33].

In the light of this information, it is aimed to have knowledge about knowledge and expectations on CI of the parents of the children who are aged between 1-12 years, without any disability other than hearing loss and for whom cochlear implantation was applied, and to develop services and supports before and after cochlear implantation surgery in line with this information.

## Methods

The study started following decision No 99950669/87, which was found to be consistent with ethical and scientific principles, made in the meeting dated 09. 03. 2016 and No 2016/03 of Faculty of Medicine Ethics Committee in Clinical Trials. 111 parents (mother and father) having children between 1-12 years who did not have any disability other than hearing loss and had cochlear implants were included in the study. 95 (85.6%) of the parents were mothers and 16 (14.4%) were fathers with an age range of 21 and 51. Parents included in the study were randomly selected, regardless of their gender, educational and socio-economic status. Before starting the study, “Informed Voluntariness Form” which described the content of the study was signed by all parents and consents of the parents who accepted to participate in the study were received by providing “Volunteer Approval Form”.

In our study, “Family-Child General Information Form” and “Information and Expectation Evaluation Questionnaire for Families Having a Child with Cochlear Implant” were used as a data collection tools.

“Family-Child General Information Form” comprised of 30 questions which include demographical variables of the children and their parents. The first 19 questions were prepared for children, whereas the remaining 11 questions were for the parents.

“Information and Expectation Evaluation Questionnaire for Families Having a Child with Cochlear Implant” is the questionnaire that evaluates the parent’s knowledge and expectations on cochlear implants. It comprised of questions concerning pre- and postoperative period. Questions in this questionnaire are placed in 4 categories. These include (1) data collection prior to cochlear implantation, (2) expectation outcomes following implant surgery, (3) data of the children and (4) data of the parents. Positive responses gathered from the questions of the questionnaire were scored as quite sufficient (1 points), sufficient (2 points), insufficient (3 points) and quite limited (4 points).

## Statistical analysis

Crosstabs were formed to determine the factors influencing knowledge and expectations of the parents. To determine whether there is no significant difference among the groups in terms of continuous variables, Independent Samples T-test was performed for 2-category variables and Oneway ANOVA test (unidirectional variance analysis) was performed for variables with 3 or more categories. In order to determine whether there is a significant difference among groups in terms of categorical variables, Chi-Square test was performed. For interpretation of results of all tests, as the level of significance p-value was determined to be 0.05. It was considered that when the p-value was lower than 0.05 there was a significant difference among the groups and when the p-value was higher than 0.05 there was no significant difference among groups. IBM SPSS (Statistical Package for Social Sciences) version for Windows Version 22.0 (IBM Corp.; Armonk, NY, USA) was used for entry of questionnaire data, the formation of tables and graphics, estimation of descriptive statistics and conduction of statistical tests.

## Results

### General information form variables

85.59% of the parents who participated in the questionnaire comprised of mothers and 14. 41% were fathers. It was determined in our study that 58 parents (52.25%) were aged between 31-40 years and 41 parents (36.94%) in the age range 21-30. The parents were asked about their educational levels and it was evaluated in 3 categories. It was determined that the educational level of 65 (58.6%) parents was primary school. When the working status of the mothers was examined, it was found that 102 mothers (91.89%) were housewives and the rest were working. The research classified the jobs of fathers in 6 categories. 44 fathers (39.64%) were self-employed, whereas 3 fathers (2.7%) were unemployed. In addition to these data, the income of 43 families (38.74%) was the minimum wage and of 17 families (15.32%) was below the minimum wage (Table 1).

Age groups	N	%
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<20 years	1	0.90
21–30 years	41	36.94
31–40 years	58	52.25
41–50 years	10	9.01
>50 years	1	0.90
Total	111	100
<b>Education Level</b>	<b>N</b>	<b>%</b>
Primary and secondary school	65	58.6
High school	33	29.7
University and higher	13	11.7
Total	111	100
<b>Occupation of fathers</b>	<b>N</b>	<b>%</b>
Unemployed	3	2.70
Retired	2	1.80
Officer	17	15.32
Self-employment	44	39.64
Worker	37	33.33
Other (building worker, driver)	8	7.21
Total	111	100
<b>Monthly income</b>	<b>N</b>	<b>%</b>
Below minimum wage	17	15.32
Minimum wage	43	38.74
2 times minimum wage	30	27.03
3 times minimum wage	13	11.71
4 times minimum wage	6	5.41
5 times minimum wage and/or >	2	1.80
Total	111	100

**Table 1:** Distribution according to age groups, education level, occupation of fathers and monthly income of parents.

In our study, the parents were asked whether they were experiencing cochlear implantation for the first time. The results indicate that of 86.49% (69 parents) of the parents were experiencing cochlear implantation the first time, while the rest of the parents had children who had previously undergone cochlear implantation surgery. When gender distribution of the children was examined, it was observed that 47.75% were male (53) and 52.25% (58) were female. Ages of the children were addressed in 3 categories. The highest number of children was included in the 5-12 age bracket which translates to 70.3%. Distribution according to the gender and age categories is presented in Table 2.

Gender	N	%
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Boy	53	47.75
Girl	58	52.25
Total	111	100
<b>Age Groups</b>	<b>N</b>	<b>%</b>
1–2 years	10	9.0
3–4 years	23	20.7
5–12 years	78	70.3
Total	111	100

**Table 2:** Distribution according to the gender and age categories of children with cochlear implant.

Ages of the children of whom hearing loss was diagnosed are addressed in 4 categories. The highest number of children was diagnosed with hearing loss at age of 0-6 months (56.8% 63 children). In the study, hearing loss of 107 children started mostly when they were between the age of 0 and 2 years with 96.4% (Table 3). Grades of hearing loss of children were evaluated in 2 categories, severe and profound. 31.53% of the children; (35 children) have a severe hearing loss, whereas 68.47% (76 children) have a profound hearing loss. Whether the children used hearing aid devices after hearing loss was diagnosed was examined. It was observed that 94.59% (105 children) used a hearing aid device while 5.41% (6 children) did not use a hearing aid. When ages of children at which a cochlear implant was inserted were examined, it was determined that 64 children (57.66%) underwent cochlear implantation surgery at age of 1-2 years and other children underwent cochlear implantation surgery after the age of 1 year. When the duration of use of cochlear implants by the children are examined, it was found that 41 children (36.94%) used their cochlear implants for 1-3 years, 13 children (11.71%) used for less than 1 year and other children used them for more than 3 years (Table 3).

Age Groups (age of diagnosis)	N	%
<6 months	63	56.8
7–11 months	16	14.4
1–2 years	26	23.4
3–4 years	6	5.4
Total	111	100
<b>Age of CI</b>	<b>N</b>	<b>%</b>
7-11 months	4	3.60
1-2 ages	64	57.66
3-4 ages	30	27.03
5-12 ages	13	11.71
Total	111	100
<b>Duration of CI</b>	<b>N</b>	<b>%</b>
>1 year	13	11.71
1-3 years	41	36.94

3-6 years	31	27.93
6 years and >	26	23.42
Total	111	100

**Table 3:** Distribution according to age groups, age of cochlear implant (CI) and duration of CI of children with cochlear implant.

### Information, expectation and satisfaction evaluation questions

In our study, knowledge and expectation evaluation questionnaire was divided into two parts namely; pre- and postoperative. Firstly, descriptive statistics, tables and graphics concerning the preoperative period were formed. Further, questions concerning the postoperative period were evaluated. Distribution according to the answers provided for the questions is presented in Table 4.

Questions	Yes		No	
	N	%	N	%
Did you obtain sufficient professional information prior to cochlear implantation surgery?	97	97.39	14	2.61
Did you obtain sufficient professional information about its effect on your child's hearing loss prior to cochlear implantation surgery?	96	86.49	15	13.51
Did you obtain sufficient professional information about effect of hearing loss on your child's speech and language development prior to cochlear implantation surgery?	99	89.2	12	10.8
Did you obtain sufficient professional information about effect of hearing loss on your child's general development and development of his/her skills (social, academic, psychological etc.) prior to cochlear implantation surgery?	75	67.57	36	32.43
Did you obtain sufficient professional information about hearing technologies (hearing aid, cochlear implantation FM systems etc.)?	85	76.60	26	23.40
Did specialists recommend a certain period of time for use of the hearing aid prior to cochlear implantation surgery?	74	66.67	37	33.33
Did specialists recommend hearing-speech-language therapy prior to cochlear implantation surgery?	91	81.98	20	18.02
Did you obtain sufficient professional technical (parts of the device, how it works, signal it irradiates etc.) about the surgery prior to cochlear implantation surgery?	85	76.58	26	23.42
Did you obtain sufficient professional information about effectiveness of cochlear implantation (development of hearing, receptive and expressive language development, speech comprehensibility etc.) prior to the surgery?	86	77.50	25	22.50
Did you obtain sufficient professional information about efficiency of cochlear implantation (hearing in a noisy environment, localization of sound etc.) prior to the surgery?	86	77.50	25	22.50
Did you obtain sufficient professional information about price of the cochlear implantation device prior to the surgery?	77	69.40	34	30.60
Did you make any payment for cochlear implantation surgery?	20	18.0	91	82.0
Did the payment you made for cochlear implantation surgery let you have financial difficulties?	17	85.0	3	15.0
Are you satisfied with the informing about cochlear implantation recommended prior to the surgery?	91	82.0	20	18.0
Did you need more information about preoperative procedures (e.g. Ease of the surgery, side effects of the surgery, duration of surgery etc.) prior to cochlear implantation?	69	62.20	42	37.80
Can your child communicate via lip-reading and sign language, as well as hearing?	60	54.10	51	45.90
Can your child communicate by using hearing together with lip-reading?	66	59.50	45	40.50
Can your child communicate by using only hearing?	85	76.60	26	23.40
Did advancement after cochlear implantation application meet your expectations in your child?	98	88.30	13	11.70
Have you ever observed participation of your child to domestic events after cochlear implant surgery?	85	76.60	26	23.40
Did the institution/university in which your child underwent surgery meet your all needs concerning the use of implant to the extent you desired?	105	94.50	6	5.50
Do you trust the implant vendor for technical support about the implant?	91	82.0	20	18.0

Were you informed by the specialists about conduction of periodical audiological evaluation for your child during the duration of use of cochlear implant?	102	91.90	9	8.10
Were you sufficiently informed by the specialists about new advancements in cochlear implant system?	63	56.80	48	43.20
Does your child need his/her implant all the time?	106	95.50	5	4.50
If you were brought back, would you again want your child to undergo to cochlear implant surgery?	110	99.10	1	0.90
According to you, what is your child's satisfaction level about cochlear implant?	Of the parents; 51.4% (N: 57) replied as very satisfied.			
According to you, what is your satisfaction level about your child's cochlear implant?	Of the parents; 52.3% (N: 58) replied as very satisfied.			

**Table 4:** Distribution according to the answers of postoperative information, expectation and satisfaction questions.

The parents were asked from which resource they obtained the information about cochlear implantation option. In this question, there are 12 different options, with the possibility of more than one choice. In this regard, it was observed that there was nobody who had heard about the cochlear implantation option from television, family physician or neurologists, whereas it was heard most commonly from audiologists (63.1%) and ENT doctors (40.5%). The parents, who needed more information about postoperative procedures (64.0%, N: 71) (e.g. Repeated hearing program, giving a promise for attending to the hearing-speech and language education program etc.) for them to decide to surgery prior to cochlear implantation, were asked about which issue they needed more information. This question was open-ended and 5 different categories were formed according to the answers the parents gave. These categories were hearing and speech training, process of hearing and speech development, usage of CI, maintenance and guarantee, postoperative procedure. The parents were asked about what specialists or institutions can guide and help you in cochlear implantation procedures. This question was open-ended and 10 different categories were formed according to the answers the parents gave. In this regard, it was observed that the specialist who can guide and help in cochlear implantation procedures was audiologists (51.4%) and ENT doctors (38.7%). (Special education institution: 9.0%, educational audiologist: 0.9%) The parents were asked about the school their child is studying. This question was replied by a total of 72 parents and they expressed that they were studying most commonly in schools for hard-of-hearing children. In the column on the far right, it expresses for how long the students studying in the relevant school have been studying in that school in average. For instance, there are 35 children studying in hard-of-hearing school an average of the duration during which these children have been studying is 3.04 years (Normal primary school: 2 years (N: 10), special subclass 2,46 years (N:27) and inclusion student in normal primary school:2,67 years (N: 72).

Self-confidence–Self-esteem	35 (%31.5)	55 (%49.5)	15 (%13.5)	6 (%5.4)
Music	14 (%12.6)	48 (%43.2)	39 (%35.1)	10 (%90.0)
Social	25 (%22.5)	67 (%60.4)	15 (%13.5)	4 (%3.6)
Behavioral	29 (%26.1)	68 (%61.3)	11 (%9.9)	3 (%2.7)
Contact	28 (%25.2)	62 (%55.9)	12 (%10.8)	9 (%8.1)

**Table 5:** Distribution of children according to acquire skills after cochlear implantation surgery

The parents were asked about which skills and to what extent their child acquired after cochlear implantation surgery. In this category, there were a total of 9 questions, asking a different skill in each question. Therefore, results according to each skill are demonstrated in the Table 5. Rows include types of skill and columns include response options. In cells, count of parents and their percentages are included. For instance, there are 42 children (37.8%) who acquired very sufficient level of hearing skills after surgery, whereas there are 5 children (4.5%) who acquired very limited level of hearing skills.

## Discussion

Paediatric cochlear implantation application is a process whose phases are all complicated for the parents. Therefore, informing the parents during each phase of this process is important [34-36]. During the cochlear implantation process, informing the families and providing consultation and education for them is a multidisciplinary process and it is well-known that multidisciplinary staffs including specialists such as ENT physician, medical surgery staff, psychologist, audiologist and speech therapists are required [37]. In the study, parents were found to be anxious about being informed about medical, educational, technical and communication issues [38]. Thus, among professional implant staff; speech and language pathologists, audiologists, surgeons, medical specialists, psychologists and trainers should be included together to inform and consult the parents [39]. One of the factors which will eliminate their worries and influences successful conclusion of cochlear implantation application was reported to be family education [40]. In the study, information on cochlear implantation most commonly learnt from audiologists (63.1%) None of the respondents said that they learned from television, family physicians or neurologists. In similar studies, families

Skill type	Very Sufficient	Adequate	Insufficient	Very Limited
Hearing	42 (%37.8)	58 (%52.3)	6 (%5.4)	5 (%4.5)
Language and Speech	23 (%20.7)	61 (%55.0)	21 (%18.9)	6 (%5.4)
Reading and Writing	21 (%18.9)	38 (%34.2)	43 (%38.7)	9 (%8.1)
Academic	16 (%14.4)	47 (%42.3)	38 (%34.2)	10 (%9.0)



gather information from communication channels such as media and news or from specialists and families of other children who have undergone cochlear implant surgery [19,36,41]. In a similar study, the majority (60%) of 60 mothers included in the study were determined to be informed by ENT physician. Furthermore, it was expressed that the families who had experience on cochlear implant surgery had more knowledge [37]. In our study, it was determined that 86.49% (96 people) of the parents experienced cochlear implantation for the first time, whereas other parents did not have children who had previously undergone cochlear implantation surgery [36]. According to the answers provided by the parents, it was understood that majority (80% and more) of the parents received sufficient professional information about effect of child's preoperative hearing loss, effect of hearing loss on child's speech and language development, effect of hearing loss on child's general development and development of skills (social, academic, psychological etc.), and hearing technology options (hearing aid, cochlear implantation, FM systems etc.) before cochlear implantation was performed. Of the parents participated in the study; 81.98% were recommended hearing-speech-language therapy prior to cochlear implantation surgery by the specialists, 76.58% received sufficient professional technical information (parts of the device, how it works, signal it irradiates etc.) about the surgery before the surgery, and in this regard, it was observed that they received most technical information from audiologists (35.1%). It was understood that they received sufficient information about effectiveness of cochlear implantation (development of hearing, receptive and expressive language development, speech comprehensibility etc.)(77.48%), efficacy of cochlear implantation (hearing in a noisy environment, sound localization) (77.48%), and price of the cochlear implantation device (69.37%). 82.0% of the parents expressed that they were satisfied with the informing about cochlear implantation recommended for their children prior to surgery. 62.2% (69 individuals) of the parents expressed that they needed more information about preoperative procedures (e.g. Ease of the surgery, side effects of the surgery, duration of the surgery etc.) prior to cochlear implantation. Additionally, 64.0% (71 individuals) of the parents reported that they needed more information about postoperative procedures (e.g. Repeated hearing program, giving a promise for attending to hearing-speech and language education program etc.) to decide to surgery prior to cochlear implantation. Parents (9.9%) reported that they needed more information about their child's hearing and speaking education prior to cochlear implantation. In a related study, the parents had great expectations for development in speech and hearing skills of their children after the surgery (97%). The parents thought that cochlear implant was the best choice for their child (98.3%). An appreciable relationship was determined among parental satisfaction with the decision for cochlear implant and expectation for development in literacy ( $p < 0.05$ ). The age at which hearing loss of a child was recognized substantially influenced post-implant expectations of the parents [37]. In our study, 51.4% of the parents thought that the specialist who may guide and help in cochlear implantation procedures was mostly an audiologist.

88.3% of the parents expressed that the advancement in their children after cochlear implantation application met their expectations and that they observed children's participation in domestic events (76.6%). 99.1% of the parents expressed that, if they were brought back, they would again want their children to undergo cochlear implant surgery. Of the parents; 51.4% declared that their children were very satisfied with cochlear implant and 52.3% declared that they were satisfied with their children's cochlear implants. 95.5% of the

parents gave the information that their children needed their implants all the time.

## Conclusion

In our study, satisfaction levels of both parents and children were determined to be high. In general, the parents found the informing before cochlear implantation surgery as sufficient, the status of being informed more extensively about education for the cochlear implant device and the surgery may influence their post-implantation expectations. In this regard, it is hypothesized that our study will be helpful in determining knowledge and expectation levels of the parents about cochlear implants. Related specialists will better understand needs and expectations of the families as well as development and support services to be provided to the patient and his/her family during different phases of cochlear implant process.

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