

Parent's Perception and Expectations from Cochlear Implants: Insights from a Government-Funded Cochlear Implants Program in Kerala

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Abstract

Introduction: Parental perceptions and expectations are the key determinants for optimal outcomes from cochlear implants (CI). This article explores the parental perceptions and expectations of very young children who are prospective candidates for CI. **Methods:** The participants of this study were 97 parents (63 mothers; 34 fathers). They completed a 40-item questionnaire which reflected the parents expected outcomes on the domains communication and social skills, academic achievements, future life, rehabilitation demands, satisfaction, stress, and professional relations. The questionnaire was administered during a group counseling session conducted for prospective CI users under the government-funded CI program in Kerala, India. The responses were descriptively analyzed to present the results. **Results:** The results reveal that parents kept high expectations on communication abilities, intelligible speech, language abilities, telephone conversation, mainstream schooling, reading-writing abilities, and secure future life after their children receive cochlear implantation. Ninety-six percent of parents strongly agreed on parental involvement, intense, and prolonged therapy for maximal benefit. About 52.3% of parents were dissatisfied with the present communication and social skills of their children. About 33.3% of parents felt stressed about the rehabilitation process, whereas 78% viewed rehabilitation as their responsibility. Decision-making on CI was difficult for 48% of parents because of differing opinions among professionals. **Conclusion:** Understanding parental perceptions and expectations will help the service providers to impart holistic habilitation strategies after cochlear implantation. Further documenting parental perceptions is important to correlate the future experiences and outcomes from CI.

Keywords: Cochlear implants, hearing loss, parental expectations, parental perceptions

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INTRODUCTION

Technological advancements in the field of biomedical science have paved way for the development of better habilitation opportunities for individuals with severe-profound sensorineural hearing loss. Cochlear implants (CI) were one such invention that had the power to provide sense of hearing, and had tremendous impact on the rehabilitation of children with severe profound hearing loss.^[1,2] These children have shown to have significant positive outcomes in various areas of auditory, speech, language, academic, social, and communication development ever since its invention. Even though the outcomes from CI are influenced by many child-related and audiological factors, parents play a vital role in the decision-making process.

Early identification and intervention of hearing loss in children have influenced/fast tracked the availability of CI as early as

possible in children receiving a diagnosis of bilateral profound hearing loss. This indeed makes the parents feel that they have limited time to decide on management.^[3] Parents usually have high expectations about the outcomes from CI, but they often decide without any guarantee on the improvement their children will show after cochlear implantation.^[4-6] Since CI are new, expensive, and high-tech, it ventures unrealistic expectations of being capable of bringing immediate changes in a child's auditory skills. This can limit the focus of parents on

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the postimplant re/habilitation process, which usually requires a long-term commitment.

Many variables need to be considered when evaluating young children for CI candidacy.^[7,8] There are standardized candidacy protocols which are being followed by the CI professionals before implantation, but some factors such as parental perception about hearing loss and their expectations from cochlear implantation are most often ignored. Researchers have predominantly used qualitative approaches such as interviews and open-ended questions to probe into parental perceptions, as they provide more information regarding the real-life situations.^[9-11] There are only few questionnaires developed specifically for studying the perceptions and expectations from CI.^[5,6,12-16]

A survey instrument developed by Zaidman-Zait and Most was used to study mothers' expectations regarding their children's cochlear implantation in Israel, focused on speech-related communication abilities, academic achievement, social skills, change in future life, and the rehabilitation process.^[6] Mothers in this study had high expectations with respect to their children's communication, social, and academic abilities after cochlear implantation. Similar methods have been adopted to study parent's expectations from children using CI in North India and result revealed parents having high expectations on all the domains studied.^[14]

Studies on the parental perceptions and expectations from cochlear implantation show that at younger ages, the process of informed decision-making is easier. Parents feel it important to have as much information as possible before implantation.^[15] The process of imparting information and educating parents before surgery is often done by a team of professionals and is always multi-faceted.^[17] The information given to parents should reflect the reality of experience, which is an insight for the professionals to apprehend how educational and informational processes provided before surgery change the parental perceptions and expectations.^[15] The perceptions of parents considering decision-making and the process of implantation are that parents' needs and experiences were very varied and may not conform to the expectations of others, including implanting teams. The finding from this study thus urges professionals to be cautious when engaging parents in the process and emphasizes the need for professionals to have appropriate training in counseling and parent education. Sharing other parent's experiences, perceptions, expectations, and outcomes are probably helpful for naive parents considering CI for their children. Therefore, knowledge about the family values and aspirations for their child can help clinicians guide parents through the decision-making process. It was also shown that the amount of time families need to process the information and make a decision varies and that practitioners should support families and not rush the process. Parents desired more comprehensive and bias-free information to assist their decision-making. Studies have also shown that all outcome measures were positively associated with parental perceptions of a child's developmental status and their expectations.^[14,18]

In the recent past, the number of younger children getting implanted has increased in developing countries like India due to Government-funded schemes. Even though there has been plenty of research on outcomes on speech perception, speech and language developments, academic performances and enhanced quality of life in children with CI, very little inquiry has been done into the parental perception on deafness and expectations from CI in Indian scenario. It is important to impart a holistic habilitation process of which parental informed decision-making and involvement are key components for a successful outcome.^[9,19]

The purpose of this study was to explore the perceptions and expectations of parents of young children who were prospective CI users in Kerala. This would help the professionals in acknowledging the factors pertaining to parent's hopes regarding their child's outcome and empowering them with up-to-date information on the efficacy of CI, and setting the stage for realistic expectations.

MATERIALS AND METHODS

Participants

Parents (63 mothers and 34 fathers) of 97 children who were prospective candidates for cochlear implantation were the participants of this study. The mean age of 97 children was 32.96 months (range = 12–60 months). All children were diagnosed with severe-profound hearing loss (with no comorbidities and structural malformations of the ear). They were fitted with hearing aids and attended at least three months of intervention before cochlear implantation. The mean age of 63 mothers was 27.86 years and that of fathers was 35.38 years. These parents were recruited from a group counseling session, which is carried out as a standard protocol as part of the Sruthitharangam Cochlear Implantation Program (SCIP), the government-funded CI program in Kerala, India.

Background information about Sruthitharangam Cochlear Implantation Program

SCIP is a government-funded program in the state of Kerala which provides one CI free of cost for children with severe to profound sensorineural hearing loss under 5 years of age. The auditory-verbal intervention for 2 years is also supported under the project. A preimplant evaluation is carried out by the team of professionals for determining the candidacy for cochlear implantation, which includes audiological test battery, speech and language evaluation, psychological evaluation, radiological evaluation, and medical examination. The parents of children thus selected for CI were called for a group counseling session to educate them on the importance of intensive speech and language intervention, care and maintenance of the speech processor, surgical procedures, implant switch on, and other related audiological procedures. The data for the present study were accumulated over three such group counseling sessions. All parents were native Malayalam speakers.

Material used

The items were selected from the Parents Expectations Questionnaire for CI developed by Zaidman-Zait and

Most, 2005. These items were translated into Malayalam and reverse translation was done to ensure consistency in meaning. Then, a native Malayalam speaker who had language proficiency in both English and Malayalam proofread the questions made in Malayalam. A few questions regarding academic achievement and communication domains that were found to have similar meanings were omitted. The details of the questionnaire used to elicit the parental perceptions and expectations are shown in Table 1. The parents were asked to rate their level of agreement for each question with a 4-point Likert scale (1–4) which ranged from strongly disagree to strongly agree.

Procedure

Clearance was obtained from the ethical committee of the National Institute of Speech and Hearing. A written consent was obtained from all the participants. All the parents were given the questionnaires in a printed format after the group counseling session and instructions regarding completing the questionnaire and rating the responses were provided by the researchers.

Descriptive statistical analysis was performed using the IBM SPSS Statistics for Windows (Version 22.0. Armonk, NY: IBM Corp.) and relevant interpretations were drawn.

Table 1: Domains and items in the questionnaire

Section	Domain	Item number
Demographic details	-	8
Preimplant perceptions	Parental involvement and therapy	1
	Present communication and social skills	2
	Stress	8
	Present rehabilitation services	1
Expectations after cochlear implantation	Communication	8
	Academic achievements	3
	Future life	3
	Social skills	2
	Rehabilitation demands	4

RESULTS

The results are represented in terms of the parent's perception and expectation from CI. The subsequent tables from Tables 2–7 show the “agree” and “strongly agree” responses reported by parents for the different questions elicited under each domain studied. In all domains, there was negligible “strongly disagree” and “disagree” responses except for stress.

Parental perception on deafness

Parent's perception of their child's hearing loss was elicited on four domains, namely the parent's role in habilitation, satisfaction over the present communication and social skills in their child, stress level felt by the parents, and satisfaction with the present habilitation services. About 97% of them understood the importance of parents' role in habilitation, 42.2% of parents were satisfied with the present communication and social skills of their children, and 38.75% of parents were satisfied with habilitation services. The percentage of parents who responded to the domain of stress is depicted in Table 2. However, all parents did not respond to question number 3 (2.13%), 7 (1.06%), and 8 (2.13%), respectively.

Parental expectations from cochlear implants

Parent's expectations on the child's development after cochlear implantation on various aspects have been categorized into communication skills, academic achievements, future life, social skills, and rehabilitation demands. The degree of agreement (agree and strongly agree responses) for different questions elicited under these domains are described below. “Strongly disagree” and “disagree” responses have not been shown as there were negligible responses.

Communication skills

Parents had high expectations regarding their child's ability to communicate easily with his/her family members (94.38%), ability to easily participate in social conversations (97.90%), improve his/her language skills tremendously (97.70%) and develop intelligible speech (96.90%) [Table 3]. They also believed that their children would be able to understand speech without relying on lip reading (95.90%), able to detect even very quiet sounds in his/her

Table 2: Parent's response to questions related to stress

	Strongly disagree (%)	Disagree (%)	Agree (%)	Strongly agree (%)
I often regret the extra time our family must devote to the problems of hearing impairment	45.74	26.60	18.09	9.57
We have more family arguments about our child with hearing impairment than we have about other things	59.57	23.40	7.45	9.57
Much of the stress in my family is related to deafness/hearing impairment	31.91	22.34	28.72	14.89
My child's behaviour has often been a source of worry to me	27.66	30.85	29.79	11.70
Family and friends usually treat my child the same as they would treat a hearing child of same age	4.26	21.28	41.49	32.98
Because of hearing loss, it was necessary for me to forget many hopes and dreams that I had for my child	42.55	28.72	21.28	7.45
My child's hearing loss created so many demands that I never had time for myself	36.17	27.66	23.40	11.70
Parents of children with hearing impairment are expected to do many things for them. This has been a burden for me	56.38	21.28	8.51	11.70

Table 3: Parent's response to questions on expectation on communication skills after cochlear implantation

With the help of the cochlear implant, my child...	Agree (%)	Strongly agree (%)
Will be able to communicate easily with his/her family	36.1	60.8
Will not need to use sign language at all	28.9	59.8
Will be able to easily participate in social conversations	30.9	67
Will be able to understand speech without relying completely on lip reading	39.2	56.7
Will be able to easily detect even very quiet sounds in his/her environment (e.g., a whisper)	46.4	46.4
Will improve his/her language skills tremendously	37.1	60.8
Speech will be intelligible	36.1	60.8
Will be able to use the telephone	43.3	51.5

Table 4: Parent's response to questions on expectation on academic achievements after cochlear implantation

With the help of the cochlear implant, my child...	Agree (%)	Strongly agree (%)
Will be able to participate easily in a regular classroom setting	35.1	60.8
Learning abilities will improve tremendously	41.1	56.8
Will achieve high standards in reading and writing	35.1	61.9

Table 5: Parent's response to questions on expectation on future life after cochlear implantation

With the help of a cochlear implant, my child...	Agree (%)	Strongly agree (%)
Will acquire normal hearing	28.9	67
Will be able to function like a child with typical hearing. Will have a dramatic change in his/her life	35.1	61.9
The cochlear implant will change my child's future	39.2	58.8

Table 6: Parent's response to questions on expectation on social skills after cochlear implantation

With the cochlear implant my child...	Agree (%)	Strongly agree (%)
Will easily make friends with hearing peers	30.9	67
Will be accepted by his classroom hearing peers. Social skills will improve tremendously	35.1	60.8

Table 7: Parent's response to questions on expectation on rehabilitation demands after cochlear implantation

With the/or after receiving a cochlear implant, my child...	Agree (%)	Strongly agree (%)
Will need to participate in intensive listening training. will undergo intensive therapy for many years	24	74
Will not need prolonged speech training like children who use conventional hearing aids	46.9	34.4
Parents of children with cochlear implants will have to put in a lot of effort into the rehabilitation process	9.3	88.7
Parents of children with cochlear implants will have to schedule a lot of time to work with their child	23.7	71.1

environment like whispers (92.80%), use the telephone (94.80%), and will not have the requirement to use sign language (88.70%).

Academic achievements

Parents had high expectations that their children will improve in their learning abilities (97.90%), be able to participate in regular classroom settings (96.95%), and achieve high standards in reading and writing (97.45%) [Table 4].

Future skills

Parents anticipate that a CI will change their child's future (98%) and that their children will acquire normal hearing (95.90%), will have dramatic change in life and function like a child with typical hearing (97%) [Table 5].

Social skills

Parents also foresee that their children will be able to make friends with hearing peers (97.90%) and will be accepted in classrooms due to improved social skills (95.90%) [Table 6].

Rehabilitation demands

Parents believed that their children need to participate in intensive listening training (96.93%), and may not require prolonged speech training like children who use conventional hearing aids (81.30%). They also anticipate that they will have to put in lot of effort into the rehabilitation process (98%) and schedule their time to work with their kids (94.80%) [Table 7].

DISCUSSION

Parental perception on deafness

The questions addressing parent's perception on hearing loss provided insight into beliefs and difficulties related to their children's hearing loss. Ninety-seven percent of parents strongly agreed to the fact that for a successful outcome, there was a need for long-term parental involvement, intense and prolonged therapy.^[20,21] The prerequisite for applying for the SCIP requires bilateral hearing aid fitting and intervention

for at least 3 months. Hence, the parents were aware about the significance of intensive rehabilitation. This preimplant habilitation has equipped the parents regarding the same. However, only 42.2% of parents were satisfied with the present communication and social skills of their children; even though they expect higher skills after cochlear implantation.^[22] All the children in this study received the diagnosis of bilateral severe-profound hearing loss and had a history of preimplant speech-language intervention for at least 3 months duration with digital hearing aids in both ears. However, their speech and language development were poor. Their preimplant speech perception abilities with hearing aids tested using aided audiograms were out of the speech spectrum in preimplant evaluations. Significantly, lower language scores are obtained in children with severe-profound hearing loss using hearing aids, and it is shown that acceleration of language development is possible with CI if they have the better preimplant residual hearing.^[23] It was quite interesting to note that 63.30% of parents did not face any stress-related issues as many studies in the literature report high-stress levels in parents of children with hearing loss. The preimplant period of intervention has made the parents settle down with respect to their psychosocial aspects and accept the hearing loss in their children and work toward achieving spoken language outcomes. About 82.98% of them did not have any family arguments related to their child's hearing loss, 72.34% of them did not regret the extra time spent for their kids, and 77.66% of them never considered their children with hearing loss being a burden for them. About 71.28% of them never left hope behind for their child.

Only 36.04% of parents reported stress due to factors such as extra time being devoted to the problems of hearing impairment, child's behavior being a source of worry, more family arguments related to child with hearing impairment, losing hopes and dreams related to the child due to the presence hearing impairment, not having time for themselves, and they consider it as their responsibility alone which creates a sense of burden. The high degree of parental stress, greater period of grief and adjustment has been shown in parents of children with hearing impairment as compared with parents of hearing children.^[12,24,25] A better understanding of stress in parents, especially mothers may result in the provision of improved services for families at both the family and organizational levels.^[26,27] Implementation of counseling sessions by professionals, parent support groups, interaction with parents with similar experiences, and support from counselors or psychologists can reduce the stress and anxiety of parents.^[14]

Some parents (38.75%) reported dissatisfaction on the current rehabilitation service delivery due to factors such as the professional approach being less satisfactory toward children and their parents and differing opinions among professionals regarding the management strategies.^[13] These findings highlight the need for a structured protocol to be developed among the CI professionals to provide unbiased information about the support services.^[28] An informative and all-encompassing preimplant counseling and

assessment protocol with the family will help in informed decision-making.^[15] This will also help parents to develop realistic expectations from CI.

Parental expectations from cochlear implants

Overall, the parents have shown high expectations on all the domains studied. 94.38% of parent's responses to questions related to communication abilities revealed high expectations after CI. Furthermore, 97.9% and 96.9% of parents expected tremendous improvements in language and speech abilities, respectively. A study by Nikolopoulos *et al.*^[5] showed that the role of CI surpassed parental expectations in the domains of communication, speech-language development, and listening skills. Similarly, in a study by Stefanini *et al.*^[22] expectations were high in domains of communication, leading to better social relations and the development of autonomy. About 94.8% of parents were confident that their children will be able to carry out telephonic conversations. The questions related to academic achievements revealed that 96.95% of parents expected their children to cope up with mainstream schooling and 97.45% of parents have high expectation on achieving high standards in reading and writing skills. About 96.97% of parents expect their children to function like other children with typical hearing with CI bringing dramatic changes in their future lives. Parents have also shown high expectations of tremendous improvements in social skills (97.4%). The parents have great hope on the implant that it will enable their child to function in the hearing world even though the outcomes from CI are highly individualistic.^[10] Parents of children using CI agree that their children can join regular schools and schools fulfilling their needs.^[22] Social skills and participations have been reported to improve in terms of good relationships with siblings, elders and peers, ability to making friendships, active participation in activities with other children.^[28]

96.93% of parents showed improved awareness about the need and importance of long-term intensive rehabilitation needed for positive outcomes in their child and they believe that parents play an important role in this success. Similar findings have been reported by Kumar *et al.*^[14] that parents are aware about the importance of intensive speech, language, and listening training which will help the clinicians to provide parents a better understanding of home training. However, the outcomes were highly individualistic, even though the expectations of parents about their child after implantation was to function with the hearing peers. The results from the present study reiterate the evidence that although the beliefs and experiences related to their children's hearing loss vary among parents, they had high expectations from CI, specifically to develop speech, language, communication, and social skills. This information will also help clinicians working with families of children with hearing loss to identify the specific areas that need to be worked intensively to meet the demands of parental expectations.

CONCLUSION

This study findings proposes professionals to address parent's aspirations, values, and expectations regarding the success of

the child while imparting information regarding management strategies. A holistic approach toward habilitation will be the key for successful outcomes in children with CI. The reality of experience is determined by the parent's expectations along with the quality of information and guidance provided to them. Further, documentation of parental perceptions is important to correlate the future experiences and outcomes from CI.

Limitations and future directions

The other factors (such as socioeconomic, service delivery, psychosocial aspects) that can have an effect on the parental perceptions and expectations were not probed into. A correlation of these factors and the parental responses would point out to the relationships among factors. Using a mixed-method and incorporating a qualitative method of data collection would have added light onto several aspects. Future studies are warranted to understand the relationship between the expectations and experience of these parents.

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Conflicts of interest

There are no conflicts of interest.

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