Benefits and Shortcomings of Cochlear Implantation in Children: Parental Reports from India

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Abstract: *Objective*: The aim of the study was to understand the rationale for choosing cochlear implantation as a rehabilitation option and the benefits and shortcomings of cochlear implants in children as reported by their parents.

Method: Ninety parents of children with cochlear implants from various parts of India completed open-ended questionnaires.

Results: The main reasons for choosing cochlear implantation include: no benefit from hearing aids, the expectation that children would have better hearing and develop age appropriate speech and language abilities. Most of the participants reported benefits of cochlear implantation in a home setting but not in school and other social settings. Most participants reported shortcomings in a home setting but only less than half reported in school and other social settings.

Conclusions: Not all respondents reported benefits and shortcomings in all settings, particularly school and other social settings. This may raise some questions about knowledge of parents about what to expect from their child's performance with a cochlear implant in different settings.

Keywords: Cochlear implants, Hearing loss, Open-ended questionnaire, Counselling, Cochlear implants in India.

INTRODUCTION

There is an increase in the number of children being implanted worldwide and this can be attributed to cochlear implants (CI) becoming cost effective [1]. Reported benefits from a CI include increased auditory development [2], better speech production [3], speech intelligibility [4], improved reading skills [5] better quality of life [6] increased self-esteem and social wellbeing [7], and better school performance [8]. Limitations include listening in noisy places and the lifespan of a cochlear implant [9].

Several researchers investigated the outcomes of cochlear implants using objective methods such as comparison between different speech processing strategies [10], improvements using different microphone technology [11], and optimal insertion depth of electrode array [12]. Very few investigators reported the perceived benefits and shortcomings by adult patients [13, 14] and parents of children using cochlear implants [15, 16].

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India is a multicultural, multi-religious and multilingual country. Hearing loss is still a taboo and some families still do not seek intervention for hearing loss for their children. Culture in India is very different within the country and different to other Western countries. The languages spoken, food, music, dances and customs differ from one state to another and these cultural differences define the people. There are over five million people in India with hearing loss as a disability [17]. It is estimated that around 15,000 individuals have a CI in India when compared to about 96,000 individuals in the United States of America [18].

In the last five to seven years some state governments of India have started schemes where cochlear implantation is offered free of charge to those children with severe to profound hearing loss whose family cannot afford to self-fund (i.e., families below poverty line). According to data released by the planning commission, a person who lives in an urban area with a monthly earning of less than $17 is considered to be below poverty line. The government schemes and the charges covered vary from state to state with some states offering cochlear implant device and surgery only, whereas others include the pre-

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implant evaluation. However, generally families have to pay for the costs incurred post cochlear implantation.

The benefits and shortcomings reported by parents have been investigated using structured questionnaires [19] and open-ended questionnaires [15, 16] in previous studies. The main benefits reported were awareness of sound, improved speech discrimination and speech production. The majority of the shortcomings were related to equipment care and maintenance. It is opined that the use of open-ended questionnaires offer parents the chance to address the issues that are important to them rather than forcing them to choose the options provided by a clinician. The open-ended questionnaires also provide sufficient time to allow the parents to reflect on various situations [20]. There are few other studies exploring the improvements in quality of life as reported by parents [21, 22] and parental descriptions on cochlear implantation [23].

It is important to understand the benefits and shortcomings of cochlear implants in real life situations. To do this it therefore becomes important to explore the opinions of the implantees or in the case of children their parents/caregivers. “Parental perspectives may be influenced by various factors including the information to which they have been exposed, the hearing healthcare system, attitudes and expectations, cultural factors and socio-economic status” [16]. Thus it becomes very important to study parental/caregiver’s perceptions in countries that have different influencing factors, for example deaf awareness, culture, economy of the country and societal perceptions. The majority of the previous studies used open-ended questionnaires, without exploring the child’s performance in specific real life situations like home, school and other social settings. Thus it becomes important to explore benefits and shortcomings in various settings to help in addressing the shortcomings and also in tailoring the information provided during informational and personal adjustment counselling.

The aim of the study was to understand the rationale for choosing cochlear implantation as a preferred option and also the reported benefits and shortcomings of cochlear implants in children as reported by their parents/caregivers.

METHOD

Permission was taken by the clinics to collect the data anonymously. We were unable to gain ethical approval as this study was not conducted under any University which had an ethical board. However, we complied with the ethical guidelines of our institutions. All participants were given the questionnaires and also a detailed information sheet about the study.

Participants

Parents/caregivers of 90 CI children from eight different CI centres in India participated in this study. These centres were based in various geographical locations of India, including Chennai, Coimbatore, Delhi, Ahmedabad, Hyderabad, Jammu, Lucknow and Pune.

Questionnaire

Participants were asked to complete a questionnaire, which included some demographic questions and the following open-ended questions. They were based on the previous studies [14, 16] with some modifications to categorise the benefits and shortcomings into home, school and other social settings.

1. Please list the reasons why you choose a cochlear implant for your child?
2. Please make a list of the benefits that <u>you</u> have noticed since your child has had a cochlear implant. List these in order of importance starting with the biggest benefit. Write down as many as you can think of;
   a) At home
   b) At school
   c) At other social settings
3. Please make a list of the problems/shortcomings that <u>you</u> have noticed since your child has had a cochlear implant. List these in order of importance starting with the biggest problem/shortcoming. Write down as many as you can think of;
   a) At home
   b) At school
   c) At other social settings

RESULTS

Demographic Information

A total of 90 respondents completed the questionnaire from 8 different cochlear implant centres

from India. The data was analysed using a qualitative content analysis method used by Graneheim & Lundman [24]. Demographic data were analysed using descriptive statistics.

Table **1** provides details of demographic information of the respondents (i.e., parents of children with cochlear implants) and also children with implants. Of the respondents, the mean age of the child participated in the study was 6.45 (S.D 4.12) years and the mean age of identification of hearing loss was 1.42 (S.D 1.23) years. The average duration of pre-implant hearing loss was 3.58 (S.D 3.03) years and the mean duration of CI use was 2.25 (S.D 2.78) years. 48% of the respondents were males and 52% of the respondents were females. 23% of the children with cochlear implants were males

Table 1: Demographic Information

	Number of respondents	
Age of child (in years) Mean ± SD	89	6.45 ± 4.12
Age at identification of hearing loss (in years) Mean ± SD	89	1.42 ± 1.23
Duration of pre-implant hearing loss (in years) Mean ± SD	81	3.58 ± 3.03
Duration of cochlear implant use (in years) Mean ± SD	89	2.25 ± 2.78
Age of the respondent (in years) Mean ± SD	81	33 ± 7.3
Gender of the child (% male)	89	48
Gender of respondents (% male)	88	23
Respondent's relationship to child (%)		
Father	87	21
Grandfather		1
Grandmother		1
Mother		77
Socioeconomic status (%)		
Higher	83	1
Higher middle		17
Middle		20.5
Lower middle		50.5
Lower		11
Type of school (%)		
Main stream	56	93
Special school		7
Cochlear implant manufacturer (%)		
Advanced Bionics	80	8.5
Cochlear		32.5
MED-EL		59
Funding pre-implant (%)		
Government schemes	82	45
NGO funding (i.e., charitable trusts)		6
Parents employment and health insurance		2
Private donors		1
Self-funding		46
Funding post-implant (%)		
Government schemes	64	12.5
NGO funding (i.e., charitable trusts)		1.5
Parents employment and health insurance		1.5
Private donors		0
Self-funding		84.5

and 77% of them were females. When asked about the socioeconomic status, 11% of them responded as lower, 50.5% of them responded as lower middle, 20.5% as middle and 17% as higher middle. Of the children attending school, majority (93%) of the children attended main stream school and 7% special school. From the respondents, 8.5% of children used the Advanced Bionics device, 32.5% of the children used a Cochlear device and 59% of children used Medel, 77% of the respondents were mothers, 21%, fathers, 1% grandmothers and 1% grandfathers. In relation to funding pre-implant 45% of them were funded by Government schemes, about half (46%) were self-funded, and 6% of them were funded by Non-governmental organisations (N.G.Os). Majority (84.5%) of the post-implant expenses were self-funded with government schemes offering help for 12.5% of patients, and 1.5% of children were funded by NGOs and 1.5 % by parent's employment/health insurance.

Reasons for Choosing Cochlear Implantation

The main reasons for choosing an implant as a preferred option for rehabilitation of children include (N: the number of responses in each category): no benefit from hearing aids (N=33); expectation that a cochlear implant would provide better hearing (N=30); expectation that child can hear well and learn speech and language (N=24); existence of profound hearing loss (N=15); expectation that a cochlear implant would result in hearing similar to normal hearing (N=12); to make child independent (N=11); and provide a better future (N=6).

Response Categories

All the respondents could think of at least one response to the benefits of cochlear implantation at home. However, some (N=10) did not report any benefits at school and in other social settings (N=13). Thirty-four respondents reported that their children were very young and not yet attending school. Of the remaining parents whose children were attending school, 46 parents reported at least one benefit and 30 of them reported at least one shortcoming. Nearly two-thirds reported shortcomings at home and nearly half reported shortcomings in other social settings.

Main Benefits Reported

The main benefits reported by parents at home were improved sound awareness (N=39), responds to commands (N= 27), improvements in expression/ spoken language (N=19), and improvements in speech understanding (N=17). Parents also credited their children's improved interaction with family and other children to the cochlear implants. The other major reported benefits were in terms of responding to the door bell and phone ringing and improved speech clarity.

At school the parental reported benefits were children responding to teachers' instructions (N=12), improved socialisation (N=12) and improved academic performance in school (N=11). Some of the other reported benefits at school include increased participation in extracurricular activities and greater interest in going to school.

Improved interaction with strangers and other children (N=22) was the biggest benefit reported by parents in other social settings, followed by improved socialisation (N=18). The other reported benefit was understanding family conversations in different environments (e.g., back ground noise, temple).

Main Shortcomings Reported

The main shortcomings reported at home were related to the financial issues of care and maintenance of the processors and parts (N= 20), followed by issues related to loss or physical damage of the implant and processor (N=18). Limitations of hearing from the implant and the adjustments the family need to make to give more time to the CI child (N=7) were the other reported shortcomings in a home setting.

The main shortcoming reported in school was difficulty in hearing in background noise (N=8). Parents also reported that children did not understand teachers in class all the time (N=6), and there were issues with

Table 2: Number of Respondents Reported at Least One Response in each Category

	Benefits	Shortcomings
At home	90 (100%)	68 (76%)
At school	46 (51%)	30 (33%)
At other social settings	77 (86%)	40 (44%)

Table 3: Main Benefits Reported

Setting	Main benefits	Number of responses (N)
Home	Improved sound awareness	39
	Responds to speech and voice commands	27
	Improved expression/ spoken language	19
	Improved speech understanding	17
	Improved interaction	14
	Speech and hearing similar to normal hearing peers	11
School	Responds to teachers instructions	12
	Improved socialisation	12
	Improved academic performance in school post CI	11
	Participates in sports and extracurricular activities	8
	Like to go to school	5
Other social settings	Improved interaction	22
	Improved socialisation	18
	Understands conversation in different environments (back ground noise, temple)	8
	Responds in public places	8
	Improved confidence, greets strangers	7
	Enjoys conversation	5

the care and maintenance of processors at school (N=5). The other shortcomings include concerns about other children breaking the processor and the possibility of damage to the processor.

Parents reported concerns about the visibility of the processor as the main shortcoming (N=14) when in other social settings. The other shortcomings at other social settings were fear of damage to the processor/implant (N=5), problems hearing in background noise and care and maintenance of the device.

DISCUSSION

The main benefits were improvements in listening and understanding, spoken language, academic performance and social interaction. Equipment related maintenance and repair issues and CI funding were major concerns pointed out in this study.

Table 4: Main Shortcomings Reported

Setting	Main shortcomings	Number of responses (N)
Home	Finance issues related to care and maintenance of the processor and parts	20
	Worried about loss or damage to implant/processor and parts	18
	Still limitation of hearing from implant - not perfect	13
	No problems	7
	Family adjustments to accommodate more time for CI Child	7
School	Problems in background noise at school	8
	Don't understand teacher in class all the time	6
	Care and maintenance at school	5
	Worried about other children taking/breaking processor	5
	Damage to the processor	3
Other social settings	Worries about the visibility of the device	14
	Worries about damage to processor/implant	5
	Problems hearing in crowd/noise places	4
	No sounds if device stopped working	3
	Care and maintenance	3

The descriptive results show that parents took nearly two years on average to make a decision on CI intervention for their child after identification of hearing loss. Many reasons like lack of awareness about available hearing solutions, non-availability of local professional services, poor family/society support, societal taboo and lack of funds could be possible reasons for this delay. These further hinder a child's opportunity to hear during the critical learning years, bringing down the achievable outcomes with a CI. Parental concern about the visibility of the device suggests that CIs are not readily acceptable in Indian society. This is contrary to the study done in Southeast Asia [16] where the reported shortcomings were mainly about repairs and the large size of the processor.

With majority of study participants falling in the lower to middle economic strata, it is worth mentioning that Government/ NGOs funded their CIs. This might be different from situations in other countries where most of CIs are funded by Government or medical insurance schemes. It is important to note that the majority of families were expected to self-fund equipment maintenance and repair expenses and/ or rehabilitation program charges, post implantation. Such an expense could mean a heavy financial burden on an average Indian family.

Listening in noisy situations such as a classroom and safety of the device were reported as major concerns in the school setting. Most of the children that went to school were enrolled in mainstream education. Though it appears encouraging, it has to be remembered that some parents did not report any benefits in a school setting and nearly two thirds mentioned some shortcomings in a school setting. This raises a concern as to whether these children receive adequate support in school in order to achieve their maximum academic potential. Exploring support systems at both special and mainstream schools could be an interesting study for the future. The use of an FM system and teaching assistants is very common in the western countries to help listening in noise situations in school. Mainstream schools need to be aware of the limitations of the CI in a noisy school environment. Cochlear implant centres along with parents need to make sure that the school teaching staff are aware of the needs of the implanted children.

The use of an open-ended questionnaire facilitated parents to report only those perspectives that were of significance to them. For example, none of the parents reported any benefit/shortcoming on telephone use and music appreciation with a cochlear implant. The mean length of time implanted was a little above 2 years. Some children should have been able to use the telephone at this stage. Maybe the expectation of 'near normal' or 'normal' performance and there being less emphasis on improving these listening skills in rehabilitation program can be reasons for parents to have overlooked these aspects.

Parent responses on reasons to opt for CI intervention indicate that some parents perceive CI not just an opportunity to make their child 'normal' or 'near normal', independent and give them a better future. This suggests that in addition to finding funding for cochlear implant and post rehabilitation charges, it is also important to set realistic expectations with parents pre-implant. However, to achieve this it is important to consider the structure of the cochlear implant team and the multi-disciplinary professionals involved, patient pathway, counselling and parental expectations before the cochlear implantation, regular monitoring of parental expectations and progress noted in children with cochlear implants overtime are all important aspects to be considered.

CONCLUSIONS

The current study reported that parents perceived a range of benefits and shortcomings in various situations including home, school and other social settings, with a CI. Funding for CI and its maintenance and improving support in social and school settings are major hurdles in the rehabilitation process. Future studies exploring the effectiveness of indigenous solutions taken up by clinicians, families, cochlear implant users, and Government to handle the concerns could be a responsible and useful step.

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CONTRIBUTION TO THE PAPER

Srikanth Chundu: Introduction, analysis of questionnaires, Results and Discussion.

Janani Jeyraman: Introduction, data collection and Discussion.

Kalyani Mandke: Introduction and Discussion.

Vinaya Manchaiah: Study design and Results.

CONFLICT OF INTEREST

The authors do not have any conflicts of interest to disclose.

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