

Original Research Article

Parental perception of benefits from cochlear implantation in children with multiple impairments

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ABSTRACT

Background: Cochlear implantation (CI) in children with hearing impairment and an additional disability was not included in candidacy criteria earlier. With advances in technology and by taking into consideration the rehabilitation-pedagogic point of view, it is made possible to implant such children. In the Indian context, very few studies have documented benefits of CI in children with multiple impairments, whether measured or perceived by parents or families. Considering the number of children with additional impairments being implanted, it will be useful to conduct such a study, aimed at obtaining parents' perceptions about benefits of cochlear implants in children with multiple impairments.

Methods: The present study is a survey of 31 children (3-15 years) using CI and having multiple disabilities. An ICF based questionnaire was developed and used to record parents' perception of benefits in terms of language development, speech perception, social interaction, communication skills (non-verbal and verbal), education, general tasks and demands, interpersonal interactions and relationships and family dynamics.

Results: Benefits were reported by all parents in all the domains i.e. listening, communication, learning and applying knowledge, interpersonal interactions and relationships and environmental factors. However, more parents reported consistent benefits in listening and interpersonal interactions. Most parents reported overall benefits from cochlear implantation in their children with multiple impairments.

Conclusions: Results of this study can be helpful in estimating outcomes from CI in children with multiple impairments. Such information can be used during pre-CI counselling to facilitate development of realistic parental expectations about the benefits of CI in their children with multiple impairments. As results are based on parental reports, overestimation of perceived benefits may be present in some instances.

Keywords: Multiple impairments, Cochlear implantation, Parental perception

INTRODUCTION

Multiple impairments/ disabilities means concomitant impairments, the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments. Multiply impaired children are

identified as having a special nature of multiple handicaps such that their effects are not simply additive, but rather they interact with each other in ways not thoroughly understood to create a complex array of secondary consequences.

Approximately 30-40 per cent of children with sensorineural hearing loss (SNHL) have additional

disabilities.¹⁻⁵ According to Fortnum et al approximately 40% of children with permanent hearing losses will have needs over and above their deafness, which will impact their learning.⁶ Within certain populations of children with Down's syndrome, 60-80% of them may have some degree of hearing loss.⁷ In India, about 10.63 per cent of the disabled persons suffer from more than one type of disabilities.⁸

Use of amplification has been a boon to persons with hearing impairment (HI). A dramatic change in the scenario of rehabilitation of children with HI is the advent of the cochlear implant (CI). Studies on efficacy of multichannel CI in the pediatric population have reported postoperative speech perception and speech production results in post-lingually deafened children and in children with congenital or acquired pre-lingual deafness.⁹⁻¹¹ All children, especially those implanted at a young age, demonstrate improvement in sound detection and in auditory perception skills. Children with multi-channel CI achieve performance levels that exceed those of their non-implanted peers who use other sensory aids including conventional hearing aids and vibro-tactile aids.

From 1995-2000, several investigators examined populations of children with a variety of handicapping conditions and compared them to children whose only deficit was hearing loss.¹² In addition to deafness, the handicapping conditions included at least one of the following disabilities: blindness, reduced cognitive ability, mental retardation, global learning disabilities, attention deficit disorder, autism, and pervasive developmental disorder. The results from all the studies were similar in that the children with multiple handicaps received significant auditory benefit post-implantation. However, they progressed more slowly, had poorer perception and linguistic skills and were less stable in their performance than children with only HI. The children with multiple handicaps ultimately achieved a continuum of results from the perception of environmental sounds to the use of oral language as their primary mode of communication. Outcome often was based on the severity of the handicapping condition. Nonetheless, even those children who demonstrated minimal auditory benefit from the implant experienced a link to their environment and to other people. Although these gains often are not measurable using objective tests, as the advantages are not as extensive as those achieved by children who have hearing loss only, they should not be discounted. The determination of CI "success" should consider a child's maximum potential rather than merely considering open-set speech understanding scores. Since children with multiple impairments demonstrated substantial gains post-implantation, it is recommended that this population be considered as candidates for implantation along with children and adults who are only hearing impaired.

Cochlear implantation in children with HI and an additional disability was not included in candidacy criteria earlier. But with the advancement of research and technology and by taking into consideration the rehabilitation-pedagogic point of view, it is made possible to implant such children. However, it is difficult to evaluate these children using standard tests, both, pre- or post-implantation. Despite the presence of additional impairments, these children often receive important benefits in daily life, with an overall improvement in quality of life. Parents are in the best position to describe what cochlear implantation has meant for their child with HI associated with one or more additional disabilities and to their family. A questionnaire based on the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) will be appropriate for obtaining parental perceptions about the benefits obtained from an intervention modality such as a CI as it offers a view at various activities that the child is likely to engage in. In the Indian context, other than the study by Kameshwaran et al, no study has looked at feasibility of CI in children with multiple impairments.^{13,14} Further, no published study has documented benefits of CI in children with multiple impairments, whether measured or perceived by parents or families. It will be useful to conduct such a study in Indian scenario, where near about 10.63% of the disabled persons suffer from more than one type of disability.⁸ Hence this study is taken up to obtain parental perceptions of benefits from CI in children with multiple impairments using an ICF-CY based questionnaire.

METHODS

The protocol for this survey study was approved by the Ethics Committee of the AYJNISHD, Mumbai. All procedures were in strict adherence to the approved protocol and the study was conducted in 2014-15 at the institute.

Participants

Parents of children visiting the institute for CI mapping procedure or therapy and who were enrolled for AVT or special education at other centers were included in the study. Inclusion criteria included a diagnosis of at least one other associated impairment (cerebral palsy, ADHD, visual impairment, Autism Spectrum Disorder, mental retardation, developmental deficits) along with hearing impairment and use of unilateral CI or bimodal hearing. Parents of children with bilateral CI, any cochlear malformation or auditory nerve deformity and non-biological parents (foster parents, adopted parents) were excluded from the study. The parent (mother or father) that accompanied the child on a regular basis during the therapy or mapping sessions was included. Parents were not excluded based on their education or work status. However, parents having more than one child with disability were excluded.

Tool

For development of the study tool, statements covering the areas in which benefits are generally observed after CI were collated. All the statements were positive and were divided into five domains with reference to ICF-CY structure - i) Listening, ii) Communication, iii) Interpersonal interactions and relationships, iv) Learning and Applying Knowledge and v) Environmental factors.¹³ The statements aimed at recording parents' perception of benefits from CI in terms of language development, speech perception, social interaction, communication skills (including non-verbal and verbal), education, general tasks and demands, interpersonal interactions and relationships and family dynamics. With the help of ICF-CY manual, appropriate three level codes were assigned to each statement. The statements on the tool encompass the domains of body functions, activities and participation and environmental factors. The tool uses a five-point response scale namely, never, seldom, sometimes, often and always. The qualifiers for the same have been derived from the ICF 0-4 qualifier scale, but this scale looks at the positive aspect of functioning instead of denoting the magnitude of the person's level of health or severity of problem. This scale suggests the benefit that the child has gained in each of the domains. As suggested in ICF, response of "NEVER" was considered as 0 on scale, 1 for seldom, 2 for sometimes, 3 for often and 4 for always. Further, "0" was taken as 0-5% benefit, "1" was taken as 6-25% benefit, "2" was taken as 26-50% benefit, "3" was taken as 51-75% benefit "4" was taken as 76-100% benefit. To begin with, the statements were prepared in English and validated by five ASLPs familiar with ICF-CY (2007). Each of the five respondents rated each statement as appropriate or not appropriate for the given domain. Statements considered as inappropriate were not included.

The final tool consists of 45 statements distributed across the five domains as follows:

Domain 1, "Listening" consists of 13 statements (maximum score 52) covering hearing function, auditory perception, sound detection, localization of sounds, etc. Domain 2 is "Communication" and includes 18 statements (maximum score 72) about child's receptive language, expressive language, speech, other communication skills such as use of gestures, lip reading, quality of voice, articulation. Domain 3 is "Learning and Applying Knowledge" consisting of 7 statements (maximum score 28) pertaining to skills such as copying and rehearsing, daily routine chores, and child's ability to undertake multiple tasks. This domain also includes attention and mental functions. Domain 4 is "Interpersonal interactions and relationships" which consists of 4 statements (maximum score 16) about child's interaction with his/her family members, siblings and others. Domain 5 is "Environmental Factors" which includes 3 questions (maximum score 12) about family

member's attitudes towards the child, and other services and policies that might help the child for his betterment.

After validation, the tool was translated in two local languages - Hindi and Marathi. For translation into these languages, the English version was translated by three laypersons who knew both languages. These translated versions were then given for re-translation back into English to three other laypersons. The version in which the back translation was the closest to the original was finalized.

Procedure

After obtaining written consent from the participants, detailed case history of the child was obtained. The tool was then administered either by asking them to fill it up in writing or by verbally interviewing them. Parents were instructed to read the statements carefully, to give the initial responses according to improvement of their children and to rate the responses.

RESULTS

Of the 31 parents 28 were mothers and 3 were fathers. Of the mothers, 23 (82.14%) were housewives and 5 were working on clerical or administrative jobs. All three fathers were working and had completed graduate level education. Of the mothers, eight had completed graduate level education and the rest (20) had completed higher secondary education.

Twenty-two of the 31 children had a single disorder associated with the hearing impairment. Of these, 15 children (48.38%) had ADHD, 5 children (16.12%) had mental retardation or developmental delay, and one child each had a cleft lip (3.22%) and autism spectrum disorder (3.22%). The other 9 children (29.03%) had more than one associated impairments (ADHD with mental retardation - 8 children; Autism spectrum disorder with ADHD with developmental delay - one child). Among these, one child had apraxia of speech, one child had Usher syndrome and one child had Dandy-Walker syndrome. One child was also diagnosed to have a seizure disorder. The chronological age of the children ranged between 3 years 3 months and 14 years one month; with the age at implantation ranging between 1 year 10 months and 8 years 6 months. The implant age ranged between 1 year 2 months and 9 years 1 month. All the children used implants from Cochlear, Ltd., Australia. None of the children had undergone any revision surgery; all had complete insertion of the electrode array and all electrodes active.

The tool consisting of 45 questions divided into 5 domains was answered by each parent and domain wise score was obtained. The highest obtainable score for each participant was 180 indicating that child is "always" showing benefit in all the domains and 0 indicates that child has "never" shown any benefit. Frequencies and

descriptive statistics were obtained for each domain. The frequency distribution for the different ratings for the five domains is shown in Table 1.

Listening

Most parents (51.6%) provided median rating of “always”, followed by median rating of “often” (38.7%). The maximum obtained score was 49 and minimum was 11. Median score for this domain was 40. Most of the scores lie below the median score. There is one outlier with scores less than the minimum obtained value.

Table 1: Distribution of responses for the five domains.

	Never	Seldom	Sometimes	Often	Always
Listening	0	3.2%	6.5%	38.7%	51.6%
Communication	0	6.5%	19.4%	64.5%	9.7%
Learning and Applying Knowledge	0	3.2%	19.4%	45.2%	32.3%
Interpersonal interactions and relationships	0	0	16.1%	22.6%	61.3%
Environmental factors	0	3.2	16.1%	74.2%	6.5%

Learning and applying knowledge

Most (45.2%) parents provided a median rating of “often” indicating that the children showed benefits in learning and applying knowledge for daily activities, followed by 32.3% parents provided median rating of “always”. The maximum obtained score was 26, minimum was 6 and median score was 19. Most of the scores lie below the median score.

Interpersonal interactions and relationships

Most (61.3%) parents provided a median rating of “always” for this domain. Maximum obtained score was 16, minimum obtained score was 6 and median score was 13. Equal distribution of scores is seen on both the sides of median. There are 3 outliers which have scored less than minimum obtained value.

Environmental factors

Most (74.2%) parents provided a median rating of “often” for this domain which includes questions regarding school admission, rehabilitation program, etc. Maximum obtained score was 12 and minimum score was 5, with a median score of 9. Most of the scores lie above the median. Most of the parents were happy about the progress that they had seen in their children due to their regular efforts, activities conducted in therapy sessions, the progress children were showing in the classrooms, school curriculum, though this progress was considerably slow as compared to their age mate peers or only deaf children. Few parents wanted that their children should show more progress, while few of them were not at all happy with the slow achievements their children had gained.

Communication

The responses obtained showed that most (64.5%) parents provided median rating of “often” for the benefits in all communicative situations. Children often showed benefits in reception and expression of language, voice and articulation. The maximum obtained score was 65, minimum was 10 and median score is 46. Most of the scores lie below the median score i.e. most of the parents perceived less than median benefits. There are 2 outliers with scores less than minimum obtained value.

The quartiles and medians obtained for the five domains are depicted in Figure 1.

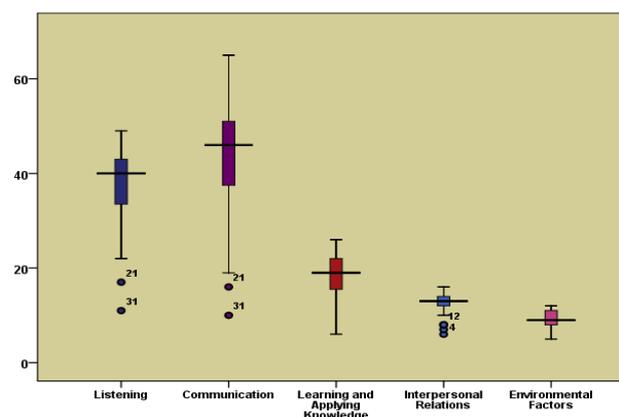


Figure 1: Box plots showing median scores and quartiles for the five domains.

Overall, in all domains except the “Learning and Applying Knowledge”, most of the parents provided a median rating of “often”. For the domain “Interpersonal Interaction and Relationship” more parents have provided a rating of “always”, indicating that more children have demonstrated benefits in socialization and participation in interpersonal interactions. Out of 31 parents 29 reported that they have perceived benefits in all domains ranging from sometimes to always. Only 2 parents reported that they have never or seldom seen benefits in listening skills, communication skills, learning and applying knowledge, and interpersonal interactions and relations.

Most of the children were compliant about wearing their devices. 83.87% parents reported that their child does not throw off the device and maintains it very well. They showed progress in listening through their devices. Most

of the parents agreed that their child has shown some improvement in communicating with them as well as with others after implantation. 27 out of 31 parents agreed that their child understands spoken language without any gestures either sometimes or always. Three children never showed progress in communicating verbally; those children always used gestures to communicate. Most reported that there was a significant improvement in interpersonal interactions such as interactions with siblings, extended family members, and connectedness to their surrounding as compared to other domains.

It is not possible to compare the scores obtained across the five domains as the number of items varies and therefore the maximum attainable score for each domain vary greatly. Hence the spread of scores is compared and depicted in the boxplots.

DISCUSSION

The aim of this study was to measure parental perceived benefits from CI in children with multiple impairments using ICF –CY based tool. Using the developed tool, the benefits in five domains i.e. listening, communication, learning and applying knowledge, interpersonal interactions and relationships and environmental factors as perceived by parents in their children after a minimum of one year usage of CI were documented.

Most parents perceived benefits in the domain of “listening” where skills such as awareness to sound, localization of sound source, attending to name, and listening through the device are probed. This implies that despite having associated impairments, the CI enabled the children to develop detection, localization and identification responses to sound and speech stimuli in the environment. The observations from this study are similar to a study by Wiley et al where more than 80% of families reported that their child showed improvement in awareness to environmental sounds.¹⁵ They were hearing their name when called out. Similar study by Hayward et al reported that children reacted to environmental sounds after CI activation, such as laughing when sounds were heard or attempting to locate the source of sounds.¹⁶ Participants in this study also indicated that CI gave their children access to enjoy music. A study by Wakil et al mentioned that majority of children with severe developmental delay developed some level of basic auditory skills including awareness to sound, association of meaning with specific sounds, and vocalization behavior; although the progress was limited.¹⁷ The results of the present study uphold the reports from the earlier studies.

64.5% parents provided a median rating of “often” for perceived benefits in the domain of “communication”. Most of the parents agreed that after CI their children showed improvement in communication. Few parents whose children had severe impairments (one having a

combination of Autism, Moderate ADHD and Borderline Intelligence and other having borderline intelligence and moderate developmental deficits) mentioned very limited benefit in enhancing communication skills. Children developed communication skills either completely oral or oral along with signs or gestures. Few children remained at the pre-implant level of using signs or non-verbal behaviors for communication. Those who did not show progress had greater severity of impairment and less benefits from therapeutic sessions.

Hayward et al reported children’s responses for communicating by using voice, sign, picture, gestures etc.¹⁶ The study illustrated enhanced and meaningful communication skills amongst the children regardless of the modality. Authors observed increase in amount and variety of vocalization. Current literature indicates that after implantation, majority of children with multiple disabilities make progress; however, it is at a slower rate, and these children attain lower levels of communication than children without additional disabilities.^{3,15,18-22} Some of these children may never obtain open-set recognition abilities or oral communication; they may, however, obtain some useful benefits from cochlear implantation, including the ability to recognize words from a closed set without lip-reading and improved open-set speech perception with the help of lip-reading.^{3,15,18,20,22} Thus, from the above-mentioned studies and results obtained from the present study it can be concluded that children with multiple impairments who have undergone CI can develop useful communication skills regardless of the modality but at the slower rate.

The domain “Learning and Applying knowledge” consists of questions such as participation in group activities, participation in classroom setting, questions regarding attention and concentration of the child, etc. Most parents stated that their children benefitted with CI as they became more attentive and are better able to participate in simple as well as complex tasks at home and in the classroom. This helps in better preparing the child for education. Berrettini et al studied the challenges and outcomes of CI in children with hearing loss and additional disabilities.²³ All parents in the study agreed that their child was more interested and attentive at home and at school. Filippo et al assessed outcome of CI in 18 deaf children with associated problems. They reported gains in self-sufficiency.¹ Thus, the results which are obtained in this domain in the present study are similar to those found in literature.

61.3% parents provided a median rating of “always” for the domain “interpersonal interaction and relationships”. 50% of the respondents have scores between 13 and 16 as seen in the boxplot. This indicates that there are benefits in this domain, wherein the child is more social, relates better with significant others in the environment and mixes with peers and siblings. This in turn provides increased learning opportunities for the child. Berrettini et al reported that most of the parents found improved

interaction of their children with their siblings and other family members.²³ Beer et al found that within one year of implant use, daily living skills and socialization behavior of the children increased modestly.²⁴ Hayward et al found that the child was better able to connect and was better included within the family or community because of access to sound with CI.¹⁶ They reported increased participation and overall inclusion in family activities/interactions, tolerance of new experience, and social interaction.

For the domain “Environmental factors” which includes questions pertaining to school admission, and benefit from rehabilitation program responses indicate that though majority parents had problems in finding school placements, once the child was in school and receiving regular therapy, parents were generally happy with the progress shown by their children. They were generally satisfied with the progress their children made and the outcomes due to the CI.

CONCLUSION

This study shows that children with multiple impairments, if given an opportunity with CI can demonstrate progress in several domains such as awareness of sounds, identification of sounds, communication, interactions with others, participation in group activities, connectedness with environment, independence in daily activities, and schooling; though sometimes progress can be slower than children with only HI. Most parents report overall improvement in all domains and satisfaction after cochlear implantation.

Implications

One of the major obstacles clinicians and therapists face is the challenge of measuring improvements for children with multiple disabilities following CI because these children are not only difficult to test with standard tests but as many researchers have reported, formal tests do not adequately capture gains within this population either because the changes are too subtle to be captured by these tests or the tests do not measure changes observed with these children at all.^{22,23,25} The current study attempts to estimate this benefit through parental reports. Results from the study indicate that after implantation most children with multiple disabilities have made progress in speech perception and communicative skills although at considerably lower rates. The results of the study can be helpful during pre-CI counselling to enable parents to develop realistic expectations about the benefits of CI in their children with multiple impairments. This study helps us to understand that even though there may be limited benefits in the areas of listening and communication or benefits at considerably slower rate, children can make marked improvement in other areas, which is a crucial development in such population and helps to improve their quality of life.

Limitations

Results are based on parent’s perception; hence it is possible that benefits are overstated. No standardized tests are used to measure the benefits. No comparison was made amongst different types of impairments; nor between male and female recipients. The results for early implanted versus late implanted could not be compared as the type and the severity of the associated impairment was different for each child and is an important factor that impacts outcomes from CI. Each domain had a different number of items and hence comparisons were not made across the domains. This study is subject to the limitations of all qualitative research. The sample is small, and local. No assumptions regarding generalization can be made.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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