

Benefits of Cochlear Implants in Children with Hearing impairment : Parental Perspectives from Tertiary Care Hospitals in Tamilnadu

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Abstract

Aim: The current study explores the benefits in children with cochlear implants (CI) from the parental perspective. The objective is to understand the concerns of parents in order to plan appropriate recommendations for habilitation and educational programs.

Method: Fifty-three parents of children with CI completed the questionnaire titled, “Parental Perspectives on CI”. The questionnaire consisted of 106 statements with 10 subsections that analyse the different aspects related to the pre and post –implantation process.

Results: The study reported that parents are satisfied with the overall development of the child. However, they expressed significant concerns regarding recurring cost of the implant, distance, travel and also the future of the child with CI.

Conclusion: Parents recognize that CI has made an overall positive impact on their children. They also recognize CI as a heavy financial liability post implantation that may not allow children to obtain the optimal benefit. The study also indicated that the government should initiate financial policies to provide the necessary support for habilitation and equipment maintenance.

Key words: Cochlear implantation, Early intervention, Habilitation, Parental perspectives,

Introduction

Cochlear implantation is established as a standard care of treatment for children with profound hearing impairment especially for children who do not benefit from hearing aids ^[1]. The development of spoken language and listening are cited as the most significant outcomes of children with cochlear implant ^[2].

Documenting outcomes or benefits of CI has radically changed the candidacy, patient care and habilitation of individuals with CI. There is a range of audiological assessment tools available to document the benefits of CI. However, these formal assessment tools are not designed to provide the information beyond the clinical setup. Though, formal audiological assessments measure the auditory response to speech, it does not reflect the outcomes in terms of speech, language and other related challenges in various environments of a child with CI. Earlier the benefits and limitations of cochlear implants have been discussed using questionnaire based studies. Parents have expressed concerns in educational and social settings post implantation ^[3]. Such specific information can be obtained using parents as informants to document functions of the child at home and in other challenging environments.

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In this context the parental interview provide valuable information that help to understand the child's level of activities in different educational and social environments besides their clinical performance [1][4][5] in India, the numbers of CI recipients have increased in the last decade. The actual benefit from an implant may vary with the data from the rest of the world, due to cultural variations, different health care systems and the costs of the implants.

The aim of the current study is to explore the benefits in children with CI from a parental perspective using a questionnaire. The data was collected from three tertiary care cochlear implant centres from three different districts of Tamilnadu. Appropriate permission was obtained from these CI centres for data collection. A contact list of 80 parents of children with CI in the age range between 2.6 to 10 years was obtained from the hospital database. Parents were contacted and briefed about the purpose of the study over the phone to obtain appropriate consent to participate in the study. Out of 80 parents only 53 parents complied to participate in the study.

Method

A validated closed – set questionnaire (Appendix I) developed by O'Neill et al. [6] was used for the study. The questionnaire was administered to the participants of the current study. The statements in the questionnaire included aspects covered under the pre-implantation and post-implantation process. The questionnaire consists of 106 questions divided under 10 subsections. The aspects covered under the post-implantation were Communication (7), General functioning (7), Self-reliance (5), Well-being and happiness (8), Social relationship (13), Education (11), Effect of implantation (9), Supporting the child (9). The aspects of pre-implantation are covered under two sub sections, Process of implantation (23), Decision of implantation (14). The questionnaire consisted of a series of statements for which the responses were rated on a five point Likert scale from 'strongly agree' to 'strongly disagree'. The responses were coded in the range of 1-5, 1 being 'strongly disagree' to 5 being 'strongly agree'. A failure to respond was classified as a missing value and coded as 0. At the end of this questionnaire, parents were asked to give general comments about the benefit of CI which were not covered in the questionnaire.

Statistics Analysis

Percentage analysis was used to analyze the response of the parents of children with CI. Spearman's correlation was applied to detect the possible relationship between different subscales related to benefits of CI. Statistical significance was accepted at $p < 0.05$ level. All data was calculated by using with SPSS 16.0 versions.

Results

The following results are the analysis of the pre-implantation subscales the "Process of implantation" and "Decision to implant". Within the subscale of "Process of implantation" there are 23 statements. It was noted that 94% scores were obtained for statement "The whole process of implantation was intrusive". 90% of the parents strongly agreed to the statement that "Only experienced teams should carry out cochlear implantation. There was high agreement (90%) among parents for statement 6 i.e., "It is important to observe his use of the implant as school/home". Nearly 98.1% of parents showed agreement for the statement "A positive attitude is a great help towards successful use of the implant".

The statements 11-20 were related to support from the implant centre. The results indicate that the parents strongly supported statement 11 (94%) "Regular tuning and checking of implant system are essential" (94.3%), Statement 12 (98%) "Feedback from assessment at the implant centre is very useful. Parents also agreed to statement 13 (94.3%) "The most important factor in choosing a device is it's reliability. It was noted that parents agreed to the statements 16 (98%) "There is a need for life time support from the implant centre" and statement 19 (98%) "Travelling to the implant centre was a burden".

The other subscale under this aspect is the "Decision to implant" that consisted of 14 statements. All parents unequivocally agreed to the statements 4 (100%) "The whole process of implantation is stressful". Statement 5 (100%) "I am happy about his progress in school" and 11 (100%) "It was a difficult time waiting for results of the assessment before implantation". In this subscale of statements statement 2(38%) "I worry that he will blame me for my decision for him to have an implant".

The box plot (fig. 1) show that the mean scores of the subscales. The parents expressed themselves to be beneficiaries and were highly satisfied particularly in the aspect of supporting the child (mean 4.8, SD 0.23, range

4.5- 5.0), communication (mean 4.6, SD 0.13, range 3.0- 5.0) and education (mean 4.007, SD 0.08, range 3.0- 5.0).

Relationship between subscales in parental perspective:

Spearman’s correlation coefficient was used to identify a possible degree of association between subscales such as communication, general functioning,

self-reliance, Well- being and happiness, social relationships and education. It has been noted that the sub scale of spoken language communication (p=0.009) and self-reliance (p=0.003) had a strong significant correlation with supporting the child. Education (p=0.035) had significant correlation with supporting the child. Also, wellbeing and happiness (p=0.015) had significant correlation with effect of implantation.

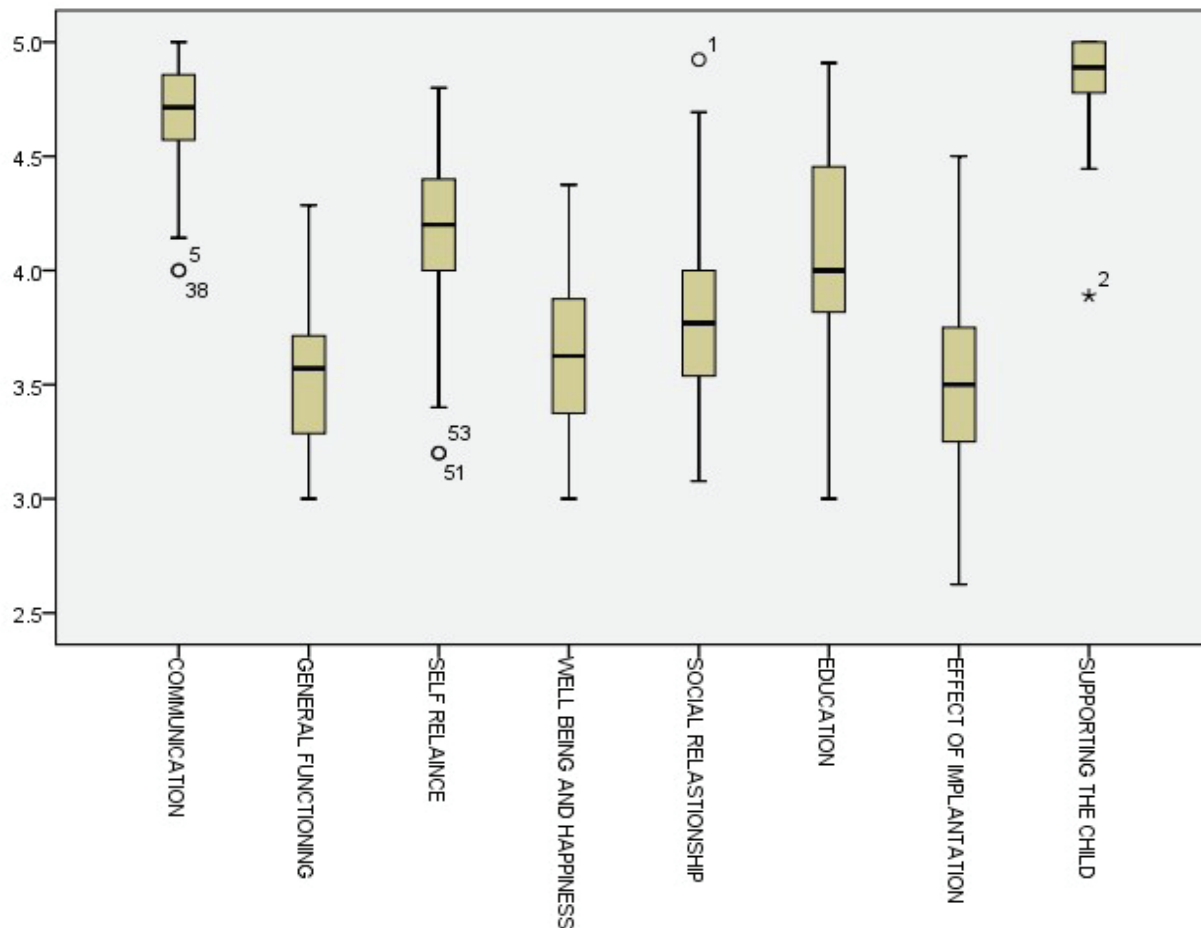


Fig . 1 : Indicates the mean scores of the subscales

Discussion

The present study strongly suggests that parents play an important role in assessing the day to performance of children with implantation. It is apparent from the responses to the questionnaire that the entire process of implantation, pre-implantation and post – implantations were reported to be highly stressful. The study also indicated that all parents who participated in the study considered implant as an option as they expected their

children to be a part of the hearing world. Such high agreement has been reported only in India in comparison with the other parts of the globe. This decision to implant strongly suggests that in a country like India parents view implantation as a treatment for deafness that will allow their child to participate in the hearing world. The other reason that can be attributed is that parents feel tremendous stress to raise a child with a hearing impairment. Due to the above reason, their decision to implant was also directed to a treatment option that

will help the child to be an effective participant in the community. It is consequential that parents have perceived that only by learning verbal communication their child will be able to have a secure future with employment [1]. Parents agreed that CI has helped their child be employed in the future [7]. However, it is also suggestive that parents who participated in the study had high expectations for an implant. For this reason the professionals should establish a realistic view regarding the outcomes of CI during the pre-implantation counseling.

The qualitative subscales of the questionnaire that focuses the post-implantation benefits of the implant suggest, parents express satisfaction in various areas of development. They expressed that there was significant progress in the area of communication and academic achievement and also observed that communication changes post-cochlear implantation. The study also reflected that as the usage of implant increased the child performed better in speech production and speech perception. It also indicated that the parents were satisfied that the child was able to hear and communicate [8][4]. Children with CI also demonstrated significant development in the areas of mainstream education and social interactions. Parents also noted that children with CI performed in par with their hearing peers in academic skills. Similar results were also documented [4]. It also indicated that the parents have perceived that overall their child had become more self-reliant and social post-implantation.

The questionnaire explored the perceptions of parents to the entire process of implantation. The parents recognize that a good working relationship has to be established with the implant centre for future support. They also identify that periodic visits to the implant centre is extremely necessary post implantation.

Apart from the benefits of cochlear implantation parents had specific concerns regarding travel and distance to the implant centre [7]. The issue seemed to persist in Western world that parents had to travel distances to visit the implant centre. This was stressful as the parent had to organize logistics for the rest of the family, while they had to bring the child to the centre. Demands of rehabilitation often yield to high parental anxiety post-implantation. The current study demonstrated that 75% of the parents in India expressed great concern related to the cost of implantation. Parents also reported that implantation is expensive and is

beyond the paying capacity, Unlike the West where CI is reported to fall within acceptable economic range. Until, recently the implant cost was paid by the parents. However, in the year 2013, the Government of India had initiated cochlear implant programs supported by the state government that provides free cochlear implants and rehabilitation for the economically underprivileged. Most of the parents participated in the study had received CI under this scheme in the state of Tamilnadu. The greatest concern of 75% of the parents was to pay for the recurring cost associated with the implants. Parents were extremely concerned with the high costs that will be incurred to maintain the device in the future.

Conclusion

The above information obtained from parents provides a better understanding to plan the individual habilitation programs and educational recommendations for the child with CI. The information can help the professionals to address the parental concerns during counseling and provide a realistic view of cochlear implantation. Specifically, parents expressed concerns regarding the recurring costs and maintenance of the CI device. As all the participants of the study received CI from the government scheme. It may be suggested that the government should initiate policies that can provide financial support for maintenance and accessories of the device. Travel to the implant centre was an important challenge indicated by the parents both physically and financially. In order to address the issue, it may be worthwhile to explore the possible network between the implant centres and district early intervention centres throughout the state of Tamilnadu. This network can be used to provide services at the nearest geographical distance eventually reducing the cost and time related to travel.

Also, India is going through digitization and making remarkable progress in the field of tele-health in reaching the remote areas of the country. It is imperative that the tele-health technology can be explored to deliver rehabilitation service to the children with CI to reduce travel time, costs and distance. The implant centres should be directed by the state government bodies to consider the above options during the candidacy for implantation. Understanding the parental perspectives help professionals and families to facilitate optimal benefit with CI for a child with hearing impairment.

Ethical Clearance: The ethical clearance was obtained from the department research committee prior to the study

Source of Funding: - Self funding

Conflict of Interest - NIL

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Type of manuscript: Original article.