

Perspective of Parents of Pre-Implant Children with Regard to Quality of Life and Health Care Services of Cochlear Implantation Programme in Kerala

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ABSTRACT

BACKGROUND

State Initiative on Disabilities [SID] survey (2015) states that 2.32 % of Kerala population are affected with one or the other form of disabilities; the Sruthitharangam scheme of Kerala Government since 2012 provides free cochlear implant surgery and rehabilitation to children with bilateral profound sensorineural hearing loss among children of 0 - 5 years age group. We wanted to measure the expectations of the parents and their perspectives before cochlear implant surgery which depends upon their understanding of the whole process of surgery and the rehabilitation after surgery and its final outcomes.

METHODS

67 parents of pre-implant children were interviewed with an open-ended questionnaire to know their perspective of government aided pre-implant programme in the state of Kerala. Children were using Hearing aids of Behind the Ear (BTE) TBE 110 HT model supplied by the government, free of cost. Children were attending pre-implant Auditory Verbal Therapy (AVT) with hearing aids at Centre for Audiology and Speech Pathology [CASP] Govt. Medical College, Kozhikode, for a minimum of 3 months. All the data was analysed using mean and percentage calculations.

RESULTS

67 pre-implant children used their hearing aids for a minimum of 3 - month period and the age range was between 12 months to 36 months. The mean age of children was 2.1 ± 0.43 years. 41 male and 26 female children, with a male to female ratio of 1.53: 1 were included in the study. Analysis of the questionnaire showed 8 benefits, 11 shortcomings, 5 expectations and 8 suggestions.

CONCLUSIONS

The parentally reported expectations, short comings, and outcomes of the use of hearing aids could be related to many factors like health care services provided by the government, and the after services of hearing aids involved. These findings help us to understand the parental perspectives of the success of cochlear implantation which can be useful during parental counselling sessions. Study is also useful to the implant centres to revise their practices accordingly and improve the information given to candidate families.

KEYWORDS

Hearing Impairment, Cochlear Implant, Pre-Implant Children and Hearing Aid

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BACKGROUND

Hearing is an important part of an active and enjoyable life. Early detection and intervention are crucial for minimizing the impact of hearing loss on a child's development and educational achievements. As per WHO 2018, the new estimate of disabling of hearing loss is 466 million people.¹ As per the State Initiative on Disabilities [SID] survey (2015), 02.32 % of populations in Kerala are affected with some form of disability.² Among them 60,925 are hearing disabled based on definition of hearing impairment in Persons with disabilities (PWD) Act 1995.³ The Sruthitharangamscheme⁴ was started by the Government of Kerala in 2012 for providing free cochlear implant surgery and habilitation to children with bilateral severe to profound sensorineural hearing loss in the age group of 0-5 years. Children with hearing aids are regularly taken up for pre-implant auditory verbal therapy after initial fitting of hearing aids.⁵ Children were forwarded for cochlear implantation, if there was no or limited benefit from strong gain hearing aids used. The majority of research on the effects of hearing aids among children has focused on speech and language outcomes. Apart from benefits of hearing aids there were several short comings and expectations that could not be ignored. Hence there was a need for understanding these short comings, expectations and suggestions to overcome the failures in government funded programmes for pre-implant children. It would enable policy makers, Surgeons, Audiologists, Rehabilitation professionals and hearing aid / implants manufacturers to understand the perspective of parents of pre-implant children and provide better services.

Objectives

- To understand the reported benefits using hearing aids among the pre-implant children. To understand the short comings, expectations and suggestions from parents of pre-implant children with hearing aids. To identify short comings of the Government funded programmes.

METHODS

67 parents of pre-implant children under the age of 3 years with bilateral profound sensorineural hearing loss, who were using hearing aids bilaterally provided under Rashtreeya Bala Swasth Karyakram [RBSK], a free scheme funded by the Government, were selected for the study for a period of 6 months from June 2017 to December 2018. An institutional ethics committee clearance was obtained before commencing the study. An ethics committee approved consent form and questionnaire was used for the study.

Inclusion Criteria

1. Children aged below 3 years and who were having hearing impairment and using bilateral hearing aids for more than 3 months were included. 2. Children who were initially assessed with approved Audiological tests and confirmed to

have hearing impairment requiring cochlear implant surgery were included. 3. Children who were undergoing pre-implant Auditory Verbal Therapy (AVT) with hearing aids in both the ears at Centre for Audiology and Speech Pathology [CASP] Govt. Medical College, Kozhikode for a minimum of 3 months were included.

Exclusion Criteria

1. Children aged above 3 years were excluded. 2. Children not using hearing aids and have not undergone minimum of 3 months of AVT were excluded.

Sample Size

PWD Act 1995 (3) showed the hearing disabled population as 60925. With an error of margin of 11.97 and confidence interval of 95 %;

Using the formula for sample size

$$n = \frac{(z^2 * p * (1 - p) / e^2)}{(z^2 * p * (1 - p) / e^2 * N)}$$

Where

Z - 1.96, N - 60925, e - 0.1197 and P - 0.5

$N = \frac{1.96^2 * 0.5 * (1 - 0.5) / 0.1197^2}{1.96^2 * 0.5 * (1 - 0.5) / 0.1197^2 * 60925}$

$N = 67.0292 / 1.0011 = 66.956$

Hence N = 67.

Study Design

A prospective cross-sectional study with a fixed questionnaire. All the children were using Hearing aids of Behind the Ear (BTE) TBE 11 OHT model manufactured by the Centre for Development of Advanced Computing (C-DAC), Thiruvananthapuram parents provided under the Government scheme. All children were attending pre-implant AVT with hearing aids in both the ears at Centre for Audiology and Speech Pathology [CASP] Govt. Medical College, Kozhikode for a minimum of 3 months. Three open ended questions were adapted from questions previously used by S Chundu et al.⁶ 2012. These questions were given to parents of pre-implant children. Following are the open-ended questions:

- List out the benefits that they have seen in pre-implant children since using the hearing aids.
- List out the short comings that they have seen in their pre-implant children since using hearing aids.
- List out the expectations and suggestions to overcome the short comings.

Parents of pre-implant children were encouraged to write their views and list them in order of importance starting with the biggest benefits, shortcomings, expectations / suggestions. All the data from the questionnaires was assembled, classified and tabulated. Standard statistical methods like percentage, Standard deviation and mean were used to calculate and compare with other studies.

Statistical Analysis

The data was analysed using the mean, standard deviation and percentages.

RESULTS

The open-ended questions were given to 67 parents of pre-implant children and were to answer those questions and asked them to write the benefits, shortcomings, expectations and suggestions. The pre-implant children have used their hearing aids for a minimum of 3-month period and the age range was between 12 months to 36 months. The average age of pre-implant children was 2.1 ± 0.43 years. There were 41 male children and 26 female children with a male to female ratio of 1.53: 1. Analysis of the questionnaire showed an overall 8 benefits, 11 shortcomings, 5 expectations and 8 suggestions. There were 45 / 67 (67.16 %) parents who were stressed in life due to the presence of a child in the family with hearing disability. The commonly observed benefits were minimal improvement in receptive and expressive language, first word utterance, improved listening and quick response to loud sound. The short comings were no response to soft sounds, frequent complaints of hearing aids and hearing aid repair services under Govt. scheme. The parents found difficulty in obtaining servicing of Hearing aids as they were sensitive to rain or water resulting in poor localization of sound.

The hearing aids were easily damaged by dust and sweat. The expectations were to have gotten improvement in localization, acceptance from society. The parents were expecting their children to hear and speak like other normal children. Most parents were less motivated to use hearing aids regularly. On the contrary, they hastened the process to get their hearing-impaired children included as a candidate for Government aided free cochlear implantation; as the parents were easily influenced by the parents of other post-cochlear implantation children at the same centre. This happened because of the regular interactions and meet between the two groups. Suggestions were about availability of water proof hearing aid, rechargeable or long-life battery, smaller size Hearing Aids. And they expected that therapy service should be made available by the Government for pre-implant children in all districts of Kerala and made easily accessible service centres for government supplied hearing aids. Some of the benefits reported by parents of pre-implants are as tabulated in Table 1.

Sl. No.	Benefits	Percentage of Respondents
1	First word utterance	93.3
2	Response to loud sound	83.3
3	Improved listening	66.6
4	Request for personal needs	40
5	Comprehension of words	35.3
6	Improved receptive and expressive language	34.6
7	Improved attention	16.6
8	Started imitating	10

Table 1. Reported Benefits Enumerated from Questionnaire (N - 67)

The short comings were frequent complaints of hearing aids, service difficulties, sensitive to rain or water, poor localization and got easily damaged with dust and sweat (Table 2).

Sl. No.	Short Comings	Percentage of Respondents
1	Frequent complaint of hearing aid	90
2	Sensitive to rain or water	83.3
3	Poor localization	66.6
4	Service difficulties	66.6
5	Get easily damaged with dust and sweat	50
6	Battery consumption is too high	40
7	Inability to hear background noise	40
8	Difficulty to get spare device	38.6
9	Parents are afraid to send children for playing	26.6
10	Reduction in size of hearing aid	25.8
11	Squealing noise	16.6

Table 2. Parental Reported Short Comings in the Services of Hearing Aids Provided

The expectations were improvement in localization, response to soft sounds, acceptance from society and that the child will hear and speak (Table 3).

Sl. No.	Expectations	Percentages of Respondents
1	Improvement in localization	83.3
2	Expected that the child will hear and speak	81.3
3	Response to soft sounds	65.5
4	Acceptance from society	62.6
5	Good performance in society	53.4

Table 3. Expectations Reported by Parents (N-67)

The important suggestions given by parents were also tabulated (Table 4).

Sl. No.	Suggestions	Percentage of Respondents
1	Government therapy centres in all districts	76.6
2	Rechargeable / long life battery	73.3
3	Increase availability of water proof hearing aid	68.6
4	Good quality hearing aids should be provided	66.3
5	Easily accessible service centres	50
6	Reduction in size of device	46.5
7	Reduction in cost of disposable battery	38.6

Table 4. Suggestions Reported by Parents

DISCUSSION

Prior social gatherings, interviews and collection of data with the help of open or closed format of semi-structured question formats are very useful in assessing the expectations of parents of children undergoing Cochlear implant surgeries. They are also similarly useful in assessing the outcome during follow-up intervention. These questionnaires would give parental expectations from children after cochlear implantation on real life situations. There are very few such studies exploring the parental expectations,^{7,8} parental satisfactions after implantation,⁹ rehabilitation following implantation¹⁰ and parental stress.¹¹ The main domains of parental expectations included were improvement in communication abilities, social skills, and academic achievements, as well as a change in their future life, rehabilitation demand, parental satisfaction and a stress-free life. The Parent's perspective of undertaking a cochlear implant in their children was that it offers deaf children an opportunity for improved social relationships. The improvement specifically was expected to improve the

children's hearing and speech which in turn also has the potential to change the children's personality, increase their level of confidence. In this study the overall benefits, short comings, expectations and suggestions were documented. In Indian context, as there are diverse cultural differences and socio-economic populations, it is mandatory to study the change in the quality of life based on parental expectation before and after the implantation.¹² Some of the benefits reported by parents of pre-implants were: 1. First word utterance in 93.3 % of children. 2. Response to loud sound in 83.3 %. 3. Improved listening in 66.6 %. 4. Request for personal needs in 40 %. 5. Comprehension of words in 35.3 % (Table 2). Prawin Kumar et al.¹² observed that 70 % of the parents reported stress due to the existence of a hearing-impaired child. In the present study the stressed out parents were 67.16 %. From her study Rashida muslim Hasuji¹³ observed that parents of pre-implant children responded positively to the questions, whether they would believe that their children would be benefited by the implant in communication with others (100 %), listening to speech without lip reading (75.9 %), and in the development of speech and language 24,1 %). However, the expectations were much higher in two domains: 1. communication and 2. The development of speech and language (86.16 %), signifying that the parents expected a definite improvement in these two areas after implantation. In the present study the expectations of parents regarding improvement in localization was 83.3 %, Expectation that the child will hear and speak was among 81.3 % of the parents, Response to soft sounds was expected by 65.5 % and acceptance from society was observed in 62.6 % of the parents (Table 3). Such studies would provide valuable information to the health care professionals regarding the important issues the families expect and their variations that could help them plan the interventions and rehabilitation of the children with cochlear implants.

A similar study by S Chundu et al.⁶ in 2012, among implanted children showed that although speech and language development was the major concern, parents reported improvement in comprehension of words, response to loud sounds, social relationship and self confidence in their children. In the present study 90 % of the parents were concerned about the frequent defects in the functioning of the hearing aids and its maintenance services. In the present study the parents were having higher expectations even before using the hearing aids, but they could not achieve them. 66.3 % of the parents suggested that Government can provide better quality hearing aids to pre-implant children who have profound hearing loss as hearing aid damage, maintenance and care was the main concern among parents. Even though speech and language development were the major achievements expected by the parents, they also looked forward to improved communication skills, social relationships, and self-confidence for their child.¹⁴ The parents were also anxious about a possible device failure and maintenance of the cochlear implant equipment was another major concern.¹⁵ Continuous counselling of parents of pre-implant children for cochlear implants is necessary to convince them in regards with child's impairment, amplification, the device, the

surgery, rehabilitation and of their expectations and outcomes. The expectations of the parents are the key factors in the selection process of children with hearing impairment which were used previously as the key criteria in the evaluation of the child's fitness for an implant.¹⁶ If such counselling is not done then the parents were bound to presume that once the implant is inserted the child would be able to hear itself immediately after switching it ON.¹⁷ Kampfe et al.¹⁶ recognized that such presumptions were possible because of the high cost of the device and its technology giving rise to unreasonable expectations. They also felt that the media was playing their role of highlighting the sensational reactions of parents towards the little responses of their children to sounds.¹⁶ Such illogical expectations from the parents would subsequently lead to stress and these expectations could lead to unrealistic forecasts, subsequent stress, and despondency in the absence of true response to sound by their children; the stress by the families' of children who have undergone CI have been the subject of many studies from various sources.¹⁸ One of analogous sources was the surgical procedure itself, even though the procedure was safe, with little chance of complications,¹⁹ it remained as a source of stress. Parent's perceptions are another source of stress when their calculations are not met with immediately.²⁰ It would take some time for the stress in parents to subside which happens only after their children show some response to sounds and conversations.

Sach & Whynes²¹ after talking to nearly 216 parents of children with CIs in Nottingham Paediatric Cochlear Implant Programmes, wherein they used a blend of open-ended and structured question formats which observed that 1. 38 % wanted improved hearing, 2. 23 % expected psychosocial and behavioural benefits, 3. 19 % mooted better moments later in life while 4. 16 % quoted improvements in speech.²¹ In a study by Holt R et al.²² who surveyed 247 parents in eastern Australia, regarding their expectations, experiences and stresses before and after CI implantation of their children, found that even though their expectations were high, they were met in 90 %. Only 10 % of parents reported poor performance by their children. The study also proved that all the doctors and health personnel and audiologists did their job well giving them ultimate satisfaction to meet the parent's realistic expectations prior to implantation and during rehabilitation.²³ Hence Perspectives of parents, guardians towards the CI, and their children could influence the acceptance by the child improvement after implantation, as these can affect factors such as the level of support given at home, roles undertaken by family members in therapy, their interactions with the child, and organisation and control in homes.²⁴ On the other hand parental perspectives towards the CI surgery also influences their view points towards the programmes of rehabilitation and their imparting relations with the child, punctuality in attending the follow-ups, interest in the verbal therapy and sincerity in home based exercises to improve their children. Results from the present study showed that the parents of CI pre-implantation children have very high expectations and the trust from the social security schemes were a bit lower. They expected that the CI surgery would totally cure the hearing impairment of

their children immediately and improve the communication with others and in speech and language development, they expect still better services and better hearing aids with low costs of repairs. They do not doubt the implant per se as they have frequent contacts with already implanted children and their parents. These findings were also observed by Nikolopoulos et al.²⁴ where 81 % and 86 % of parents interviewed responded positively in response to two fields; the success of the surgery and improved hearing in children respectively. Whereas 75 % of the patients trusted that CI would certainly help the child in this domain to some extent.²⁵

CONCLUSIONS

The emphasis given to various aspects of shortcomings was different in this study from other countries. The parentally reported expectations, short comings, and outcomes of use of hearing aids could be related to many factors like health care services provided by the government, the after services of hearing aids involved. These findings help us understand the parental perspectives of the success of cochlear implantation and will be useful during parental counselling sessions. The study also would be useful to the implant centres to revise their practices accordingly and improve the information given to candidate families. The study could be useful for the hearing aid manufacturers and government to improve the quality of hearing aids and service centres that will help each candidate for a better outcome. Government pre-implant therapy centres at district headquarters would reduce commutation time and expenditure incurred towards transportation.

Data sharing statement provided by the authors is available with the full text of this article at jebmh.com.

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