Pediatric Cochlear Implantation—Why the Delay

Shenal Kothari · Nirnay Kumar Keshree ·
Salaj Bhatnagar

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Abstract The aim of the study was to evaluate the factors that act as barriers and delay the process of cochlear implantation in children with congenital profound sensorineural hearing loss. This is a cross sectional observational study in which 154 children with profound sensorineural deafness attending ENT outdoor from Jan 2013 to June 2014 at Sri Aurobindo Institute of Medical College and PG Institute, Indore, were included in the study. Information was taken from the parents of the candidates regarding the reasons for the delay in reporting, the delay in intervention and a detailed history was also taken to evaluate the possible reason for the hearing loss with the help of open ended questions. The most common cause for the delay in reporting was lack of information about the availability of technique and procedure for cochlear implant. Financial constrain was the most common cause for the delay in getting the cochlear implant surgery.

Keywords Cochlear Implant · Brain Plasticity · Critical period · Auditory verbal therapy

Introduction

Cochlear implantation is the most successful sensory prosthesis currently in use and is a gift of hearing to deaf population. There is enough evidence to state that cochlear

implant surgery when done in time holistically improves the quality of life of congenitally deaf children. The advantages of cochlear implant surgery are multifold as it affects the communication skills of the individual. It is a well-known fact that auditory stimulation at first 6 months of infancy is vital for acquiring speech and language [1]. In account of critical period for speech and language acquisition, difficulty in hearing during first 4–5 years of life has an irreversible negative impact on auditory processing skills and academic, social, emotional and behavioral repertoire [2].

As per the data from WHO 360 million individuals in the world suffer from disabling hearing loss, and of these 9 % are children and 91 % are adults [3]. With the increasing evidence of the safety of cochlear implant surgery in infants increasing number of younger infants are receiving implants [4–6]. After locomotor disability in India deafness is the second most common form of disability [7]. In India, of all the disabilities, about 7 % of children born with hearing deficit, and the prevalence is reported to be higher in rural than urban areas, irrespective of the gender differences [8]. This difference might be attributed to the lower socio-economic status of the rural population often leading to malnutrition, poorer health education and inadequate medical facilities which all increase the risk of hearing problem.

In the developing countries like India there are many hindrances for cochlear implant surgery. Deafness has many unwanted consequences like delayed and/or limited speech and language development, limited access to education, social aloofness or ridicule, underemployment or unemployment and all these have a negative bearing on physical and mental health of the child. Therefore, aural and verbal (re)habilitation should be within the reach of every deaf child. This should be done at the earliest to bring him to the mainstream of the society. Cochlear implant is indicated for all children fitting into the candidacy criteria. It is an

S. Kothari (✉) · N. K. Keshree
Department of ENT, Sri Aurobindo Medical College and PG
Institute, Indore, India
e-mail: drshenal@gmail.com

S. Bhatnagar
Sri Aurobindo Institute of Speech and Hearing, Indore, India

established fact that children who undergo early cochlear implantation achieve better outcomes than those implanted later. The plasticity of brain limits the development of the speech recognition and language acquisition after the critical period (age 0–6) years. Central neural organization for audition is likely to be affected if a child is deprived of auditory stimuli before attaining 84 months of age [9–11].

The high cost of the cochlear implant devices are beyond the reach of most of the needy candidates. Despite these financial constraints early implantation is the need of the hour and it will benefit both the society and the individual. If we calculate the financial burden of rearing a deaf child, it will in all probabilities exceed significantly the onetime cost of cochlear implant surgery. Apart from the economic concerns, in the upbringing of the deaf children there is also a need for special education and a social support system. Even after putting in all the efforts aforementioned, contribution of the deaf individual in terms of his social role or meeting his own financial needs will fall short. This population due to absence of auditory perception cannot acquire speech and language required for the desired quality of life and hence independence.

There can be one or multiple causes for hearing loss in a child. The list of risk factor for hearing impairment is long and includes, any illness or condition requiring admission of 48 h or more to NICU, syndrome of conductive and or sensorineural hearing loss, family history of permanent childhood sensorineural hearing loss, consanguineous marriage, craniofacial anomalies, in utero infection by TORCH group of organism, birth asphyxia (Apgar score of 3 or less at 1 min of age), hyperbilirubinemia (serum bilirubin level >20 mg/dl, postnatal infection), syndromes of progressive HL (neurofibromatosis, osteoporosis & Usher's syndrome), neurodegenerative disorders (Hunter syndrome, Friedreich's ataxia & Charot-Marie-Tooth syndrome), head trauma, recurrent or persistent otitis media for at least 3 months (JCIH, 2007).

So, in order to detect the lacunae which prevent the hearing disabled population from getting timely access to hearing and speech a study was carried out at SAMCPGI, Indore. Also, wherever possible an attempt was made to identify the cause for the disability. This study included all the children attending ENT outdoor from Jan 2013 to June 2014 suffering from severe to profound sensorineural hearing loss. By resolving the factors responsible for delay congenitally hearing impaired population can be offered programs for early diagnosis and intervention and also to take up remedial measures wherever possible.

Materials and Methods

154 children with severe to profound sensorineural deafness attending ENT outdoor from Jan 2013 to June 2014

were included in this cross sectional observational study. It includes both the categories of children, the once who have undergone CI surgery and those who are to be implanted. Information was taken from the parents of the candidates regarding the reasons for the delay in reporting and a detailed history was also taken to evaluate the possible reason for the hearing loss by asking open ended questions. The implant team in our department felt that upper limit of 3 years was in acceptable time frame for cochlear implantation and were included in the study. The target population was all such children who didn't have access to auditory intervention or to CI surgery until after age of 3 years. All children who could benefit from hearing aid and had less than severe to profound hearing loss were not included in the study. The data was collected with main emphasis on age of detection of hearing loss and age of implantation. If there is a delay, the reason for the delay was sought. Data was analyzed for demographic information, complaints, onset and nature of problem, family history and medical history and prior medication. Demographic information included, if the child lived in an urban or rural community. All the information was compared with risk factors for hearing impairment. Open ended questions were asked to parents for assessing the reason of delay in identification and intervention of hearing loss in their children.

Results

Demographic characteristics, onset, age of identification and aural intervention of sample are shown in Table 1. More than 95 % of children were identified with severe to profound hearing loss after their first birthday. (Table 1).

In total, 76 subjects had an average age at implantation of 5.07 years and the median age of implantation of 4.5 Years. Table 2 shows the cause of delay in assessment and intervention of hearing loss in children. In all patients there were more than one reasons for delay in the decision for implantation. High cost of the device delayed the decision for cochlear implant surgery in 96.10 % children. None of the children had undergone newborn screening for hearing assessment and therefore none of them were detected early enough for early start of the intervention process. (Table 2).

Non availability of technically qualified staff for guidance, referrals and care was a barrier for delay in approach in 36.36 % cases. Parental factors (like illiteracy, non acceptance to surgery, denial to accept the disability) were responsible for delay in most of the cases. There was a definite difference in delay for children from an urban (41.3 %) or rural (58.3 %) community.

Table 1 Demographic characteristics, onset, age of identification and types of hearing loss of sample

Sample characteristics	N 154
Male/Female	85/69
Rural	58.7 %
Urban	41.3 %
Socioeconomic class (SEC)	
Upper SEC	15.5 %
Middle SEC	36.5 %
Lower SEC	48.0 %
Education of the parents	
Below 10th standard	24 %
Up to 10 + 2 standard	51 %
Graduation	14 %
Higher than graduation	11 %
Age of children	
Mean (SD)	5.62 year (2.9)
Age range	10 months to 11 years
Age of identification	
Within 1 months after birth	0.65 %
Before 1 year (2–12 months)	3.9 %
1–3 years	87.79 %
After 3 years	7.66 %
Age of aural intervention (with hearing aid)	
Before 1 year (2–12 months)	4.5 %
1–years	57.79 %
After 3 years	37.66 %
Age of aural intervention (with cochlear implant)	
Implanted child	76
Age range	11 months to 7 years
Mean (SD)	5.07 (2.6)
Self funded/sponsored	22/46
Before 1 year (2–12 months)	2/52
1–3 years	19/52
3–5 years	32/52
After 5 years	22/52

Discussion

Normal hearing is crucial to normal development of language and this “normal” language and listening cannot develop in absence of auditory experience of spoken language and interaction. Number of auditory skills are present in infants born with normal hearing and these are crucial to development of language; many of these proficiencies appear to be present as early as birth or beforehand [12–15]. Children with severe to profound sensorineural hearing loss do not have the benefit of early exposure to spoken language due to limited linguistic input and therefore lag behind in development of spoken language [16–22].

Table 2 Causes of delay in intervention (reported by parent)

Lack of awareness (what to do and where to go ?)	76.6 %
Parental delay in acceptance of hearing loss due to social stigma	20.12 %
Delay due to casual approach (child is too small and hearing loss is not visible)	36.36 %
Consulted other professionals but poor referrals and hope	36.36 %
Belief in fake spiritual myths	10.38 %
Hope from future medical sciences invention (i.e. Gene therapy)	3.24 %
Delay in children acceptance of hearing aid	13.63 %
Fear from intervention and or surgery	5.84 %
Fully aware but financial problem	
a. For hearing aid and oral rehabilitation	31.81 %
b. For cochlear implant and oral rehabilitation	96.10 %
Delay due to more than one reason listed above	97 %

Earlier implantation prepares the brain systems for better language learning during infancy and therefore provide an earlier start in language learning [23–25]. Neural plasticity is believed to make significant contributions during sensitive periods in the maturation of the auditory system, in barn owls [26] and this has also been demonstrated in human [9, 10, 27, 28]. The auditory system can mature in a normal fashion only if there is adequate sound stimulation [29]. The deprivation period of more than 3 years when the child is under the age of 6 years restricts the normal maturation of auditory cortex. The auditory system can retain its plasticity during the period of deafness since the re-introduction of stimulation by the cochlear implant resumes the normal maturational sequence within this critical period [29]. This makes early detection and timely intervention mandatory if we want these children to join the mainstream of the society or to attend normal school. In one study by Tye-Murray et al. [30] it was found that children implanted before the age of 60 months showed significantly better speech production than those children implanted after the age of 60 months.

The very same results were later reported by Fryauf-Bertschy et al. [31]. Similar reports stating better outcome with implantation before the age of 60 months have been reported by Connor et al. in 2000 (higher expressive and receptive vocabulary score [32], Geers, Nicholas et al. in 2003 (higher verbal reasoning scores [33]) Geers in 2003 (better reading skills [34]) and Svirsky et al. in 2000 (spoken language acquisition, [35]) when compared to children implanted after the age of 60 months.

As per the demographic data collected according to the open ended questionnaire, 0.65 % children were detected at the age of 1 month, 3.9 % children were detected between 1 month and 1 year, 87.79 % children were detected between 1–3 years and 7.66 % children fell in age more

than 3 years, who were included in the study. Out of these 76 children have been implanted and 32 are waiting to be implanted, 46 could not be implanted for various reasons like age more than 7 years or existence of other comorbid medical conditions. In this study the optimal upper age was 3 years for implantation. Children who receive implants at earlier age outperform their peers who are implanted at a later age. This is reflected in all the areas of speech and language development. These children can achieve performance comparable to their normal hearing counterparts if implanted within 2 years of age [4, 5, 36–38].

Early identification of hearing deficit is the most important and key factor for timely intervention in the management of congenitally hearing impaired population. Various studies mentioned above support this statement. Due to lack of availability of adequate hearing screening programs in India detection of deafness in early infancy is not possible. Although some institutes run a deafness screening program, most medical centers need to incorporate the same.

The most significant inhibiting factor for Cochlear implant surgery is the cost of the device. It is very difficult for a common man to afford a cochlear implant. These patients suffer from dual disability which is not understood by others as they do not look disabled by appearance and are absolutely healthy otherwise. Therefore, the concern and sympathy in the society is negligible. Even the insurance agencies do not have any provision for CI surgery and do not re-emburse the expense of the implant surgery. Arranging for the finances takes a long time and by this time the critical period has already passed resulting in delayed intervention. Maximum parents (96.1 %) said that cost was the barrier which prevented cochlear implant surgery of their child at early age.

At the rural level there is lack of awareness about the value of early intervention. Even the health professionals involved in the child care do not know the value of early implantation. It is still believed by few professionals especially at the rural level that the intervention should not be done in early years. In this case study 10.38 % patients reported late due to this myth. There is lack of awareness about existence of the cochlear implant technology in many rural areas. In this situation it is not possible to spread the related benefits. The trained personnel to educate the implanted children is again a major obstructing factor. This prohibited children from early intervention. It is very important to have centers providing effective postoperative AVT in rural parts of India as it is not possible for all parents to actually shift. Traveling long distances for diagnosis and treatment hindered parents to approach the right institute. Therefore, timely referrals were delayed.

Illiteracy of the parents also contributes to non-compliance regarding the investigations as well as agreement to

take the treatment. It is very difficult to counsel these parents regarding the need of the implant and its benefits due to educational handicap. In our study 36.36 parents reported late for this reason and it was only after they met the implanted children undergoing AVT that they could be convinced.

Many parents (20.12 %) were not ready to accept the disability and therefore no medical assistance was sought by them and this denial delayed the intervention. Some of them did approach charlatans to solve the problem but this was of no use. When they reported, the child had crossed the critical period. This issue is of major concern especially in rural India. Also, at times allied medical specialists give false hope to the parents that they can cure the deafness of the child. Implantation in these children is delayed because lot of time elapses in decision making for therapy. Our study had 10.38 % such patients. Eight children had medical issues and could be operated only after this was treated. Some of the conditions like psychosocial delay in six patients prevented the implantation. Four parents had issues regarding wearing of the external device. They could however be easily convinced. Parents of nine children fit CI candidates were worried about getting the child operated at an early age and by themselves decided to wait until the child was 4–5 years in spite of the counseling efforts.

Conclusion

The data suggested that in majority of patients cost prevented children from receiving cochlear implants at the right age. The other factors that delay cochlear implant surgery are inadequate hearing screening programs for the newborn, ignorance about the importance of early intervention and referral to an implant center amongst the parents and primary care providers. These delays in implantation can be overcome by taking appropriate measures to improve facilities for early detection. Initiatives must be taken by the social organizations, NGOs and local government bodies to financially support all such families. The insurance companies need to incorporate schemes for the benefit of profoundly deaf pediatric population. The life of congenitally deaf children can be improved and the cost of their care to society can be reduced only with radical changes in the infrastructure designed to take care of such disabilities. To conclude, to resolve the factors that delay cochlear implant surgery, there should be universal neonatal hearing screening, facility for early referral, diagnosis, and intervention for infants with hearing loss and awareness of the benefits and efficacy of cochlear implants for young children. This will allow increased rates of language acquisition in the children who are still in the critical period of their development.

In conclusion to overcome the effects of deafness, all infant should have access to hearing screening by objective instruments (automated auditory brainstem response, otoacoustic emission) by 1 month of age, the audiological and medical evaluation to confirm the presence of hearing loss should have been completed by 3 months of age and early intervention services should be started as soon as possible after diagnosis preferably not later than 6 month of age (Joint Committee on Infant Hearing: JCIH, 2007).

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