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Parental Awareness of Children with Cochlear Implant

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Abstract – A large number of parents are getting cochlear implants for their children with hearing impairment. This leads to getting their children admitted into regular schools. Since now schools have started taking admissions of children with disabilities it was important to note the parents' experiences and all that they face in schools. Therefore, present study is conducted on 'Experiences of parents of children with cochlear implant attending regular school – A Survey'. It is a descriptive survey with purposive sampling. The study collected parental experiences in three major areas – administrative, scholastic and non-scholastic. 30 parents participated in this study whose children used cochlear implant for more than 3 years, were 6 – 16 years in age, attending regular school from minimum 3 years. A questionnaire was developed and validated for the study and was further translated to English, Hindi and Marathi. Questionnaires were responded either through interview method or mail.

The overall experiences of parents of children with cochlear implant attending regular school were found to be positive. The study concluded that even though there are several challenges faced by the children with cochlear implant and their parents in a regular school set up, a majority of children were happy according to their parents and the parents were satisfied with their experiences in regular schools.

Keywords - Cochlear Implants, Children, Schools

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INTRODUCTION

Cochlear implantation has become a widely used technology for children with severe to profound hearing impairment who do not benefit with conventional amplification. Cochlear implant gives a child with HI a useful representation of sounds in the environment and helps him/her to understand speech, and acquire spoken language. As of December 2012, approximately 3, 24,000 people worldwide had cochlear implants surgically implanted (Estimates provided by the U.S. FDA). In India, though it is an expensive technology, more and more persons with HI are getting access to CI. This number has gone up considerably since it has been introduced in the Revised ADIP scheme (2014).

CI for congenitally deaf children is considered to be most effective when implanted at a young age, during the critical period in which the brain is still learning. Researchers have shown that young children with CI who have received pre and post therapies develop language skills at a rate comparable to children with normal hearing and many succeed in regular classrooms. As most children with CI are likely to be educated orally, a majority of them approach regular schools for their education. Under the RTE Act 2009 and PWD Act 1995, no school can deny admission to children with

disability (CWD). Also, due to the zero rejection policy regular schools are increasingly admitting children with CI. However, there is no research detailing the experiences of these children attending regular schools alongside children with normal hearing. It is not clear whether a child with Ciattending regular school has

similar experiences as that of a normal hearing child. Based on the areas of school experiences, the present study was subdivided into 3 major areas.

- A. Administrative Experience
- B. Scholastic Experience
- C. Non-scholastic Experience

NEED AND RATIONALE FOR THE STUDY:

The need for conducting the present study is as follows:

 The obtained experiences will help in counselling other families during the educational intervention of their children with cochlear implant. Since the parents are often anxious about placing their child in a regular school environment, this survey will help in guiding them towards developing realistic expectations from the regular school setting for their children with CI.

AIM AND OBJECTIVES OF THE STUDY:

The aim of the study was to survey the experiences of the parents of children with cochlear implants attending regular schools. Based on the aim, the objectives framed were as follows:

- To collect "school administrative experiences" of parents of children with cochlear implant attending regular school.
- To collect "scholastic experiences" from parents of children with cochlear implant attending regular school.
- To collect the "non-scholastic experiences" from parents of children with cochlear implant attending regular school.

Research design:

The present study is a survey research.

Sampling:

Purposive sampling method was used in the present study.

Research questions:

Based on the above mentioned objectives, the research questions framed were as follows:

- What are the experiences of parents of children with cochlear implant studying in regular school with regard to school administration?
- What are the experiences of parents of children with cochlear implant studying in regular school about their scholastic participation?
- What are the experiences of parents of children with cochlear implant studying in regular school about their children's nonscholastic participation?

METHODOLOGY:

Descriptive survey research design was used for conducting the present study. Parents of children with cochlear implant attending regular school were recruited as the participants of the study through purposive sampling. A researcher made tool was

developed and used with the participants. Details of children were taken and 30 samples were finalized. The inclusion criteria of the children were as follows:

- Age between 6 16years.
- Both girls and boys.
- Minimum implant age of 3years.
- Congenital or pre-lingual hearing loss.
- Bilateral severe to profound sensori-neural or mixed hear in gloss.
- Use of a multichannel cochlear implant of any company in one ear with or without a hearing aid in the other ear.
- Attending regular school for a minimum 3years.
- No presence of any associated impairment such as mental retardation, autism spectrum disorder, attention deficit hyperactivity disorder, visual impairment, cerebral palsy, cleft lip and palate or any syndrome.

Here, language spoken and the education of parents were not marked as the inclusion criteria hence, we were open to any language of the parents. An Informed consent was taken from the parents. The questionnaire was administered on the parents by the researcher. The questionnaire was read out (interview method) by the researcher depending on the parents' literacy and was mailed to 1 participant.

RESULTS OF THE STUDY:

Following are the results obtained:

Area A: Administrative Experiences

The total scores for Area A for the 30 participants ranged from 19 to 27 with a median score of 21. It indicated that out of the 30 parents 29 parents had a Fair experience while 1 parent had a Good experience for administrative aspects at their children's school and for their admission procedures. 56% parents stated that the schools got their children with cochlear implant admitted without any resistance. This could be because of the 'Right to Education Act (RTE)' which enforces the 'Zero rejection policy' among schools. 29 participants stated that the schools laid no conditions for admitting their child in the school. 83% parents got their child admitted to the very first school that they approached. 23% parents stated that the schools provided the facility of a visiting special educator mostly once or twice a

month, which shows these schools invite Sarva Shiksha Abhiyan (SSA) special educators. 63% schools were aware of hearing impairment as a disability as well as about children with hearing impairment.

Area B - Scholastic Experiences

The total scores of parents for Area Branged from 33 to 54 with a median score of 42. It indicated that out of the 30 parents 27 parents had a Fair experience while 3 parents had a Good experience for their child's scholastic experience. 96% parents agreed that they are worried about their child's higher educational opportunities. 73% parents followed with the fact that the same medium of instruction at home as well as school would benefit the child more and made sure the language used with the child remained same. 93% schools did not provide exemption from one language paper but most of the parents stated that they will enquire once their child in 10th and 12th class for board exams. According to the parents, 40% children could always follow the teacher's dictation and 40% children could sometimes follow and at times had missed the dictation given by their teachers. Rest of the 6 students couldn't follow when their teacher dictated. A majority of children (43%) did not require visual help to communicate whereas 26% children sometimes needed the visual support or lip reading and 30% always needed visual support for communication. 90% parents stated that the class teacher does not check the proper functioning of their child's implant machine. 73% parents stated that the teachers does not give extra time to their children after class to clarify concepts. One parent said that the teachers sometimes had taken remedial classes for their child and rest of the 23% school teachers always made sure of giving extra time and remedial help to the children after classes. 70% children sat in the first row in their class. 93% parents stated that the school does not have too low expectations in academics from their child, whereas 16% parents felt that the school holds too high academic expectations from their child. 30% stated that their child never lags behind other children in 100% felt that their child may underperforming and can display better performance than current and 63% parents were satisfied with their child's progress.

Area C - Non scholastic Experiences

The total scores of parents ranged from 50 to 69 with a median score of 64. It indicated that out of the 30 parents 27 parents had a Fair experience while 3 parents had a Poor experience for their child's scholastic experience. 90% parents stated that their child understands his/her peer's conversational language well. 93% parents stated that their child could interact fluently with his/her classmates and 60% children interacted with their teachers without hesitation. 73% parents stated that their child did not need any support of non-verbal cues to

communicate. 93% parents positively felt that their child was treated equally in the class. 100% parents stated that their child had normal hearing friends. 86% parents observed that their child was more comfortable with other children having normal hearing. 63% parents assured that their child was not teased or bullied by other children. 86% parents feel that the class strength in their child's class is too high ranging from 30 - 70 students per class. All 100% parents stated that their child's bench partner is a normal hearing child. 83% parents stated that their child was comfortable with their bench partners when they sat with normal hearing children. 76% said that their child does not feel left out in the class at all. 86% children never faced other children destroving the implant machines and parents said that their classmates were aware of the importance of the implant. 76% parents stated that no attitudinal barrier or neglect is shown by other parents or other staff members towards their child. 80% of the children were equally encouraged to take part in school functions and festivals and 90% of the parents stated that the teachers always spoke to them encouragingly in the Parent-Teacher-Meetings. 93% parents stated that their child was happy to attend regular school.

CONCLUSIONS OF THE STUDY:

- 1. The overall experiences of parents of children with cochlear implant attending regular school are positive.
- 2. More positive experiences are reported in administrative and scholastic areas, as compared to non-scholastic area.
- 3. Though there are several challenges faced by the children and the parents, majority are happy and satisfied with their experiences in regular schools.

LIMITATIONS OF THE STUDY:

- 1. The sample size was very small, i.e. 30 participants only.
- 2. The participants in the present study were not geographically scattered but were all from urban area like Mumbai.
- Clinical assessment of the children was not carried out to corroborate the reports of the parents. There is a possibility that parents have over or under rated their child's performance.
- 4. Experiences in public schools versus private schools were not compared.

RECOMMENDATIONS FOR FURTHER RESEARCH:

- Similar studies could be conducted covering large sample from more districts.
- Comparative study on the basis of economic backgrounds can be done.
- A comparative study on the basis of unilateral CI and bilateral CI can be taken up.
- Experiences of parents based on type of school can be reported.

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