

International Journal of Research in Special Education

E-ISSN: 2710-3870
P-ISSN: 2710-3862
IJRSE 2022; 2(2): 01-04
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www.rehabilitationjournals.com
Received: 03-04-2022
Accepted: 05-05-2022

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Challenges faced by parents during post-operative rehabilitation for children with cochlear implant under ADIP scheme

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Abstract

Parents of children with disabilities share the concerns of all parents about child-rearing, about education and also have additional concerns related to their children's disabilities. Understanding the concerns and perspectives of these parents is essential to working with them effectively as partners in their children's education. Just as it is unwise to generalize about students as if all students were the same or about parents as if all parents or all families were the same, so it is unwise to generalize about all parents of children with special needs, assuming that they are all the same. Not only is the range of special needs and disabling conditions vary, but parents and families also vary in their identity, styles, concerns, approaches, values, involvement, and backgrounds. Having said that, it is possible to articulate a set of issues and concerns that commonly arise for many parents of children with disabilities. Not every concern will apply to every child and every child's family; however, it is useful for re/habilitation professionals as well as paraprofessionals to sensitize and orient some common concerns that are unique to families of children with disabilities. Parents play the most important role in the overall development of their child with disability. It is the right guidance of parents that develops the character as well as the overall development of the child. Rout and Khanna (2012) found that in India, the mean age of detection of hearing loss among children is approximately 3 year (standard deviation: 1.3 year) and habilitation begins on average at the age of 7.4 year (standard deviation: 4.1year). The majority of published research studies investigating cochlear implantation in children have focused on children's audition, speech production, speech perception, spoken language development as well as. Cognition. As time goes on, it is becoming more possible to report on longer-term outcomes of children's functioning in their everyday lives at home, at school, and in the community. The present research study aims to study the challenges faced by parents in post-operative rehabilitation of children with cochlear implantation under ADIP scheme.

Keywords: Post-operative rehabilitation, parents of cochlear implant children, rehabilitation professionals, challenges

Introduction

The efficacy of cochlear implant in children is becoming increasingly well established, particularly in terms of auditory and speech perception outcomes (Nikolopoulos *et al.*, 2001^[21], and speech production (Robbins *et al.*, 1994)^[13]. The success of pediatric cochlear implants has also been documented in terms of language skills (Hasensteb and Toby, 1991; Robbins *et al.* 1994)^[13] and educational achievement (Selmi, 1985)^[16]. Hearing loss causes difficulties in the ability of understanding speech sounds and, hence, result in social and family withdrawal, low self-esteem isolation, loneliness, depression, and irritability. All these factors affect the quality of life (QoL), for they impaired socialization and individual's participation in the group the person belongs to severe and or bilateral profound sensorineural hearing loss has been long regarded as a change that does not allow the individual to communicate or even identify environmental sounds such as alarms and siren, which limits their social activities. Currently, electrical inputs stimulate the remaining nerve fibers of the cochlea. Assistance to Disabled persons for purchasing/fitting of aids/appliances (ADIP) scheme is to assist the needy disabled persons in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances that can promote their physical, social and psychological rehabilitation, by reducing the effects of disabilities and enhance their economic potential. Cochlear Implantation under ADIP Scheme: The objective of inclusion of cochlear implantation under the revised ADIP Scheme (effective from 2014) is to provide cochlear implant to children and support for auditory verbal habilitation to operated children through empanelled rehabilitation centers.

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Need for the Study

Hearing parents with a recently diagnosed child with deafness generally find themselves negotiating with a world previously unknown to them. After the diagnosis of their child's deafness, parents may be presented with, or need to seek out, a great deal of information about deafness and the educational, communication, and technological options for deaf children. Given the need to integrate and assimilate so much information at a time when they are likely to be experiencing heightened emotions, making decisions about cochlear implantation is often difficult and stressful for parents. Parent engagement in schools is a shared as well as collective responsibility in which schools and other community agencies and rehabilitation professionals are committed to reaching out to engage parents in meaningful ways, and parents are committed to actively supporting their children's learning and development. This relationship between rehabilitation professionals and parents rather than stakeholders cuts across and emphasizes children's health and learning in multiple settings like; at home, in school, in out-of-school programs, and the community. Parents play the most important role in the overall development of their child with disability. It is the right guidance of parents that develops the character as well as the overall development of the child. Parenting is an ongoing job. It is not something one can get away from once the time comes, because children need their parents from time to time, to stay on the right track. Parenting and child development in the domain of disability go hand in hand. The proverbs that the apple does not fall far from the tree and that the branch grows as the twig grows can well-describe the effects of parenting styles on child growth and development. All development is interrelated and cannot be defined under water-tight categories. The role of parents in child development is responsive, responsible, and never-ending. It governs the responses, actions, thinking, and decision-making of a child in all the areas of personality. While children are, in many respects, the primary most direct consumers of such services, parents or carers are also users of these services. Parents or carers are also often more able to comment on their experiences and those of their children than the children themselves, who are typically too young to do so. This is particularly true of deaf children, who have additional communication difficulties. The implant of CI in children and adolescents with severe or profound hearing loss goes beyond improvement in the perception and production of speech and language development, thus encompassing physical and mental health, that is QoL. Parents can provide a good evaluation of the process of therapeutic intervention evaluation with their children. Their satisfaction is a marker for the development of children and shows that CI reaches or exceeds intervention expectations.

Explanation of Key Terms

- 1. Children with Cochlear Implant:** For the present study, children with cochlear implant refers to children who are surgically implanted with cochlear implant by the Doctors registered with AYJNISHD (D) under ADIP scheme who are under the age range of two to six years residing in Mumbai.
- 2. Post-operative Rehabilitation Services:** Those children who are operated under ADIP scheme availing services which includes mapping, language, and speech

therapy by the rehabilitation professionals those who are registered under AYJNISHD (D) ADIP scheme in Mumbai.

- 3. Parents of Cochlear Implant:** For the present study, those parents whose child has been surgically implanted and are taking post rehabilitation services under ADIP scheme in Mumbai.
- 4. Rehabilitation Professionals:** For the present study, rehabilitation professionals refer to professionals who are registered with AYJNISHD (D) under ADIP scheme in Mumbai.
- 5. Challenges:** For the present study, challenges refer to the score obtained by parents of children with cochlear implant in researcher made tool in the domain of services and care and maintenance.
- 6. Aim of the study:** To study the level of challenges among the parents of children with cochlear implant availing post-operative rehabilitation services under ADIP Scheme.

Research Questions

The study addresses the following research questions:

RQ1: What is the level (h/m/l) of challenges in services faced by parents of Children with cochlear implant availing post-operative rehabilitation services under ADIP Scheme?

Review of Literature

The identification of a child's hearing loss is a distressing time for parents, often eliciting intense emotional responses to diagnosis (Koester and Meadow-Orlans, 1990). Following these initial responses, parents must undergo a process of adaptation to the various challenges uniquely associated with raising a child who is deaf, which include modifying communication strategies, becoming involved in medical and educational decision making, working with professionals across a range of disciplines, learning about technological support, obtaining appropriate intervention programs and services, and dealing with additional financial and childcare pressures (Calderon and Greenberg, 1993; Sass-Lehrer, 2012) ^[5, 15]. Today, one of the first rehabilitation decisions that parents must be faced is whether or not to select a cochlear implant (CI) as the sensory aid of choice for their child who is deaf- an increasingly common pediatric rehabilitation option (Spencer and Marschark, 2003) ^[17]. Following the stressful, taxing decision to implant their child (Incesulu, Vural and Erkam, 2003; Li, Baid, and Steinberg, 2004; Ruben, 1995; Spencer, 2004) ^[22, 17, 19], these parents confront other unique challenges. They must cope with considerable anxiety and fear before and during their child's surgery (Chute and Nevins, 2002; Perold, 2000) ^[20] followed by an extremely demanding rehabilitation process that requires extensive parental involvement (Christiansen and Leigh 2002; Chute and Nevins, 2002) ^[20]. Parents must also gain knowledge about CI's maintenance and troubleshooting (Incesulu et. Al; 2003) ^[22]. The philosophy of family-centered early intervention emphasizes families' strengths, the empowerment of parents to support their children's current and future learning and development, and the enhancement of parent-professional collaborative relationships (Bruder,

2000)^[2]. If these are desired outcomes of early intervention programs, then, adopting an agentic perspective in practice and research is warranted. As illustrated in this study, action theory provides insight into the daily actions and processes of parents and children that foster the enactment of the agency. Our view is that parents, in concert with important others (their children, family members, and professionals) take an active stance toward their parenting practices and the promotion of their children's outcomes following cochlear implantation.

Archbold *et al.* (2008)^[1] found that parents visiting their cochlear implant center had concerns about long-term re/habilitation support, lack of qualified professionals, and further education support. Information obtained from such studies conducted by a cochlear implant center would help support the parent and the CI user through the process, strengthen the re/habilitation program, and maximize benefits derived from a CI.

The cochlear implant has provided the clinical audiologist with a tool that can bring sound to many of these children with profound hearing loss. With early identification provided by newborn hearing screening programs and cochlear implants, the therapeutic landscape for a profoundly deaf child has improved immensely. Many audiologists have embraced cochlear implants so enthusiastically that they have begun to persuade parents of their value, sometimes at the time of diagnosis. It is very tempting for audiologists to assuage parents' pain by suggesting an implant right away, as if this could cure the deafness (Luterman, 2003)^[9]. Parents face practical tasks following implantation surgery. Transporting a young child to and from clinic visits may involve special arrangements and costs, especially when private transportation is not available or the travel distance is considerable (Sach & Whyne, 2005)^[6].

Methodology

The purpose of this research is to review the challenges of parents of cochlear implant children under the scheme of ADIP. The method of study was a descriptive survey using a researcher-made tool having a three-point rating scale. The sample consists of 30 parents of cochlear implant children under ADIP scheme. Five experts working in the field of Deafness were asked to list out the major areas and sub-areas under challenges of cochlear Implant. As the list received from the experts, researchers developed tool accordingly in each area and sub-area. The tool was administered to parents of cochlear implant children (n=30) facing the challenges in ADIP scheme. With the parents' consent, the researcher administered the tool, and data was collected using a survey method in Mumbai. The data gathered was analyzed in terms of qualitative analysis. Descriptive and Inferential statistics were used to analyze the data in the study. Means and standard deviations were used to analyze the distribution of the values of each item. t-test and one-way analysis of variance (ANOVA) along with Post-hoc test was used to draw the inferences on stated hypotheses.

Results and Discussions

Table 1: Data with regard to ADIP Challenges in Services

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
ADIP Challg In Serv	30	1.00	9.00	4.9667	2.05918

From the table No 1.1 it can be stated that the number of participants (N) was 30, Mean obtained is 4.9667 and Standard Deviation is 2.05918.

Table 2: Data with regard to ADIP Challenges in Care and Maintenance

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
ADIP Challg In CM	30	2.00	7.00	4.2667	1.41259

From the table No 2 it is can be stated that number of participants (N) was 30 Mean obtained is 4.2667 and Standard Deviation is 1.41259. Assistance to disabled persons for purchasing/fitting of aids/appliances (ADIP) scheme of Government of India is to support the indigent individual with disabilities in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances that can promote their physical, social and psychological re/habilitation, by reducing the consequences of disabilities and augment their economic potential. This scheme aims in facilitating the individual with disabilities by bringing suitable, durable, standard aids, and appliances within their reach.

The present study aimed to study the challenges level about the post-operative rehabilitation services among parents of ADIP CI beneficiaries. Upon data analysis, it was seen that the null hypothesis are accepted but yet, parents have also reported various challenges during therapy and mapping of the child as well as vary in the individual responses to the satisfaction level among the parents. The parental outlook presented in this study succors to develop a better understanding of parental needs and therefore gives ideas of improving services and support during the different stages of post-operative rehabilitation.

Parents are the critical evaluator of their children's well-being following therapeutic intervention. This perception is critically important in the assessment of outcomes as formal objective measures may not reflect the child's functioning in everyday situations like at home and school environment. Therefore, a parent is in the position in the household that makes them uniquely placed to assess the impact of implantation in the context within which the child grows up. This broader view of outcomes can complement the assessments measured by the professionals at the implant center, school, or home. ADIP CI scheme was launched with the purpose to help the hearing-impaired children of the lower socioeconomic family.

The parental outlook presented in this study helps to develop a better understanding of parental needs and therefore ideas of improving services and support during the different stages of post-operative rehabilitation. Furthermore, parents as a stakeholder can stipulate a good estimation of the process of therapeutic intervention about their children. Their challenges level is an indicator and sign for the development of children and shows that CI reaches intervention goals set by the Government of India under the ADIP scheme.

Recommendations

1. There was emphatic agreement among parents, advocacy groups, rehabilitation professionals as well as schools that early identification of difficulties for the child was essential. Parents and advocacy groups

suggested that the identification process needed to begin as early as possible in the child's life and certainly before school entry. Technological advances can ensure interventions at the earliest age. Parents and advocacy groups are particularly concerned that, in the absence of early intervention, secondary behaviours could develop that would endanger the child's progress within school. Schools aware that as the identification and assessment process is often protracted, slippage could occur in the provision of appropriate supports for the individual child.

2. Regarding the range and level of supports available for children with special needs especially children with cochlear implant, participants raised a number of important issues. These, in turn, relate to: some specific types of disability or demographic groups; some difficulties with the new allocation system; the role and function of special provision; and issues regarding education personnel.
3. Future research should focus on the association between expanding the candidacy profile of cochlear implants (e.g., degree of hearing loss, speech perception ability) and assessing consequent outcomes. Long-term studies are needed to assess health-related quality-of-life outcomes (both generic and disease-specific) in subjects with bilateral cochlear implantation. Future research should focus on developing quality-of-life instruments specifically designed for people with severe-to-profound hearing impairment, so that patient-reported outcomes associated with unilateral and bilateral cochlear implantation can be assessed quantitatively.

Bibliography

1. Archbold Sue Sach, Tracey O'Neill, Ciaran Lutman, Mark Gregory, Susan. Outcomes From Cochlear Implantation for Child and Family: Parental Perspectives. *Deafness & Education International*. 2008;10:120-142. 10.1002/dei.243.
2. Bruder MB. Family-Centered Early Intervention: Clarifying Our Values for the New Millennium. *Topics in Early Childhood Special Education*. 2000;20:105-115. <https://doi.org/10.1177/027112140002000206>
3. DesJardin JL, Eisenberg LS, Hodapp RM. Sound beginnings: Supporting families of young deaf children with cochlear implants, *Infant & Young Children*. 2006;19:179-189.
4. Dromi E, Ingber S. Israeli mothers' expectations from early intervention with their preschool deaf children, *Journal of Deaf Studies and Deaf Education*. 1999;4:50-68.
5. Greenberg M, Speltz M, Deklyen M. The role of attachment in the early development of disruptive behavior problems. *Development and Psychopathology*. 1993;5(1-2):191-213. doi:10.1017/S095457940000434X
6. Jamieson JR, Pedersen ED. Deafness and mother-child interaction: Scaffolded instruction and the learning of problem-solving skills, *Early Development and Parenting*. 1993;2:229-242.
7. Kluwin TN, Stewart DA. Cochlear Implants for Younger Children: A Preliminary Description of the Parental Decision Process and Outcomes. *American Annals of the Deaf*. 2000;145(1):26-32. <http://www.jstor.org/stable/44393185>
8. Koester LS, Meadow-Orlans KP. Parenting a deaf child: Stress, strength, and support. In D.F. Moores & K.P. Meadow-Orlans (Eds.), *Educational and developmental aspects of deafness*, 1990, 299320. Washington, DC: Gallaudet University Press.
9. Kurtzer-White, David Luterman. Families and children with hearing loss: Grief and coping. 2003. <https://doi.org/10.1002/mrdd.10085>.
10. Meadow-Orlans KP, Sass-Lehrer MA. Support services for families with children who are deaf: Challenges for professionals, *Topics in Early Childhood Special Education*. 1995;15:314-334.
11. Meadow-Orlans KP. Stress, support, and deafness: Perceptions of infants' mothers and fathers, *Journal of Early Intervention*. 1994;18:91-102.
12. Meadow-Orlans KP, Spencer PE, Koester Lynne. The World of Deaf Infants: A Longitudinal Study. *The World of Deaf Infants: A Longitudinal Study*. 2010, 1-278. 10.1093/acprof:oso/9780195147902.001.0001.
13. Robbins TW, James M, Owen AM, Sahakian BJ, McInnes L, Rabbitt P. Cambridge Neuropsychological Test Automated Battery (CANTAB): A Factor Analytic Study of a Large Sample of Normal Elderly Volunteers. *Dement Geriatr Cogn Disord*. 1994;5:266-281. doi: 10.1159/000106735
14. Sach T, Whynes DK. Pediatric cochlear implantation: The views of parents, *International Journal of Audiology*. 2005;44:400-407.
15. Sass-Lehrer, Marilyn. Early Intervention: Birth to Three. *The Oxford Handbook of Deaf Studies, Language, and Education*: 2012. Second Edition. 1. 10.1093/oxfordhb/9780199750986.013.0006.
16. Selmi A. Monitoring and evaluating the educational effects of the cochlear implant. *Ear and Hearing*. 1985 May-Jun;6(3 Suppl):52S-59S. DOI: 10.1097/00003446-198505001-00010. PMID: 3839476.
17. Spencer P, Marschark M. Cochlear implants: Issues and implications, *Oxford handbook of deaf studies, language, and education*, New York Oxford University Press, 2003, 434-448.
18. Tobey EA, Hasenstab S. Effects of a Nucleus multichannel cochlear implant upon speech production in children. *Ear and Hearing*. 1991 Aug;12(4 Suppl):48S-54S. DOI: 10.1097/00003446-199108001-00007. PMID: 1955090.
19. Li, Yuelin, Lisa Bain, Annie G. Steinberg. "Parental decision-making in considering cochlear implant technology for a deaf child." *International Journal of Pediatric Otorhinolaryngology*. 2004;68(8):1027-1038.
20. Chute PM, Nevins ME. The parents' guide to cochlear implants. Washington, DC: Gallaudet University Press. 2002.
21. Nikolopoulos TP, Lloyd H, Archbold SM, O'Donoghue GM. Pediatric cochlear implantation: The parents' perspective. *Archives Otolaryngology Head Neck Surgery*. 2001;127:363-367.
22. Incesulu A, Vural M, Erkam U. Children with cochlear implants: Parental perspective. *Otology & Neurotology*. 2003;24:605-611
23. Ruben RJ. Language: The outcome measure for the linguistically developing cochlear implant patient. *International Journal of Pediatric Otorhinolaryngology*, 1995;33:99-101.
24. Christiansen JB, Leigh IW. Cochlear implants in children: Ethics and choices. Washington, DC: Gallaudet University Press. 2002.