

Parental Knowledge and Understanding of Monitoring and Maintenance of Cochlear Implant under ADIP Scheme

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Abstract

Introduction: The present study was carried out to assess the parental information about cochlear implant (CI) monitoring and maintenance. **Methods:** A questionnaire was developed during the study period aimed toward assessing parental knowledge, perception, and information with respect to CI monitoring and maintenance. This questionnaire was used to interview the parents of children implanted under the assistance to disabled persons for purchase/fitting of aids and appliances (ADIP) scheme. 30 parents of cochlear implantees were interviewed in this study. The feedbacks of the parents were recorded and later analyzed to compute the results. **Results:** The results showed a good internal consistency between the questions with a Cronbach's alpha value >0.7 . The results are suggestive of the need for better training programs postimplantation for parents as these could aid in the reduction of maintenance costs in the form of replacement of parts and troubleshooting appointments. **Conclusion:** The study showed a poor knowledge and understanding of cochlear implant in parents and showed a need for better training programs and counselling.

Keywords: ADIP scheme, cochlear implant, rehabilitation

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INTRODUCTION

Parents having normal hearing with recently diagnosed children with hearing impairment generally find themselves negotiating a world previously unknown to them. A large study conducted by the Gallaudet Research Institute^[1] obtained quantitative data from 439 parents' responses to a 12-page questionnaire entitled, "survey of parents of paediatric cochlear implantees" questionnaire. The authors reported that parents were largely motivated by a desire for their children to develop spoken language that their major sources of information were medical and audiological professionals (with other families with implanted children also an important information source), and they found the process of making the decision to implant difficult and stressful.

The possible treatment options available for children with sensorineural hearing impairment are either a cochlear implant (CI) or by means of a hearing aid (HA). In either case, the families of the hearing-impaired children, particularly their parents, are involved. Training in HA monitoring should serve to familiarize parents with the function of HAs and help them to become comfortable with their daily use. The specific situation of the parents of hearing impaired children, especially

their psychological distress, has been investigated in a number of studies.^[2-8] The results of these studies provide initial evidence of increased parental psychological distress.^[2,5,7,8] The variability among children's outcomes with CIs might be difficult to accurately predict for an individual child.^[9-12]

Unfortunately, most parents do not receive appropriate nor adequate training in HA visual and listening checks.^[13] The development and implementation of an effective parent training program in the area of HA listening checks is essentially needed. These programs will help hearing-impaired child's habilitation effective in overcoming the difficulties imposed by the child's hearing impairment. The same holds good in terms of effective parent training program for the CI users too. Families may benefit from audiological counseling that acknowledges the multifaceted challenges that arise. Audiologists can work in partnership with families to promote consistent device uses in daily life situations.^[14]

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Under ADIP scheme, many children with hearing impairment over the years have been fitted with CI. Most of the parents of these children are reported to be belonging from lower socioeconomic strata and lack of understanding about the implant. Socioeconomic status is defined as a measure of one's combined economic and social status;^[15] subsequently, lower socioeconomic strata includes individuals at lower end of these measurements. Under ADIP scheme, postsurgical management of the CI users is provided free-of-cost by the government which includes different parts of the CIs, i.e., maintenance of battery, up to a period of 2 years. After 2 years of implantation, parents are supposed to maintain their child's implant accessories with their own expenses. Therefore, it is essential for the parents to understand the cost involved in the CI and its maintenance to use the device optimally, efficiently, and most importantly the continuity after 2 years of free service period. Since the child's benefit from the CI is directly dependent on the parent's ability to check and troubleshoot the equipment, enhancing their knowledge is imperative. This may be achieved by manuals such as CIs equipment troubleshooting guide^[16] as well as other documents provided with the CI. Therefore, the aim of the study is to assess the knowledge and understanding of parents or caregivers about monitoring and maintenance of CIs for their children who have undergone CI surgery under ADIP scheme using questionnaire. Further, the study is also aimed to discuss the awareness among parent/caregiver and provides possible solution to improve the same. To obtain these aims, three objectives were outlined in this study: first, to develop a questionnaire to check the primary caretakers/parents knowledge on monitoring and maintenance of CIs under ADIP scheme; second, to check the familiarity of maintenance and monitoring of CIs performance of 30 parents of children with cochlear implanted children under ADIP scheme; and the third objective was to gather data on the amount of awareness and parental perception or primary caregiver perception regarding the implanted device and its conditions.

METHODS

Parents/caregivers of 30 children with hearing impairment who underwent CI under ADIP scheme and were currently taking habilitation/rehabilitative services were included in the study. The CI children were within the age range from 2 to 7 years (mean age, 4.4 years). The study was conducted in 2 phases. First phase involved developing a questionnaire in English and translated to Bengali. Second phase involved administration of the questionnaire developed after validation in Bengali. The closed-set questionnaire was administered and the results were recorded. The results were analyzed using SPSS version 16.0 (IBM, New York, USA).

Study design: Descriptive research

Inclusion criteria

Parents were only included in the study when they met the preset criteria, which was that their children had been implanted under ADIP scheme, the children or their parents

did not have any associated (cognitive, neurological, etc.) problems, the children had severe-to-profound hearing loss, and had been receiving rehabilitative services for around one year. Another aspect considered was that the parent had a minimum education of up to class 8.

Ethical approval

Written informed consent was obtained from all patients included in the study. Along with this, approval was obtained from the institute where the study was carried out. The topic was presented along with the procedure in front of an ethical committee following whose approval the study was commenced.

Questionnaire: Preparation of questionnaire

Aspects related to CI maintenance and parental perceptions were listed. While keeping these in mind, statements for the questionnaires were formed. This questionnaire was developed in English and translated to Bengali. Translation procedure as described by the international guidelines^[17] was adopted while preparation of the questionnaire. Translation was done by a bilingual translator whose mother tongue was Bengali but was also proficient in English. A different professional translator further back translated this translation.

Finally, keeping the clientele in mind, a questionnaire with 20 questions was drafted by the first author, which was reviewed by 3 audiologists and approved by 5 auditory verbal therapists (AVTs) providing rehabilitative services, to make sure that the language of the questions remains relevant. A sample questionnaire was administered first while considering the parental reviews on the same; finally, a final questionnaire was drafted and administered. The validity of the questionnaire was tested quantitatively through Cronbach's alpha method.

RESULTS AND DISCUSSION

The results were analyzed and have been discussed below. The results have been discussed under the heading of the aforementioned objectives.

Questionnaire

The first objective of the study was to develop a questionnaire [Appendix A] and assess the internal consistency of the same using Cronbach's alpha. The results showed internal consistency using Cronbach's alpha with a value of >0.7 . This shows that the questionnaire has a good internal consistency validating the requirement that the questions are interrelated.

Cochlear implant maintenance and monitoring

The second objective was to gather data using the questionnaire to find out about parental knowledge, which showed the following results. The first question asked to parents was whether they have received any orientation about monitoring and maintenance of CIs. The responses gathered showed that 83.33% of the parents reported having received some training, while around 14% responded negatively.

When parents were interviewed, questions directed toward ownership of accessories showed that 100% of parents owned

the battery tester and moisture kit and used them on a regular basis; this may be attributed to the fact that it was provided along with the implant. To the contrary however, it was seen that when they were asked about the purchase of any other accessories for CI maintenance, whether they knew how and where to purchase them, the responses were negative for 83.33% and 80% of the parents, respectively. This reflects lack of complete knowledge or information regarding the CI and accessories, which may be needed for its maintenance and efficient usage. Present finding is supported by the existing literature using HAs.^[18] They reported that the actual task of monitoring the HAs must be known to the parents due to varying degrees of professional contact. The same may be seen to be true for CI users.

It was seen [Figure 1] that 66.66% of parents reported checking whether the CI was working 6–7 times a week, but 50% of the parents only cleaned the CI once a week. Subsequently, it was also seen that 20% of the parents had even greater time duration between two cleaning sessions, while some were yet to do the same. A study by Stith^[19] suggested parents to complete the Ling 6 sound test 3 times a day to ensure that the HA or CI is working correctly. The habilitation programs designed to train the parents of hearing-impaired children often recommend that parents perform a daily HA check.^[20,21] The need for similar programs for CI is highlighted in this study.

Parental perception, behavior, and training

The last and third objective of the study was to study the parental perception, which showed the following results. Accounts by parents of children with CIs have been of interest for some time.^[22] Previous research has demonstrated that the parents of children with CIs undergo more psychological distress than parents of children with HAs^[23,24] or even the parents of children with normal hearing.^[5] Typically, on finding a problem, 66.66% of the parents reported calling their audiologist, 16.66% parents reported waiting for their audiologists next visit, and 16.66% consulted their AVT therapist. About 76.66% of the parents felt that the most helpful individual regarding CI monitoring and maintenance was the

audiologist who switched on the system and in regular contact after surgery, while 13.33% felt that the AVT therapist had been most helpful.

When asked as to how adequately they had been instructed to check the CI daily, 76.66% reported being trained very well, whereas 23.33% reported as good. Similar statistics were found when asked regarding level of instruction regarding daily cleaning of CI. Along similar lines, when asked about how adequately they had been instructed regarding troubleshooting, 43.33% reported very well, 40% responded with very good, 13.33% reported poor, and 3.3% responded with very poor.

It was found in a previous study that the parents of children with CIs report concerns related to speech and language development, possible device failure, and maintenance of the implant equipment.^[25] In the current study, however, it was seen that 73.33% believed that the CI was working 100% of the time based on responses and 26.66% believed it worked for 75% of the time.

When the parents were inquired regarding their level of comfort and then proficiency, 50% reported being very comfortable, 40% being comfortable, and 10% being having an okay level of comfort. Similarly, with level of proficiency for trouble shooting, 63.33% reported being very proficient, 30% being somewhat proficient, and 6.6% reported being barely proficient. When asked as to why they did not perform regular checks and cleaning of the CI, most parents seemed clueless, especially about the cleaning. A small population, i.e., 23.3%, reported not having time to clean regularly and 66.66% reported meaning to however forgetting and 10% reported not finding any reason for cleaning. When checking the comfort of parents regarding trouble shooting and performing daily checks, 66.66% reported that they themselves were not comfortable rather their partners were. In case of trouble shooting 63.33% reported being very comfortable but, 66.66% of the parents were dependent upon the audiologist and would visit the audiologist in case of any trouble. The results showed that the optimal intervention should involve a coordinator-led team of professionals from multiple disciplines; provide information in all related topics and services (e.g., medical, educational, technical, communication); emotional support is essential; and parents should be given an opportunity to meet parents of other implanted children to achieve these informational and emotional needs. In addition, information delivery should be customized to the needs of the family at various intervals throughout the process.^[26] The results of a study on familiarity, working memory, and transfer suggested that students might benefit from first doing problems framed in terms of topics that are familiar to them.^[27] The same thing may be considered in this aspect that this comfort and efficiency of one partner and not the other may be attributed to the factor of familiarity in learning.

Finally, when the parents were asked as to how much more training would they deemed as required, 40% reported not

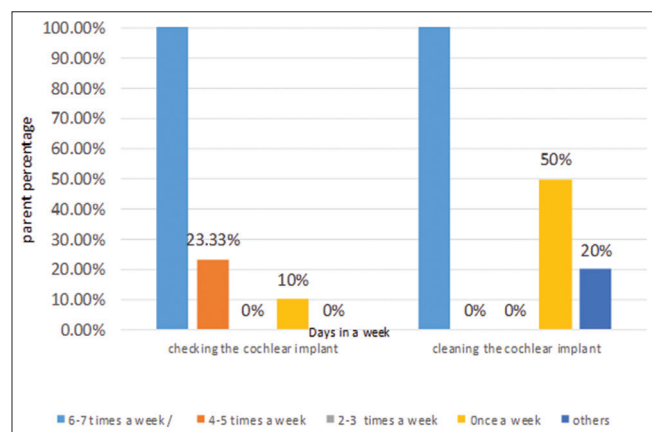


Figure 1: Parental frequency of checking and cleaning of cochlear implants based on days

needing any more training, 50% felt that a little more but brief review would be helpful, and 10% felt the need for comprehensive training. Researches on the needs of the parents themselves have also shown that parents of children who are implant candidates or recipients expressed a strong need for a wide range of information pertaining to medical, educational, technical, communication, and other concerns as well as a need for emotional support and psychosocial interventions.^[26,28,8]

SUMMARY AND CONCLUSION

The above study showed that parental knowledge of CI was incomplete as was the ability to use them efficiently. Although some basic aspects of the CI usage such as daily-listening checks were seen as common knowledge, knowledge about aspects such as cleaning was found to be poor. This could be potentially one of the causes of slow development of these children. The results were suggestive of the need for better training programs postimplantation for parents as these could aid in the reduction of maintenance costs in the form of replacement of parts and troubleshooting appointments. The results also showed the developed questionnaire to be effective at measuring the aimed aspect. The questionnaire has been developed in English and translated to Bengali; however, since it has been developed keeping ADIP scheme in mind, in future, it may also be developed in other regional languages. This would aid the individuals going through CI under ADIP scheme dwelling in their respective states across India.

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Conflicts of interest

There are no conflicts of interest.

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APPENDIX

Appendix A

Parent questionnaire

Date: _____ participant number _____

Please answer the questions listed below. We appreciate your help in gathering information about cochlear implants and their care and maintenance.

What is the age of your child? ____ Years ____ months

I. Cochlear implant monitoring and maintenance

1. Have you received training for cochlear implant maintenance? ____ yes ____ no
2. If, you answered “yes” to question 1 who provided that training (mark all that apply).
 - A. The audiologist who fit your child’s cochlear implant
 - B. The respective company representative
 - C. The AVT therapist
 - D. Another parent
 - E. Other (please specify) _____
3. Do you own any of the following items?
 - A. Cochlear implant batter tester ____ yes ____ no
 - B. Cochlear implant moisture kit ____ yes ____ no
4. Have you been told regarding any additional items?
 - A. To purchase them ____ yes ____ no
 - B. How and where to purchase them ____ yes ____ no
5. Please indicate how frequently you use the items listed below when checking or cleaning your child’s cochlear implant.
 - A. Cochlear implant battery tester.
 - A. 6-7 days of the week
 - B. 4-5 days a week
 - C. 2-3 days a week
 - D. Once a week
 - E. Other (please explain) _____
 - B. Cochlear implant moisture kit.
 - A. 6-7 days a week
 - B. 4-5 days a week
 - C. 2-3 days a week
 - D. Once a week
 - E. Other (please explain) _____
6. How many times a week do you check your child’s cochlear implant?
 - A. 6-7 days of the week
 - B. 4-5 days a week
 - C. 2-3 days a week
 - D. Once a week
 - E. Other (please explain) _____
7. How many times a week do you clean your child’s cochlear implant?
 - A. 6-7 days of the week
 - B. 4-5 days a week
 - C. 2-3 days a week
 - D. Once a week
 - E. Other (please explain) _____

II. Parental perception and behavior

8. What do you typically do in the event that you find a problem with your child's cochlear implant?
 - A. Call your audiologist
 - B. Wait for your AVT therapist's scheduled visit
 - C. Wait for the your next scheduled appointment with your audiologist
 - D. The company representative
 - E. Other (please explain) _____
9. Please indicate which of these individuals were most helpful to you in providing training on care and maintenance of your child's cochlear implant (mark all that apply).
 - A. The audiologist who switched on your child's cochlear implant
 - B. AVT therapist
 - C. An audiologist
 - D. A company representative
 - E. Other (please specify) _____
10. Please indicate how adequately you feel you have been instructed regarding how to perform a daily check on your child's cochlear implant.
 - A. Very well
 - B. Good
 - C. Ok
 - D. Poor
 - E. Very poor
11. Please rate how adequately you feel you have been instructed regarding how to clean/maintain your child's cochlear implant.
 - A. Very well
 - B. Good
 - C. Ok
 - D. Poor
 - E. Very poor
12. Please rate how adequately you feel you have been instructed regarding how to troubleshoot your child's cochlear implant.
 - A. Very well
 - B. Good
 - C. Ok
 - D. Poor
 - E. Very poor
13. Do you feel confident that you know how to properly use the items listed below?
 - A) Cochlear implant battery tester
 - A. 100%
 - B. 75%
 - C. 50%
 - D. 25%
 - E. <25%
 - B) Cochlear implant moisture kit ____ yes ____ no
 - A. 100%
 - B. 75%
 - C. 50%
 - D. 25%
 - E. <25%
14. How much of the time do you believe that your child's cochlear implant is working properly?
 - A. 100%
 - B. 75%
 - C. 50%
 - D. 25%

E. <25%

15. Please rate how comfortable you feel checking your child's cochlear implant?

- A. Very comfortable
- B. Comfortable
- C. Ok
- D. Uncomfortable
- E. Very uncomfortable

16. Please rate your level of proficiency for troubleshooting your child's cochlear implant

- A. Very proficient
- B. Somewhat proficient
- C. Barely proficient
- D. Less than proficient
- E. Not proficient at all

17. Is there any other information about your child's cochlear implant that you would like to know? (If yes, please indicate what that would be)? ____ yes ____ no

18. What are the most frequent problems that you encounter with your child's cochlear implant?

(Please specify below)

19. For what reasons might you not check or clean your child's cochlear implant on a daily basis? (Please check all that apply.)

- A. I'm too busy and can't find the time
- B. I mean to but I often forget to check them
- C. I am not sure what to do
- D. I do not see a reason for having to check and clean them every day
- E. I have been shown how to check and clean hearing aid/s but i still do not feel comfortable doing it.
- F. Other (please explain) _____

20. How much more training in cochlear implant monitoring, care, and troubleshooting do you feel you need?

- A. None, I think I am doing well
- B. A brief review would be helpful
- C. I need comprehensive training
- D. Other (please explain) _____