FACTORS AFFECTING EARLY COCHLEAR IMPLANTATION IN CHILDREN

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CERTIFICATE

This is to certify that this dissertation entitled **"Factors Affecting Early Cochlear Implantation in Children"** is a bonafide work submitted as a part for the fulfilment for the degree of Master of Science (Audiology) of the student with Registration Number: 20AUD009. This has been carried out under the guidance of the faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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This is to certify that this dissertation entitled "**Factors Affecting Early Cochlear Implantation in Children"** has been prepared under my supervision and guidance. It is also being certified that this dissertation has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled "**Factors Affecting Early Cochlear Implantation in Children**" is the result of my own study under the guidance of Dr. Geetha C, Associate Professor in Audiology, Department of Audiology, All India Institute of Speech and Hearing, Mysuru and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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Abstract

Aim and objective: *The purpose of the current study was to analyse the demographic, parental, professional, and other factors which may be responsible for the delay in age of diagnosis and cochlear implantation in children.* ***Method:*** *Thirty parents of cochlear implantees with severe to profound hearing loss participated in the study. The children underwent unilateral CI after three years of age. For the analyses of factors, demographic and audiological information were collected from the case files, and a questionnaire was developed and administered through a telephonic interview on the parents. The questionnaire consists of questions regarding the factors, which had to be answered on 5 points Likert scale.* ***Results:*** *The results revealed that majorly parental factors delay the age of implantation. The results showed a negative correlation between the age of implantation and the mothers' education and for the parental factor like consulting many professionals for a second opinion. A positive correlation between the age of implantation, missing appointments, and taking care of family members has been observed. There was no correlation between age of implantation and professional factors. There was no effect of gender, geographical location, or source of funding on the age of implantation.* ***Conclusion:*** *The study suggests that parental factors like missing appointments, taking care of family members, and mothers' education contributed to delayed diagnosis of hearing loss and cochlear implantation in children. It can be inferred that parents' attitude toward their child's hearing loss has to be dealt with initially for improved outcomes. There is a need for more public awareness and education to avoid the barriers to late implantation.*

Chapter 1

Introduction

Hearing loss is a partial or total inability to hear. Most children have severe to profound congenital hearing loss (Sanderson et al., 2014). In India, the prevalence of newborn hearing loss ranges from 1.59 to 8.8 per 1000 births (Verma et al., 2021). Although India's health outcomes are improving, the rate of hearing impairment is still high. It is of great concern, especially since hearing loss can negatively affect children's speech, language, developmental, educational, and cognitive outcomes (Lieu, 2004). Early detection and treatment of hearing loss in children are critical for good speech and language development in the early years of life and optimal academic performance in later years (Elloy & Marshall, 2012).

Cochlear implantation (CI) has become a commonly accepted option for children with severe to profound hearing loss whose parents prefer spoken language development (Fitzpatrick et al., 2011; Hammes et al., 2002; Niparko et al., 2010). A cochlear implant is a surgically implanted electronic hearing device that electrically stimulates a nerve in the inner ear to produce a usable hearing sensation (Food & Drug Administration, 2017). Recently the Food and Drug Administration has approved cochlear implantation for infants of 9 months and above (FDA, 2020), enabling auditory stimulation at a very young age.

High performance of very early implanted children has been reported (Dettman et al., 2007; Holman et al., 2013; Leigh et al., 2013). A study done by Anderson et al. (2004) compared the auditory performance of early implanted and late implanted children

through Evaluation of Auditory Responses to Speech (EARS) test battery and concluded that children implanted at a young age develop auditory skills at an earlier chronological age, allowing for faster language development, which in turn leads to good reading, writing, and other scholastic skills (Sharma et al., 2020).

As the children's age of implantation increased, they continued to fall more behind in auditory/language performance compared to their age-matched peers who had used CI for a similar amount of time (Hammes et al., 2002)**.** After the critical period (in the age range of 0–6 years), the brain's flexibility restricts the development of speech recognition and language learning. If a child is denied auditory input before the age of 84 months, the central brain organization for audition is likely to be damaged (Sharma et al., 2002). Hence, early cochlear implantation is necessary to minimize auditory deprivation (Fitzpatrick et al., 2011).

Despite the advantages of early implantation, many children are still implanted far into their preschool years despite the earlier diagnosis (Fitzpatrick et al., 2011) due to various factors. The most common factors leading to late implantation are public insurance (Armstrong et al., 2013; Lester et al., 2011), some parental factors, and certain other factors such as delay in identifying hearing loss and financial constraints (Whelan et al., 2021), inadequate neonatal hearing screening programs (Jeddi et al., 2012), ignorance of parents and health care physicians about the significance of early intervention and referral to an implant center (Sapra et al., 2015). Delays in cochlear implantation have also been linked to parental views about cochlear implantation, medical co-morbidities, and linguistic obstacles (Lester et al., 2011; Wiley & Meinzen-Derr, 2009).

A study by Kothari et al. (2015) conducted in India revealed that in 96.10 % of children in their study, the device's high price put off their decision to have a cochlear implant. In a developing country like India, inadequate newborn hearing screening and financial constraints might lead to late cochlear implantation. Hence, the Government of India has launched various schemes and programs like the Assistance to Disabled Persons Scheme (ADIP) scheme in 2014, where cochlear implants are given free of cost or with some amount of financial assistance for the eligible candidates (Kumar & Kameswaran, 2017). Rashtriya Bal Swasthya Karyakram (RBSK) is launched by the Ministry of Health and Family Welfare to identify and treat birth defects, deficiencies, diseases, and developmental delays, including disabilities, in children from birth until age 18, and the National programme for prevention and control of deafness (NPPCD) has recently started to distribute CI to children with severe to profound hearing loss free of cost.

1.1 Need for the study

Cochlear implantation is strongly recommended for persons with severe to profound hearing loss with limited benefit from amplification devices (Balkany et al., 2002; Fitzpatrick et al., 2011; Papsin & Gordon, 2007; Wheeler et al., 2007). Children with cochlear implantation have good hearing performance and language acquisition comparable to children with normal hearing (May-Mederake, 2012; Moog & Geers, 1999; Peixoto et al., 2013). Early auditory exposure provided by cochlear implantation and listening training positively impacts spoken language development in children with hearing impairment (Nicholas & Geers, 2006). Quality of life assessment in children using hearing devices is of utmost importance, as it has already been established that hearing loss affects the child's overall well-being (Carney & Moeller, 1998; Lin & Niparko, 2006). Delay in

implantation leads to delay in speech and language development, lower levels of social interaction, poorer communication, feelings of isolation, poorer academic achievement, and low self-esteem, which might later emerge as behavioural, socio-emotional, or learning challenges (Looi et al., 2016).

There are few studies analyzing the factors which would have led to delayed cochlear implantation. These studies found that demographic factors like parents' education, socioeconomic status, and geographical location have delayed the surgery (Fitzpatrick et al., 2015; Jeddi et al., 2012; Noblitt et al., 2018; Whelan et al., 2021). Few studies have shown audiological factors like progressive hearing loss have delayed the decision of cochlear implantation (Fitzpatrick et al., 2011, 2015). However, these studies have concentrated on audiological, parental, or socioeconomic factors that have delayed the surgery. Other factors like professional factors that could have led to the delay have not been researched extensively. Hence, the present study explores all possible reasons that would have delayed the CI in children.

In addition, most studies on exploring the factors leading to the delay in CI are carried out in other countries. In India, the prevalence of hearing impairment among neonates was 4 per 1000 births (Varshney, 2016). In addition, the identification of hearing loss is also delayed due to various reasons. An essential factor is inadequate newborn hearing screening (Lester et al., 2011). India is a land of diverse language and culture, which varies from region to region, presenting us with several socio-cultural factors that can affect rehabilitation. A study by Kothari et al. (2015) done in India found that the critical factor is financial constriction to afford cochlear implantation.

Since the Government of India launched various schemes and programs (ADIP, RBSK, NPPCD) for cochlear implantation, many children have been implanted. Because of the introduction of these schemes and programs, the financial burden on the parents/family is reduced. Over time, there is an improvement in the age of implantation of children. Even then, our clinical observation shows that many children are implanted over 2 to 3 years old. As mentioned above, early cochlear implantation helps achieve good cognition, speech and language skills, and psychosocial skills, which helps in good academic performance and ultimately results in good career prospects (Anderson et al., 2004; Sharma et al., 2020; Swanepoel et al., 2009).

Several reasons can contribute to the delay in cochlear implantation (Kothari et al., 2015; Lester et al., 2011). Hence, there is a need to study the factors leading to the delay in cochlear implantation in children who underwent cochlear implantation in a government institute. Analysing the factors resulting in delay would help the professionals plan steps to advance the age of implantation.

1.2 Aim of the study

The present study aimed to analyse demographical, parental, professional, and other factors responsible for the delay in cochlear implantation in children.

1.3 Objectives of the study

- To study the effect of the following demographic factors on the age of cochlear implantation in children:
    - The effect of gender on the age of cochlear implantation

  - The effect of geographical location on the age of cochlear implantation
  - The effect of family history of hearing loss on the age of cochlear implantation

- To study the effect of education of parents on the age of cochlear implantation
- To study the correlation between parental factors and age of implantation in children.
- To study the correlation between professional-related factors and age of implantation in children.
- To study the correlation between other factors such as transportation, source of funding, and delay in adjusting to hearing aids on the age of implantation.

Chapter 2

Review of Literature

Children with severe to profound sensorineural hearing loss who do not benefit from hearing aids now have better treatment options and outlooks because to cochlear implantation. (Kim et al., 2010). Recently, there has been an increased interest in understanding the factors leading to delayed cochlear implantation in children. This chapter focuses on studies that have attempted to understand the barriers to early cochlear implantation in children. The studies are grouped based on the type of factors leading to delay in cochlear implantation.

2.1 Audiological and Medical factors

Fitzpatrick et al. (2011) conducted a research study to examine the factors which have led to the late cochlear implantation among children with early-onset permanent sensorineural hearing loss. The study included 43 children with cochlear implants who were enrolled in a Canadian outcomes study. A detailed review of the participant's medical chart was done to identify the potential factors for the late cochlear implantation among 45 children who have been implanted more than 12 months after hearing loss confirmation. From the chart, age of diagnosis of hearing loss, age of cochlear implant candidacy, and age of implant was noted. The results revealed that the median age of hearing loss diagnosis was nine months, and the gap between diagnosis and a unilateral implant was 9.1 months. CI was delayed in 11 children due to the progressive nature of the hearing loss, four children due to other complex medical conditions, and three children due to other factors like borderline hearing level for cochlear implant candidacy.

Fitzpatrick et al. (2015) conducted a similar population-based study in the same geographical location. The study included 118 cochlear implanted children after 12 months of hearing loss diagnosis. A thorough analysis of the clinical traits of these 118 children showed that progressive hearing loss (52.5%) and complex medical problems (16.9%) were attributed to late implantation. The authors also stated that, for children with permanent hearing loss of any degree, the ongoing follow-up has to be maintained to ensure appropriate intervention. Similarly, Armstrong et al. (2013) found that the cochlear implantation was late due to medical delays (neurocognitive issues or patients with complex medical co-morbidities that complicated the candidacy process).

2.2 Parental and family factors

Parental or family factors are the ones that have majorly affected the age of implantation. A study by Jeddi et al. (2012) assessed the parents' education level and socioeconomic status at the age of implantation in 96 children with profound sensorineural hearing loss who underwent cochlear implantation below six years of age. The information was gathered through the cochlear implantation center's patient database and conversations with the parents. For the parent interviews, a 31-item survey was prepared, which comprised demographic information (7 items), hearing loss history (11 items), medical history (2 items), and the child's birth history (11 items). The mean age of hearing loss diagnosis was 9.35 months. The authors attributed this to denial of a child's hearing loss by parents and other family members, which prevents referral to a physician, resulting in a delay in the diagnosis of hearing loss, inadequate newborn hearing screening, and lack of awareness about the symptoms of hearing loss. The authors found that as the education of the parents increases, there was a decrease in the age of implantation.

Armstrong et al. (2013) retrospectively reviewed data of children who underwent cochlear implantation under 15 years of age to identify the possible barrier to late implantation. The study considered 57 individuals with pre-lingual SNHL and collected information on demographics, age of hearing loss diagnosis, age of implantation, and etiology of hearing loss to identify the hurdles. Surveys were sent to audiologists, speech pathologists, and neuropsychologists who were the consultative members of the cochlear implant evaluation team to identify barriers to implantation.

Results showed that potential barriers leading to more than 12 months between identification and implantation were parental delays (missed/delayed appointments due to failure to attend candidacy evaluation appointments, uncertainty about the candidacy process, difficulties navigating the system,hesitation about evaluations, and surgery). The primary issue discovered was parental, with delayed/missed appointments or reluctance to undergo assessments or surgery. The authors also showed that cultural factors delay cochlear implantation; two of the participant's parents were involved in the Deaf Community and were resistant to CI. Similarly, Fitzpatrick et al. in 2011 and 2015, conducted a study to find out the potential barrier to cochlear implantation and found that family hesitation delayed the implantation in 9% of children.

2.3 Socioeconomic status and geographical locations

As the cost of the CI is high, the socioeconomic status of the family plays an important role. Kothari et al. (2015) investigated the factors responsible for the delay in the cochlear implantation of children with profound congenital hearing loss through a cross-sectional observational study in India. A total of 154 children were included in the study. A detailed case history was taken, and open-ended questions were asked to the parents of

the subjects to identify the potential factors for the delay. The questions were based on the delay in identifying hearing loss and the delay in intervention. The results showed that the cost of the implant is the primary factor that delayed the surgery. The author found that, in rural areas, there is a lack of awareness about cochlear implantation and the importance of early intervention among parents as well as health professionals. The parents had no information about the available technique and procedure of cochlear implantation, and many were ready to accept their child's hearing loss. The parents decided to wait until the child was aged 4 to 5 years for the implantation regardless of intensive counselling. The authors strongly emphasize on universal newborn hearing screening program throughout India.

The study by Jeddi et al. (2012) also found that socioeconomic status affects the age of implantation in children with profound sensorineural hearing loss. Fitzpatrick et al. (2015) reported that around 5.9% of children had delayed CI due to their geographical location. Noblitt et al. (2018) published the results of a study including 35 children with cochlear implants. The barriers to the rehabilitation of cochlear implant children were investigated, and the questionnaire was sent to the parents of the children or through a telephonic interview. The author reported that children who are from rural residences and lower socioeconomic class were diagnosed with hearing loss later compared to children from urban residences and good socioeconomic class. The author also noted that parental education also influenced the rehabilitation process.

2.4 Transportation and other factors

From 2008 through 2019, Whelan et al. (2021) conducted case-control research study by comparing the medical records of Amish patients with the controls who are age-

matched having cochlear implantation to identify the barriers to cochlear implantation. Age at first otolaryngology appointment, age at surgery, implant sidedness, number of post-operative audiology and otolaryngology consultations, and perioperative complication profile were recorded. For descriptive analysis, social aspects such as distance from home to hospital, transportation, insurance, and telephone/electricity accessibility were gathered. Since 2008, 232 children have undergone CI, including 8 Amish children. The author found that the Amish are isolated from much of civilization and are austere in their rejection of many modern technologies. The authors also reported that Amish patients had fewer audiologic and otologic appointments than age-matched controls. Amish children with CI encounter specific hurdles to care, such as transportation and technological difficulties, resulting in fewer hearing-related appointments than an age-matched group.

Lester et al. (2011) investigated the social and healthcare factors in 59 pre-lingually hearing-impaired children. Demographic and healthcare factors were collected from the parents through telephonic interviews with open-ended and unscripted questions. They concluded that children who underwent newborn hearing screening (NBHS) had implanted earlier than those without NBHS. Type of insurance (Medicaid, private) also had a significant impact on the age of cochlear implantation. The authors came to the conclusion that parental delays and delayed referrals for care can be avoided by educating families and local healthcare professionals, especially family physicians, on the significance of early identification and intervention.

2.5 Public and Private Insurance

Chang et al. (2010) assessed the influence of socioeconomic status on cochlear implantation with adequate Medicaid reimbursement. For the study, 133 patients were

taken. Among them, 69 were privately insured, and 64 were Medicaid insured. The authors found no significant difference between the groups in the age of implantation, but Medicaid-insured patients had missed more follow-up visits. They concluded that wherever Medicaid reimbursement is appropriate, eligible children, regardless of socioeconomic status, have equal access to cochlear implantation. Armstrong et al. (2013) also compared the age of diagnosis and implantation of children with private insurance and public insurance. Public-insured children had a delay in both diagnosis and implantation compared to privately insured. This was due to system delays (uninsured status, delays in getting insurance approval for appointments, evaluations, or hearing aids).

Similar to the studies mentioned above, Dornhoffer et al. (2021) aimed to determine the factors like demographic and audiological factors which has led to the delay in the time of surgery in adults. A total of 492 patients were included in the study. They collected information regarding pre-implantation audiological outcomes, time to implantation, and demographic details of each subject. Age at implantation, race/ethnicity, history of hearing aid use, sex, health insurance provider, pre-operative audiometric data, and time to implantation were all taken from their adult cochlear implant database. The findings indicated that race had an impact on the time of implantation. The results didn't show a significant difference in sex, health insurance status, and audiological results.

To summarize, the above literature emphasizes that various factors could delay cochlear implantation in children. Most studies have shown that financial constraints, parental education, socioeconomic status, inadequate newborn hearing screening, progressive hearing loss, insurance type, and other miscellaneous factors delay surgery in children. However, most studies on exploring the factors leading to the delay in CI are

carried out in other countries. Research studies about factors leading to the delayed CI in India are limited. Hence, there is a need to study the factors which would have led to delayed implantation in children.

Chapter 3

Method

The present study aimed to analyse the factors responsible for the delayed cochlear implantation in children in a government institute. A retrospective review of case files of CI children who are availing/availed services at a government institute was included in the study. Informed consent was taken from the parents of cochlear implanted children.

The method of the study was divided into four phases:

3.1 Phase I: Collecting information from the case files.

3.2 Phase II: Development of the questionnaire.

3.3 Phase III: Translation of the questionnaire into Kannada.

3.4 Phase IV: Telephonic interview with the parents of the cochlear implanted children.

3.1 Phase I: Collecting information from the case files

Information regarding demographic details (name, age, gender, address, socioeconomic status, education, and occupation of parents), associated problem, type, and degree of hearing loss were gathered. Further, age of initial diagnosis, age of hearing aid fitting, age of initial intervention, duration of therapy taken with hearing aids, date of cochlear implant recommended, date of surgery, and scheme through which the child underwent cochlear implantation were gathered from the case files.

3.2 Phase II: Development of the questionnaire

3.2.1 Formulating questions to include different factors

A thorough literature review of previous studies on delayed cochlear implantation was conducted to develop a comprehensive English questionnaire. The first step in creating the questionnaire was to determine the possible factors that would delay cochlear implantation in children. Once the factors were listed, the questions were developed using those factors.

The questionnaire had 27 questions and was divided into two parts. Part I consisted of demographic details. Part II had a questionnaire which included questions regarding the age of HL suspected, diagnosed, age of initial intervention, age of implantation, parental factors, professional and other factors. A few questions were open-ended, and the remaining were based on a rating scale.

3.2.2 Formulating a rating scale for the questionnaire

Each question was given a five-point Likert rating scale to indicate the response. The response categories were as follows: 1 = Not at all ; 2 = Slightly; 3 = Moderately; 4 = Very much; 5 = Extremely or 1 = Never; 2 = Rarely; 3 = Sometimes; 4 = Often; 5 = Always. For a few questions, the respondents were given a sixth response category (not applicable (N/A)) to indicate the items that did not apply to them.

3.2.3 Content validation by Audiologists

After the formulation of the questionnaire was completed, it was sent to five audiologists to provide qualitative and quantitative feedback on the questionnaire. They were given a content validation questionnaire and were asked to rate each question based on its relevance, clarity, and comprehensiveness on a five-point Likert scale; the response

categories are as follows: 1 = Strongly disagree; 2 = Disagree; 3 = Unsure; 4 = Agree; 5 = Strongly Agree.

3.2.4 Preparation of the final questionnaire

The questionnaire was modified based on the feedback and suggestions received to make it more comprehensive and contextually relevant. The finalized English questionnaire had 27 questions which is given in Appendix I. The next phase was to translate the developed English questionnaire into Kannada.

3.3 Phase III: Translation of the questionnaire

The questionnaire was translated using the widely acknowledged American Association of Orthopedic Surgeons (AAOS) (Beaton et al., 2000) guidelines, which include a forward, backward translation process. The following five steps were included in the procedure:

3.3.1 Forward translation

The first step in translation and adaptation is to generate multiple forward translations (Hambleton, 1993; Thammaiah et al., 2016). Hence, the questionnaire was given to two adult bilingual translators from speech and hearing who were proficient in both English and Kannada. Each of the translators independently produced a forward translation copy.

3.3.2 Synthesizing popular translation

Following the multiple forward translation step, a single combined approved version of the forward translations was generated. This approach involves all translators

and researchers. All the translators and primary researchers participated in this process to reach a consensus for framing the consolidated version of the translations.

3.3.3 Backward translation

As a means of confirming effective original-to-target language translation, the second key phase in the translation-adaptation process is suggested. It serves as a quality check, highlighting significant inconsistencies and conceptual flaws, and aids in mapping the semantic equivalence of the translated measure's original and target versions (Beck et al., 2003). Outsourced bilingual translators who are not affiliated with the study group and are unfamiliar with the research concept should perform the backward translation (Baeza et al., 2010). Hence, the consolidated approved version was independently translated into English by an adult bilingual translator with a non-medical background.

3.3.4 Analysis by the expert committee

In the next step, a comparison was made of all the versions (Forward translation, synthesized common translation, and back translation) to prepare the pre-final version of the questionnaire. The entire translations were reviewed, the errors were identified, and a final version was produced. The translated questionnaire is given in Appendix II.

3.4 Phase IV: Telephonic interview with the parents of the implanted children

Participants

A total of 30 participants were included in the study. The mean current age of the participants was 6.51 (±1.81) years. Among them, 16 were males, and 14 were females. The demographic details of the participants are given in Table 3.1. All the participants had

bilateral severe to profound hearing loss during the initial diagnosis and had average intelligence.

Table 3.1

Demographic details of the sample.

Sample characteristics	Number of participants (Percentage)
Male/Female	16/14
Rural	19 (63.33%)
Urban	11 (36.67%)
Socioeconomic class	
Upper SEC	2 (6.67%)
Middle SEC	1 (3.33%)
Lower SEC	27 (90%)
Education of mother	
Primary education	1 (3.33%)
Higher primary	3 (10%)
SSLC /10th	3 (10%)
ITI / Diploma	0 (0%)
PUC	12 (40%)
Under Graduation	10 (33.33%)
Post-graduation	1 (3.33%)
Education of father	
Primary education	3 (3.33%)
Higher primary	3 (3.33%)
SSLC /10th	8 (26.67%)
ITI / Diploma	2 (6.67%)
PUC	9 (30%)
Under Graduation	3 (3.33%)
Post Graduation	2 (6.67%)

Note. SEC = Socioeconomic class.

Inclusion and Exclusion criteria:

- The children who had undergone cochlear implantation and availing/availed services at a government institute.
- Children who have been implanted at or after three years of age were included in the study.
- The parents of the cochlear implanted children were native Kannada speakers.
- All the children had undergone unilateral cochlear implantation.
- Children with abnormal cochlea/auditory nerve were excluded from the study.
- Children with additional disabilities were excluded from the study.

Administration of the questionnaire

An informed consent was taken from the parents of the participants. The developed questionnaire was administered to the parents through telephonic interview. The author carried out a systematic telephonic interview and noted the rating given by the parents for each question.

Statistical analysis

The data collected from each parent and case file details were tabulated and analysed using Statistical Package for the Social Sciences (SPSS for Windows, version 25) software. Shapiro-Wilk test of normality was performed to know the distribution of data. Descriptive statistics were carried out to summarize the data. Spearman's correlation was performed to know the correlation between variables and age of implantation. Independent t-test and Mann-Whitney test were carried out to compare the effect of demographical factors on the age of implantation.

Chapter 4

Results

The present study analysed the factors responsible for late cochlear implantation among children. A total of 30 participants were included in the study, and information was collected from their case files and from a questionnaire administered to the parents of the CI children. Variables included in the study to see the effect on the age of implantation were as follows:

- Demographic factors: gender of the child, geographical location, family history of hearing loss.
- Parental factors: education of the parents, awareness about the cochlear implantation, intake of medications as a treatment for hearing loss, missing appointments, consulted many professionals for a second opinion about the diagnosis and management, taking care of other family members or another child, family support, fear of the surgical procedure, possessed cultural or superstitious belief, had a fear of re-implantation, up gradation or maintenance cost, and had the opinion that the child is too young for the CI.
- Professional factors: delays in the diagnosis of hearing loss, inappropriate referrals, inadequate information about CI given to the parents during the initial diagnosis of hearing loss, and taking a long time for the CI candidacy evaluation.
- Other factors like transportation, delay in processing the application for the CI under schemes, child taking a long time to get adjusted to the hearing aids, and scheme under which child underwent CI.

Table 4.1 shows the clinical characteristics of all 30 children with cochlear implants. The mean age of hearing loss suspected by parents or family members was 13.03 (±8.826) months. Permanent bilateral severe to profound sensorineural hearing loss was diagnosed at a mean age of 16.83 (±9.865) months for all children. The mean age elapsed between suspicion of hearing loss and the final diagnosis is 3.80 (±5.095) months.

Among 30 children, two children underwent newborn hearing screening at birth and were referred for further detailed evaluation, and the age of diagnosis of hearing loss in them was 7 and 16 months, respectively. A total of 29 were fitted with hearing aids after the diagnosis of hearing loss and attended listening training. One of the children underwent CI surgery directly after the diagnosis of hearing loss. The mean age of hearing aid fitting in 29 children was 26.17 (±14.130) months. The mean age of CI recommended, and CI surgery was 42.03 (±12.277) and 53.53 (±14.139) months, respectively.

Table 4.1

Clinical characteristics of 30 children with cochlear implant (age and time in months).

	Mean(SD)	**Median**	**IQR**	**Minimum**	**Maximum**
Age of suspension of hearing loss	*13.03 (8.826)*	9	11	2	36
Age of diagnosis of hearing loss	16.83 (9.865)	15.5	11	4	48
The elapsed time between suspected and diagnosed	3.80 (5.095)	2	5	0	21
Age of hearing aid fitted (N=29)	26.17 (14.130)	22	16	11	72
The elapsed time between diagnosis and hearing aid fitting (N=29)	11.03 (13.983)	6	13	0	62
Age at which listening training started with hearing aids (N=29)	28.21 (15.303)	24	18	11	72
Therapy with hearing aids (N=29)	15.28 (10.110)	12	15	3	36
Age of CI recommendation letter issued	42.03 (12.277)	40	21	14	60
The elapsed time between diagnosis and CI recommendation letter issued	25.50 (13.68)	24	17	0	51
Age of cochlear implantation	53.53 (14.139)	50	18	36	84
The elapsed time between CI recommendation letter and surgery	11.60 (8.520)	11	9	2	40

The normality of the data was tested with the Shapiro-Wilk test; most of the parameters were not normally distributed. Hence, non-parametric tests were performed. The results of the same are given below:

4.1 Demographic factors

4.1.1 Effect of geographical location on the age of implantation

There were 11 children from urban and 19 from rural regions. The median age of implantation for children living in urban and rural was 48 and 54 months, respectively, as shown in Figure 4.1.

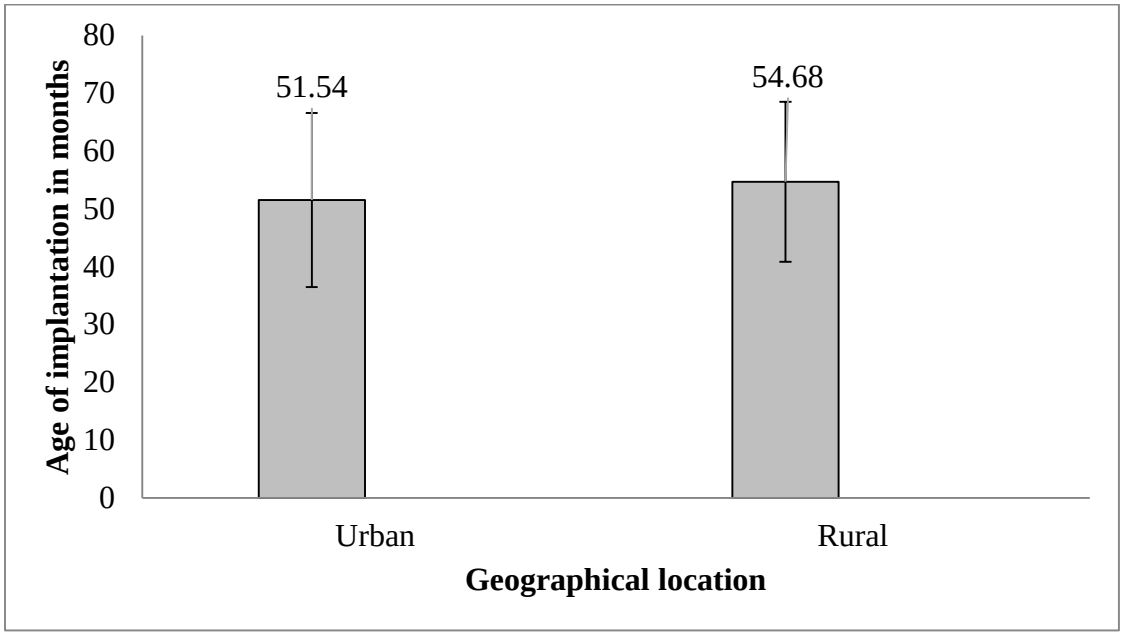

Figure 4.1.

Bar graph showing the comparison of age of implantation in months for urban and rural children.

Shapiro-Wilk test was used to test the normality. As the data were not normally distributed, the Mann-Whitney test was carried out to compare the age of implantation between rural and urban areas. The results showed no significant difference between the age of cochlear implantation and geographical location (z = -0.820; p = 0.412), though the median age of implantation was higher in children living in rural areas.

4.1.2 Effect of gender on the age of implantation

There were a total of 16 males and 14 females included in the study. The median age of implantation of male and female were 53.5 and 46 months, respectively, as shown in Figure 4.2. Shapiro-Wilk test was used to test the normality. As the data were normally distributed, an Independent sample T-test was carried out. There was no significant difference between the age of cochlear implantation and gender (t = 0.969; p = 0.341).

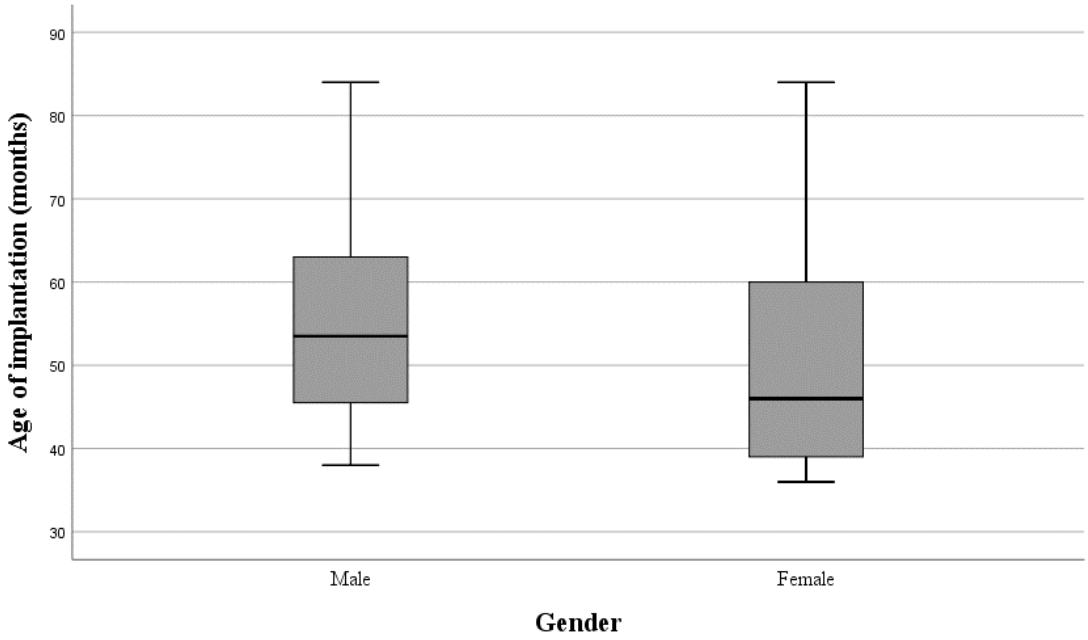

Figure 4.2.

Box plot showing the age of implantation in months for males and females.

4.1.3 Effect of family history on age of implantation

The details about the family history of hearing loss were collected from the case files. Among 30 children, six children had a positive family history, such as the elder brother, father, and cousins having hearing loss. The median age of implantation for children with positive and negative family history is 48 and 52.5 months, respectively, as shown in Figure 4.3. The Mann-Whitney test was carried out to see the effect of family history on the age of implantation. The results revealed no significant difference between the age of cochlear implantation and family history ($z = -0.364$, $p = 0.716$).

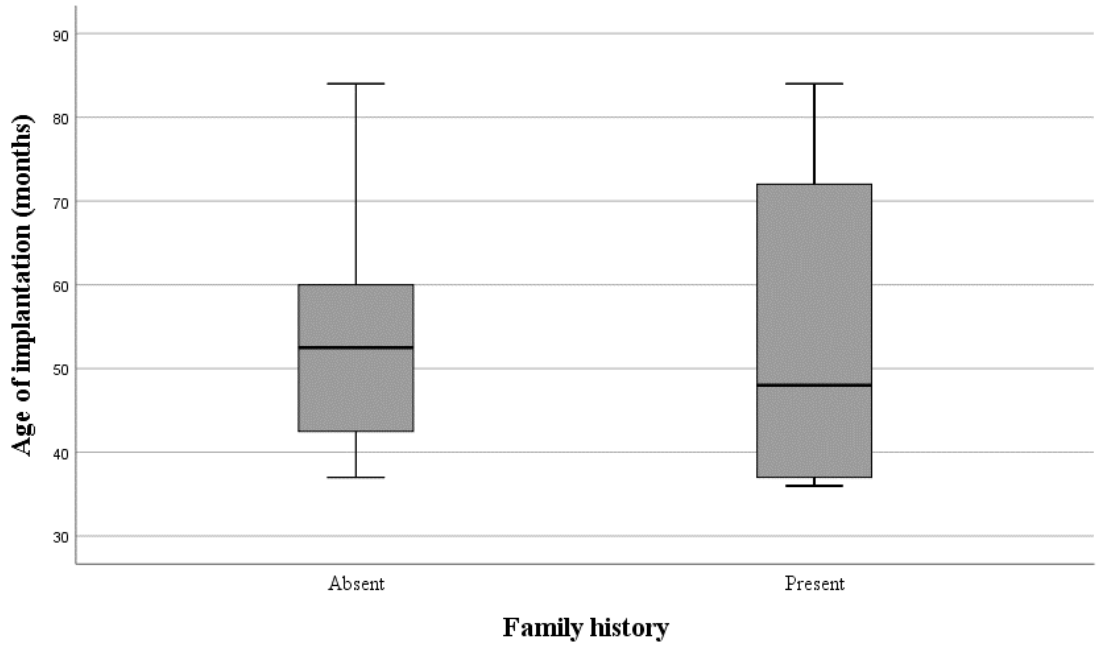

Figure 4.3.

Box plot showing the age of implantation in months for children with family history absent and present.

4.2 Parental factors

4.2.1 Correlation between the education of parents and age of implantation

The details on the father and mother's education were collected and correlated with the age of the implantation of the child. Table 4.2 shows the mean, median, SD, minimum and maximum age of implantation with their father's and mother's education levels.

Table 4.2

The mean, median, standard deviation, minimum and maximum age of implantation of children with their fathers' and mother's education levels.

	Age of implantation (months)				
Education of father	**Mean**	**Median**	**SD**	**Minimum**	**Maximum**
Primary education	75.33	75.00	3.512	72	79
Secondary/high school	51.00	54.00	10.817	39	60
SSLC	47.88	47.50	9.418	36	60
ITI/Diploma	40.50	40.50	4.950	37	44
PUC	58.56	52.00	15.485	43	84
UG	42.00	41.00	5.568	37	48
PG	55.00	55.00	15.556	44	66
Education of Mother					
Secondary/high school	69.00	75.00	18.735	48	84
SSLC	55.00	44.00	20.809	42	79
PUC	54.33	56.00	12.551	38	84
UG	44.40	43.00	6.947	36	54

Spearman's correlation was carried out to see the correlation between the age of cochlear implantation and the education level of father and mother, as the data were not normally distributed on the Shapiro-Wilk test of normality. The results revealed that there was no correlation between the education of the father and the age of implantation (ρ = -0.176, p = 0.353), and there was a moderate negative correlation between the education of the mother and the age of implantation (ρ = -0.413, p = 0.023). As the education level of the mother increases, there is a decline in the age of implantation. Further, the comparison of age of implantation across different education levels of parents could not be done, as the sample size is less in each category.

4.2.2 Correlation between parental factors and age of implantation

The questionnaire was administered to the parents of the CI children through telephonic interviews. Five-point Likert rating scale is used (e.g., 0 indicates never and 4 indicates always) to indicate the responses to each question. Various parental factors were correlated with the age of implantation of the children using Spearman's correlation. The questions with similar rating scales have been grouped together and given in Tables 4.3, 4.4 and 4.5.

Table 4.3 shows the parent's response frequency about the awareness of CI. Table 4.4 shows the parent's response frequency about the factors like tried other medications for HL, missing appointments, consulted professionals second opinion, family support, believes that a child is too young for the CI. Table 4.5 shows the parent's response frequency about the factors like taking care of other and family members/children, fear of the surgical procedure, re-implantation, up-gradation or maintenance cost.

Table 4.3

The response frequency of parents about the awareness of CI

Parents response	Response Frequency
Completely unaware	28
Not aware	0
Slightly aware	0
Aware	0
Completely aware	2

Table 4.4

The parents' response frequency for the different questions on parental factors (tried other medications for HL, missing appointments, consulted professionals second opinion, family support, believes that a child is too young for the CI).

Parents response	***Tried other medications for HL***	***Missing appointments***	***Consulted for a second opinion***	***Family support***	***A belief that a child is too young for the CI***
Never	28	23	20	0	21
Rarely	1	3	5	3	2
Sometimes	1	2	2	2	5
Often	0	2	2	5	2
Always	0	0	1	20	0

Table 4.5

The parents' response frequency for the different questions on parental factors(taking care of other and family members/children, fear of the surgical procedure, re-implantation, up-gradation or maintenance cost).

Parents response	***Taking care of other children delayed CI***	***Taking care of family members delayed CI***	***Fear of the surgical procedure***	***Possessed cultural or superstitious beliefs***	***Fear of re-implantation, up-gradation, or maintenance cost***
Not at all	11	18	10	20	17
Slightly	2	3	6	2	4
Moderately	3	4	4	5	4
Very much	2	4	5	2	2
Extremely	3	1	5	1	3
NA	9				

Note. NA – Not applicable.

The response frequency shows that most of the parents have 'Never ' tried any other medication, possessed cultural or superstitious beliefs, and were not reluctant to CI due to the maintenance cost involved, re-implantation, and are unaware of CI. In addition, most of the parents reported they 'Always' had family support for their child's hearing loss. They had a fear of the surgical procedure and complications to a variable degree. Most of the parents reported that taking care of other children is not a factor that affects the age of implantation.

Spearman's correlation was carried out to see the correlation and there was no correlation between age of implantation and awareness about the cochlear implantation (ρ = 0.232, p = 0.217), tried any other medications for their child's hearing loss (ρ = 0.025, p = 0.897), taking care of other child delayed the surgery (ρ = 0.308, p = 0.174), family support (ρ = 0.124, p = 0.514), fear of the surgical procedure (ρ = -0.40, p = 0.834), possessed cultural or superstitious belief (ρ = 0.16, p = 0.933), had fear of re-implantation, up gradation or maintenance cost (ρ = -0.142, p = 0.456) , taught that child is too young for the CI (ρ = 0.255, p = 0.174).

However, there was a correlation between age of implantation and missing appointments by the parents (ρ = 0.393, p = 0.032), consulting many professionals for a second opinion (ρ = -0.393, p = 0.032), taking care of the family members (ρ = 0.364, p = 0.048). The results of the factors which had a correlation with the age of implantation are discussed below.

4.2.2.1 Missing appointments. A scatter plot of the parent's response is given in Figure 4.4, which shows that there are fewer missing appointments and there is a decrease in the age of implantation. Spearman's correlation was carried out to see the correlation between age of implantation and parents' missing the appointments given by professionals for the diagnosis and management of hearing loss. The results revealed a weak positive correlation between the age of implantation and missing appointments by the parents (ρ = 0.393, p = 0.032).

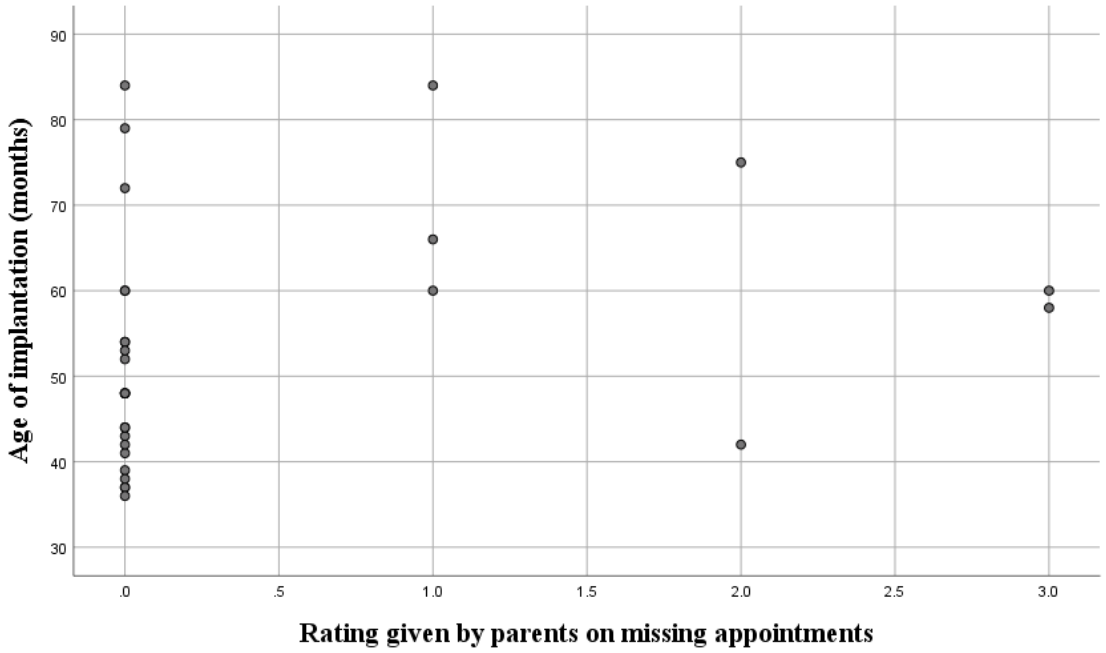

Figure 4.4.

Scatter plot showing response for missing appointments by the parent's vs. age of implantation in months. (0 = Never, 1 = Sometimes, 2 = Rarely, 3 = Often, and 4 = Always).

4.2.2.2 Consulted many professionals for the second opinion. Spearman's correlation was carried out to see the correlation between age of implantation and parents consulting many professionals for a second opinion about the diagnosis and management of hearing loss. The results revealed a weak negative correlation between the age of implantation and consulting many professionals for a second opinion ($\rho = -0.393$, $p = 0.032$). A scatter plot of the parent's responses is given in Figure 4.5, which shows that as the parents consulted many professionals for a second opinion, the age of implantation was less compared to parents who didn't consult for a second option regarding their child's hearing.

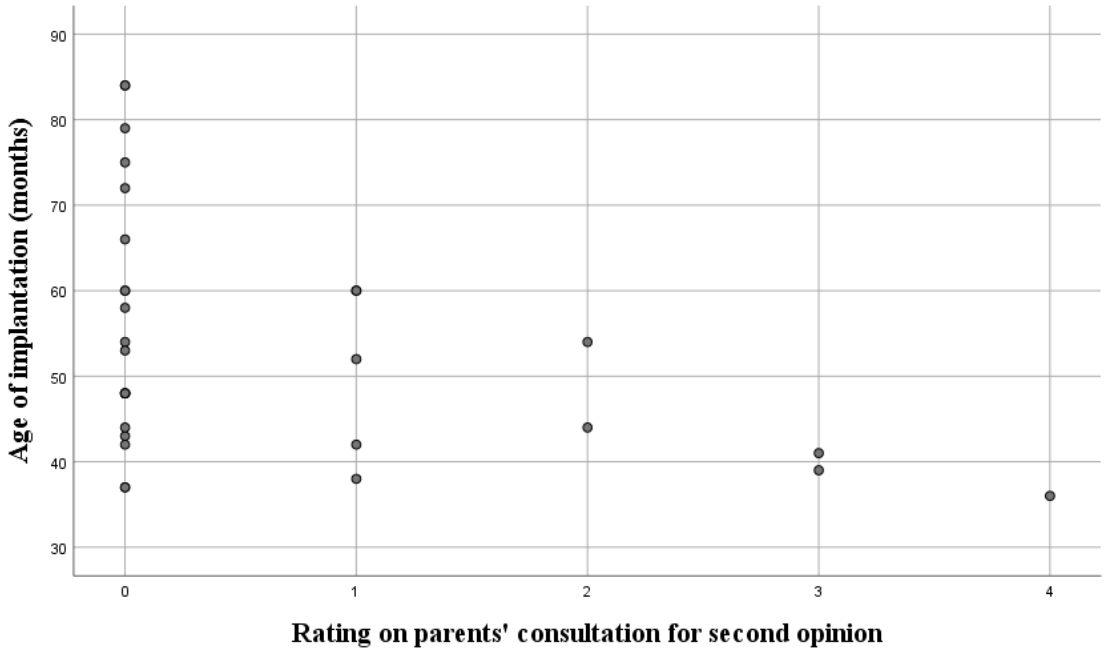

Figure 4.5.

Scatter plot showing response for consultation for the second opinion vs. age of implantation in months. (0 = Never, 1 = Sometimes, 2 = Rarely, 3 = Often, and 4 = Always)

4.2.23 Taking care of family members. Spearman's correlation was carried out to see the correlation between age of implantation and delay due to taking care of the family members. The results revealed a weak positive correlation between the age of implantation and taking care of the family members ($\rho = 0.364$, $p = 0.048$). A scatter plot of the parent's responses is given in Figure 4.6, whereas when the parents reported no delay in implantation due to taking care of family members, the age of implantation was less compared to parents who reported delay due to taking care of family members.

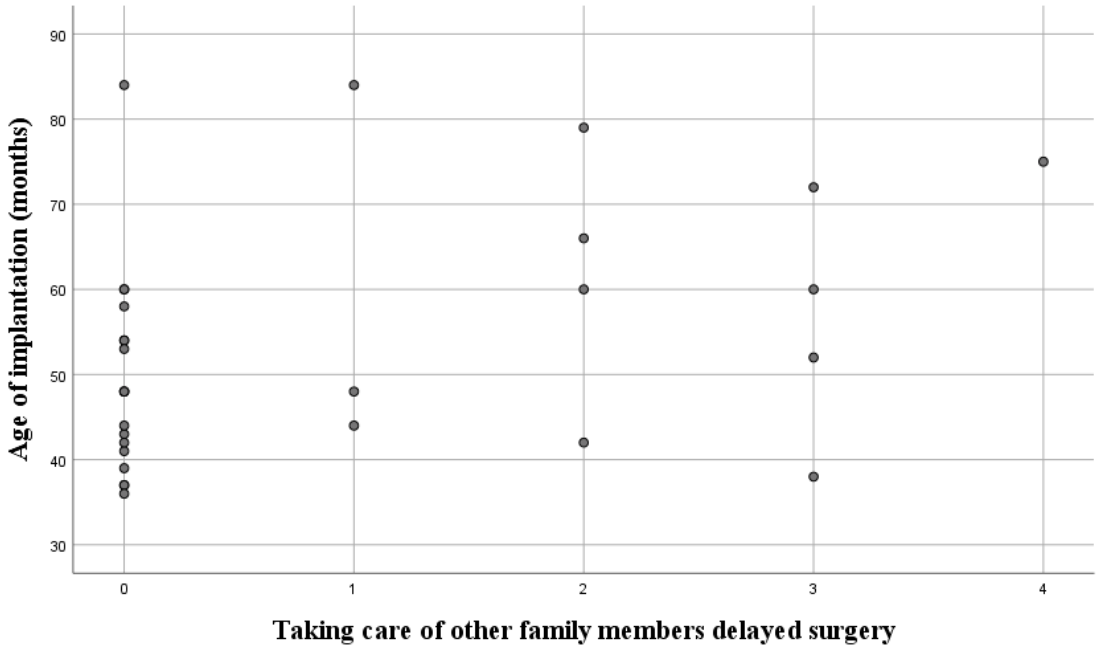

Figure 4.6.

Scatter plot showing response for taking care of family members vs. age of implantation in months. (0 = Never, 1 = Sometimes, 2 = Rarely, 3 = Often, and 4 = Always)

4.4 Professional factors

The questionnaire was administered to the parents of the CI children through telephonic interviews. Five-point Likert rating scale was used (e.g., 0 indicates never and 4 indicates always) to indicate the responses to each question. Various professional factors were correlated with the age of implantation of the children using Spearman's correlation.

The questions with similar rating scales have been grouped together and given in Tables 4.6 and 4.7. Table 4.6 shows the parent's response frequency for the questions of whether received adequate information about CI during the initial diagnosis. Table 4.7 shows the parent's response frequency for the questions about the delay in diagnosis of HL by the professionals, whether received appropriate referrals by professionals, and taking a long time for the CI candidacy evaluation.

Table 4.6

The response frequency for the question of whether received adequate information about CI during the initial diagnosis.

Parents response	Response Frequency
Not at all	10
Just heard the term	0
Some information	9
Most information	5
Completely information	6

Table 4.7

The parents' response frequency for the professional factors questions.

Parents response	***Delay in the diagnosis of HL by the professionals***	***Appropriate referrals by professionals***	***Taking a long time for the CI candidacy evaluation***
Never	21	5	23
Rarely	9	1	4
Sometimes	0	4	3
Often	0	2	0
Always	0	18	0

Parents were asked a question regarding whether they received adequate information from professionals regarding CI as a management option for hearing loss. The frequency of the parental response to the question is given in table 4.7, which shows that majority of the parents reported that either they didn't receive the information or some information was given by the professionals about CI as a management option during initial diagnosis. Spearman's correlation was done, and there was no correlation between age of implantation and information received about CI during the initial diagnosis of hearing loss ($\rho = 0.015$, $p = 0.938$).

Parents were asked whether they received appropriate referrals from the different professionals for their child's diagnosis and management of hearing loss, and most of the parents responded 'Always.' Further, for the question regarding whether there was a delay in the diagnosis of hearing loss by the audiologist and delay in CI candidacy evaluation most of the parents reported 'Never.' The response frequency for these questions is given in Table 4.8. Spearman's correlation was carried out, and there was no correlation between age of implantation and delay in the diagnosis of hearing loss by the professionals ($\rho = 0.324$, $p = 0.080$), inappropriate referrals by the professionals to the parents ($\rho = 0.122$, $p = 0.522$), taking a long time for the CI candidacy evaluation ($\rho = -0.46$, $p = 0.810$).

4.5 Other factors

4.5.1 Source of funding for CI

Among 30 children, two children underwent cochlear implantation through self-funding, whereas 20 under the ADIP scheme, six under the RBSK scheme, and two under the NPPCD program. The median age of implantation under the self-funding, ADIP scheme, RBSK scheme, and NPPCD are 47.5, 48, 54, and 55 months, respectively. The

mean, median, minimum, and maximum age of implantation of different schemes and self-funding are given below in Table 4.8.

Table 4.8

The mean, median, standard deviation, minimum and maximum age of implantation of children under different schemes.

Source of funding	Age of implantation (months)				
	Mean	**Median**	**SD**	**Minimum**	**Maximum**
Self-funding	47.50	47.50	9.192	41	54
ADIP	52.85	48.00	13.335	37	84
RBSK	57.33	54.00	20.704	36	84
NPPCD	55.00	55.00	4.243	52	58

Spearman's correlation was carried out to see the correlation between the age of cochlear implantation and children implanted through different schemes like ADIP, RBSK, NPPCD, or self-funding. The results revealed no correlation between the scheme through which the child underwent CI and the age of implantation ($\rho = 0.144$, $p = 0.449$), though the age of implantation was the lowest for self-funding.

4.5.2 Other factors like transportation, the processing time of the application, child adjusting to hearing aid

Some factors like transportation issues, the processing time of the application for free CI schemes, the child adjusting to hearing aid were correlated with age of implantation using Spearmen's correlation. The parents' response frequency for each of the questions are given in Table 4.9.

Table 4.9

The parents' response frequency for the transportation issue, the *processing time of the application, and the child adjusting to hearing aids.*

Parents response	**Transportation**	***Delay in processing the application for the CI under schemes***	***The child took a long time to get adjusted to a hearing aid***
Never	19	12	8
Rarely	3	6	6
Sometimes	4	4	7
Often	1	4	6
Always	3	2	2
NA		2	1

Note, NA – Not applicable

Table 4.9 shows that, for most of the parents', transportation (i.e., the distance of the rehabilitation centre) was not the major concern for the delayed CI. Twenty-eight children underwent CI through different schemes, and CI had been approved 3-4 months after the application submission. Twenty-nine of the children were given a hearing aid after the diagnosis of hearing loss, and one child directly underwent CI after the diagnosis of hearing loss.

Spearman's correlation was carried out to see the correlation between the above factors with the age of implantation of the children. The results revealed that for factors like transportation ($\rho = -0.208$, $p = 0.270$), delay in processing the application for the CI under schemes ($\rho = -0.013$, $p = 0.947$), a child taking a long time to get adjusted to hearing aids ($\rho = 0.135$, $p = 0.486$), there was no correlation with age of implantation.

Chapter 5

Discussion

Normal hearing sensitivity is essential for normal language development because language and listening cannot develop in the absence of auditory experience with spoken language and interaction (DeCasper & Fifer, 1980). Due to restricted linguistic input, children with severe to profound sensorineural hearing loss do not benefit from early exposure to spoken language and hence fall behind in the development of spoken language (Brasel & Quigley, 1977). Early implantation strengthens the brain connections leading to improved language development during infancy, allowing for an early start in language learning (Hammes et al., 2002).

The present study aimed to evaluate the factors affecting early implantation in children. Factors were collected by administering the questionnaire to the parents of implanted children and from the case files. The mean age of diagnosis of hearing loss in the study was 16.83 (±9.865) months. Several studies have shown the age of diagnosis of congenital hearing loss as being younger that was found in the current study. The mean age of hearing loss diagnosed was three months (Dalzell et al., 2000) and six months (Russ et al., 2004) reported in two different studies. The probable reason for the early identification of hearing loss in those studies can be due to the implementation of newborn hearing screening. In India, due to the lack of newborn hearing screening programs, detection of hearing loss in early infancy is difficult. In the present study only two, out of 30 children were reportedly had newborn hearing screening.Furthermore, the current study included only children implanted after the age of three years of age.

The time lapse between diagnosis of hearing loss and hearing aid fitting, and cochlear implantation is 11.03 (±13.98) and 38.76 (±16.97) months, respectively. This is a huge lapse leading to auditory deprivation for a longer duration. Though many a times, children are brought for assessment early, the intervention is not initiated immediately. It shows lack of awareness among the parents about the importance of early intervention.

5.1 Demographic factors

Children from rural residences and lower socioeconomic classes were diagnosed with hearing loss later, and there was a delay in the implantation as well (Fitzpatrick et al., 2015; Jeddi et al., 2012; Noblitt et al., 2018). This could be due to a lack of awareness among the public and physicians and the high cost of the device, which hinder people who are economically weaker from the implantation (Jeddi et al., 2012; Kothari et al., 2015). In the present study, the median age of implantation in urban and rural was 48 and 54 months respectively. However, there was no statistical difference between the children living in the urban and rural in terms of age of implantation. This shows an increased awareness in the rural population and the awareness level is similar across different regions.

In addition, it was found that even though 27 (90%) of the parents were from lower socioeconomic class, there was no delay in the age of implantation compared to the middle and higher socioeconomic class. It could be because most of the children have undergone cochlear implantation through the government schemes (ADIP, RBSK, NPPCD) in which cochlear implantation is given free of cost to children with lower socioeconomic class.

5.2 Parental factors

The results showed that as the education level of the mother increases, the age of implantation decreases in children. These results are in agreement with Jeddi et al. (2012). This could be attributed to an increase in the parents' awareness about hearing loss and its symptoms and the importance of early identification and intervention (Lester et al., 2011). Other parental factors like missing appointments and taking care of family members resulted in the delay in cochlear implantation. These results are in agreement with Armstrong et al. (2013). Family support and decision for CI have delayed the diagnosis and management of hearing loss (Fitzpatrick et al., 2011).

Armstrong et al. (2013) found that parental attitude towards surgical procedures and complications had a high impact, and there was a reluctance towards the CI due to fear and complication of the surgical procedure. Whereas in the present study, even though parents of the implanted children had fear about the surgical procedure, there didn't delay the surgery because of these factors. This could be attributed to the professionals' effective counselling of the parents and also by other parents, whose children have already undergone the CI. The author also found a delay in the age of implantation due to cultural factors, whereas in the present study though six parents possessed cultural/superstitious beliefs, there was no correlation with the age of implantation.

Fitzpatrick et al. (2015) found that family hesitation and decision on CI delayed implantation in 9% of children. In the current study, 34% have reported that family support is not adequate. Nevertheless, the results showed no correlation between the age of implantation and these factors. In the present study, three parents thought their child was too young for the surgery, but there was no delay in implantation; this can be attributed to

effective counselling by the professionals and seeing the other children who underwent CI at the same age as their child.

None of the parents tried alternative medications like home remedies or Ayurveda to cure their child's hearing loss or for the management of hearing loss; this shows that there is an increased awareness among the public regarding the diagnosis and management of hearing loss. An interesting finding of the present study was that there was a decrease in the age of implantation as the number of opinions taken increased. Consultation for second opinion shows parents' motivation towards their child's hearing loss which could have led to early implantation compared to others who didn't consult another professional for the second opinion.

5.3 Professional factors

Education of the primary care provider and other professionals regarding early identification and intervention of hearing loss helps in early identification and appropriate referrals for further testing in children with hearing loss (Jeddi et al., 2012; Lester et al., 2011). Though, parents reported not receiving most of the information regarding the CI at the time of the initial diagnosis of their child's hearing loss, the results show no delay due to inappropriate referrals by professionals.

5.4 Transportation and other factors

A study by Whelan et al. in 2021 showed transportation facilities to the hospital or rehabilitation centre can affect the age of implantation and other service delivery. In the present study, even though around 63 % of participants are from rural areas, transportation didn't hinder them from accessing rehabilitation care.

Other factors like processing time for the CI application for children who underwent CI under government schemes were assessed, and the parents reported there was no time delay in processing the application. Usually, the surgery was done by 3-4 months after the application was submitted.

Chapter 6

Summary and Conclusion

The present study aimed to analyse the factors responsible for delayed CI in children as early cochlear implantation helps to achieve good speech and language skills, cognition, and psychosocial skills. Analysing the factors resulting in delay would help the professionals plan steps to advance the age of implantation. The study included analysing the factors from the participant's case files and developing and administering the questionnaire to the parents to elicit information regarding different factors. The questionnaire was also translated to Kannada using AAOS guidelines. The study was conducted on 30 participants with severe to profound hearing loss who underwent CI at or above the age of 3 years. The questionnaire was administered to the parents of the participants.

The responses were tabulated, and descriptive, inferential statistics and correlations were carried out using SPSS software (v 25 for Windows). The results are as follows:

- There was no statistically significant effect of gender (male vs. female), geographical location (urban vs. rural), family history of hearing loss (positive vs. negative), source of funding for CI (ADIP, RBSK, NPPCD, self-funded) on the age of implantation.
- As the education level of the mother increased, there was a decrease in the age of implantation.

- There was a correlation between parental factors like missing appointments and taking care of the family members, and age of implantation.
- As the parents consulted many professionals for multiple opinions about their child's hearing loss diagnosis and management, the age of implantation decreased.
- There was no correlation between parental factors like awareness about CI, tried other medications, family support, fear of surgery, maintenance cost or re-implantation, possessed cultural/superstitious beliefs towards their child's HL, taking care of other siblings, and belief that the child is too young for surgery and the age of implantation.
- There was no correlation between professional factors like delay in diagnosis and candidacy evaluation, inappropriate referrals, inadequate information about CI to the parents, and the age of implantation.
- There was no correlation between transportation issues, the processing time of the application for the children who underwent CI through the scheme, the child took a long time to get adjusted to hearing aids and the age of implantation.

It can be inferred from the above results that attitude of parents toward their child's hearing loss has to be dealt with initially for improved outcomes. There is a delay in the identification of hearing loss due to inadequate newborn hearing screening among infants. Hence, there is a need to implement hearing screening in all hospitals. Public awareness and education must be increased to avoid the barriers to late implantation. In addition, even

though the parents give counselling about intervention, they don't understand the importance of early intervention.

Hence, universal neonatal hearing screening, a facility for early referral, diagnosis, and intervention for infants with hearing loss, and awareness of the advantages and efficacy of cochlear implants for young children should be implemented to address the variables that delay cochlear implant surgery. This will enable children who are still in the crucial stage of development to acquire language at higher rates.

6.1 Clinical implications

- The study results throw light on the importance of effective counselling to parents and family members regarding the importance of early identification and intervention of hearing loss in children.
- Awareness programs have to be carried out for parents and professionals (primary care providers) about the factors that will delay the CI in children, which in turn help appropriate referrals.

6.2 Future direction

- The study was conducted with 30 participants. Further, the study can be conducted on more participants to generalize the findings.
- More studies are required to compare the age of implantation across socioeconomic status, educational background, and source of funding with adequate number of participants.

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Appendix I

Questionnaire

PART 1

Demographic Details

1. Case Name:
2. Case Number:
3. Age/Gender:
4. DOB:
5. Address/Place: Urban / Rural
6. Socioeconomic class: Slab I/ Slab II/Slab III
7. Education of the parents: Mother: Father:

PART 2

1. Is newborn hearing screening done for your child? Yes or No
   If Yes, after how many days after birth ----------
   What was the result of the hearing screening? Pass / Refer (recommended for further testing)
2. At what age was the hearing loss suspected? ……months/ years.
3. Age of initial diagnosis of hearing loss ……months/ years.
4. Age at which the child started using hearing aid …… months/ years.
5. Age at which listening training was started…… months/ years.
6. Duration of listening training taken with hearing aid ……months / years.
7. Age at which cochlear implantation was done ……years.
8. Ear in which cochlear implantation is done ……(Right / Left / Bilateral)
9. Is the child using a hearing aid in the opposite ear? Yes/ No
10. Did you know about cochlear implantation before your child was diagnosed with hearing loss? Please choose one of the five options.

0	1	2	3	4
Completely unaware	Not aware	Slightly aware	Aware	Completely aware

11. Did you receive any information regarding cochlear implantation as a management option after your child's diagnosis?

0	1	2	3	4
Not at all	Just heard the term	Some information	Most information	Complete information

12. Have you tried any other medications as a treatment for hearing loss? (e.g., AYUSH, home remedies)

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

13. Did you miss the appointments given by doctors or other professionals during evaluations?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

14. Have you received appropriate referrals from different professionals (General physician, ENT doctor)?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

15. Have you consulted multiple hearing care professionals for a second opinion regarding the diagnosis of hearing loss?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

16. Do you think there was a delay in the diagnosis of hearing loss by the professionals?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

17. Did Cochlear Implantation candidacy testing (e.g., audiological, radiological) take a lot of time?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

18. Did you receive your family support for the assessment and management of your child?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

19. Do you feel that the distance between your native place and the rehabilitation centre affected your child's diagnosis and management of hearing loss?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

20. Do you feel that the child took a long time to get adjusted to the hearing aid? (e.g., 2-3 months)

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

21. Taking care of other children (younger or elder siblings) delayed the CI surgery. (Applicable if there are siblings)

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

22. Taking care of other family members (except siblings) delayed the CI surgery.

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

23. Did you delay the decision of Cochlear Implantation due to the fear and complications of surgery?

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

24. Did you show any cultural/superstitious beliefs towards your child's hearing loss?

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

25. Were you reluctant towards cochlear implantation due to maintenance cost, re-implantation, or up-gradation?

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

26. Have you thought that your child is too young to use a hearing aid or cochlear implant?

0	1	2	3	4
Never	Rarely	Sometimes	Often	Always

27. Processing the application for a free Cochlear Implantation scheme or other funds or grants (ADIP, RBSK, CM funds, etc.) took much time.*

0	1	2	3	4
Not at all	Slightly	Moderately	Very much	Extremely

*Applicable for children who underwent CI through Government Schemes or Funds

Appendix II

ಪ್ರಶ್ನಾವಳಿ

ಭಾಗ 1

ಜನಸಂಖ್ಯಾ ವಿವರಗಳು

1. ಪ್ರಕರಣದ ಹೆಸರು:

2. ಪ್ರಕರಣ ಸಂಖ್ಯೆ:

3. ವಯಸ್ಸು/ಲಿಂಗ:

4. ಹುಟ್ಟಿದ ದಿನ:

5. ವಿಳಾಸ/ಸ್ಥಳ: ನಗರ/ಗ್ರಾಮೀಣ

6. ಸಾಮಾಜಿಕ ಆರ್ಥಿಕ ವರ್ಗ: ಸಾ್ಯಬ್ I/ ಸಾ್ಯಬ್ II/ಸಾ್ಯಬ್ III

7. ಪೋಷಕರ ಶಿಕ್ಷಣ: ತಾಯಿ: ತಂದೆ:

ಭಾಗ 2

1. ನಿಮ್ಮ ಮಗುವಿಗೆ ನವಜಾತ ಶ್ರವಣ ಪರೀಕ್ಷೆಯನ್ನು ಮಾಡಲಾಗಿದೆಯೇ? ಹೌದು ಅಥವಾ ಇಲ್ಲ

ಹೌದು ಎಂದಾದರೆ, ಹುಟ್ಟಿದ ಎಷ್ಟು ದಿನಗಳ ನಂತರ ----------

ಶ್ರವಣ ಪರೀಕ್ಷೆಯ ಫಲಿತಾಂಶವೇನು? ಪಾಸ್ / ಉಲ್ಲೇಖಿಸಿ (ಶಿಫಾರಸು ಮಾಡಲಾಗಿದೆ ಹೆಚ್ಚಿನ ಪರೀಕ್ಷೆಗಾಗಿ)

2. ಯಾವ ವಯಸ್ಸಿನಲ್ಲಿ ಶ್ರವಣ ದೋಷವನ್ನು ಶಂಕಿಸಲಾಗಿದೆ? ..... ತಿಂಗಳುಗಳು / ವರ್ಷಗಳು.

3. ಶ್ರವಣದೋಷದ ಆರಂಭಿಕ ರೋಗನಿರ್ಣಯದ ವಯಸ್ಸು .....ತಿಂಗಳು/ವರ್ಷಗಳು.

4. ಮಗು ಶ್ರವಣ ಸಾಧನವನ್ನು ಬಳಸಲು ಪ್ರಾರಂಭಿಸಿದ ವಯಸ್ಸು ..... ತಿಂಗಳುಗಳು / ವರ್ಷಗಳು.

5. ಆಲಿಸುವ ತರಬೇತಿಯನ್ನು ಪ್ರಾರಂಭಿಸಿದ ವಯಸ್ಸು..... ತಿಂಗಳುಗಳು/ವರ್ಷಗಳು.

6. ಶ್ರವಣ ಸಾಧನದೊಂದಿಗೆ ತೆಗೆದುಕೊಳ್ಳಲಾದ ಆಲಿಸುವ ತರಬೇತಿಯ ಅವಧಿ ..... ತಿಂಗಳುಗಳು / ವರ್ಷಗಳು.

7. ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟ್ ಅಳವಡಿಕೆಯನ್ನು ಮಾಡಿದ ವಯಸ್ಸು ..... ವರ್ಷಗಳು.

8. ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟ್ ಅಳವಡಿಕೆಯನ್ನು ಮಾಡುವ ಕಿವಿ .....(ಬಲ / ಎಡ / ದ್ವಿಪಕ್ಷೀಯ)

9. ಮಗು ಎದುರಿನ ಕಿವಿಯಲ್ಲಿ ಶ್ರವಣ ಸಾಧನವನ್ನು ಬಳಸುತ್ತಿದೆಯೇ? ಹೌದು ಅಲ್ಲ

10. ನಿಮ್ಮ ಮಗುವಿಗೆ ಶ್ರವಣ ದೋಷವಿದೆ ಎಂದು ರೋಗನಿರ್ಣಯ ಮಾಡುವ ಮೊದಲು ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟೇಶನ್ ಬಗ್ಗೆ ನಿಮಗೆ ತಿಳಿದಿದೆಯೇ? ದಯವಿಟ್ಟು ಐದು ಆಯ್ಕೆಗಳಲ್ಲಿ ಒಂದನ್ನು ಆರಿಸಿ.

0	1	2	3	4
ಸಂಪೂರ್ಣವಾಗಿ ತಿಳಿದಿಲ್ಲ	ಅರಿವಿಲ್ಲ	ಸ್ವಲ್ಪ ಅರಿವಿದೆ	ಅರಿವಿದೆ	ಸಂಪೂರ್ಣ ಅರಿವಿದೆ

11. ನಿಮ್ಮ ಮಗುವಿನ ರೋಗನಿರ್ಣಯದ ನಂತರ ನಿರ್ವಹಣಾ ಆಯ್ಕೆಯಾಗಿ ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟೇಶನ್ ಕುರಿತು ನೀವು ಯಾವುದೇ ಮಾಹಿತಿಯನ್ನು ಸ್ವೀಕರಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಸ್ವಲ್ಪ ಮಾಹಿತಿ	ಹೆಚ್ಚಿನ ಮಾಹಿತಿ	ಸಂಪೂರ್ಣ ಮಾಹಿತಿ

12. ಶ್ರವಣದೋಷಕ್ಕೆ ಚಿಕಿತ್ಸೆಯಾಗಿ ನೀವು ಯಾವುದೇ ಇತರ ಔಷಧಿಗಳನ್ನು ಪ್ರಯತ್ನಿಸಿದ್ದೀರಾ? (ಉದಾ., ಆಯುಷ್, ಮನೆಮದ್ದುಗಳು)

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

13. ಮೌಲ್ಯಮಾಪನದ ಸಮಯದಲ್ಲಿ ವೈದ್ಯರು ಅಥವಾ ಇತರ ವೃತ್ತಿಪರರು ನೀಡಿದ ಅಪಾಯಿಂಟ್‌ಮೆಂಟ್‌ಗಳನ್ನು ನೀವು ಕಳೆದುಕೊಂಡಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

14. ನಿಮ್ಮ ಮಗುವಿನ ಶ್ರವಣ ಸಮಸ್ಯೆಗಾಗಿ ನೀವು ವಿವಿಧ ವೃತ್ತಿಪರರಿಂದ (ಸಾಮಾನ್ಯ ವೈದ್ಯ, ಇಎನ್‌ಟಿ ವೈದ್ಯರು) ಸೂಕ್ತ ಉಲ್ಲೇಖಗಳನ್ನು ಸ್ವೀಕರಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

15. ಶ್ರವಣ ನಷ್ಟದ ರೋಗನಿರ್ಣಯಕ್ಕೆ ಸಂಬಂಧಿಸಿದಂತೆ ಎರಡನೇ ಅಭಿಪ್ರಾಯಕ್ಕಾಗಿ ನೀವು ಬಹು ಶ್ರವಣ ಆರೈಕೆ ವೃತ್ತಿಪರರನ್ನು ಸಂಪರ್ಕಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

16. ವೃತ್ತಿಪರರಿಂದ ಶ್ರವಣ ದೋಷದ ರೋಗನಿರ್ಣಯದಲ್ಲಿ ವಿಳಂಬವಾಗಿದೆ ಎಂದು ನೀವು ಭಾವಿಸುತ್ತೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

17. ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟೇಶನ್ ಉಮೇದುವಾರಿಕೆ(candidacy testig) ಪರೀಕ್ಷೆ (ಉದಾ., ಆಡಿಯೋಲಾಜಿಕಲ್, ರೇಡಿಯೊಲಾಜಿಕಲ್) ಸಾಕಷ್ಟು ಸಮಯ ತೆಗೆದುಕೊಂಡಿತು.

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

18. ನಿಮ್ಮ ಮಗುವಿನ ಮೌಲ್ಯಮಾಪನ ಮತ್ತು ನಿರ್ವಹಣೆಗಾಗಿ ನಿಮ್ಮ ಕುಟುಂಬದ ಬೆಂಬಲವನ್ನು ನೀವು ಸ್ವೀಕರಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

19. ನಿಮ್ಮ ಸ್ಥಳೀಯ ಸ್ಥಳ ಮತ್ತು ಪುನರ್ವಸತಿ ಕೇಂದ್ರದ ನಡುವಿನ ಅಂತರವು ನಿಮ್ಮ ಮಗುವಿನ ರೋಗನಿರ್ಣಯ ಮತ್ತು ಶ್ರವಣ ದೋಷದ ನಿರ್ವಹಣೆಯ ಮೇಲೆ ಪರಿಣಾಮ ಬೀರುತ್ತದೆ ಎಂದು ನೀವು ಭಾವಿಸುತ್ತೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

20. ಮಗು ಶ್ರವಣ ಸಾಧನಕ್ಕೆ ಹೊಂದಿಕೊಳ್ಳಲು ಬಹಳ ಸಮಯ ತೆಗೆದುಕೊಂಡಿತು ಎಂದು ನೀವು ಭಾವಿಸುತ್ತೀರಾ? (ಉದಾ., 2-3 ತಿಂಗಳು)

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

21. ಇತರ ಮಕ್ಕಳನ್ನು (ಕಿರಿಯ ಅಥವಾ ಹಿರಿಯ ಒಡಹುಟ್ಟಿದವರು) ನೋಡಿಕೊಳ್ಳುವುದು CI ಶಸ್ತ್ರಚಿಕಿತ್ಸೆಯನ್ನು ವಿಳಂಬಗೊಳಿಸಿತೆ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮವಾಗಿ	ತುಂಬಾ	ಅತ್ಯಂತ

22. ಇತರ ಕುಟುಂಬ ಸದಸ್ಯರನ್ನು (ಸಹೋದರಿಯರನ್ನು ಹೊರತುಪಡಿಸಿ) ಆರೈಕೆಯು CI ಶಸ್ತ್ರಚಿಕಿತ್ಸೆಯನ್ನು ವಿ ವಿಳಂಬಗೊಳಿಸಿತೆ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮವಾಗಿ	ತುಂಬಾ	ಅತ್ಯಂತ

23. ಶಸ್ತ್ರಚಿಕಿತ್ಸೆಯ ಭಯ ಮತ್ತು ತೊಡಕುಗಳ ಕಾರಣದಿಂದ ನೀವು ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟೇಶನ್ ನಿರ್ಧಾರವನ್ನು ವಿಳಂಬ ಮಾಡಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮವಾಗಿ	ತುಂಬಾ	ಅತ್ಯಂತ

24. ನಿಮ್ಮ ಮಗುವಿನ ಶ್ರವಣ ದೋಷದ ಬಗ್ಗೆ ನೀವು ಯಾವುದೇ ಸಾಂಸ್ಕೃತಿಕ / ಮೂಢನಂಬಿಕೆಗಳನ್ನು ತೋರಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮವಾಗಿ	ತುಂಬಾ	ಅತ್ಯಂತ

25. ನಿರ್ವಹಣಾ ವೆಚ್ಚ, ಮರು-ಇಂಪ್ಲಾಂಟೇಶನ್ ಅಥವಾ ಉನ್ನತ-ದರ್ಜೆಯ ಕಾರಣದಿಂದಾಗಿ ನೀವು ಕಾಕ್ಲಿಯರ್ ಅಳವಡಿಕೆಗೆ ಇಷ್ಟವಿರಲಿಲ್ಲವೇ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

26. ಶ್ರವಣ ಸಾಧನ ಅಥವಾ ಕಾಕ್ಲಿಯರ್ ಇನ್‌ಪ್ಲಾಂಟ್ ಅನ್ನು ಬಳಸಲು ನಿಮ್ಮ ಮಗು ತುಂಬಾ ಚಿಕ್ಕವನು/ ಚಿಕ್ಕವಳು ಎಂದು ನೀವು ಭಾವಿಸಿದ್ದೀರಾ?

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮವಾಗಿ	ತುಂಬಾ	ಅತ್ಯಂತ

27. ಉಚಿತ ಕಾಕ್ಲಿಯರ್ ಇಂಪ್ಲಾಂಟೇಶನ್ ಯೋಜನೆ ಅಥವಾ ಇತರ ನಿಧಿಗಳು ಅಥವಾ ಅನುದಾನಗಳಿಗಾಗಿ (ADIP, RBSK, CM ನಿಧಿಗಳು, ಇತ್ಯಾದಿ) ಅರ್ಜಿಯನ್ನು ಪ್ರಕ್ರಿಯೆಗೊಳಿಸಲು ಹೆಚ್ಚು ಸಮಯ ತೆಗೆದುಕೊಂಡಿತಾ? *

0	1	2	3	4
ಇಲ್ಲವೇ ಇಲ್ಲ	ಇಲ್ಲ	ಕೆಲವೊಮ್ಮೆ	ಆಗಾಗ	ಯಾವಾಗಲೂ

*ಸರ್ಕಾರಿ ಯೋಜನೆಗಳು ಅಥವಾ ನಿಧಿಗಳ ಮೂಲಕ CI ಗೆ ಒಳಗಾದ ಮಕ್ಕಳಿಗೆ ಅನ್ವಯಿಸುತ್ತದೆ.