

# Expectations and Experience of Children with Unilateral Cochlear Implantation: A Parental Perspective

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**Abstract** To find out parental expectations regarding outcomes of unilateral cochlear implantation prior to surgery and experience received by them after cochlear implantation and 1 year of regular auditory verbal therapy, with respect to the communication abilities, social skills and participation. Total of 200 parents of hearing impaired children participated in the study. A closed ended questionnaire containing 13 questions were used to collect the data. The participants were instructed to complete all the questions provided based on their expectations and experiences. The descriptive statistics were used to determine the frequency and percentage. Among 200 parents, almost all (95%) of the parents expected to have improvement in all the subscale of communication abilities, social skills and participation. 68.5% of the parents experienced improvement in their child's communication abilities, such as, response to quiet sounds, repetition of words without seeing speaker's face, elimination of use of gestures, easy communication and verbal expression for needs, thoughts and feelings. 76% of the parents experienced improvement in social skills and participations, such as, good relationship with elders, siblings and peers, making friends outside the family, actively participating in the activity done by other children and easily accepted by peers in the classroom. A large number of parents met with their expectations and a small proportion of families were found to be

disappointed due to high hopes and unrealistic expectation before implantation, which had adverse effect on the children's performance.

**Keywords** Unilateral cochlear implantation · Parental expectation and experience · Communication abilities · Social skills and participation

## Abbreviations

CI Cochlear implantation  
AVT Auditory verbal therapy  
HI Hearing impaired

## Introduction

A cochlear implant is a surgically implanted electronic device that provides a sense of sound to a person who is profoundly deaf or severely hard of hearing [1]. Cochlear Implant plays an important role in development of listening skill, communication abilities, social skills and participation and helps the individuals to progress in their life as an ability to carry out successful livelihood [2]. Parents of hearing impaired (HI) children have an important role in decision making for cochlear implantation (CI) to their child [3]. The parents have high expectations regarding outcomes of CI [4, 5]. Parents' expectations may vary and may or may not match with expectation of others, including implanting teams [6]. The parents expected changes in the area of mainstream primary education, better social achievements, social versatility, broader options for further education, better employment and improved social independence, communication abilities and better quality of life

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as a major outcome of implantation [7]. Due to lack of information, parents may have unrealistic expectation regarding outcomes of CI prior to the surgery [8]. This unrealistic expectation may cause disappointment to the parents which may have adverse effect on the performance of the child [9]. Due to low competence parental stress has been reported in children with HI [10], which may affect the quality of life of their parents. However parental satisfaction with regards to outcomes of implantation may depend on the level of expectation that parents have. Parents with high hopes and unrealistic expectations may experience their child to be deaf even after CI and so the intensive rehabilitation effort remains necessary for a long time or even throughout life [11]. As the children acquire more listening experience with cochlear implant, the parental expectation often change over time [12]. Parents wisely adapt their expectation on the basis of their child's development [13]. There are very few studies in India [14–16], which states about the development of listening, receptive, and expressive skills, communication abilities, social skills and participation. The present study focus on parental expectations regarding outcomes of CI before surgery and experienced received by them as a outcome after CI and 1 year of regular auditory verbal therapy (AVT) with respect to communication abilities, social skills and participation.

### Participants

A total of 200 (146 female and 54 male) parents of HI child between the age ranges of 30–45 years participated in this study. All the participants were native Gujarati language speakers. The children included, were between the ages ranges of 2–6 years and had hearing age of 1 year. Inclusion criterions for the children were: 1. bilateral congenital deafness, 2. unilateral CI, 3. Attended minimum 1 year regular AVT, 4. Absence of other associated problems.

### Procedure

The study was carried out in 2 phases, Phase-I, development of questionnaire, Phase-II, administration of questionnaire and analysis of result. The questionnaire used in the study was composed of different questions relating to communication abilities, social skills and participation. Prior to designing the questionnaire, other questionnaires developed on similar topic were reviewed. These included: A comparison of anticipated benefits and received outcomes of pediatric cochlear implantation: parental perspective [8], outcomes form cochlear implantation for child and family [17], quality of life in pediatric cochlear

implantation [18]. The questionnaire was developed in English, translated in native language and designed to collect the information about parental expectation before CI and experience received as an outcome of CI after attending 1 year of regular AVT. The questionnaire was divided into two sections. Section one consist of demographic data such as name, age, gender, address etc. Section two consists of 13 closed ended questions related communication abilities, social skills and participants. The questionnaire was distributed among 10 qualified audiologists and doctors to review and validate, and the questions were revised based on their suggestions. The questionnaire was personally distributed to the parents and instructions were given to complete all the questions. As formal informed consent was taken, participants were verbally informed that confidentiality of the information collected will be maintained. Data collection related to expectations were asked before cochlear implant surgery during audiological assessment and data collection related to experience was obtained after 1 year of regular AVT.

### Instruction

Participants were instructed to complete the questionnaire based on their expectation and experiences.

### Statistical analysis

The data was collated using Microsoft excel program for further statistical analysis. Descriptive statistics were used to determine the frequency and percentage of participants by using SPSS 14.0 version.

### Results

Among 200 parents, 85% of parents reported that, the use of device by their child was more than 10 h/day and remaining 15% parents said the usage to be less than 10 h/day, which was 6 to 8 h/day. Of the 200 children, 30% of the children were in play group, 27.5% children were in kindergarten and rest of them were not receiving any education as they were below the age of schooling.

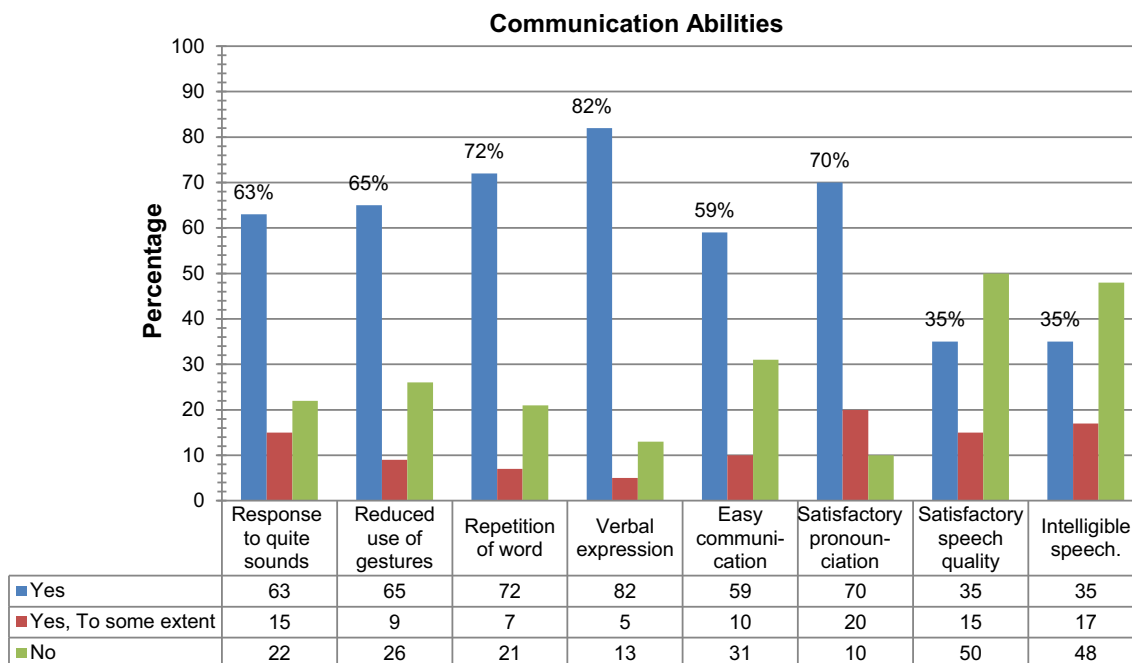
The items in the subscale of communication abilities, social skills and participation describes the development of listening skills, receptive skills, expressive skills, speech intelligibility and social achievements in everyday situation. Among 200 parents, almost all (95%) of the parents expected their child to have improvement in all the mentioned subscale of communication abilities, social skills and participation, and very few parents (5%) who didn't

expect anything as they were not aware about outcome of CI.

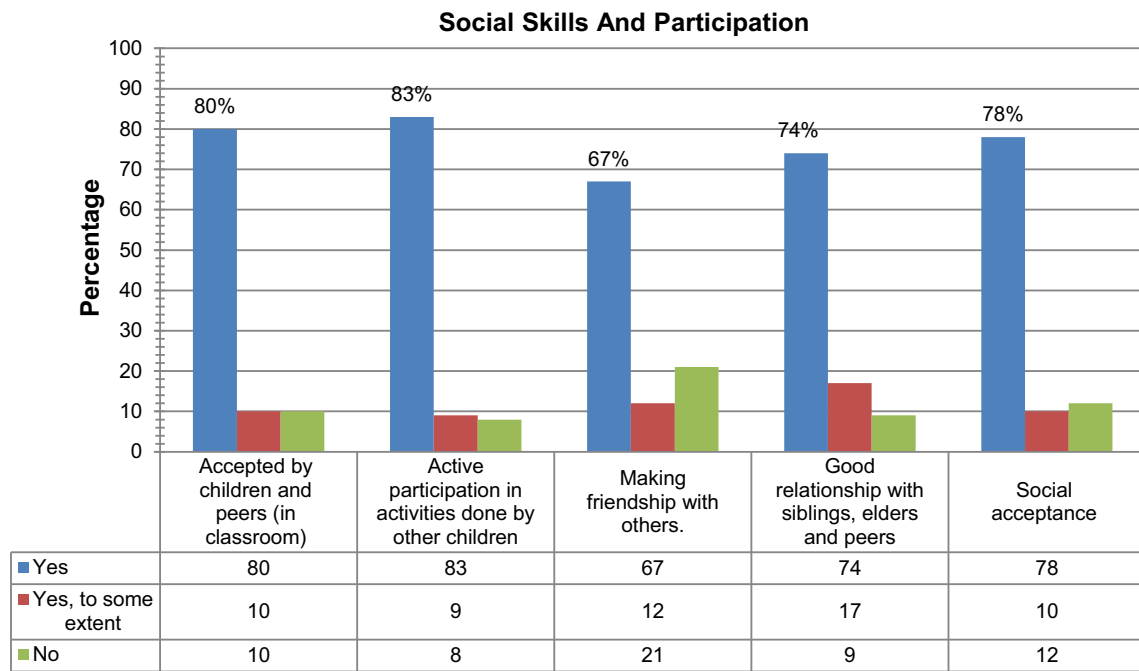
Figure 1 shows the details of experience received by the parents with respect to communication abilities. The results of communication abilities reveals that, majority (78%) of the parents reported that, their child responds to quiet sounds such as bird chirping sounds, ling six sounds, whistlings, whispers etc. Of the 78% of parents, 15% of them reported that their child respond on quiet sound to some extent. Around three-fourth (74%) of the parents reported that, use of gestures were reduced by their child after few months of regular AVT, in which 9% of them reported to use gestures by their child to some extent along with verbal expression. 79% of the parents reported that, their child repeat the words without seeing speaker's face, in which 7% of the children had partial repetition of the words. A vast majority (87%) of the parents experienced that their children were able to express needs, thoughts and feelings through verbal expressions, and only 5% of them reported that their child could express with the help of gestures. 59% of the parents reported that their child had easy communication after 1 year of regular AVT, whereas 10% of them found little difficulty while communicating with their child. The child's pronunciation was satisfactory for 70% of the parents, whereas 20% of them were satisfied to some extent. Satisfaction regarding child's quality of

speech was reported by half (50%) of the parents, in which 15% of them were satisfied to some extent. More than half (52%) of the parents experienced that their child's speech was intelligible to other people, in which 17% of them found difficulty to understand during first communication and needed more attention.

Figure 2 shows the details of the experience received by the parents with respect to social skill and participation. Out of 200 parents, most of the parents (90%) experienced that their child is easily accepted by other children and peers in the classroom, whereas 10% of them experienced that, their child faced little difficulty while accepting by peers. More than three-fourth (83%) of the parents experienced that, their child is actively participating in most of the activity done by other children and 9% of them were experienced, their child having partial participation. More than half (67%) of the parents noticed that, their children were able to make friends outside the family, Whereas 12% faced little difficulty while making friendship with others. 74% of the parents experienced, their child is having good relationship with elders, peers and siblings; whereas 17% noticed fair relationships. More than three-fourth (88%) of the parents experienced, their child is no more socially isolated and accepted to some extent, whereas social isolation was experienced by 12% of the parents.



**Fig. 1** Representation of the response of parents under various subscales in percentage. *Note:* Description of the results only shows the percentage of parents who stated Yes and Yes to some extent



**Fig. 2** Representation of the response of parents under various subscales in percentage. *Note:* Description of the results only shows the percentage of parents who stated Yes and Yes to some extent

**Discussion**

The present study was 1 year prospective follow up of successful unilateral cochlear implanted children. The study focused on the parental expectation and experience regarding the outcomes in communication abilities, social skills and participation after CI and 1 year of regular AVT. The results of communication abilities showed improvement in response to quiet sound, reduced use of gesture, repetition of word without seeing speaker face, verbal expression for his/her wants needs, thoughts, and feelings, easy communication, satisfactory pronunciation. Similar results were obtained in the study by Hyde [8], where parental perspective regarding comparison of anticipated benefits and received outcomes of pediatric CI was studied. 61.9% of the parents experienced their child responding and detecting very quiet sounds (e.g. a whispers), 90% of children express their needs, wants, and feelings verbally. Huttunen and Valima [13] found that the attention of the child could be drawn by calling his/her name after 6 months of hearing age. Also, the signs/gestures were no longer used by the child for the purpose of communication at the hearing age of 2 years, and communication got easier following 6 months from activation of the implant. Another study by Archbold et al. [17] reported 79% of the children being able to communicate even in dark where lip

reading was impossible and able to cope in new situations after CI. Similar results were revealed by Yorgun et al. [18] where speech pronunciation was found to be satisfactory by 76.4%. Therefore, even in our study, the parents reported the better outcomes in communication abilities of the child. These results might be suggestive of the fact that these children were implanted during critical age that would have helped in development of language skills. Also, the focus provided by parents of children who attended regular AVT for minimum 1 year was appropriate with interactive home training and active participation in the rehabilitation process. Also, these children had used CI device regularly for more than 10 h/day and therefore were exposed to speech stimulation continuously during the usage of the device.

Also, in the present study it was found that the social skills and participation had improved in various aspects as good relationship with siblings, elders and peers, social acceptance by society, ability to make friendship with others, active participation in activity done by other children, accepted by children and peers in classroom. Similar result was reported by Hyde [8] where it was found that the social relationship of the child with siblings, elders and peers was significantly greater than expected. Also, Huttunen and Valima [13] reported social relationship of the child with siblings, elders and peers improved as the number of social acquaintance with the child increased.

Considering these studies with the result of the present study, one can understand that the social skills and participation of the children might improve since their communication abilities increased with increasing age leading to the increment in peer interaction as they were attending regular school. Also, it was reported by the parents of these children regarding their extrovert attitude towards society with improvement in communication. Hence, these findings are suggestive of the positive attitudes of the majority of parents to CI in their children's life and had high level of satisfaction regarding outcomes of CI.

However, few of the components of the questionnaires such as, parental satisfaction regarding their child's quality of speech and intelligibility were found to be less improved. Few earlier studies (Sue Archbold et al. in 2008) have reported similar results where, 20% of parents disagreed that their expectations of implantation for their children had been exceeded. It was attributed to the fact that the development of quality of speech requires minimum 3 years of hearing age [17]. Speech intelligibility develops over longer time scale than speech perception and improvement in speech intelligibility required up to 10 years after CI [19–22]. Similar conditions were reported by Sach and Whyner (2005) and Huttunen and Valima (2010) where few of the parents revealed the outcome of CI not up to their expectations [13, 21]. Therefore it was recommended that the clinician should assess the functioning and programming of the speech processor of cochlear implant, judge the need for more intensive habilitation for the children in whom improvement was not observed. Hence, in the present study, the quality of speech and intelligibility were not found to reach parents' expectation which could be due to the lack of parent–child interaction in these individuals as well as due to the lack of

thorough understanding about the outcome of CI. Also, it can be attributed to the irregular usage of the devices lesser than 8 h per day and performance of the implantation after critical age. Therefore, as the quality of speech keeps improving over longer time scale, there might be the need of intensive evidence based therapy along with interactive home training for the improvement of these aspects in these children with CI.

## Conclusion

Expectations of a relatively large number of parents whose children received implants were substantially high and these expectations were largely reflected in their subsequent experiences with their child's development. A small proportion of these families were disappointed with the outcomes of implantation because of little experience. Thus, it is suggested to all the parents of HI children, to have an appropriate information regarding outcome of CI prior to surgery, to set realistic expectation and to overcome with impractical expectation. It is also suggested to the parents that, having good parent–child interaction, more usage of device and regular practice at home will result in better outcome and experience. Future study can be carried out focusing child's quality of speech and speech intelligibility.

## Compliance with Ethical Standards

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Ethical Approval** All procedure performed in this study including human participants were in accordance with the ethical standards of the institutional ethics committee.

**Appendix**

**Questionnaire**

**Demographic Data:**

Child’s name:	Language used at home:
Child’s age:	Usage of device (in hours/day):
Parent’s name:	Hearing age of child:
Parent’s age/sex:	Child school standard:
Parent’s education	

**Sub Scale-1, Questions related to Communication Abilities:**

Sr. No	Questions	Yes	Yes, To Some Extent	No
1	Is your child able to response to quiet sound?			
2	Is your child able to repeat the words without seeing speaker’s face?			
3	Is your child able to eliminate the use of gestures?			
4	Are you able to communicate with your child as easy as normal child?			
5	Is your child able to express his wants, needs, feelings and thoughts and feelings verbally?			
6	Are you satisfied with your child’s quality of speech?			
7	Is your child’s speech intelligible to unknown people?			
8	Are you satisfied with your child’s pronunciation?			

**Sub Scale-2, Questions related to Social Skills and Participation:**

Sr. No	Questions	Yes	Yes, To Some Extent	No
1	Does your child have good relationship with elders, siblings and peers?			
2	Is your child being socially accepted after implant?			
3	Is your child able to make friends outside the family?			
4	Does your child actively participate in activities done by other children?			
5	Is your child accepted by normal children and peers in classroom?			

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