

Societal and Parental Attitude towards Pediatric Hearing Loss in Rural India: A Preliminary Study

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ABSTRACT

Introduction: Although age of identification and intervention has been documented in many studies, cause of delay between identification of hearing loss and hearing aid fitting/intervention has not been thoroughly investigated. Important parent consideration affects the time interval from diagnosis to intervention as some parents choose to delay the process of intervention and some even avoid follow up.

Need of the study: Attitude of the society and family members towards children wearing hearing aids can affect the outcome of rehabilitation of a hearing impaired child. As a child spends most of his time with parents, the perspective of a hearing impaired child's parent towards hearing loss, its causes and hearing aid use can decide the outcome of rehabilitation drastically.

Thus, there is a need to study the societal and family reaction towards hearing-impaired child using hearing aids, as well as the parent's perception and reaction towards hearing loss and its causes and hearing aid use.

Objective:

The objective of the study is to identify:

- The social reactions to hearing loss in children and hearing aids.
- The parents' perception about hearing loss and its causes and hearing aid fitting.
- The child's attitude towards hearing aid use.

Methodology: A total of forty participants were interviewed using a self developed questionnaire. Two children (5%) had been fitted with moderate class hearing aid bilaterally. Four participants (10%) reported to have first shown their child at hearing screening camps. Participants were asked if they knew about hearing loss and hearing aid before their child was diagnosed as deaf. Thirty two

participants (80%) reported negatively with only eight participants (20%) reported to have awareness regarding hearing loss and hearing aid. Participants were asked about the extra time they spend with the hearing impaired child, which they wouldn't have if the child had normal hearing. Fourteen participants (35%) reported that they spend more than five hours behind their hearing impaired child, in comparison to normally hearing child. Participants were also asked about the time period, which their child took to accept the hearing aid. Twenty two participants (55%) reported that their child took three to six months to accept the aid. Ten participants (25%) reported that their child had taken more than one year to accept the hearing aid. Participants were also asked about the probable cause of their child's hearing loss. Fourteen participants (35%) reported that they were uncertain about the cause of their child's hearing loss. Participants were also asked about the concern of the child's father towards the child's disability. The participants on being asked about their husband's perception regarding hearing aid and speech therapy, thirty four participants (85%) reported that their husbands find hearing aid and speech therapy to be beneficial for the child with six participants (15%) responding negatively to the question. Two participants (5%) reported their child's grandparents to be least supportive. Ten participants (25%) reported other family members to be least supportive. Participants were also asked about their family member's observation regarding improvement in speech and hearing capability of the child, six months after fitting of hearing aid and speech therapy, thirty four participants (85%) reported that their family members observed improvement in the child's speech and hearing capabilities after hearing aid fitting and speech therapy. Twenty six participants (65%)

reported that the child gets highly disturbed by traffic noise while wearing hearing aid. Five participants (12.5%) reported sound of loud crackers to be most disturbing to the child. Twenty participants (50%) reported that between 1-2 years of age they suspected hearing loss in their child. This finding is suggestive of the awareness among participants regarding the treatment of children with hearing loss. Only 4 participants (10%) reported, the hearing loss to have been identified at hearing screening camps. 65% of the participants reported that it took them 3-6 months to accept their child's hearing loss and the benefit provided by the hearing aid & speech therapy. Sixty percent of the participants reported to be spending 3-4 hours extra time with their child with hearing loss. Fifty five percent of participants reported that it took 3 to 6 months for the child to accept the hearing aid. Thirty nine percent of participants expressed concern over the traveling charges for therapy with thirty eight and thirty four percent of participants reporting concern for hearing aid maintenance and hearing aid repairing.

Conclusion: This study has attempted to highlight various areas such as societal and parental level of understanding of hearing loss and hearing aids and also other issues associated with it. The results of the study if incorporated in parental counseling procedure could help in maximum mobilization of resources towards the hearing impaired children. Future research on this study using a large sample is required for generalization of the results.

Keywords: Societal, parental, attitude, pediatric, hearing loss, hearing aid fitting

INTRODUCTION

Diagnosis of hearing loss can have a drastic impact on the family. A parent's hopes, aspirations, and beliefs about the child's future are overwhelmed by shock, disbelief, fear and despair. Early identification and intervention of hearing loss is necessary for effective utilization of critical period for speech and language development and prevention of loss of auditory plasticity, due to auditory deprivation. Although age of identification and intervention has been documented in many studies, cause of delay between identification of hearing loss and hearing aid fitting /intervention has not been thoroughly

investigated. Important parent consideration affects the time interval from diagnosis to intervention as some parents choose to delay the process of intervention and some even avoid follow up.

Need of study:

Societal and family members attitude towards children wearing hearing aids can affect the outcome of rehabilitation of a hearing impaired child. Brimacombe, Danhaver, and Mulac, (1983) have reported negative impressions of hearing impaired children towards hearing aids. As a child spends most of his time with participant, the perspective of a hearing impaired child's participant towards hearing loss, its causes and hearing aid use can decide the outcome of rehabilitation drastically.

Thus, there is a need to study the societal and family reaction towards hearing-impaired child using hearing aids, as well as the participant's perception and reaction towards hearing loss and its causes and hearing aid use.

Objective of the study: -

This study aims to identify:

1. The approximate age of identification and of hearing aid fitting.
2. The social reactions to hearing loss in children and hearing aids.
3. The parents' perception about hearing loss and hearing aid fitting.
4. The child's attitude towards hearing aid use.

METHODOLOGY

A total of 40 parents of hearing impaired children were interviewed. The participants were drawn amongst the pool of hearing impaired children who were receiving speech and language therapy at SVNIRTAR, Olatpur, Cuttack, Odisha. The interview was conducted in one-to-one setting by the investigator.

Inclusion criteria:

All the participants satisfied the following inclusion criteria:

1. Were parents of hearing impaired children.

2. Had a monthly income of less than rupees six thousand.
3. Resided in rural or semi urban areas of Odisha
4. Had been regularly availing speech and language therapy services for their children at SVNIRTAR.
5. All the parents consented for the study.

Instrument: -

A 36-item questionnaire consisting of 32 close ended questions and 4 open ended questions was designed to gather data on age of identification and intervention as well as societal and parental perception of hearing loss and hearing aid fitting process. As the parents were the primary facilitators for auditory, speech and language development, the questionnaire was administered on the parents of hearing impaired children. The results obtained were tabulated and subjected to statistical analysis.

Statistical analysis: -

Statistical analysis was carried out using Microsoft Excel for Windows software. Descriptive analysis was used to estimate the percentage occurrence of responses to each question items in each category.

RESULTS

The participants' age ranged between 23-41 years with a mean age of 28.1 years. The participants had a gender distribution of 3:1 with thirty participants being female and the rest being male. The mean age of the hearing impaired children was found to be 3.9 years with age ranging from 2-6 years. In the interview, sixteen participants (40%) reported to be coming for therapy since last one year. Twenty four participants (60%) reported to have attended speech and language therapy sessions for a period of more than one year. A total of two children (5%) had been diagnosed with moderately severe to severe degree of hearing loss and 38 children (95%) had been diagnosed with severe to profound degree of hearing loss all the children had been fitted with behind the ear hearing aids binaurally

though the Government of India funded scheme.

In response to the question "parents literacy", four participants (10%) were found to be illiterate. Amongst the rest, twenty participants (50%) reported to have received education upto matriculation level with the rest participants equally having received education upto intermediate and graduate level. All the participants reported to be having a monthly family income of less than Rs. 6500 per month.

Eight participants (20%) reported to have first shown at government hospital. Two participants (5%) reported to have been referred by NGO's. Twenty two participants (55%) reported to have first shown to an otorhinolaryngologist. Four participants (10%) reported to have first shown to an audiologist and four participants (10%) reported to have first shown their child at hearing screening camps.

Participants were asked if they knew about hearing loss and hearing aid before their child was diagnosed as deaf. Thirty two participants (80%) reported negatively with only eight participants (20%) reported to have awareness regarding hearing loss and hearing aid.

Participants were asked as to how long it took them to accept their child's hearing loss and hearing aid. Twenty six participants (65%) reported that it took them three to six months to accept that their child has hearing loss and that use of amplification device and speech and language therapy will be beneficial for their child. Ten participants (25%) reported that it took them six to nine months. Two participants (5%) reported that it took them less than three months to accept the hearing loss of their child and only two participants (5%) reported that it took them more than nine months to accept their child's hearing loss.

Participants were asked about the extra time they spend with the hearing impaired child, which they wouldn't have if their child had normal hearing. Fourteen participants (35%) reported that they spent more than five hours behind their hearing

impaired child, in comparison to a normal hearing child. Two participants (5%) reported to be spending more than one hour and twenty four participants (60%) reported to be spending three to four hours more on their hearing impaired child. Participants were asked as to whether their child suffered from itching or infection in the ear due to ear mould. In this, twenty eight participants (70%) consented that their child do have problems and twelve participants disagreed on it. Out of the participants who agreed nineteen participants (72.5%) reported occurrence of problem once in a month with nine participants (17.5%) reporting their child to be having itching and infections due to ear mould, once in fifteen days.

Participants were also asked about the time period, which their child took to accept the hearing aid. Twenty two participants (55%) reported that their child took three to six months to accept the aid. Ten participants (25%) reported that their child had taken more than one year to accept the hearing aid.

Participants were also asked about the probable cause of their child's hearing loss. Fourteen participants (35%) reported that they were uncertain about the cause of their child's hearing loss. Two participants (5%) reported genetic factor to be the probable cause. Six participants (15%) reported superstitious belief and sixteen participants (40%) reported disease to be the probable cause.

In response to the question "What all things does the child do to avoid wearing hearing aids", thirty two participants (80%) reported that the child directly denied wearing the aid. Four participants (10%) reported that their child cried when was made to forcefully wear the aid. Participants were also asked about the concern of the child's father towards the child's disability. Fourteen participants (3.5%) reported that their husbands regularly ask about the therapeutic activities and progress. Thirteen participants (32.5%) reported that their husbands participated in therapeutic

activities at home. Eleven participants (27.5%) reported that their husbands hardly spared any time for the child from their schedule.

The participants on being asked as to whether they find speech therapy and hearing aid to be beneficial for the child, thirty eight participants reported positively with two participants (5%) reported speech therapy and hearing aid to be of little help.

The participants on being asked about their husband's perception regarding hearing aid and speech therapy, thirty four participants (85%) reported that their husbands find hearing aid and speech therapy to be beneficial for the child with six participants (15%) responding negatively to the question.

On being asked about the mode of communication used by family members for the child, Twenty seven participants (67.5%) responded to both (oral and gestural) category followed by 11 participants (27.5%) responding to the gestural mode. Thirty six participants (90%) reported to have learned signing the best with the child, with four participants (10%) reporting the father to have best learned to sign.

Thirty two participants (80%) reported that the child likes to be with them most of the time, followed by four participants (10%) responding that the child favored his/her father more than their participant.

Thirty six participants (90%) reported that the family members did not know about the activities done in therapy.

In response to the question regarding the most supportive member in the family, sixteen participants (40%) responded saying that all family members were supportive with twelve participants (30%) reporting their husband to be only supporting member and ten participants (25%) reporting their participant and father-in laws to be most supportive.

In response to the question regarding the least supportive member in the family, twenty eight participants (70%) reported

none to be least supportive in their family. Only two participants (5%) reported their child's grandparents to be least supportive. Ten participants (25%) reported other family members to be least supportive.

Participants were also asked about their family member's observation regarding improvement in speech and hearing capability of the child, six months after fitting of hearing aid and speech therapy, thirty four participants (85%) reported that their family members observed improvement in the child's speech and hearing capabilities after hearing aid fitting and speech therapy.

In response to the question regarding the effect of the child's disability on the family income, thirty eight participants (95%) reported the child's disability to be affecting the family's income. In response to the same question, the participants reported three major areas of concern. Thirty nine participants (32.5%) reported traveling charges for therapy as the prime economic concern followed by hearing aid

maintenance and hearing aid repairing reported by thirty eight and thirty four participants as the second and third areas of concern.

The participants on being asked whether their neighbor have found any differences in speech and hearing ability of the child after six months of hearing aid usage, twenty eight participants (70%) reported positively stating that the neighbors communicate with the child more than before.

The participants also expressed concern over the situations in which amplification disturbed the child. Twenty six participants (65%) reported that the child gets highly disturbed by traffic noise while wearing hearing aid. Five participants (12.5%) reported sound of loud crackers to be most disturbing to the child.

The participants reported a variety of responses to the open set question "what are the three most common questions asked by family members". The responses of the participants are tabulated in the table given below.

Table 1: for three most common questions asked by family members

S.no.	Questions	Frequency	Percentage
1.	Can he/she listen with this machine?	26	21.66
2.	What is done in the speech therapy?	18	15
3.	How much time, will the therapy continue?	16	13.33
4.	Will hearing loss subside in future?	31	25.83
5.	Will he/she wear it throughout the life?	29	24.16

In response to the question "what is the most disturbing remark made by the society"? The responses of the participants are tabulated in the table given below.

Table 2: for the most disturbing remark made by society

S.no.	Questions	Frequency	Percentage
1.	You are wasting money behind your child.	13	32.5
2.	He/she will never speak like a normal human being.	18	45
3.	He/she will have problem in education.	7	17.3
4.	He/she will have problem in marriage.	1	2.5
5.	This machine will not be of much help.	1	2.5

In response to the question, "what are the most frequent questions asked by the neighbors or strangers about hearing aid"? The responses of the participants are tabulated in the table given below.

Table 3: for the most frequent questions asked by neighbors and strangers about hearing aid and speech therapy

S.no.	Questions	Frequency	Percentage
1.	Is this a radio or a walkman?	29	36.25
2.	What is this?	21	26.25
3.	Can he/she listen with this machine?	16	20
4.	Why he/she is not speaking properly?	5	6.25
5.	For how much time, will therapy continue?	5	6.25
6.	What is done in speech therapy?	4	5

In response to the question, “two common suggestions given by the people”, the participants’ responses are given in the table below.

Table 4: for two most common suggestions given by people

S.no.	Questions	Frequency	Percentage
1.	Consult an otorhinolaryngologist	13	16.25
2.	Show him/her to the deity.	19	23.75
3.	Consult a homeopathic/ayurvedic doctor.	24	30
4.	He/she will speak lately.	18	22.5
5.	He/she will be able to hear with the help of hearing aid.	3	3.75
6.	Consult at neurology department in hospital	3	3.75

DISCUSSION

Sweetow and Barrager (1980), via use of a questionnaire survey attempted to study the need for the audiologist to translate complicated terminology into language easily understood by the parents and the need for written information related to hearing impairment to be dispersed were repeatedly stressed. The need for audiologists to suggest techniques for parents to communicate with their newly identified hearing impaired child was mentioned by many parents.

Twenty participants (50%) reported that between one to two years of age they suspected hearing loss in their child. As the critical period for speech and language development has maximum plasticity up to three years, late identification and intervention of hearing loss will limit the outcomes of rehabilitation. Hence, awareness programs are needed to be instituted at the grass root level, so that hearing loss can be identified and intervention can be provided as early as possible. Most of the participants (55%) had first shown their child to the otorhinolaryngologists, followed by pediatricians (20%). This finding is suggestive of the awareness among participants regarding the need for medical treatment of children with hearing loss. Only four participants (10%) reported the hearing loss to have been identified at hearing screening camps. This statistics indicates the amount of screening programmes that still needs to be organized in Odisha for early identification of hearing loss in children. Almost eighty percent of

participants reported that they had no idea about the hearing aid, before their child was diagnosed deaf. This is a reflection of the view of common people regarding hearing aids and hence, maximum awareness regarding hearing loss and amplification devices needs to be increased for facilitating easy inclusion of the hearing aid users into the society. Sixty five percent of the participants reported that it took them three to six months to accept their child’s hearing loss and the benefit provided by the hearing aid & speech language therapy. Hence, the motivation of the parents would be less during the first six months of therapy, thus, directly affecting the outcome, as the child would lose much of the critical period for speech and language development. For this, appropriate goals must be set for counseling the participant of a hearing impaired child. Almost sixty percent of the participants reported to be spending three to four hours extra time with their child with hearing loss. This finding can be helpful in counseling the participant of a child newly diagnosed as hearing impaired. Almost seventy percent of participants reported that their child had itching and infections due to the use of ear mould with seventy two percent of participants reported itching & infection to have occurred once in a month. These findings suggests that the participants must be demonstrated clearly and lucidly, the process to clean ear moulds & other ancillary maintenance problem, during the counseling process and also to support the explanation with clear easily understood written instructions and troubleshooting information regarding both hearing aids and

ear moulds. Hearing aids represent a turning point after which the hearing loss is no longer invisible. Johnson & Danhaver (1982) described a phenomenon called the hearing aid effect, to represent the negative bias of hearing impaired to accept the hearing aid. Fifty five percent of participants reported that it took three to six months for the child to accept the hearing aid. The findings can help in counseling the participant regarding such problems after hearing aid fitting during the counseling process. This finding also can help the therapist to plan his therapy accordingly. On being asked about the probable cause of hearing loss, forty percent of the participants reported the hearing loss to have been caused by disease with fifteen percent participants attributing superstitious beliefs to be the probable cause. Hence, this finding suggests the need for implementation of awareness programme at the grassroot level for reducing the ignorance towards hearing loss, and issues associated with it. Almost thirty three percent of female participants reported that their spouses participated in the therapeutic activities, while sixty seven percent reported that their spouses could hardly spare time for therapeutic activities at home. This finding raises the concern regarding the perception of hearing disability by the hearing impaired children's father. Hence, it is necessary that both the participant and the father be present during the counseling process prior to fitment of hearing aids and that it must be made essential for the father to attend therapy sessions at least once in a month, so that the outcomes of rehabilitation are easily visible to him. Ninety percent of participants reported their family members to be ignorant of the therapeutic activities. Hence, it is necessary for the family members to attend speech & language therapy sessions, for the improvement to be maximized. The response to the questions regarding the least & most supportive family members towards the child's disability appeared to be equivocal. On consultation with the

preschool special educator, it was found that the answers were not corroborating with the information supplied by the special educator. The participants when being asked again reported negative attitude of their family members and the child's father towards the child's disability.

Thirty eight percent of participants reported their child's disability to be an financial burden on their family's economy. Thirty nine percent of participants expressed concern over the traveling charges for therapy with thirty eight and thirty four percent of participants reporting concern for hearing aid maintenance and hearing aid repairing. As all the participants belonged to middle and lower socioeconomic group, the findings signified the importance of financial concern of the family for availing rehabilitative services. Many participants may have been ignorant of the fact that traveling charges are covered under the ADIP scheme for attending therapeutic services at government rehabilitation centers. Thus, the participants need to be made more aware about the facilities, so that dropout ratio can be minimized.

The responses of participant to the question "three common questions asked by the family members to the participant". The family members ignorance towards hearing loss, hearing aid and the rehabilitation program. Hence, proper counseling of the family members needs to be done for maximizing the rehabilitation goals.

The responses of participants to the question "most disturbing remark made by the society" indicate the ignorance and negative attitude towards hearing loss woven in the social fabric.

The responses of participants to the question "most frequent questions asked by neighbours or strangers" draws attention towards the lack of awareness regarding need of hearing aid and speech therapy for effective rehabilitation, in the society.

Responses of participants to the question "two common suggestions given by people" indicate the ignorance of the society towards hearing loss in which

approximately twenty four percent of people referring the child to a deity indicates about the superstitious beliefs attached with hearing loss.

CONCLUSIONS

It is well accepted that the hearing impaired child's chances for successful communication and academic achievement are greatly enhanced if the child's parents can emotionally accept the child and are dedicated to maximize the child's potential (Kricos B.P, 1987). Blair, Wright and Pollard (1981) stated that lack of knowledge regarding hearing loss and hearing aids might contribute to the child's difficulties in using hearing aids and decreased motivation to use amplification appropriately.

This study has attempted to highlight various areas such as societal and parental level of understanding of hearing loss and hearing aids and also other issues associated with it. The results of the study if incorporated in parental counseling procedure could help in maximum mobilization of resources towards the hearing impaired children. Future research on this study using a large sample will help in generalization of the results.

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