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Original Article

Age of suspicion, identification and intervention for rural Indian children with hearing loss

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Abstract. It is crucial to understand factors which delay the commencement of aural habilitation in children. Alleviating the factors will help reducing the delay to an extent in a developing country like India where universal newborn hearing screening programs is yet to begin at a national level. The present study aims to find age of suspicion, identification and intervention availed for children with hearing loss who approached hearing evaluation camps conducted in rural West Bengal. Data was obtained from evaluation of 209 children with moderately severe to profound degree of hearing impairment, present with a complaint of not being able to speak and hear. The family members, mostly mothers, suspected hearing loss in the child at a mean age of 1.5 years when the children did not respond to name-call, clap and vehicle horns. However the parents consulted any doctor primarily a specialist by an average age of 2.4 years. As many as 21% of the doctors during the first visit assured the parents not to worry as the child would learn language with age and only 33.4 % were referred for aural rehabilitation. The average age at which children were brought to an audiologist for the first time was 9.3 years yet 95% of parents did not perceive delay in the initiation of aural rehabilitation. Children with mild to moderate degree of hearing loss and with unilateral hearing loss who account for 40% of the childhood hearing loss do not attend even rural camps. Factors like child rearing practices, ignorance about the importance of intact hearing sensitivity and critical age for speech development along with lack of aural rehabilitation services contributed to the delay in identification and habilitation.

Key words: Rural India, hearing impairment, identification and intervention

1. Introduction

Hearing impairment (HI) of any degree has a profound effect on children: it delays development of speech, slows educational progress, and leads to being stigmatized. In India, 15.93% of the school going population (6-14 years) are at risk of having a hearing disorder (1). The National Sample Survey Organization estimates, that the prevalence of speech disability is 8.3% in the urban areas and 8.9% in rural school going children (2). This estimate may be on a lower side as the data is collected by the primary school teachers and social workers. These workers often miss or ignore lower degree of hearing loss, especially in the absence of an objective tool or scale to measure or document the hearing loss. Most of the studies in India indicate a higher prevalence and incidence of hearing impairment in the rural population as compared to the urban residents (3, 4). If taken together a total of 25%of Indian children under the age of 14 require the consolation of an audiologist and a speech language pathologist (ASLP). At present there are only 1567 registered ASLP in India (5) which is too little to suffice the present need (1). In addition to the meagre numbers of professionals who are concentrated around cities which accommodates less than 30% of Indian population. Almost all the training institutes are in cities and function on an IBR (Institution Based Rehabilitation) model. However the majority (72.2%) of Indian population is still based in 500.000 villages and the rest reside in more than 200 towns and cities (6). The social, economic, cultural, infrastructural and educational facilities available to the rural population differ significantly from the urban inhabitants, and hence would be their perceptions. There is a need to explore the status of aural re/habilitation in children and its perception in the rural areas.

In a broad sense the term audiological re/habilitation or aural re/habilitation refers to a wide range of modalities and activities used by an ASLP to maximise the child's ability to live and communicate with the speaking world around

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him. As usually observed in clinical practice most of the parents and other family members of children with HI prefer waiting for the child to speak till she/he grows beyond two to three years and then take the child for medical consultation. The audiologist who is a healthcare professional specializing in identifying, diagnosing, treating and monitoring disorders of the auditory and vestibular system portions of the ear is often approached at a quiet later age. Studies over the past decade have shown considerable variability in the age of identification, diagnosis, and intervention among specific settings and geographic areas (7).

Area specific studies to appreciate these issues are considered necessary; especially for India which houses 15% of the world's population (6). Unlike in many of the western countries universal newborn hearing screening is yet to begin in India at a national level (8). Habilitation initiatives towards the child are taken up by the parents, and often the initiation of it crosses the critical age of the child. Thus about 34% of children with HI are detected after five years of age (9). Understanding factors contributing to the delay would help reducing it.

The present study was undertaken to gain a better understanding of parental efforts made towards alleviating HI in their child. Of specific interest were, (a) the age of suspicion, (b) age at which medical and audiological intervention was availed, (c) recommendations of the medical professionals and (d) perceived delay if any when they approached an audiologist at various hearing loss identification and hearing aid fitment camps conducted by AYJNIHH (ERC), an aural rehabilitation centre in eastern India.

2. Materials and methods

2.1. Participants

The participants of the study consisted of 209 children aged 1.6 years – 15 years (mean ± SD: 9.3 ± 3.76) and their caregivers.

2.2. Tool

A 25 item questionnaire designed for the caregivers was used in the study (Appendix:1). The instrument contained multiple-choice questions and open-ended items about the child's demographic information, auditory behavior, the person who noticed it, age at which it was noticed and the details of the professionals visited for help along with their recommendations. Before implementing it, the questionnaire was validated by 5 audiologists, with an eight years or more working experience in pediatric audiology.

They were asked to rate individual questions on a three point scale, 0- in appropriate, 1- needs modification, 2-appropriate. Modifications were incorporated till each of them rated all the items as appropriate. An interview was conducted in a one to one set up after explaining the purpose of the study and assuring strict confidentiality.

2.3. Procedure

After a brief case history and rapport building with the child and caregivers a regular audiological evaluation protocol was followed. The various tests under the protocol included otoscopic examination, pure tone audiometry and admittance measures. Receptive language age and expressive language age was informally assessed following which a detailed interview was taken using the developed questionnaire. The obtained data was tabulated and statistically analyzed using Statistical Package for Social Sciences (SPSS) for Windows Version 11 (SPSS Inc., Chicago, Illinois, USA).

3. Results

Majority (93.3%) belonged income group of less than rupees 6500 per month, a cut-off used by the government of India to consider free distribution of hearing aids under the AIDP scheme (Scheme of assistance to disabled persons for purchase/ fitting of aids/ appliances).The participants belonged to rural areas and mostly resided (78 %) in a joint family. A sizable 18% of the fathers and 29% of the mothers were illiterate. The family members mostly mothers (65.6%) suspected the child to be having a hearing loss at an average age of 1.5 years (SD: 1.04). The indicators which arouse suspicion of hearing loss in the child included; no response to name call (65.6%), no response to clap (13.4%), lack of speech development (10%) along with other indicators such as lack of response to vehicle horn and thunder. Consultation of a medical professional, primarily an Ear Nose Throat specialist (85%) was availed by 2.4 years (SD: 2.5) of age. Table 1 and figure 1 indicate that only 17.7% of the children were suspected of having hearing loss during 0.5 years.

Opinion of a physician was availed before 1 year by 30.6% of the children. A very few (5.7%) of the children attended aural rehabilitation programme by 3 years of age. On their first medical visit 70% of the children were diagnosed of having speech and hearing difficulties. Merely 33.4% were advised to get the child checked for his hearing, avail speech

therapy or to attend special school. Some (21.1%) parents were assured by the doctor not to worry and take some medicine as the child will speak at a later age.

Table 1. Age of suspicion, identification and intervention for HI children.

Sl No.	Age (years)	Suspicion of hearing loss by caregivers (Cumulative percentage)	Visit to the first doctor (Cumulative percentage)	Commencement of aural rehabilitation (Cumulative percentage)
1	0-0.6	22%	12%	0.0%
2	0.7- 1	45%	30.6%	0.0%
3	1.1- 2	77%	58.4%	1.4%
4	2.1- 3	94.3%	79.9%	5.7%
5	3.1- 5	100%	92.8%	11.5%
6	5- 15		100%	100%

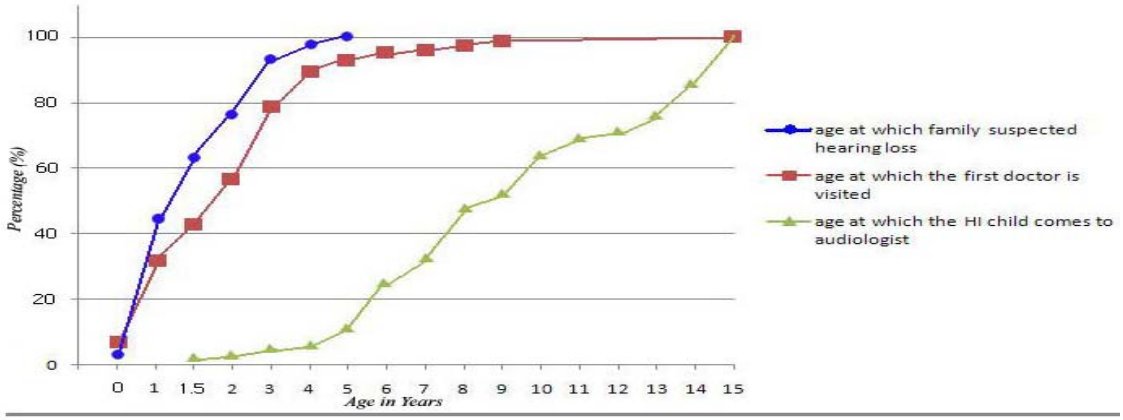

Fig. 1. Age of suspicion, medical consultation, initiation of aural rehabilitation in children attending Hearing Evaluation Camps.

Only 53% of the parent's consulted a second doctor regarding the child's hearing loss and speech delay. Half (50%) of the children were recommended to initiate aural habilitation, 3 of them were asked not to worry and rest were referred to an Ear Nose Throat specialist, paediatrician or an audiologist for needful. Most (95.2%) of the parents did not perceive any delay in accessing aural rehabilitation for their child.

The audiological evaluation of majority (89%) of the children indicated bilateral severe to profound degree of sensoryneural hearing loss, a few (4.0%) of the children had hearing loss of moderately severe degree. Some (6.7%) of the children did not co-operate for hearing evaluation. As many as 17% of the children had a history of ear-discharge, 7% of the children had a B type of tympanogram. A B type tympanogram is mostly suggestive of a conductive pathology. Eight children who had active ear-discharge in at least one ear were not considered for the study. During clinical observation of the communication capabilities, 6% children were found to be having a verbal mode of communication and the rest used both verbal and nonverbal means. The verbal means of expression was restricted to word level. A few true words mostly accompanied with gestures were used for communication. The true words included expressions for mother, father, brother, grand parents, favourite food items, no, yes, give, want to go for toilet, name of a favourite toy mostly ball etc. None of the children with severe or higher degree of hearing loss expressed themselves in simple sentence or in a sentence of higher order of complexity.

4. Discussion

Early identification paradigms have changed considerably because of the recognized benefits of early detection of hearing loss within the first year of life (10-12). Due to the implementation of universal newborn hearing screening programs in almost 99% of birthing hospitals in the United States, parents are no longer likely to be initiating the identification process (13) rather the neonates

would be screened for hearing loss before hospital discharge.

In India aural rehabilitation is initiated by the parents hence gets significantly delayed. Specifically, the mean age of identification by parents and hearing aid fitting were both later than the Joint Committee on Infant Hearing, 2007 targets (14). The Joint Committee on Infant Hearing recommends identification of hearing loss by 3 months and commencement of intervention by 6 months of age (14). In eastern India children with HI are detected at a mean age of 3.03 years (SD: 1.3) and aural habilitation commences by a mean age of 7.38 (SD: 4.06) (15). Prior to universal newborn hearing programme in America, Sjoblad et al, have reported the median age of identification to be 18 months and hearing aid fitting is about 20 months (7). Epidemiological data from the United Kingdom is probably the most comprehensive data on age of identification of hearing loss on a large population of children. Prior to Universal Newborn Hearing Screening Programme, the average age of suspicion of hearing loss was 18.8 months, confirmation of hearing loss was 26 months, the average age of prescription of hearing aids was 30 months. The average age of fitting of hearing aids was 32 months (42.3 months for moderate hearing loss, 23.5 months for severe hearing loss, 13.9 months for profound hearing loss) (16). In the absence of a Universal Newborn Hearing Screening Programme the age of suspicion of hearing loss is uniformly around 18 months but the age by which the child access aural rehabilitation is substantially delayed in India. The delay in part can be ascribed to the child rearing practices and the unjustified use of traditional wisdom in several cases. It is not uncommon to hear the mother saying “I suspected the child to have hearing loss at around 1-1.5 years but my family members suggested me not to worry as the father and the uncle of the child spoke late by five years of age”. Many caregivers try home remedies like placing a pebble, beetle nut or a marble under the child’s tongue to get clear speech. Some astrologers in eastern India recommend wearing a precious green coloured stone (Panna) to get fluent speech.

In India there is poor identification of children with mild to moderately severe degree of loss both at camps as well as at instutional set up (15, 17). Children having mild to moderately severe degree of hearing loss to develop speech which suffices the purpose of functional communication to an extent in a rural setup and, hence may be overlooked out of ignorance. However a child with mild hearing loss can miss 25- 40% of the speech signals at home and up to 50% of the information at school (18). Moderate degree of hearing loss limits the conversation unless the child is within few feet of the speaker and affects all aspects of speech (18). If detection of hearing loss is left to parents, identification was typically initiated by concerned about their child's auditory responses, their lack of or delay in speech and language development, or their poor performance in school (13). Auditory stimuli like name-call, table bang, clap etc along with commonly asked questions like what is your name, where do you live etc should be avoided for the purpose of screening hearing loss. The stimuli have intensity of 65 dB A and above. Most of the clinics have a noise level of 65 dB A and above during the working hours and the clinician reflexively becomes louder than 65 dB A to make himself audible. If such stimuli are used, children having moderately severe degree of hearing loss (56- 70 dB HL) and below would be identified as having hearing sensitivity within normal limits.

Only seven percent of the present case load had conductive component while 17% of the children had a history of ear discharge. Otitis media is a common cause of conductive hearing loss in both urban (5. 33%) and rural (33.59%) children (3). Children having a conductive hearing loss exhibit signs of earache, ear discharge, swelling and redness of the ear. Such overt symptoms are less likely to be overlooked by parents than the Ear Nose Throat specialist.

Secretory otitis media (SOM) which is associated with this age range is mostly asymptomatic and might or might not cause a mild degree of hearing loss. The hearing loss of a milder degree may be ignored by parents or might be treated by the local medical practitioners. The child may not visit an audiologist because of its milder nature and as it does cause significant impairment in speech to influence the activities of daily living. This may be a contributing factor towards a very low case load of individuals with conductive hearing loss approaching an audiologist working in a rehabilatitative setup (15, 17). The fact that parents first consult the Ear Nose Throat specialist for their child’s hearing and speech difficulty is indicative of the accessibility of the Ear Nose Throat specialist even by the rural masses. The guidance provided by a doctor establishes the future action plan of the caregivers. The majority of the Ear Nose Throat specialists as in the study prefer to wait rather than instantly recommending for an aural rehabilitation programme. Targeting awareness programmes for the Ear Nose Throat specialist would have far-reaching effect in bringing down

the age of commencement of aural rehabilitation by 6- 7 years on an average. A striking finding was that majority of the caregivers did not perceive any delay in the initiation of the aural habilitation programme. Majumdar and Sah (19) explored the awareness of critical age regarding speech and language development amongst parents of children with HI. The study included two groups of caregivers, group 1, belonging to slum areas and group 2, from non-slum areas. There was a significant difference (p=.01) between their perceptions about critical age. Group 1 had a relatively poor awareness (37%) than the group 2 where 82% of the caregivers agreed to the importance of critical age in speech and language development of the child (19).

5. Conclusion

This paper elaborates the sequence of events that happens before a child with hearing loss approaches for rehabilitation to a rural hearing evaluation and hearing aid distribution camp. More than 40% of the children with hearing loss are missed even on conducting rural camps. There were no cases with unilateral or mild to moderate degree of hearing loss who account for 40% of permanent childhood hearing loss(20, 21).There is a substantial delay in suspecting the hearing loss and in accessing audiological help. The delay is attributed primarily to the lack of universal newborn hearing screening programme in West Bengal and in India. Beliefs and ignorance of the caregivers, perception of physicians, most of who neither did nor recommend for an audiological evaluation on visiting them add to the delay. A lack of adequate audiological and speech and language services in the state along with poor legal provisions for implementation of early intervention contribute maximally to the delay. Keeping in view the late identification of the majority of children, coupled with lack of resources for aural habilitation, there is a need to develop educational setups which exclusively educate using the Indian Sign Language.

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Appendix-1
English translation of the Bengali/ Hindi questionnare

Case No…… Date…… Place…….

1. Name of the child: ……. Age/Sex:……..
2. Language used by the caregiver: Hindi/ Bengali/ Odiya/……
3. Primary complaint about the child:
4. Monthly Income in rupees: Below 6500 / Between 6500- 10,000 / above 10, 000.
5. Family Structure: Joint / Nuclear /…….
6. Relegion: Hindu / Muslim / Sikh / Others
7. Address:Village:……House.No……Post……..Police station……..Distict……..Pin code……. State……..
8. Literacy (Father) : Literate / Illiterate.
9. Literacy (Mother): Literate/ Illiterate
10. Do you have any body in your family who has hearing impairment? (Yes/ No)
11. Who first suspected hearing loss in the child? …… ……
12. The hearing loss was first suspected at what age……
13. What made you/ the person suspect hearing loss in the child. ……
14. How old was the child when you first consulted a medical professional. .....
15. Name, designation and address of the medical professional. Do you have the prescription by the doctor……
16. What did the medical professional advice/ diagnosis. ……..
17. Did you consult any other doctor……..
    Name/ Address/ Designation of the doctor……
18. What did the second doctor/ Audiologist advise……
19. Do you feel there is a delay in accessing / commencing aural re/ habilitation; YES/ NO
20. How does your child communicate: Demonstrate using three–four examples ……
21. Did the mother have any disease/ fall/ any other significant medical condition which you were worried about during your /mothers gestational ages……
22. Did the mother have any complications during pregnancy……..
23. Did the child suffer from any disease since birth……..
24. Did your child have earache, ear discharge or any other infection in the ear……..
25. Name five sounds and the distance from which he/she can respond to them.
    1.
    2.
    3.
    4.

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