



Identification and Intervention of Hearing Loss in Maharashtra: A Survey of Parental Experience

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Abstract

Background Universal newborn hearing screening is not yet fully implemented in India at a national level due to many challenges like cost, limited specialist staff, loss to follow-up, and importance of hearing in speech language development. Most often the parents identify and initiate intervention for the child's hearing loss after the critical period of development is over. There is a need to explore the age at which children are detected and identified with hearing loss, fitted with appropriate intervention, and the barriers faced during this process.

Method Data was collected from parents of 60 children with hearing loss aged between 2 and 6 years. A questionnaire comprising of 27 items was developed and administered on parents through face-to-face and telephonic interviews. The data was descriptively analyzed to study the parents' responses.

Results The median age at suspicion was 12 months, median age at identification was 18 months, and age at initiation of intervention was 24 months in children with hearing loss between the age range of 2 to 6 years. Financial constraint was reported to be the most common barrier among the others faced by the parents.

Conclusion This study highlights the current status of the age at identification and intervention of hearing loss in children in Maharashtra. These findings can help to create awareness regarding the need for early identification and appropriate management in children with hearing loss for development of adequate verbal communication skills.

Keywords

- ▶ identification of hearing loss
- ▶ intervention of hearing loss
- ▶ parental experience

Introduction

The most commonly used sense for communication is hearing. In humans, the ability to listen helps us to connect to the world. Verbal communication with other people depends on our ability to hear and understand speech sounds. Audition leads to the development of speech, verbal language, cognition, pragmatics, and educational development. Hearing loss at birth has an adverse effect on a child's overall development.¹ Childhood hearing loss affects

speech production, language development, and cognition of a child, consequently affecting academics leading to under achievements in school.^{2,3} All these will have an impact on a child's self-esteem and social skills. Communication difficulties lead to social isolation, poor self-concept, and lesser employment and vocational choices, leading to frustration and might cause hyperactivity or stubborn behavior, introversion, restlessness, and aggression in children with hearing loss.⁴ Four-hundred sixty-six million persons in the world

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have disabling hearing loss (6.1% of the world's population) with around 432 million (93%) of these being adults and 34 million (7%) of these being children.⁵ In India, hearing impairment is seen in 19% of the total disabled population, in which 20% are between the age group of 0 to 19 years.^{6,7} In Maharashtra, it has been found that around 91 children per lakh population have hearing loss in the age group of 0 to 4 years. In the age group of 5 to 9 years, 238 children per lakh population are found to have hearing loss.⁸

It has been proved that the first 3 years of a child's life are crucial for the rapid development of speech and language and this is the period when the human brain is developing and maturing. If the hearing loss is identified at an early age and followed by immediate intervention before 12 months of age, it helps in acquiring better speech-language skills as compared with those who are identified and intervened after the critical period of the child's life.⁹ Universal newborn hearing screening is not yet fully implemented in India at a national level due to many challenges like cost, limited specialist staff, and loss to follow-up.¹⁰ In clinical practice, most of the times, it is observed that parents and other family members of children with hearing loss keep on waiting and hope that the child will speak as he/she grows and then approach the medical professionals for advice. The audiologist is approached at a later stage, generally after medical consultation. Sirur and Rangasayee¹¹ in their study reported that the age at identification of hearing loss dropped down by 9.59 months from 1989 to 2008; however, it had not even reached 12 months by 2008. In a study by Kumar et al,¹² the mean age at suspicion crossed 19 months, age at identification crossed 24 months, and mean age at intervention initiation of hearing loss crossed 29 months. Most often the parents identify and initiate intervention of the child's hearing loss after the critical period of development is over.^{11,13} Thus, the aim and objectives of this study were to explore the age at which children were suspected, identified with hearing loss, and fitted with appropriate intervention along with the reasons that lead to the delay in detection, identification, and intervention of hearing loss in Maharashtra state.

Methodology

Study Design

An exploratory survey was conducted at School of Audiology and Speech Language Pathology, Bharati Vidyapeeth (Deemed to be University), Pune, Maharashtra, India. The study protocol was approved by the institutional ethical committee (ECR 518/Inst/MH/2014/RR-17) and it was performed from January 2021 till March 2021. Data was collected using the purposive sampling method.

Questionnaire

A 27-item questionnaire was developed in English based on literature review and researcher's experience. Content validation was done with help of five audiologists and speech-language pathologists who had more than 5 years of experience in this field. The questionnaire was finalized after incorporating the suggestions provided by the experts. The finalized questionnaire was translated in Marathi.

Participants

The questionnaire was administered through face to face and/or telephonic interview on 60 parents of children with hearing loss aged between 2 and 6 years. The parents of children with moderate-to-profound hearing loss, having the first language Marathi, were included in the study, whereas parents of children with mild and functional hearing loss; parents whose first child was diagnosed with hearing loss; parents who were audiologists, speech-language pathologists, special educators, or teachers by profession; and parents with any known neurological or psychological problem were excluded from the study. Informed consent was taken from all the parents before questionnaire administration. The total time taken for completing the questionnaire was 20 to 30 minutes.

Data Analysis

The data obtained from all the respondents were tabulated and analyzed using descriptive statistics on Statistical Package for the Social Sciences (SPSS) software version 20.

Results

Among 60 parents, 48 mothers and 12 fathers participated and responded to the interview.

The demographic information of the respondents is listed in **Table 1**.

Information regarding the hearing screening at birth was collected from the participants. It was found that only one child out of 60 had undergone hearing screening at birth. With regard to birth history, 76% of the children had no significant history during, pre-, peri-, or postnatal period, while 6% of the children had associated issues.

The median age at the suspicion of hearing loss is found to be 12 months. Forty percent respondents were mothers ($n = 24$) who suspected that the child had hearing loss, followed by the father ($n = 13$) and grandparents ($n = 13$). Others included neighbors and family physicians. The reason behind suspicion of hearing loss as reported by majority of the respondents was a lack of response to loud sounds such as utensil noise, vehicle honking, television sound, calling out the child's name, and other speech sounds. About 8.33% of the respondents noticed that child was not speaking despite the increase in chronological age. Five percent reported that they came to know about hearing loss when the child underwent a medical evaluation. The median age at which parents consulted a physician for the child's hearing loss was 13 months. Majority of the parents ($n = 52$) responded that physicians referred them to audiologists, whereas 12% of parents mentioned referrals to otolaryngologists. The most commonly performed test at several setups was the auditory brainstem response (ABR) audiometry. About 43.33% of parents ($n = 26$) reported that their child underwent only the ABR test in the first place, followed by ABR and audiometry ($n = 16$). Only 18% of the parents ($n = 11$) reported that their child underwent a battery of tests and hearing aid trial. Ninety-five percent of the parents ($n = 57$) were informed regarding the tests to be conducted for hearing evaluation by

Table 1 Description of demographic details of parents/respondents of the children

Demographic information		Frequency (n)	Percentage (%)
Respondents' age	20–30 years	40	66.6
	31–40 years	17	28.3
	Older than 41 years	3	5
Mother's educational qualification	Xth grade	39	65
	Graduate	19	31.6
	Postgraduate	2	3.3
Father's educational qualification	Xth grade	40	66.6
	Graduate	18	30
	Postgraduate	2	3.3
Mother's occupational status	Unemployed	48	80
	Farming	11	18.33
	Domestic worker	1	1.66
Father's occupational status	Government service	3	5
	Private service	46	76.6
	Farming	11	18.33
Family structure	Joint	35	58.3
	Nuclear	25	41.6
Geographic region	Urban	39	65
	Rural	21	35
Family history of hearing loss	Yes	4	6.66
	No	56	93.3

the audiologists. Recommendations given by audiologists to the parents were also studied. It was found that 60% of the parents ($n = 36$) reported that audiologists recommended hearing aid fitting. Only 5% of the parents got recommendation directly for cochlear implant surgery. Recommendation for auditory training along with hearing aid fitting was less. Eighty percent of the parents responded that they denied the child's hearing loss after identification, whereas 20% ($n = 12$) accepted the hearing loss. About 51.66% of the parents ($n = 31$) received economic and/or emotional support from their family, whereas 48.33% did not receive any support. The results indicated that 50% of the participants ($n = 30$) sought a second opinion from another audiologist and 23.33% of the participants ($n = 14$) sought a second opinion from professionals or people other than hearing professionals. About 76.66% of participants ($n = 46$) did not seek any opinion.

The median age at identification of hearing loss in children was found to be 18 months. The median gap between the age at identification and suspicion of hearing loss was calculated to be 4 months as depicted in ►Table 2. The gaps were calculated by subtracting the age at the suspicion of hearing loss in months from the age at identification of hearing loss in months.

Qualitative analysis was performed to study the parental barriers in the process of suspicion and identification of hearing loss. As seen in ►Table 3, economic aspect was the most common barrier faced by 78.66% of the participants ($n = 47$). Out of these 17 participants faced other barriers along with economic problems. Barriers related to services offered

by different professionals were faced by 18.33% of the participants ($n = 11$). As reported by the respondents of the study, this barrier led to the possible delay in the process significantly. About 11.66% of the participants ($n = 7$) faced familial issues. Other than these, only five participants faced travelling or distance-related barriers, the other five faced issues due to the lockdown, and the remaining five had to receive other treatment for the child's additional problems that led to the gap in the process of identification of hearing loss.

As it can be seen from ►Table 4, the median age at which hearing aid fitting was done (intervention initiated) was 24 months. The gap between the age at intervention initiated and the age at identification of hearing loss was calculated by subtracting the age at identification of hearing loss in months from age at intervention initiation of hearing loss in months and it was found to be 3 months.

►Table 5 depicts the barriers faced during the process of intervention of hearing loss in children. Results revealed that 83.33% of the participants ($n = 50$) faced economic issues and 10% of the participants ($n = 6$) faced familial barriers. Barriers related to service delivery by professionals and waiting for surgery were faced by only 1.33% of participants. About 13.33% of the participants ($n = 8$) did not report of any barriers during the intervention process.

Discussion

This study revealed that mothers primarily suspected hearing loss in their children, followed by fathers and grandparents.

Table 2 Descriptive statistics of age at suspicion and identification of hearing loss and the perceived gap

	Age at the suspicion of hearing loss (mo)	Age at identification of hearing loss (mo)	Gap (mo)
Median	12	18	4
Minimum	2	6	0
Maximum	30	40	28
Interquartile range			
25	7.25	12	1
50	12	18	4
75	18	23	7

Table 3 Barriers in the process of suspicion and identification of hearing loss

Barriers	n = 60
Economic	47 (78.33%)
Service delivery	11 (18.33%)
Familial	7 (11.66%)
Travelling	5 (8.33%)
Lockdown	5 (8.33%)
Other treatment	5 (8.33%)

It was noticed that as mothers spend most of the time with their child during daily activities like feeding, playing, and bathing, it is quite natural for them to realize the child's hearing loss first as compared with the other family members. This finding was in concurrence with the previous literature studies.^{13,14} The reasons behind suspicion of hearing loss as reported by the respondents in the study were the child not responding to loud sounds, vehicle sounds, calling out a name, and no speech development. Similar findings were reported in the literature.¹²⁻¹⁴

The median age at suspicion of hearing loss in children in this study was found to be 12 months. Majority of the children were suspected of having a possible hearing loss after 3 months of age. These findings concur with the previous studies done in India that indicate the mean age at the suspicion of hearing loss to be around 13 to 15 months.^{12,13,15} However, the median age at the suspicion of hearing loss was 8 months in a western study done by Harrison and Roush.¹⁶ Specific attention is not paid toward the child's listening development and this could have been one of the reasons for the delay in suspicion of hearing loss. Another possible reason could be attributed to the differences in the overall structure of the culture in developed versus developing countries. Results also indicated that most parents visited medical professionals after suspecting the child's hearing loss that was similar to a study done by Jafari et al,¹⁷ where they reported 57% of the parents visited physicians first, followed by audiologists and speech therapists. The median age at the first visit to a health care professional after suspicion was observed as 13 months in this study. However, this finding was not in agreement with another study done in India where the age at the first visit to a medical professional was by 2.4 years.¹³

Most of the children had undergone their hearing evaluation at the hospital setup. The test battery approach for diagnosis of hearing loss was not followed at the center where the parents first visited, and it was observed that only ABR testing was performed. One positive finding of this study was that majority of the parents were counselled by the audiologists regarding the tests to be done and their results.

The median age at identification of hearing loss was observed to be 18 months in this study. The median age of identification in this study does seem to have lowered as compared with previous literature findings. Previous studies done in India with regard to the mean age at identification of hearing loss were quite scattered, varying anywhere from 23 to 39 months.^{12,15,18,19} However, it was observed that identification of hearing loss was still not as per JCIH guidelines.²⁰

It was observed that 80% of the parents denied that their child had hearing loss and majority of them were stressed, upset, shocked, and unaware of the cause of hearing loss and available treatment. Few of them were emotionally drained. Similar reactions have been reported in other studies, where they have mentioned similar feelings of denial, guilt, and anxiety.^{18,21} An explanation for these reactions possibly could be that majority of these parents who had children diagnosed with hearing loss were hearing parents; thus, they might have been unaware of hearing loss and its impact on communication development. Results also indicated that 50% of the parents sought a second opinion for their child's hearing loss after identification of hearing loss that could be attributed to the parent's denial of the diagnosis. Also, most of the parents or family members did seek other treatment options for their child's hearing loss. Similar findings were reported in a previous study by Merugumala et al.¹⁴ This study finding with regard to the gap between age at suspicion and age at identification of hearing loss revealed that the median gap between age at suspicion and age at identification was 4 months. Majority of the research studies done previously also reported similar results where the average gap between age at suspicion and identification of hearing loss was around 5 months.^{16,22,23}

A possible explanation for this gap was studied by understanding the barriers faced during the process of suspicion and identification of hearing loss. Our study finding revealed that economic, familial, and travel barriers were the primary reasons followed by barriers related to service delivery by

Table 4 Median age at identification of hearing loss and intervention initiated in months

	Age at identification of hearing loss (mo)	Age at intervention started (mo)	Gap (mo)
Median	18	24	3
Minimum	6	11	0
Maximum	40	59	48
Interquartile range			
25	12	18	1
50	18	24	3
75	23	31	10

Table 5 Barriers in the process of identification and intervention of hearing loss

Barriers	n = 60
Economic	50 (83.33%)
Familial	6 (10%)
Service delivery	1 (1.66%)
Waiting for surgery	1 (1.66%)
Nil	8 (13.33%)

professionals where there was misguidance from the professionals. Also, there were many appointments given for additional testing or cancellations in appointments due to child's health-related issues that could have contributed to this gap. A novel finding in this study reported that the gap was observed due to unavailability of clinical services due to the global pandemic. Similar findings have been documented in the literature. Few studies done across countries revealed that most of the parents faced issues related to service delivery by professionals and these included problems with appointment scheduling, repeated testing, multiple appointments, inadequate referrals by professionals, and lack of testing facilities along with travel time needed to visit the center.^{11,14,18,24,25} Studies done in India also revealed familial barriers such as gender bias in the family, underestimation of child's hearing loss by family members who take decisions, and domestic priorities led to cause a gap between the suspicion and identification process.¹⁴

This study revealed that the median age at intervention services initiated in children with hearing loss was 24 months. Previous studies from the literature reported variability in the age at which intervention of hearing loss was initiated. Some studies have reported the median age at intervention initiation as more than 15 months.^{16,24,25} Although the age at intervention initiated for children with hearing loss in this study was lower as compared with that of previously conducted Indian studies, still intervention initiation does not seem to follow JCIH²⁰ guidelines.

Results of this study with respect to the gap between the age at identification and age at intervention initiated were reported to be 3 months. This finding is in agreement with previous studies reported in the literature across countries and in India that have documented that the mean gap between age at identification and intervention of hearing

loss to be 2.14 months,²² 7.1 months,²³ 5.2 months,¹⁷ and 3 months, respectively.¹⁶

The results of this study described the possible barriers that could have led to the gap between identification and intervention process in children with hearing loss. They were related to economic barriers such as cost of the amplification device and familial barriers such as decision whether amplification device is really necessary. These findings concur with previous studies done in India that have reported possible reasons as affordability of hearing aid purchase, shortage of professionals and rehabilitative services, lack of awareness, parental attitude,¹² inadequate referrals from the professionals, low socioeconomic status, lack of testing facilities, lack of awareness in parents, gender bias,¹¹ long travelling distance, cost of hearing aids, and decision making.¹⁴ Prolonged repeated testing, resource limitations, child's noncooperation, and different results by different professionals were also few other reasons reported.¹⁸ Studies done across other countries also reported barriers related to service delivery by the professionals such as multiple appointments for assessment, waiting for follow-up appointments, misguidance from the professionals, payment-related issues, and difficulties with ear molds as possible reasons for the delay in intervention process.^{16,24,25}

Conclusion

This study has provided information regarding the current age at suspicion, identification, and intervention initiated in children with hearing loss. The age at identification and intervention of hearing loss has lowered; however, it still fails to meet the JCIH guidelines. The gaps between age at suspicion, identification, and intervention of hearing loss were pertaining to economic, familial, or service delivery barriers faced by the parents. The findings of this study can be helpful to create awareness regarding the need of early intervention in children with hearing loss.

Conflict of Interest

None declared.

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Appendix A1

Questionnaire in English

Instructions

This questionnaire will collect information regarding the identification and intervention of hearing loss in children. I will be asking you a few questions and you are supposed to answer them. Please listen carefully to each question and answer properly.

I) Suspicion of hearing loss

1. Who suspected that the child cannot hear properly?
 2. At what age did suspect that your child cannot hear properly?
 3. Why did suspect that your child cannot hear properly?
 4. When did you consult the doctor for the child's hearing problem?
 5. What were the doctor's recommendations when you visited him/ her?
 6. Did your doctor send you to the specialist for a child's hearing problem?
 - Yes
 - No
- If yes,

- a. Whom did he/ she send you to?
 - ENT
 - Audiologist and speech language pathologist
 - Pediatrician
 - any other
- b. What were their suggestions/ recommendations further?

II) Identification of hearing loss

7. What was a child's age when you first visited an audiologist and speech language pathologist?
8. Where was the hearing evaluation done?
 - Hospital
 - Private clinic
 - Institution
9. Did the audiologist and speech language pathologist explain to you about the different tests to be done?
 - Yes
 - No
10. Which tests did the audiologist and speech language pathologist perform?
 - BERA
 - Audiometry
 - Immittance evaluation
 - OAE
 - Other
11. Were you explained about the test results by the audiologist and speech language pathologist?
 - Yes
 - No
12. What was the child's age when the diagnosis was given?
13. What were the further recommendations given by the audiologist and speech language pathologist?
14. What was your and child's father's reaction when you first heard about his hearing loss?
15. What were the family members' reactions after you told them about child's hearing loss?
16. Were you given opportunities by the audiologist and speech language pathologist to ask questions?
 - Yes
 - No
17. Did the audiologist and speech language pathologist answer your questions/queries satisfactorily?
 - Yes
 - No

- a. If no, kindly give reasons why do you feel so?
18. Did you visit any other center/hospital for a second opinion?
 - Yes
 - No
19. How many centers did you visit?
20. Did you take any other opinion apart from your doctor or audiologist and speech language pathologist for your child's hearing problem?
 - Yes
 - No
- a. If yes, who did you take it from?
21. What difficulties did you face during this process?
 - Socio- economical
 - Familial
 - Service delivery by professionals

III) Intervention of hearing loss

22. What was the child's age when he was fitted with a hearing device?
23. Was the hearing aid fitted in one ear or both the ears?
 - a. If child was fitted with one hearing aid, when was the second hearing aid fitted?
 - b. Did the audiologist insist on fitting devices in both ears?
 - c. Did you feel that the child requires two hearing aids?
 - If yes, why?
 - If no, why not?
24. Did the child undergo any tests with the hearing aid?
 - If yes, which tests had he undergone?
25. What difficulties were faced during the fitting of/ purchase of hearing devices?
 - Socioeconomical
 - Familial
 - Service delivery by professionals
26. What was the child's age when therapy initiated?
27. Did the family members support in intervention process?
 - Yes
 - No
- a. If yes, how did they support?
- b. If not, why did they not support you?