

Qualitative analysis of parents' experience of hearing loss of their school going children of a rural area of Nagpur

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Introduction: Qualitative research methods provide a means of collecting and interpreting narrative or observational data about such interactions, leading to a deeper understanding of the process of health care delivery. This approach was used to clarify key themes from parents' comments about challenges on paths to detect hearing impairment. **Materials and Methods:** An exploratory descriptive qualitative research design is used. In-depth interviews by using a semi-structured questionnaire and focus group discussions (FGD) were held with parents, and other study groups. A study was conducted in Deaf Dum Rural School, Saoner, Nagpur district, Maharashtra, India. Purposive voluntary sampling is utilized. Semi-structured and in-depth interviews and FGD were conducted in private rooms. A FGD guide covered open-ended comments to the set of questions. **Results:** Parents of 65 children (59%) replied to the questionnaire. Out of them, 55 (85.6%) were the parents of school children resides in the hostel. The majority of the children have profound hearing impairment (75.86%). Theme analysis revealed perceptions about causes, ways, and means of early detection, and powerful emotions experienced by parents at FGD. **Conclusions:** Reaching beyond numerical analyses, qualitative studies allow for expression of junior doctors, Deaf and Dump School teacher and parents' thoughts, feelings, and experiences. This study provides a means of collecting and interpreting narrative or observational data.

Key words: Focus group discussion, hearing impairment, qualitative analysis

INTRODUCTION

According to WHO, deafness is one of the most neglected disabilities and is worse in developing countries.^[1] It had been estimated in a study by UNICEF that nearly 35 million children suffered from hearing impairment of various grades in India.^[2] In a survey, 4 out of 1000 children born in India were found to have severe to profound hearing loss.^[3] Hearing loss in children is a cause for parental as well as physician concern.^[4] It is indeed a big challenge to provide special education, vocational training, and employment to this large population. There are only 540–550 special schools that cater to 3% of children with hearing impairment.^[5]

While there is a growing consensus that the aim of practicing evidence-based medicine is sound, many

aspects of health care delivery are difficult to study in randomized controlled trials.^[6] Qualitative research methods provide a means of collecting and interpreting narrative or observational data about such interactions, leading to a deeper understanding of the process of health care delivery.^[7] This approach was used to clarify reasons for delays in recognition, causes of hearing impairment, and challenges of parents of hearing impaired rural children.^[7-9]


Children whose hearing loss is not identified until, for example, 2 or 3 years of age may suffer from permanent impairment of speech, language, and learning.^[10, 12]

This study determines key themes from parents' comments about challenges on paths to detect hearing impairment and also determine sociodemographic factors associated with hearing impaired rural children.

MATERIALS AND METHODS

Research design

An exploratory descriptive qualitative research design was used to explore and describe theme and effect of the experience of parents of children having hearing impairment and teachers involved in educational

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rehabilitation. Focus group discussions (FGDs) were held with parents, junior doctors, and teachers to capture their experience about early detection, diagnostic difficulties faced. The critical incident method was used.^[11]

Study settings

A study was conducted in Deaf Dum Residential School, Saoner, Nagpur district, Maharashtra, India, during the period January to April 2011.

Study samples

Subjects for the study were recruited from Deaf and Dum School, Saoner. The data were abstracted onto a standard information sheet and entered into a computerized database (Excel 2007). Demographic details of the child, including residence details, caste, religion, family type, etc. were documented.

Purposive voluntary sampling was utilized. Four focus groups were conducted in rural settings. This included 78 respondents [Table 1]. The duration of the focus groups varied between an hour and an hour and a half. The groups met only once. The respondents were persons having one or more children living with hearing impairment.

Data collection

Focus group discussions were conducted in a school class room. A brief demographic check list was completed by all respondents with the help of a school teacher. The parents' answers to these descriptive questions formed the basis of this qualitative analysis of the diagnostic process from the parents' perspective.

Focus group discussions were conducted in the local language by a principle and co-investigator of the study, since all the respondents, including illiterate parents, were more comfortable expressing themselves in the local language. The majority of the respondent subjects used the Marathi language. The FGDs were video-audio recorded, transcribed verbatim, and translated into English. After each focus group, field notes were written reflecting observations, methodology, and perceptions. The analysis of the data was conducted using transcripts in Marathi (the common language of the people of Maharashtra) by the first author. The data were further explored, using content analysis, for the identification of recurring themes. Transcripts were

Table 1: Focus group discussion breakup

Focus group composition	Number of respondents
Parents of hearing impairment (Group 1)	18
Parents of hearing impairment (Group 2)	20
Parents of hearing impairment (Group 3)	20
School teacher and other management personnel	10
Junior doctors	10

read several times and coded, and emergent themes were identified. The in-depth and semi-structured interviews used for the collection of data were complementary in the method.

Protection of human subjects

The research protocol was approved by institutional ethical committee providing protection of human subjects (research project number 258).

RESULTS

Two researchers independently examined the data for themes. A total of 261 quotes from 58 parents formed the basis of the analysis. Initially, quotes were independently sorted into categories by the two researchers. Once all categories were identified, a search was made for underlying themes. The researchers then grouped individual themes into common themes, using the constant comparative method of data analysis.^[11] Eight common themes were identified, which form the basis of this report. These themes together with illustrative examples are explored in this section.

This paper outlines manifestations of deafness in early childhood, efforts made by parents and physician to seek early intervention. Parents of children with suspected impairment of hearing have faced the challenge of early recognition and prompt diagnosis. The salient points and the main observations derived from the discussions with each group are presented.

Parents of children of Deaf and Dumb School

Most of the participants were unaware of the causes of deafness in spite of having a child with hearing impairment (98%). Only two participants were aware that infection during pregnancy might cause hearing impairment in the newborn. Most of the participants expressed their inability to recognize the symptoms of deafness in small children (93.10%). The earliest they could think of detecting hearing impairment was in a 1.5- to 2-year-old child.

Table 2 reveals 58 replies to the questionnaire (100%) response. The range of ages of final diagnosis of hearing impairment was 2–7 years. The mean age at diagnosis for the responders was 3.3 ± 1.7 (mean \pm SD) years. Table 3 shows the number of parents mentioning each theme, together with illustrative quotes.

Eight principal themes emerged from the data. These were experiences about diagnosis and treatment, place of first assessment, parent reactions to diagnosis, reasons for delays in diagnosis, hearing aids, school issues, and other social issues.

Themes

Experiences of the diagnostic process (care seeking)

These were divided into three sub-themes: method, age at detection, and at-risk identification.

(i) Method and age at early detection

The majority of the parents were ignorant about early detection of hearing impairment. Almost all parents were not aware of early detection of hearing impairment in spite of either one or more children are affected with hearing impairment.

Quote 1

"I wasn't comfortable with my 6 months old baby who was not responding to claps and other loud sounds. Child was not able to look at us when sound was created from behind. For this problem consulted physician but there was no improvement for 2 years. Even after 2 year, baby was not able to speak a single word, then I thought baby might be suffering from serious illness. Rightly or wrongly this was my decision to consult a good doctor and he declared that my child was not able hear properly. He suggested me to wait and watch."

Quote 2

"When my child was 2 years old, I came to know that he was not able to speak, my family members misguided

Table 2: Sociodemographic characteristics of the children

Variables	Number (N = 58)	%
Age in years		
6-10	15	25.86
11-15	24	41.37
>15	19	32.75
Sex of child		
Males	28	48.28
Females	30	51.72
Education of child		
Nursery	7	12.06
Primary	38	65.51
Middle school	12	20.69
Religion		
Hindu	46	79.31
Boudha	12	20.69
Type of family		
Joint	36	62.06
Nuclear	12	20.69
Degree of HI		
Mild (20-40 dbL)	0	0
Moderate (41-70 dbL)	1	0.17
Severe (71-95 dbL)	13	22.41
Profound (>95 dbL)	44	75.86
Mean age at first consultation	18 months	
Range of ages in years at final diagnosis of hearing impairment	2-7 years	

me, they said that one of my relative started talking at the age of 7 years. Therefore, I listen to them and waited for 5 more years, ultimately my child is not able to speak a single word".

(ii) Early recognition

Quote 3

"I have mixed feeling, my own experience shown me that when my child was 6 month old, while playing with him, he was no responsive to clapping sound and there was no reflex reaction to cooker wheeze". At one year of age "child need to see my face and watch mouth." My doubt was that my child is having hearing impairment, for this consulted specialist and confirmed HI both ears. It was shocking for me."

(iii) At-risk identification:

Difficulty with accurate risk factor recognition was an important sub-theme. In cases where parents themselves recognized that their child had a risk factor (elder child was hearing impaired) when the professionals overlooked it, there appeared to be an understandable loss of confidence in the system. In other cases, the presence of a neonatal risk factor was completely missed by both parents and professionals. Sometimes this was in part due to the parents not realizing that their child was at risk and being slow to act. Parents expressed unawareness about risk detection.

Quote 4

There was always 5-6 months between each test, and they use to say "We should see next time and next time, I found this very hard". It was not affordable to many parents to go ahead with further investigations.

(2) Who supported during process

Quote 5

"There was a family history of hearing loss but we did not think of it earlier."

"My relative told me that your child will be alright after treatment. Nobody suggested me to whom should I contact first, but doctor told me that hearing aid is very costly, it was not affordable to me, and hence I gave up my idea of treatment".

Place of first assessment

The majority of the children were first assessed by a private physician (58.52%), then by a PHC physician and a less number of children were assessed at the district hospital.

Table 3: Themes, subthemes, and illustrative quotes

Themes and sub-themes	No (%) responding to this theme N = 58	Illustrative quotes
Experiences about diagnosis and treatment		
Means and method of detection	58 (100%)	"I was not aware of manifestations of hearing impairment"
Unable to respond to loud sound	8 (13.79%)	"Nobody have guided me properly to seek proper treatment "hearing aid", I express my dissatisfaction".
Unable to concentrate	2 (3.45%)	"He was no responsive to clapping sound and there was no reflex reaction to cooker wheeze".
Unable to produce sound (speak)	58 (100%)	At one year of age "child need to see my face and watches mouth"
Doctor	13 (22.41%)	
School	58 (100%)	
Age at detection		
<6 months	4 (6.90%)	"My first child was HI, so I was worried about this child, at age 6 and subsequently consulted doctor but of no use..."
6-12 months	13 (22.41%)	
1-3 years	7 (12.06%)	
>3 years	42 (72.41%)	
At risk detection		
Family history	8 (13.79%)	"There was a family history of hearing loss but we did not think of it earlier"
Very sick child at birth	4 (6.90%)	
Exposure to loud sound	1 (1.72%)	
APH	1 (1.72%)	
Ear infections	1 (1.72%)	
Who supported during process		
Family members and relatives	47 (81.03%)	"My relative told me that your child will be alright after treatment. Nobody suggested me to whom should I contact first, but doctor told me that hearing aid is very costly, it was not affordable to me, hence I gave up my idea of treatment"
Health care providers	51 (87.93%)	
Place of first assessment		
PHC	15 (25.86%)	"My child was 6 month old that time shown to PHC doctor, he assured me that it will be alright, nothing to worry, after one year repeated examination and testing was done but no proper guidance was provided to me". My experience is hopeless
Rural hospital	07 (12.06%)	
District hospital	02 (3.45%)	
Private physician	34 (58.52%)	
Place of final assessment		
Pediatrician	07 (12.06%)	The majority of them of the opinion that "after admission to school we came to know that our children are not able hear thereby unable to speak".
ENT consultant	17 (29.30%)	We are very happy with the school procedure and assessment. Four (6.90%) have expressed economic constraints for repeated consultation resulted in to frustration.
School	58 (100%)	Two (3.45%) receive counseling in this regard and they were comfortable.
Parent reactions to diagnosis		
Not intense	8 (13.79%)	"Reaction to the diagnosis was sometimes, but not always, less intense when parents were expecting possibility of HI, usually due to the presence of a known risk factor (Family history)."
Denial	7 (12.06%)	"As there was no family history in either of our families we found it a little unreal to think that two of our three children could have a hearing problem."
Upset	37 (63.79%)	Shock/upset 7 (12.6%). "It was more of a shock to me when the possibility of some sort of deafness was discussed."
Reasons for delays in diagnosis		
Parental	48 (82.76%)	"He was at times uncooperative and became easily bored."
First physician delay	37 (68.79%)	Difficulty with test interpretation 9 (12.16%). "The different types of people gave many different results."

Contd...

Table 3: Contd...

Themes and sub-themes	No (%) responding to this theme N = 58	Illustrative quotes
Specialist delay	4 (6.9%)	Need for prolonged repeat testing 7 (12.06%). "He was tested at 15 months, 2 years, and 5 years. This was the frustrating time. At each test we were told he hadn't tested consistently... wait another month." Resource limitations 7 (12.24%). "Most of the time testing machine was out of order, doctor not available, private testing was not affordable to me. It was discouraging!"
Hearing aids		
Using regularly	4 (6.90)	The different types of people gave many different advises ¹⁷ (29.30)
Not using	54 (53.10)	"Some advised hearing aids but it was very costly, it was not affordable to me, government should provide it at free of cost." "We have seen our child learning through hearing aid, I find little progress in speech development once fitted with hearing aid. My child became happy, cheerful and willing, I think."
School issues – expectation from school		
Expecting hearing, and language	58 (100%)	"We are extremely happy with school, our children started reading, writing and have shown improvement in reading and producing sound of TV and Crackers." 37 (63.79).
Repeat grade	27 (46.55%)	"My child is 13 years old he has learned technical things through school, I am extremely happy with school environment".
Need more facility	12 (20.69%)	"My child made incredible progress in his writing and attention in study after admission to school; therefore, I have started attending school along with my child and learning teaching methods so that I should find more and more progress in my child.
No language development	13 (22.41%)	

Quote 6

"My child was 6 month old that time shown to PHC doctor, he assured me that it will be alright, nothing to worry, after one year repeated examination and testing was done at different places but no proper guidance was provided to me. My experience is hopeless..."

Quote 7

"I have consulted doctors, specialists, spiritual healer, and constant prayer of God but of no use, only school is showing some ray of hope."

Place of final assessment

All the students were finally assessed in the school; however, a less number of students were assessed by an ENT consultant (29.30%).

*Parent reactions to diagnosis***Quote 8**

"Reaction to the diagnosis was sometimes, but not always, less intense when parents were expecting possibility of HI, usually due to the presence of a known risk factor" (family history).

Quote 9

"As there was no family history in either of our families we found it a little unreal to think that two of our three children could have a hearing problem."

Quote 10

"Shock/upset 7 (12.6%). "It was more of a shock to me when

the possibility of some sort of deafness was discussed."

Quote 11

"I was not aware of early manifestations of HI even doctor did not advise me in spite of repeated consultation. This was a time of great frustration for many parents, who describe feeling of helplessness and anxiety. Again parents emphasized the need for support at this time".

Reasons for delays in diagnosis

Many parents experienced lengthy delays before a diagnosis of hearing loss was finally confirmed. Delay was thought by the parents to be due to lack of knowledge, improper guidance, poor economic conditions, and resource limitations resulting in delays in diagnosis. This was a time of great frustration for many parents, who describe feeling of helplessness and mental tension. However, many parents agreed upon delay were due to their ignorance.

Quote 12

"He was at times uncooperative and became easily bored."

Difficulty with test interpretation 9 (12.16%). "The different types of people gave many different results."

Need for prolonged repeat testing 7 (12.06%). "He was tested at 15 months, 2 years, and 5 years. This was the frustrating time. At each test we were told he hadn't tested consistently... waits another month."

Resource limitations 7 (12.24%). "Most of the time government testing machine was out of order; doctor not available, private testing was not affordable to me. It was discouraging!"

School issues: Expectation from school

Quote 13

Parents gave numerous examples of communication difficulties and lots of understandings also positively impacted their child development. Almost all parents had good experiences; they often mentioned personal qualities of school teachers as being "helpful" and "positive". Ultimately, all the parents expressed satisfaction about school services. "Still I found some improvement in social skills and very less improvement in speech."

Hearing aids

Most of the parents were not aware of hearing aids and their uses. Even educated parents often experienced great difficulty in procuring and use of a hearing aid.

Quote 14

"Some advised hearing aids but it was very costly, it was not affordable to me, government should provide it at free of cost."

School teachers (Deaf and dumb school)

Parent-teacher meetings were suggested as a good forum for talking about deafness, for sensitization of the parents. The only preventable cause of hearing loss according to them was noise-induced hearing loss. They were aware of causes such as ear infections, trauma, congenital, etc. They were very happy to see the progress made by those children in their schooling and social life. They were more concern about rehabilitation facilities in the school. Apart from educational rehabilitation expected to have vocational rehabilitation for such children. For this, they needed to have a lot of support from management and government. They agreed that awareness is low in the community, and efforts were needed to improve it. They recommended dissemination of information about hearing impairment and facilities for the diagnosis and rehabilitation in schools, institutions, and offices.

Junior doctors

The participants said that hearing impairment is an important public health problem that has not been given due importance in medical education as well as by the general community. The role congenital causes, infections as a cause of hearing impairment, was highlighted. All the participants were in favor of early detection of hearing impairment in children. Developmental delay, abnormal behavior, unable respond to loud sound, and delay in language development help us in early detection of hearing impairment in children less than 2 years of age. They suggested that health workers

should be trained in disseminating information about hearing impairment through community meetings.

DISCUSSION

Principal findings: Qualitative analysis gave valuable insights into the operation of the delay in care seeking, diagnosis, and educational rehabilitation program, which were not apparent from quantitative analyses alone. Important themes emerged with implications for improvements in early care seeking, early detection, and most notably largely positive experience with school for deaf and dumb and difficulties for parents and providers with accurate risk factor identification. These results were consistent with quantitative reports of screen performance.^[13]

Parents experienced very powerful emotions at the time of diagnosis including denial, shock, and upset, with a great need for emotional support. Communication difficulties between parents and providers were often reported. It is unclear from this study how much these resources were utilized or how helpful they actually were. Many parents experienced delays in the diagnostic process and resource limitations all contributed to parents' feelings of frustration and lack of support. Support once a firm diagnosis was established appeared excellent. Comparison with other studies and comments on the screening process were generally more positive in this study.^[13]

However, difficulties in confirming diagnoses and with achieving hearing aid fitting were still prominent themes, highlighting the need to address these issues to ensure overall program success.^[13,14] Our findings also support quantitative data on the need for communication and support issues are also addressed.^[10] The parent questionnaire inquired predominantly about methods of improving the system of detection of children with hearing loss, hence may have invited more negative comments than positive ones. In another study,^[10] the parent comments used for analysis were all written. This is somewhat unusual in qualitative research, where narrative comments are usually either transcribed or abstracted. However, in this study qualitative inquiry (e.g. focus group, in-depth interview) was the important study tool. Extensive analysis of taped interviews with parents was also studied in this study.

The groups consisting of the school teachers of Deaf and Dumb School were, in our opinion, the best informed. Moreover, they were very much concern about further social development of children in the school.

Many studies have highlighted the importance of noise exposure as a preventable cause of deafness. Brookhouser et al.,^[15] in their study on noise-induced hearing loss, found

that NOHL in the pediatric population has received scanty attention. This fact was also brought out in their discussion with junior doctors and school teachers in another study.^[16] This fact was also brought out in our discussion with parents, junior doctors, and school teachers. In a study conducted by Aust *et al.*,^[17] the statistics, in 1981, showed the average age at the initial diagnosis of the children with the hearing impairment to be between 3.3 and 3.4 years. In 1989, this average age came down to 13.4 months. In our study, mean age at first consultation was 18 months and the range of ages at the time of final diagnosis of hearing impairment was 2–7 years and the mean age of final diagnosis was 3.4 years.

Shah *et al.*^[18] reported challenges of early recognition and prompt referral for diagnosis among preschool children with suspected impairment of hearing. Predominant delay seems from parents and primary care physicians, lack of knowledge about deafness in children, and reluctance to refer to a proper diagnostic facility. These findings are consistent with the findings of this study. However, earlier study was a quantitative study.

The concept of early identification and intervention though not new, is yet to gain a foothold in India. Nikam and Dharamraj attempted infant hearing screening in 1971,^[19] Basvaraj *et al.*^[20] carried out screening for hearing impairment in Bangalore in 1984. AYJNIHH,^[21] Mumbai, in 1985, conducted a 3-year project on screening the preschool children for early identification and intervention of hearing loss, using the high-risk register (HRR) approach. Once hearing impairment is suspected, the child undergoes a battery of audiological investigations are done to confirm the presence, type, and severity of hearing loss.^[22]

CONCLUSIONS

Qualitative enquiry into the process of detection of hearing loss provided a valuable adjunct to the challenges of early recognitions and prompt referral for diagnosis. Upon reaching beyond numerical analyses, qualitative studies allow for expression of parents' thoughts, feelings, and experiences. This form of enquiry provides a tool for listening collectively to parents' insights and positive inputs provided by the school teachers and management. The need for disseminating information about various aspects of deafness was felt by all the groups. Awareness levels were low, wrong practices were prevalent in the community, and there was a lack of serious concern for deafness as a health problem. Inclusion of qualitative research in program evaluation and application of the findings to future program planning and development will enable providers to better meet the needs of children

with hearing loss and to adequately support and inform parents.

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