



State of deaf children in West Bengal, India: What can be done to improve outcome



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ARTICLE INFO

Keywords:

Child
Deafness
Age of suspicion
Age of diagnosis
Deafness outcome
Newborn hearing screening

ABSTRACT

Objective: Prelingual deafness in children demands urgent action as best outcome is dependent on earliest possible diagnosis and intervention. Objective of this study was to determine age of suspicion, diagnosis, intervention, and outcome in a representative group of deaf children in West Bengal, India, and suggest ways of improving these parameters.

Methods: In this cross-sectional study, ages of suspicion, diagnosis, intervention and outcome of 303 randomly selected deaf children were elicited from a cohort of 1316 children with deafness identified in an earlier study. **Results:** Median ages of suspicion, diagnosis and amplification were 18, 72 and 84 months respectively. Age of suspicion was significantly related to parental education ($p < 0.05$); age of diagnosis to parental education and socio-economic status ($p < 0.001$) and children's geographic location ($p < 0.01$). Following diagnosis, 86% of children received hearing aids but only 6% used their aids consistently; 86% were non-verbal, 12% could communicate with a mixture of speech and gesture and only 2% with speech alone.

Conclusion: Current situation of deaf children in West Bengal, and evidence indicates, in much of India, is insupportable. However, widely diverse socio-economic conditions and scarcity of public health infrastructure preclude one solution of the problem for the whole country. In absence of the ideal universal newborn hearing screening, rigorously monitored and costed pilot programs of different models of early detection and intervention using newborn hearing screening, targeted screening and trial of calibrated noisemakers by primary care workers should be tried to see which works best where, so that successful programs can be scaled up over time.

1. Introduction

There has been remarkable progress in management and outlook of deafness in children during the last two decades, yet childhood deafness continues to pose enormous challenges for its timely detection and amelioration in developing countries. The progress in childhood deafness has been threefold, 1) early detection of hearing loss through Newborn Hearing Screening (NHS), 2) advances in hearing amplification and in cochlear implant technology, and, 3) accumulation of evidence that children's acquisition of language during the first few years of life is critical in avoiding many of the long term adverse consequences of deafness. There is consensus that when deafness is detected soon after birth and deaf children are provided with early language support along with amplification of hearing, they can make progress in language, literacy, cognitive and social development commensurate with their age matched peers [1–3]. However, this progress is dependent on a tight time frame of early action in all three areas of identification, amplification and intensive language and educational

support (Early Hearing Detection and Intervention, EHDI). The internationally accepted EHDI standard is, 'all infants to be screened by 1 month of age, diagnosis of hearing impairment confirmed by 3 months and intervention started by 6 months of age [4]. Increasing delay of identification or intervention after this period is associated with worsening prognosis for the child's future outcome because of the presence of a sensitive period in children's speech and language development which is thought to extend from birth to around three to four years [5,6]. Although advance in outlook of deaf children has happened widely in developed countries, this has not been the case in most developing countries including India where there has been little systematic progress in early identification of children with permanent hearing impairment apart from some isolated praiseworthy efforts in few institutions [7–9]. Unfortunately, information about the true state of children with deafness in India is sparse. Available research shows that even in the best centres most children with deafness are diagnosed late in India [10–12]. Majority of children with permanent hearing impairment now attend mainstream schools under the Sarva Shiksha

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Abhiyan (universal education movement) [13], but a substantial minority continue to attend special schools, sometimes still called 'Deaf & Dumb' schools [14]. Deaf children have a much higher risk of dropping out or being out of school in India [15,16]. Most school children with deafness are prescribed hearing aids, distributed under a scheme of the Ministry of Social Justice and Empowerment, called the ADIP scheme [17] or donated by charities or bought privately by parents. However, there is little information about the process and quality of this service, details about timing of amplification, children's use of hearing aids and their audiological supervision or their outcome. Aim of present study was to gather systematic information about a representative group of children with deafness regarding their demographics, age of suspicion, diagnosis, subsequent intervention and outcome, and assess this information in light of current EHDI standards and aims of the National Programme for Prevention and Control of Deafness (NPPCD) in India [18] with a view to make recommendations about ways forward.

2. Methods

The study was carried out in West Bengal which is a state in the eastern part of India with a population of 91 million [19]. In economic and social development West Bengal is currently a middle ranking state in India with a per capita GDP of about 1600 US dollars (India, 1709 US dollars in 2016 [20]). Overall literacy rate in the state is 76%, but level of literacy is lower in rural areas and among women. As in most of India, West Bengal shows a skewed sex ratio of its population with an average 950 females per 1000 males [19]. People of West Bengal are mostly Hindu (70% of population), with a substantial minority (27%) Muslim population [21]. The health infrastructure in West Bengal, including in public health, is significantly worse in rural than in urban areas and most specialist health services are concentrated in and around the metropolitan city of Kolkata and among a few larger urban centres. It is fair to say that as one goes further away from urban centres, availability and quality of health infrastructure worsens.

The current study utilised a sample from an earlier research from this demographic background on prevalence of severe and profound sensorineural hearing loss in school children [22]. In brief, the earlier study was a comprehensive survey of all children with special need (CWSN) in 14 out of 20 districts which make up West Bengal. The survey included all children with CWSN in mainstream elementary schools (age group, 6–14 years) as well as all children of similar age in special schools in those districts. For mainstream elementary schools, we argued that all children with severe or profound hearing loss would have been identified as 'children with special need' because of their severe problem with hearing, speech and communication at the school entry age of 6 years. Comprehensive audiological assessment, including pure tone audiometry, of 10,763 children with special need in mainstream elementary schools identified 3984 children showing severe or profound SNHL (≥ 71 dB). A further 1022 children were identified with similar loss in special schools in the same districts, giving a total of 5006 children with severe or profound sensorineural loss among a school population of 8,654,057 in these districts, with estimated prevalence of 0.58 (CI 0.57–0.59) per 1000 children. The 14 districts in the previous study were spread throughout West Bengal. For the present study, West Bengal was stratified into four regions of North, South, West and Central. One previously studied district was selected randomly from each region, apart from the contiguous northernmost districts of Siliguri and Jalpaiguri, which were combined as one district because each had a relatively small number of deaf children and were similar in demographic character. Total number of deaf children identified in the earlier study in these selected districts were 1316 (Siliguri/Jalpaiguri 249, Maldah 241, Bankura 431 and South 24 Parganas 395). Approximately 25% of children from each of the four districts were selected by simple random sampling for the present study, giving a total 303 children. Except the towns of Siliguri and Jalpaiguri and a few smaller urban centres, bulk of the study area was rural and not

significantly dissimilar in character to the rest of the 14 districts.

Following free, informed consent from parents or guardians, a preformed questionnaire was used in face to face interview with parents in their homes to elicit information about their children. In most cases one or both parents and close family members supplemented each other's information for a better picture of the child. Copies of all relevant documents relating to the child's health and hearing were collected. Ethical approval for the study was obtained from Institutional Ethics Committee.

3. Statistical analysis

Numbers and percentages were used for categorical data, median and interquartile ranges for continuous non-symmetrical data. Chi-square and Fisher exact test were performed to find significance level for categorical data. Kruskal-Wallis one-way analysis of variance and Mann-Whitney *U* test for independent 2 mean tests were conducted to find significant difference among median of outcome variables. Significance level was set at $P < 0.05$ for all tests. STATA 11 software (STATA Corp, College Station, Texas) was used to perform the analysis.

4. Results

Table 1 shows the socio-demographic profile of the 303 children and their families. The literacy rate and religious distribution of the parents in the study were similar to that of the population of West Bengal but the level of economic distress indicated by 'below poverty line (BPL)' rate was two and a half times more in the study population, 53% vs 20% [19]. Table 2 shows median age of children in the study was 12 years (IQR, 10–14). Age of suspicion, diagnosis of deafness and receiving hearing aids were 18, 72 and 84 months respectively. Sex distribution was almost equal. Fifty four percent of the children were delivered at home and the rest were institutional deliveries. Of the 303 children, 260 (86%) received hearing aids but 14% fell through the net and did not receive hearing aids. Of those receiving hearing aids, 66% discarded their aids within 12 months, often within a few weeks' of

Table 1
Sociodemographic profile of participating children.

Variable	No. of children Number (%)
Study location	
North (Siliguri, Jalpaiguri)	61 (20.1)
Central (Maldah)	62 (20.5)
West (Bankura)	93 (30.7)
South (24 Parganas South)	87 (28.7)
Father's education	
Illiterate	81 (28.2)
Elementary school ^a	148 (51.4)
Secondary school and above ^b	59 (20.5)
Father's occupation	
Unskilled labour/farmer	167 (55.9)
Business/service	122 (40.8)
Deceased	10 (3.3)
Mother's education	
Illiterate	117 (39.1)
Elementary school ^a	143 (47.8)
Secondary school and above ^b	39 (13.0)
Religion	
Muslim	72 (23.8)
Hindu	231 (76.2)
Below poverty line (BPL)	
Yes	160 (52.8)
No	143 (47.2)

Missing data: 15 for father's education; 4 for father's occupation; 4 for mother's education.

^a Class I to VIII.

^b Class IX and above.

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