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# Barriers to prompt diagnosis and management of children with hearing loss

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### Abstract

**Background:** Paediatric hearing loss is associated with a significant public health burden, though early detection and treatment curtails the limitations associated with hearing loss. Despite the obvious advantages of early detection and treatment, multiple barriers exists. This study explored major barriers experienced by caregivers and teachers to timely detection and management of children with hearing loss in Ibadan metropolis

**Methods:** A mixed-methods descriptive cross-sectional study was done. The study population were parent/caregivers of children with hearing loss aged 6-12 years residing in the study area. A four-stage sampling technique was used to select respondents for the study. A total of four Focused Group Discussion (FGD) and 203 questionnaires were administered to the target population. Qualitative data were analysed using ATLAS.ti software (Version 7) while quantitative data were analysed using descriptive and inferential statistics. (p-value <0.05)

**Results:** The FGDs revealed that mothers do not recognize the signs and symptoms of hearing loss and experienced difficulty seeking healthcare because of embarrassment/shame. High transportation costs to special schools and communication difficulties were examples of barriers to management identified. The qualitative data showed that among caregivers, identified barriers to management were: difficulty in learning sign language, financial handicap, high transportation costs.

**Conclusion:** The major barriers to timely detection and management of children with hearing loss were transportation costs to health facilities and special schools, financial inability to utilize care in health facility, and caregiver embarrassment to seek medical help.

Keywords: Pediatric, hearing loss, barriers, early detection, caregivers

### Introduction

Hearing loss is the partial or total inability to hear occurring in one or both ears. The prevalence of congenital hearing loss among newborns range between 0.83% to 3.43%.<sup>1</sup> At least 1.4 million children (18 years or younger) have hearing problems and it is estimated that 3 in 1,000 infants are born with serious to profound hearing loss.<sup>2</sup> Globally, about 796,000 babies suffer permanent hearing loss within the neonatal period annually and majority of these new-borns reside in developing countries where routine hearing screening is not readily available.<sup>3,4</sup> Childhood hearing loss is of serious public health concern; 32 million children globally live with disabling hearing loss.<sup>5</sup> Nearly 90% of those with hearing loss live in low- and

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middle-income countries where limited resources pose a challenge to the successful implementation of new-born hearing screening.<sup>6</sup>

Hearing loss whether permanent or fluctuating has become common among children and if not detected and managed early it may attract serious health consequences. Detection and intervention for

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hearing loss prior to six months of age results in significantly better outcomes than intervention after six months of age.<sup>7</sup> Children who had Early Hearing Detection and Intervention (EHDI) before 6 months of age achieved higher vocabulary, articulation, cognitive, social and emotional development than those who has the same interventions but at a later period.<sup>8</sup> Benefits of early intervention has been shown to include; cultivating the best potential language skills, producing an optimal parent-child relationship which is essential for the child's language development with emphasis placed on important variables such as parental knowledge, attitudes, support and counselling.

In Nigeria, over 8.5 million of the general population suffer from hearing loss and children are the most vulnerable group to ear defects. Studies have shown that no fewer than 3.5 million Nigerian children of age 15 years and below have hearing problems.<sup>9</sup> The prevalence of unilateral and bilateral hearing loss among Nigerian school children is 54.1% and 45.9% respectively,<sup>10</sup> while persistent failed hearing screening among high-risk new-borns is 41.3%.<sup>11</sup>

The attitudes and existing knowledge of parents of children with hearing loss are key influencing factors in whether primary presentation is delayed or not.<sup>12</sup> Even though both parents and caregivers have major roles to play in the early detection of hearing loss in children, it has been shown that majority of parents are unaware of the signs of hearing loss in young children; and are either unconcerned about hearing loss as a health problem or ignorant of the need for early detection.<sup>13</sup> This parental behaviour may be related to presence of barriers to accessing required healthcare, thus, this study was designed to assess barriers to timely diagnosis and treatment of children with hearing loss in Southwest Nigeria.

### Methodology

This was a cross-sectional study conducted in Ibadan metropolis, Oyo state, southwest Nigeria, that utilized mixed methods (qualitative and quantitative methods) of data collection. The target population were eligible parent/caregivers of children with hearing loss aged 6-12 years attending schools for the deaf.

#### Data Collection Qualitative component

Four focused group discussions (FGDs) were

conducted with a sample size of 6-8 participants per group. These participants were grouped into young adult male, young adult female, older adult male and older adult female. Older adults were aged: 41-60 years, while young adults aged: 20-40 years. Data was collected until point of saturation.

# Quantitative component

The minimum sample size for this study for the study was determined to be 203. Respondents were selected using a multi stage sampling technique. The semi-structured interviewer administered questionnaire used was developed by the researchers based on review of literature and the information obtained from focus group discussion. The Cronbach's Alpha Model technique was employed to measure the reliability of the instrument. The alpha coefficient obtained from the analysis of the pre-test was 0.63, an indication that the questionnaire was reliable.

Ethical approval (13/479/1012) was obtained from the Oyo State Ethical Review Committee, Ministry of Health, Ibadan, Oyo State.

# Results

#### Qualitative

A total of four FGDs were carried out in the following categories:

FGD 1: older caregivers (male), FGD 2: older caregivers (female), FGD 3: younger caregivers (male), FGD 4: younger caregivers (female). A total of 30 participants were recruited in this component of the study. The average number of children per participant was four (4); and the mean age of participants' children with hearing loss was 9.6 years. Majority of the participants were married females of Yoruba ethnic group, they were mainly traders with only primary education. The discussions took place in a secured environment and all interviews conducted in Yoruba language.

### Barriers to timely detection and management

An identified challenge was failure to recognize early the signs and symptoms of hearing loss.

"sincerely, I just thought she was slow in talking, I didn't know those were signs that she cannot hear" (old adult \_female)

"the child was talking before illness, so I thought it was the sickness that affected him that he will be fine when he is well" (young adult\_female).

The participants reported signs such as abnormal crying, lack of response to communications after

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sickness and lack of basic speech at time periods expected for children within their age groups:

"I detected since when the child was little and makes no move when there is a sound which is unusual for babies" (young adult \_male).

Detection was related with the knowledge that after a certain period/age, a child should be able to say few basic words and to repeat sounds:

"We knew something was wrong because the child was already a year and half, and so should speak but she was not" (young adult\_female).

"We thought it was the illness that made the child quiet at first" (old adult male).

The application of ineffective therapies could also be barrier to management. The older parents/caregivers especially the grandmothers gave the children herbal mixtures while some caregivers opted to go to religious houses for prayers.

"I started giving him herbal medicine to make him talk" (old adult \_female)

"It was his dad that took us to the traditional doctors who gave us native drugs, he was getting better, then it became worse again" (young adult \_female).

"I took this child to different [religious] programs, .... and all" (young adult\_female).

"We have been trusting God to help us cure him, that is why we take him to the church all the time" (old adult\_male).

Some participants found it difficult to take the child to the hospital because they were embarrassed

"I prefer native medicine and I have somebody that bringsit to the house because I don't want to take him outside to the hospital. I feel bad and embarrassed when I see other children that can talk" (old adult \_ female).

Some mothers regardless of their child's hearing loss still enrolled their children in regular schools. Subsequently, the learning difficulty became obvious from the child's performance due to the inability of the regular school to cater for the hearing deficit of the child.

"It was not easy at all. The former school was a normal school for non-impaired but [he] was not coping" (young adult male).

"The child was attending a normal school until the teacher advised that we let her attend a special school" (young adult \_female).

"The child was attending a private school before, until the teacher called us to help the child by taking her to a special school" (old adult\_male). Advice was also received after making enquiries from other people:

"It was my mother-in-law that advised the child to be taken to a special school" (young adult\_male),

"We enquired and someone whose child was also impaired advised us to allow him to attend an impaired school where her child is " (old adult\_ female).

In caring for the child, participants reported difficulty in communicating with the child and the high cost of transportation to the special schools due to the few Deaf schools available and the distance to these schools.

"A woman in my neighbourhood whose child also suffers this hearing loss like my child was the one who helped out with the suitable school for my child where he is performing excellently well now" (old adult\_ female)

"... this school is far from our home and I spend a lot but I am trying hard for the child to be successful later in life" (old adult\_female).

"I spend a lot bringing this child to this school because of far distance, but I don't mind, I want my child to have a bright future" (old adult\_male)

#### Quantitative

Two hundred and three respondents were recruited into this stage of the study. Among the respondents there were more females (M: F = 1:1.2), and most were in 31 - 45 years age bracket. The other sociodemographic data are shown in Table1.

Table 1: Socio-demographic characteristics of caregivers

Variables	Frequency	
Sex		
Male	94	
Female	109	
Age group		
$\leq$ 30 years	43	
31 – 45 years	88	
> 45 years	72	
Occupation		
None	3	
Farmer	16	
Trader	89	
Civil servants	65	
House-wife	9	
Others	21	
Marital status		
Single	53	
Married	119	
Divorced	15	
Widowed	11	
Separated	5	
Ethnicity		
Yoruba	176	
Hausa	15	
Igbo	12	
Education		
No formal	32	
Primary	31	
Secondary	60	
OND/NCE	57	
HND/BSc	14	
Postgraduate	4	

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#### Table 2: Detection of Hearing Impairment

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Variable	Frequency	Percentage (%)
Route of confirmation of hearing loss		
Hospital screening	24	15.4
Non-screening (observation, intuition, perception)	132	84.6
Who was the first to detect		
Father	7	4.5
Mother	86	55.1
Grandmother	46	29.5
Grandfather	0	3.8
Health-worker	6	7.1
Others	11	7.1
Was there a delay in early detection		
Yes	92	59.0
No	64	41.0
Who takes major decision regarding the health		
of the deaf child		
Father	104	51.2
Mother	60	29.6
Grandfather/grandmother	15	7.4
Father in-law/mother in-law	1	.5
Neighbor	2	1.0
Health worker	10	4.9
Teacher	5	2.5
Others	3	1.5
Age treatment started		
$\leq$ 5 months	8	8.7
6 – 11 months	10	10.9
1-2 years	48	52.2
$\geq$ 3 years above	26	28.3

Table 3: Care and Management Practices

	Caregivers	
ITEM	Yes N (%)	No N (%)
Taking the child regularly to the hospital	84(53.8)	72(46.2)
Hospital visits with the child	119 (58.6)	84 (41.4)
Use of traditional/herbal medicines	89 (43.8)	114 (56.2)
Enrollment in a special school	155 (76.4)	48 (23.6)
Enrollment in a mainstream school	55 (27.1)	148 (72.9)
Access to free hearing aids	62 (30.5)	141 (69.5)

Table 4: Barriers to timely detection and management of hearing impairment

Barriers	Yes N (%)	No N (%)
Embarrassment to see a physician	139(68.5)	64(31.5)
Difficulty in learning sign language	146(71.9)	57(28.1)
Distance to a deaf school	112(55.2)	91(44.8)
Lack of funds to visit a health facility	124(61.1)	79(38.9)
Distance to a health facility	107(52.7)	96(47.3)
Difficulty in socializing	120 (59.1)	83(40.8)
Access to free hearing aids	66 (32.5)	137 (67.5)
Parent felt insulted because of the child	136 (66.9)	67 (33)
Unwelcome attitude of health workers	87 (42.8)	116 (57.1)

There was delay in detecting hearing loss in the majority of the children (59.0%) (Table 2); the average age at detection of hearing loss in the children was 1.6 years.

Observation, intuition and perception were modalities often employed by the mothers and grandmothers which made them the first set of relations to detect/suspect hearing loss in the child (55.1%), however, major decisions on the health of the deaf child were often taken by the fathers (Table 2).

Treatment/care for the hearing loss was varied, 58.6% of the parents/caregivers sought health care for the child via hospitals and enrolled the child in a special school (76.4%), while 43.8% of the

parents/caregivers pursued the course of traditional/herbal medicines usage (Table 3).

Among the caregivers, 16.3% reported lack of knowledge/ignorance of early signs and symptoms as factors that contributed to the late detection of hearing loss in children (Figure 2). The commonest barrier to timely detection and management was embarrassment to visit a healthcare facility (74.4%). Other identified barriers among caregivers are shown in Table 4.

### Discussion

Hearing loss is regarded as a global health burden with barriers to detection that include poor awareness, inadequate resources and lack of necessary expertise.<sup>14</sup> This burden rest mainly in low and middle-income countries with common occurrence of late identification of hearing loss due to lack of access to prophylactic, diagnostic and intervention services.<sup>15</sup> Female respondents were more than males in this study population, similar to observation seen in other studies,<sup>16,17</sup> this is probably related to the fact that females tend to play the role of caregivers more often.

Detection of hearing loss at an early age enables quick intervention. The basis for early identification and management of infant hearing loss is hinged on the right route of confirmation, and also on the prior knowledge and attitude of parents/caregivers towards hearing impairment.<sup>18</sup> Suspicion by a family member is a mode of detection of hearing loss often seen in developing countries,<sup>19</sup> this was confirmed by observations from this study which showed that mothers and grandmothers were the first to detect hearing loss in their children. This observation may be due to the intimate involvement of mothers and grandmothers in child care in the typical African society. Despite the keen attention of the womenfolk to child health, there was still a relative delay in the detection of hearing loss with the average age at detection of 1.6 years. This corresponds to observations from other studies from Africa which highlighted that most cases of hearing loss were detected after the first birthday.<sup>20,21</sup> Multiple factors which are probably interconnected may contribute to the late detection of hearing loss.

Failure of new-born screening for hearing loss and the lack of widespread new-born screening programs in many African countries is a major contributory factor to late detection of hearing loss in Africa.<sup>22,2</sup>

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The lack of new-born screening for hearing loss is a likely contributor to the late detection of hearing loss seen in this study. The study respondents often relied on subjective screening methods such as observation, intuition and perception before concluding on hearing loss as a possible diagnosis in the affected children. Therefore, the need for hearing screening at birth is essential in order to detect hearing loss early and facilitate prompt actions that are necessary for correction. Early detection and swift clinical intervention can improve the hearing potential of the child<sup>24,25</sup> and this will have a major impact on subsequent development and can help to improve their linguistic and educational outcomes.<sup>26</sup> Hence the need for strong advocacy across the African continent to institutionalize new-born screening for hearing loss.

Another factor, which could be a likely barrier to early detection is lack of knowledge of early signs and symptoms of the respondents. Some of the respondents exhibited ignorance of the importance of signs such as the inability of the children to develop basic speech. A possible cause for this incomprehension by the parents may be due to the socio-cultural backgrounds and certain beliefs about a tolerable age-range before a child is expected to talk which may stretch beyond clinically acceptable developmental milestones.<sup>27,28</sup> However, some parents in the index study had good knowledge about signs and symptoms relating to hearing loss; this corroborates earlier studies which showed that some parents of children with hearing loss have good knowledge of signs attributed to hearing loss.<sup>18,28-30</sup>

The disparity in the knowledge level of the parents may be related to differing level of education and child care experience. The interplay of culturalreligious beliefs and health related decisions such as use of herbal treatments demonstrated in this index study had been documented by earlier studies.<sup>28</sup>

Other major highlighted barriers to timely detection and management of hearing impairment shown in this study were embarrassment to seek medical opinions possibly due to likely stigmatization, insults and embarrassment received by parents as a result of their deaf child/children, lack of money for health care accessibility and long distance to special schools and health facilities. These barriers are similar to barriers faced by parents of children with hearing loss in India,<sup>31</sup> thus, suggesting that African and Asian countries which collectively accounts for majority of

the worldwide burden of deafness<sup>26</sup> may have similar barriers to timely diagnosis and treatment of hearing loss in children. Thus, strategies to overcome these identified barriers may have widespread application in multiple countries with possible resultant reduction in the burden of hearing loss worldwide.

The attitude of health workers was identified as a potential barrier to the management of children with hearing loss in this study. This study output corroborates the report of Luterman and Kurtzer,<sup>32</sup> which showed that good hospital-friendly service helps to make the parents/guardians of children with hearing loss comply with hospital care and treatment. Insults and embarrassment are one of the major barriers the study respondents had against seeing a physician for treatment of their hearing-impaired children. This is similar to a study by Ebrahimi et al<sup>33</sup> which found out that half of all the mothers with hearing impaired children were scorned and usually feel ashamed of having a deaf child in the family because of the stigma, thereby serving as a barrier in the management of their children.

Furthermore, the lack of financial support and affordability of medical services was another major barrier to access health facilities thereby preventing timely detection and management of the hearing loss. About two-thirds of the respondents reported that the lack of health care visits was due to non-availability of money needed to access health care services, this was a pertinent major barrier. This is similar to what was reported by Ogunkeyede et al<sup>25</sup> which found out that the choice of health care accessibility was influenced by the socio-economic status and not educational level. The health care decision-making was also imbalanced; the major decisions regarding health issues were taken by the fathers in this study. This imbalance could be a possible barrier to health seeking especially if the father does not actively encourage seeking health care and/or does not provide adequate funds to access healthcare. It has been shown that higher social status of women and female autonomy are associated with improved access to health services.<sup>34</sup>

Distance to the health facility and school was also seen to be another barrier. More than half of the respondents complained about the distance of their houses to the health facilities and special schools. These results correspond with other studies which reported barriers such as lack of proximity of health facilities and schools to their communities.<sup>35</sup> Apart from the distance to the health facilities and schools, lack of good road network to health facilities and schools, could also hinder visitation to health facilities and schools.

Earlier studies have shown that providing support for parents/guardians of children with hearing impairments can be beneficial in the enhancement of early detection, management and in the helping children to develop their communication skills.<sup>1</sup> thus, lack of such support could be detrimental to the development of these children. The supports required include social, family and governmental supports. The study respondents had access to both social and family support but enjoyed minimal or no governmental support. The relative lack of robust support systems emphasizes the need to establish durable support structures to help parents confront the challenges of raising children with of hearing impairment.

# Conclusion

The results from this study showed that barriers contribute to the late detection of hearing loss in children. Thus, there is need for clear policy recommendations and implementation strategies on screening for hearing loss in children. Such implementation strategies should include utilization of hospital ante natal visits to sensitize parents on the knowledge of infant hearing loss and the right management approach and the provision of affordable medical services for proper diagnosis and prompt intervention in close proximity to the citizenry are also required to reduce the burden of hearing loss.

Conflict of interest: Nil

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