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5 Case Reports of Maternal Experiences during Pregnancy, Peripartum and Infancy Periods of their Profoundly Deaf Children under the Socioeconomic Situation in Nigeria

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Authors' contributions

This work was carried out in collaboration between all authors. Author REK designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Authors JF and KDE managed the analyses of the study. Author KDE managed the literature searches. All authors read and approved the final manuscript.

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Case Report

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ABSTRACT

The incidence of profound hearing loss is global, but the challenges and perception of mothers during pregnancy, peripartum and infancy of their children with profound hearing loss appear to differ from country to country and between developed and developing countries. The aim of this study was to investigate the experiences of five mothers of profoundly deaf children in Calabar, Southeastern Nigeria, during pregnancy, peripartum and infancy of such children, including how

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these 5 mothers interpreted their children's disability, relative to the socioeconomic situations in Nigeria. A qualitative methodology aimed at having a holistic and indepth understanding of the experiences of these 5 mothers, was employed. The results revealed that these 5 mothers were initially suspicious of their children's disability when they noticed the children's developmental delay, resulting in frustration and worry. There was no newborn screening test for the disability as done in developed countries, thus denying parents expeditious preventive measures. Mothers' ignorance of the aetiological factors of the abnormality, wrong diagnosis by unskilled health workers in available hospitals and spiritual belief, coupled with socioeconomic factors such as poverty and very strange healthcare system, all were the experiences of mothers which of course, obstructed choices of solution to the abnormality. The information collected from these 5 mothers indicates socioeconomic impediments, ignorance and spiritual belief system will continue to negatively affect the management of profound deafness in Nigeria.

Keywords: Profoundly deaf children; maternal experiences; South Eastern Nigeria; socioeconomic status.

1. INTRODUCTION

Nigeria is a populous West African nation with a population of 166.6 million people and a high poverty rate of 62.6% [1]. The high poverty rate affects the capacities of average parents to acquire proper education and choices of health seeking behaviours for their children. For instance, healthcare service provision for deaf children and elders is virtually not existing in most West African countries. This is further compounded by very poor feeding patterns and general food insecurity [2]. It is known that deficiency in healthcare systems is evident in low and middle income countries like Nigeria where millions of people are below the poverty lines [3]. In such countries, there is lack of financial protection for the cost of healthcare, causing individuals to be responsible for payment for their health needs [4]. Many may not seek appropriate healthcare because of their inability to pay [5]. This serves to subvert the globally publicized efforts of the World Health Organization (WHO) and the United Nations in achieving universal coverage of healthcare for all.

In such low income countries, unlike their counterparts in developed countries, there is a widening gap in health inequalities among citizens [6]. This poverty situation has adversely affected the healthcare of profound deaf children whose parents cannot pay for their healthcare.

WHO [7] defines profound deafness as the inability of the better ear to detect the quietest sound at a frequency of 81 decibels or greater. WHO [7] reports that between 1985 and 2011 there were about 360 million people with hearing disability worldwide, out of which 328 million were adults and 32 million were children less than fifteen years of age. Current estimate of hearing impaired people globally is 538 million [8]. Some individuals have diagnosedhearing loss due to congenital or genetic abnormality before speech and language acquisition, and others have hearing loss due to any cause, but after language or speech has been learnt [9]. This implies that those with post lingual hearing loss are still able to communicate and integrate to an appreciable extent in society, if hearing aids are provided on time to prevent long term hearing loss [10].

Of the 141 million live births in 2012, 127 million were from developing countries, 6 per 1000 had permanent congenital or early hearing impairment, being three times higher in developing than developed countries [11,12]. In fact, 80% of people who have hearing impairment live in low and middle income countries [13,11,8], with 75% living in Sub-Saharan Africa [14]. Due to paucity of data in this subject [15], the exact incidence and prevalence of profound deafness is not known in Nigeria. However, Amusa et al. [16] report that in Nigeria, one out of seven children have impaired hearing.

It has also been reported that out of 75% of hearing impaired people in Sub-Saharan Africa, 2.8% live in Nigeria [16].

Because most cases of hearing loss are not easily detected globally [17,13,12] routine screening which could have been done to detect this disability is not performed, thereby missing early diagnosis. Children in developing countries like Nigeria are more at risk of hearing impairment due to a combined effect of maternal infections in pregnancy, inappropriate healthcare service provision and poverty [15,14]. Because of

high cost of rehabilitative care for the deaf and the general socioeconomic situation in developing countries like Nigeria, it is important to understand the experiences of mothers of profoundly deaf children and their interpretation of their children's disability from their experiences. However, the experiences of mothers may include state of health and regularity of antenatal attendance during pregnancy, absence of newborn screening test during peripartum (immediately after delivery), poverty and lack of financial resources for healthcare services, ignorance and superstition about the aetiology of the profoundly hearing loss, besides frustration, worry and emotion.

The aim of this study, therefore, was to investigate the experiences of 5 mothers during pregnancy, peripartum and infancy periods of their children with profound hearing loss and explore the meanings that these 5 mothers make of their children's disability from their experiences, in view of the socioeconomics in a developing country like Nigeria.

2. METHODOLOGY

A qualitative research methodology of Creswell [18], Punch [19] and Patton [20] was used in this study. The qualitative methodology offers a plausible result, allowing sensitivity to the context of study which is central in qualitative inquiry and analysis [20], thus, providing an avenue for in-depth analysis of a variety of specific details that are often overlooked with other methods [19]. For instance, a qualitative inquiry elucidates how socioeconomic and political systemsin a society function, allowing this method of enquiry to systematically gather perspective on what happens within that system and the consequences for those involved. In this case, the experiences of mothers and the meaning these mothers make of their children's disability in view of the socioeconomic situation were explored. As a qualitative research, the terms reliability and validation cannot be used since the purpose of a qualitative research is to know the 'specific phenomenon and not to generalize [18].

Thus, a qualitative research design was employed in this study by interviewing participants who were recruited from the only school for the deaf in Cross River State, Southern Nigeria, called Special Education Centre, Calabar. This study was started after ethical approval from the Nigerian National Code for Health Research Committee, via the Ministry of Health of Cross River State, Nigeria.

The limitation of this study is that sample size of only five mothers is not adequate to draw inferences, although it is a qualitative study.

2.1 Sampling Method

A purposeful sampling method [19] was adopted to explore the experiences of 5 mothers of profoundly deaf children. This method allowed the deliberate recruitment of participants and sites deemed to be able to give an understanding of the phenomenon under study [18].

A total of five participants were recruited for this study based on the inclusion and exclusion criteria. The inclusion criteria consisted of 5 mothers of children with profound deafness, X mothers of children noticed to be deaf within the first year of life and Y mothers of non-syndromic children. These criteria were determined from the school records. Also determined from the school record were the exclusive criteria which consisted of Z mothers of profoundly deaf children noticed after the first year of life from any cause, and ZZ mothers of syndromic children. The Principal of the special education school meticulously reviewed the records of most students in order to identify the students who met the selection criteria. Letters were then sent by the Principal of the school to the mothers of the students inviting them to participate in the study. The ages of the participants ranged from 33 to 52 years. They all reside in Calabar, Southern Nigeria, although they come from different states and ethnic groups such as Ibo, Efiks, Ibibio and North Cross River State of Nigeria. The participants, who were of different social classes, were recruited for the study from the only school for the deaf in Calabar, Cross River State of Nigeria (Table 1).

Thus, children of parents of different social classes with this disability attended this school.

2.2 Data Collection

After self introduction to the participants, the purpose of the study was explained to them. This was provided in an information sheet besides a consent form which they read, understood and signed before the study started. A one to one in-depth interview was conducted by semi-structured questions such as to maintain

Table 1. Participant s' demographics and characteristics

Participants	Age	Tribe	Marital status	Occupation	Level of educational attainment
Participant 1	41	Ibibio	Married	Petty business woman	Primary school
Participant 2	35	Ibo	Married	Civil servant	College of Education
Participant 3	33	Efik	Single	Unemployed	Secondary school
Participant 4	52	North Cross River	Married	Civil servant	Secondary school
Participant 5	40	North Cross River	Married	Business woman	Secondary school

F = Female

some consistency over the concepts that were under investigation [21], although participants were free and allowed to add anything after the questions were exhausted. Additional open-ended questions were asked in order to clarify certain points, e.g., if there was problem in the hospital and if husbands were supportive during the period, and what husbands did for a living.

In each interviewing session, emotionality and sensitivity in interviewing was incorporated, [19]. Participants were made to feel comfortable prior to commencement of the interview by engaging in discussions on general day to day issues which led to more relaxed mood of the participants. All these enabled greater openness as the interview went on and consequently leading to greater data collection, as participants felt comfortable to narrate their experiences freely without hiding information, thus leading to greater data collection [19].

2.3 Data Analysis

With the consent of participants, all interview sessions were audio taped and transcribed, so that each word would be exactly recorded in the same way that it was spoken by the participants [22,20]. The data were thematically analysed using Smith and Osborn seven stages of thematic analysis [22]. These stages are:

I. Read single transcript (i.e., note initial comments/ ideas).
II. Generate initial themes (i.e., transform comments in themes).
III. Create initial list of themes.
IV. Cluster themes (order the list of themes into connected area).
V. Create a list/table with super ordinate themes and subthemes.
VI. Go to new transcript/repeat above process and refine list (table of themes).
VII. Create a final list/table with super ordinate themes and subthemes.

Following these thematic stages, listening to the audio-taped data and reading through each transcribed information singly occurred. Initial themes were generated by the process of coding which required labeling and naming the data while reading line by line through the transcribed data [19] in each transcript. These initial themes were thereafter grouped or clustered to form subthemes [22] in each transcript. This process was repeated for all the transcripts. The data were then summarized to form a final list of themes and subthemes by pulling together clustered themes [19] of single transcripts.

3. RESULTS

The experiences of mothers were grouped into pregnancy/peripartum periods and infancy periods as shown in Fig. 1. The peripartum is defined as the period before and immediately after the birth of the child.

3.1 Pregnancy/ Peripartumperiods

Participants' narratives and their accounts showed that they experienced good and proper pregnancy periods with no participant narrating experience which indicated that the pregnancy period was inappropriate.

Participants were in good health, so they could not attribute their health to their children's disability. Also, mothers narrated their experiences of regularity and consistency of

antenatal visits to the hospital in an attempt to establish their health seeking behaviours during these periods. All participants admitted experiencing minor Normal pregnancy symptoms. Participants also narrated how supportive their spouses were during the pregnancy and peripartum periods as shown in Fig. 1.

3.2 Infancy Period

Mothers narrated their experiences during the infancy periods of their disabled children based on five themes (Fig. 2) which consisted of initial suspect, illness/diagnosis, finding solutions, capabilities of children and hope for the future.

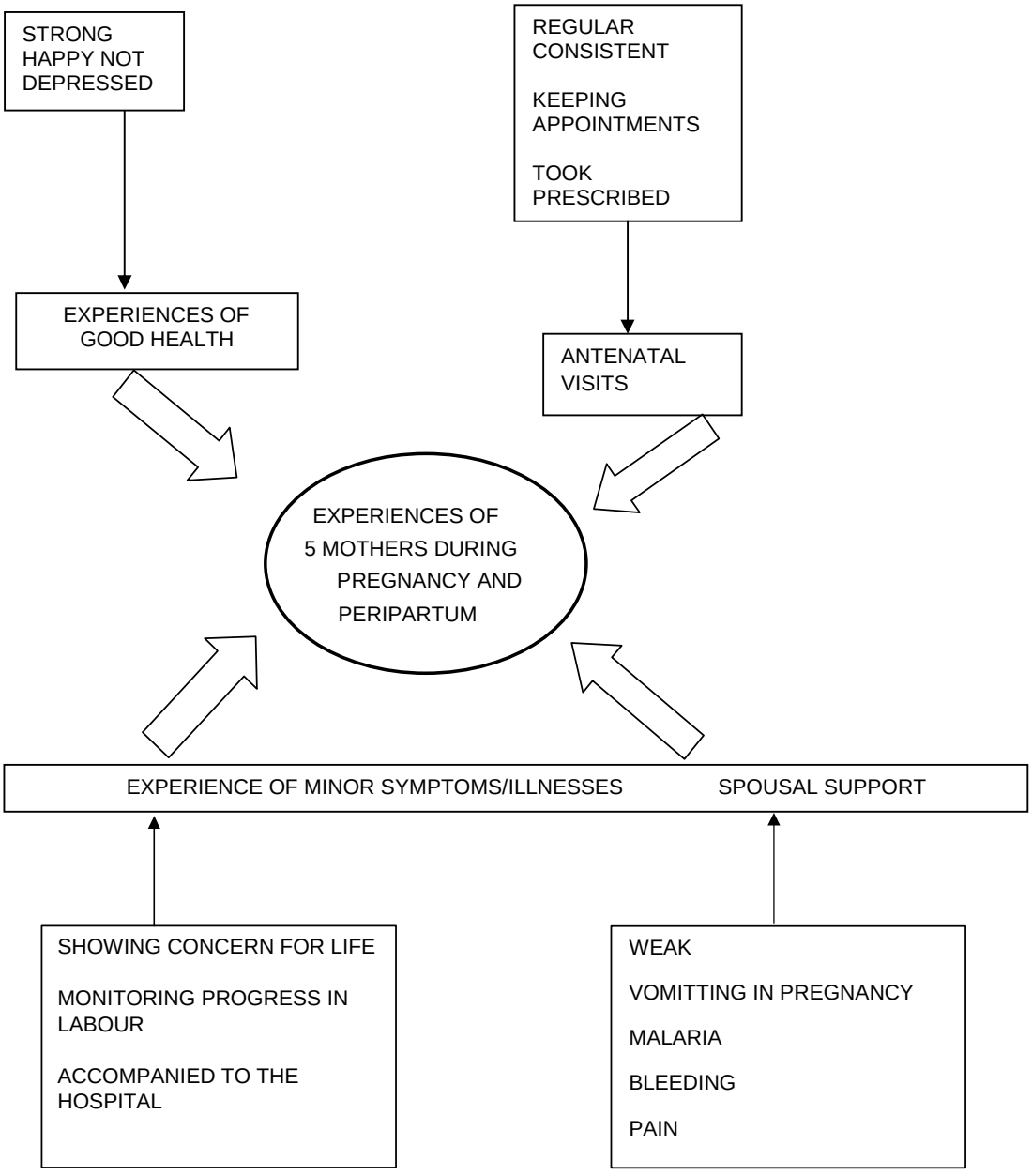

Fig. 1. Summary of findings on maternal experiences during pregnancy and peripartum periods

Mothers initially observed a developmental delay of their children. They suspected a disability but were initially not sure of its manifestation to be a hearing impairment. A mother narrated that her daughter delayed in everything, but one day noticed that her daughter could not hear the sound of a vehicle's horn.

Other mothers narrated the experience of developmental delays of their children which they noticed before the children took ill. Participants expected a good development after such illnesses. For instance, a mother narrated that the neck of her child was still not strong after being discharged from the children's hospital, even at the age of seven months when the neck was supposed to be strong. The situation did not get better.

One other participant revealed her experience of noticing an inability of her child to hear and talk appropriately for her age after recovering from an illness, and expected the condition of her child to get better after some time, but it remained the same.

Another mother gave an account of how she compared her experiences during the infancy period of her disabled child with those of previous children and narrated how she suspected an abnormality when her hearing impaired child failed to show similar 'normal signs' as those of previous children.

A participant also revealed how her child was admitted in the neonatal unit at birth since her baby was not able to give an appropriate cry. After discharge, she started noticing a delay in development when the child started growing.

3.3 Illness/ Diagnosis

When mothers first noticed their children's disability, and when the children were first diagnosed with a hearing impairment, they had a feeling of frustration, worry and emotion. Another mother expressed how worried she was, and became more worried because of the consequences of hearing disability.

3.4 Finding Solutions

Mothers did several things in trying to find solutions for this disability, which further illustrated the level of knowledge and beliefs of the average parent in Nigeria with respect to disability.

One mother went to a prayer home where she was advised to store her urine for three days and use the urine to wash the ear of her disabled child. When there was no improvement, she and her spouse went to one doctor to find out what the problem was.

Another participant narrated going to different places to determine if somebody was responsible, indicating that she attributed the disability to a supernatural cause initiatedby someone.

Another participant admitted that after trying different options, she continued to back to the hospital with her disabled child. Others said after having been in the hospital on several occasions, she stopped going because she noticed no improvement.

3.5 Capabilities of Children

Some mothers gave account of their children's ability despite their inability to hear.

This, of course, was narrated by mothers with cheerful looks and joy-filled faces.

3.6 Hope for the Future

Some participants hoped that their children's problem would be mitigated through the purchase a hearing aid in future, while others hoped for a solution of this disability either through spiritual means or with time.

The meaning mothers made of their children's disability in view of the socioeconomic situation in Nigeria

In exploring the meanings that mothers made of their children's disability based on their experiences, in view of the socioeconomic situations in a developing country like Nigeria, two major themes emerged (Fig. 3) which include challenges and perception.

3.7 Challenges

With respect to the challenges, participants revealed the challenges this study presented and things that could have contributed to the development of their children's disability. A participant narrated her challenges to uncover and identify the deficiencies of the healthcare system which she encountered during the peripartum, and felt that might have contributed

to the disability of her child. She narrated that she was taken to a private hospital which, although more expensive than government hospitals, lacked in all of the necessary medical equipment for proper management of the illnesses, because of strike action by staff of government hospitals. Thus, she narrated that she was not sure of her child's treatment since she was being treated in a different hospital from where her premature newborn was receiving treatment, especially since the private hospital she was delivered lacked a neonatal unit.

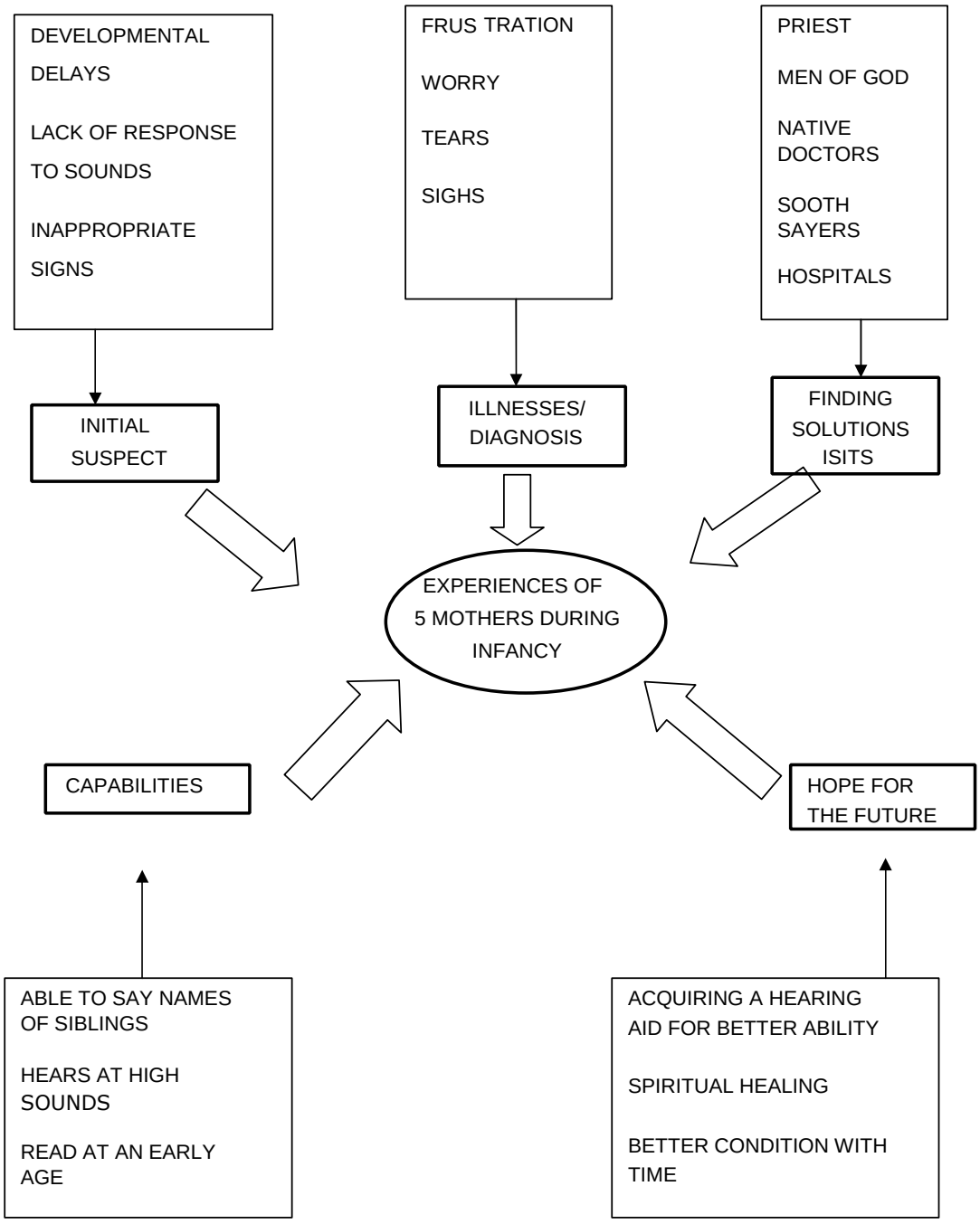

Fig. 2. Identified themes and subthemes on the experiences of 5 mothers during infancy period peripartum

Another participant expressed annoyance when narrating her initial incorrect diagnosis and inappropriate treatment during the infancy period of her child, despite her prompt access to the hospital. The participant felt this played a contributory role in the development of her child's disability.

3.8 Perception

Two participants attributed the illness of their children to lack of adequate healthcare arising from socioeconomic factors. Besides, most mothers believed that their children's disability was of a spiritual origin because of the experience they encountered, indicating a lack of knowledge on the risk factors of hearing loss. This affected their method of seeking solutions to the problem. For example, a participant narrated her dream of seeing a baby being taken out of water, and this was similar to her husband's dream.

4. DISCUSSION

Based on the results of this study, participants' narratives revealed the experiences that they encountered during pregnancy, peripartum and infancy periods of their children with profound hearing loss. Most of these participants gave accounts of how they experienced and noted a developmental delay in their children which initially prompted their suspicion of a problem, coupled with frustration and worry when they were confronted with the diagnosis of their children's profound hearing loss.

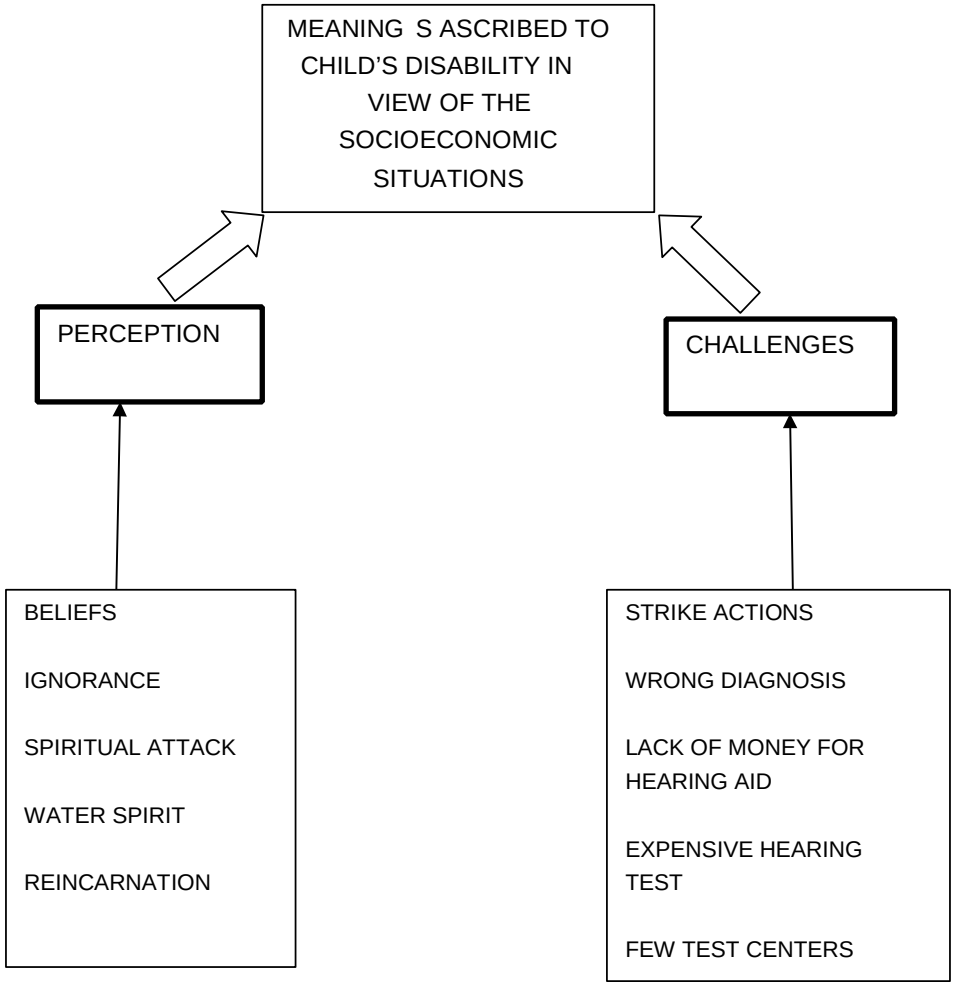

Fig. 3. Identified themes and subthemes of the meanings that the 5 mothers make of their experiences in view of the socioeconomic situations in Nigeria

These narrated experiences were in line with the experiences of parents in the United Kingdom when their children failed the newborn screening test and subsequent hearing test [23]. Contrary to this, no mother in this study gave an account of her child being tested or screened for a hearing deficit during the newborn period, indicating that this routine test is often overlooked among neonates in Nigeria. It is apparent therefore, that diagnosis of problems as such may be possible only when parents are able to suspect the problem, which may be far beyond the period of peak receptivenesss that is critical in the prevention of long term hearing loss and its consequences [10]. It is also apparent that most Nigerian parents are known to be ignorant of the aetiological risk factors of hearing impairment [24], hence their choices on solutions for their children's problem are affected.

In this study, mothers perceived their children's disability to be of a spiritual origin, which agrees with previous research in Nigeria [24]. Participants narrated their experiences of seeking spiritual and traditional help initially, and when no visible outcomes were seen, they resorted to medical treatment as a second option. This further extends the time before proper medical intervention is made. Thus, the burden of this disability can be intensified when the critical period for medical intervention to be most beneficial is missed.

In addition, participants of this study made meaning out of their experiences especially the challenges they faced during the peripartum and infancy periods. The narration of a mother on her experience of an initial wrong diagnosis of her child's illness despite her prompt access to the hospital, emphasizes the enormity of problems that unskilled medical personnel present in the delivery of healthcare in Nigeria. The argument in this case is that the severity of the disability could have been adverted, thereby preventing a complication like profound deafness. This possibility emphasizes the need for the government to make it a priority to invest more on healthcare system of the country.

The instability of government hospitals as a result of frequent strike actions by staff was identified as a challenge by one of the participants in this study. Hospitals managed by the government are known to be less expensive and better equipped with medical facilities for the citizens than the privately owned hospitals. Although the strike action by the government hospital staff might not be directly causal to this disability, the meaning that these participants made out of the socioeconomic health determinant was that, because of strike actions in government hospitals, their neonates were delivered in private hospitals which lacked essential facilities like a neonatal unit. This resulted in doubting the quality of care that was given to the babies which they felt must have played a contributory role to the development of the hearing loss.

Participants' narrative also revealed their inability to afford a hearing aid because of its cost. A participant, from her narrative felt that hearing aid would have greatly ameliorated condition in line with other findings [23]. This suggests that in developed economies where there is financial protection for the cost of healthcare [4], a child's hearing disability may be duly managed since the cost of hearing devices may be greatly less than the cost in developing countries like Nigeria.

The socioeconomic health determinants which can be considered as the situations in which an individual is born into, grows up, live and work, attains a level of knowledge and education besides culture, housing and healthcare system [25], are all known to be contributory to a significant level of health inequalities within and between countries [6]. This buttresses the need for governments of developing countries to set up a reform in the provision of healthcare services and improve the general situations in their countries if the United Nation's universal coverage of 'health for all' must be achieved.

The highlight of this study was that mothers of children with profound hearing loss in Nigeria narrated their experiences during pregnancy, peripartum and infancy of the children, and the meaning they made out of their experiences regarding the cause of their children's disability. Initially they experienced a developmental delay of their children which prompted a suspicion of the problem and frustration when their children were diagnosed of the disability, although no mother in this study gave an account of her child being screened for a hearing deficit at birth as their counterparts in developed countries. Secondly, because most Nigerian mothers are known to be unaware of the aetiological risk factors of hearing loss, their choices for solutions are affected. Thirdly, mothers perceived their children's disability to be of a spiritual origin and so sought for spiritual and traditional help which yielded no effect on the visible outcome. Thereafter they resorted to medical treatment as

a second option. Fourthly, there was wrong diagnosis of the cases despiteprompt access to the hospital, thus portraying the negative aspect of the Nigerian medical personnel. Even though government hospitals are better equipped than private ones, mothers reported to private hospitals because of regular strike by staff of government hospitals. This resulted in doubting the quality of care. Finally, participants could not afford to buy hearing aids for their disabled children because of poor socioeconomic situations which were grossly considered to contribute to the hearing loss of their children.

5. CONCLUSION

In conclusion, mothers experienced minor or no problem during the pregnancy of their profoundly deaf children, but rather noticed slow developmental delays of such children. Parents sought for all possible solutions to the disability of their children without success, and then took the children to the hospital for diagnosis, oftenwhen it was late. Moreover, most of the hospitals had unskilled staff combined with absence of newborn screening test devices. Socioeconomic situation, poverty and ignorance affected the early report of such cases to hospitals. It is recommended that government should strengthen the hospitals by providing newborn screening test equipment and educate mothers on the need for neonates to have newborn screening test.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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