

Arming Parents with Children who are Deaf in Zimbabwe: Key Ammunition in Care and Education

Phillipa Mutswanga

Senior lecturer Zimbabwe Open University, Department of Special Needs Education and Disability Studies

Abstract

Hearing parents with deaf children who participated in this study likened the discovery of their children's congenital hearing loss to a war without weapons. The study took its focus against the informally shared experiences. Additionally, a dearth of knowledge from other studies on the topic from a Zimbabwe context also prompted this study. The stories of four pairs of parents' parenting experiences with congenitally deaf children were qualitatively analysed using the thematic analysis. The terms deaf and hearing impairment are used interchangeably as hearing loss ranges from mild (hard of hearing) to profound. The phenomenological design was applied to the study because of its naturalistic principles. Semi-structured in-depth interviews with six participants and two narratives of parents with deaf children were used. Observations were an ongoing process which gave insights into other areas needing further clarity or probes. The findings were thus triangulated. Patterns of blame shifting tendencies; misunderstanding and misconceptions emerged from the study. Other common indicators were that most parents faced milestones in caring and educating their congenitally deaf children. Other emerging themes included: lack of parental support; victims of ignorance and bitterness; genetic impacts as root causes; isolation; absence of interventions. Counselling, education and parental support were identified as care giving ammunitions. Participants further expressed lessons learnt from the lived experiences. The discovery of a child's impairment exuded patterns of milestone implying that parents went through various critical processes and stages before they came to terms with the conditions and that confirms the need lack of parental support throughout the child's developmental stages. Against this background the study explored the experiences of parents in caring and educating children with congenital hearing loss with a view to army and pre-army parents to be with possible care giving and educational ammunition.

Keywords: arming parents, deaf children, care and education, ammunition, Zimbabwe.

1.0 INTRODUCTION

Informal conversations with the majority of parents with children with congenital hearing loss likened the discovery of the conditions to a war battle without weapons. This inspired the development of this study with a view to directly or indirectly tap more experiences from which lessons could be learnt. Other informally encountered participants described such discoveries as a blow and traumatic experience despite their educational status quos or the development status of their countries. Using the narrative experiences of four pairs of parents the study aims to arm and empower the affected in managing their children's malfunction hearing systems. Congenital deafness is a hearing loss that a person is born with and ranges from mild to profound. The thrust of this study is to promote independent living and recognition of deaf people as equal members in the hearing world. Insights obtained from the experiences of parents are expected to be instrumental in reducing the impacts brought by the condition. Terms deaf and hearing impairment (HI) are used interchangeably in this study and people who are deaf as people first despite their impairment thereby promoting the person first philosophy in the field of disability studies.

The gaps surrounding the phenomenon were obtained both formally and informally. The impact of the discovery of a child's congenital deafness on a family is speculatively described as a rough and difficulty life journey with limited hope to a rich destiny. Furthermore, parents generally have a tendency of comparing and contrasting their children's developmental upbringing thus, usually question any noticed anomalies or retardations. Due to all this, parents are sometimes described as the *paramedics* to the child's medical history. However, when parents discover the impairment of their child they often worry whether their children will make a better life considering the imposed impacts and setbacks caused. The National Research Council (2004)'s support postulates that, hearing loss impacts on communication and interpersonal functioning of a person's quality of life. Thus, some parents question how their children who cannot talk or hear will make it in a hearing world where audition and spoken (oral) languages are a pre-requisite.

Against this background, this study therefore felt that one's being is strengthened by significant others. Selected principles from the ubuntu philosophy guides this study, thus it supports the person first theory. In support, Khoza (2006) and Mandela (2006) propose that in the interest of creating communities with justice and mutual caring ubuntu concept should be guided by principles of compassion, dignity, humility, reciprocity and mutuality. This is summarised by Mbiti (1969) who proposes that, *you are because I am and I am because you are*. In line to such expectations ubuntu philosophy is expected to restrict the automatic dehumanisation of any person or group of people. Considering all these sentiments, one wonders where the Africans' being-ness

sometimes vanishes into yet it is inculcated from birth into every African child as he/she grows even though it differs here and there from country to country. The selected principles are hoped to assist parents accept the discovery of their children's congenital hearing impairment (HI) with justice and compassion and provide further care for their social and educational needs with equity and equality as they do for other hearing children.

With reference to the preceding sections, it makes one wonder why hearing people or societies inertly regulated by ubuntu continue to stigmatize and discriminate people with HI. Despite the ongoing advocacy and paradigm shifts, stigma against people who are deaf or generally people with disabilities (PWDs) seem to continue irrespective of one's status quos. Thus, this study proposes the adage; *to be forewarned is to be armed*, to be considered as an integral principle in rearing children with HI. The study therefore aims to prepare parents with children with congenital deafness to approach the dilemma with positive wisdom and ammunition in order to transform the mindset of the hearing world. The study intends to make parents with deaf children ambassadors in helping the society at large positively handle all hearing loss matters with informed positive caring styles. The findings are expected to transform all people who read this study to consider *a child as a child* despite his/her impairments as guided by the selected principles of ubuntu. In other words the study encourages the person first philosophy and also the adage; *disability does not mean in ability* especially where early intervention was rendered.

Besides speculated views, this study acknowledges several studies to have influenced its development. Hintermair, (2006)'s study which focused on two early intervention centres for children who are deaf serviced with Cochlear Implants and their families at the British Columbia Children's Hospital (BCHH), is one of the examples. The study collected data through written responses to the self-reported retrospective parental experience questionnaire as well as the audio-taped transcribed interviews which were subjected to extraction of critical incidents using NVIVO software. Hintermair's study encourages concerned parents to focus on their lived coping experiences of raising children with HI and/or with cochlear implants from the time of diagnosis to the present status. Another study inspiring this study was a longitudinal study by Lederberg and Golbach (2002) which investigated the impact of child deafness on mothers' stress, size of social networks and satisfaction with social support. Twenty-three hearing mothers of deaf children and 23 hearing mothers of hearing children completed a series of self-report experiences on questionnaires after their children attained 22 months, 3, and 4 years. Furthermore, Pipp-Siegel, Sedey, and Yoshinaga-Itano, (2002) studied stress experience in 184 mothers with deaf and hard-of-hearing children relating to (a) demographic characteristics of the children; (b) degree of hearing loss, age of identification, language ability, mode of used communication and (c) characteristics and perceptions of the mothers. In agreement, Hintermair (2006) summarizes all these findings by concluding that, personal and limited social resources influenced the coping process of most parents. Zimbabwean parents' coping experiences seem under-researched, thus this study was developed though not focused on coping with cochlear implantations. The study's thrust was to explore how hearing parents' lived experiences could give insights on how they could cope with children with congenital hearing impairment in Zimbabwe with a view to give them ammunition which could arm them in caring and meeting such children's caring and educational needs.

1.1 Other Studies and Researchers s Contribution

Hearing parents who participated in this study received the news of the diagnosed congenital deafness of their children differently although same patterns emerged in some instances. With regards to this, Leigh (2009) assets that for a deaf child growing up in a culturally Deaf family, Deaf identity is likely to be a natural evolution based on family of origin. Such parents are likely to conform and help their child develop alliance with Deaf Culture. However, hearing parents are generally reported to deny their children with HI such opportunities and to also take long to approve the alliance (Nolan and Tucker, 1981).

Following such reasons Leigh (2009) proposes that hearing parents are likely to pronounce desires to have their children with HI meld into the hearing society. This is probably the reason why the majority of hearing parents need more parental support as soon as their children's hearing losses are detected to help them cope with diagnosis and plan early intervention.

The National Institute on Deafness and other Communication Disorders (NICDCD) (2016) accepts that all children are unique whether hearing or deaf thus will always need parental interventions to mould them to expectations. The same authors and Madell, Novak and Zubritsky (2005) suggest that, despite the noted facts, a child who is deaf brings with it a lot of challenges and it is for these reasons that parents with children diagnosed as deaf will always require accurate information to manage the child and use the information to get the required support. Studies also posit that, in most instances 95% of deaf children are born to hearing parents (Madell, *et al* (2005). That further confirms the necessity for parental support because worldviews of hearing and deaf people are different. With regards to these facts NICDCD (2016) further postulates that parents' expectations, plans and dreams often change once a child is diagnosed as hearing impaired.

Thus, reaction to the disclosure of a child's deafness differs from parent to parent because many issues

come into play. As a result, hearing parents may be affected by both the child's disclosed situation; worry over their own knowledge deficiency about the child's condition and financial constraints. On the other hand, NICDCD (2016) and Leigh (2009) point out that some professionals may create despondency and despair by the way in which they manage the process of disclosure to parents. NICDCD (2016) proposes that upon diagnosis of the child's deafness some parents may develop feelings of abject misery which Nolan and Tucker (1988) describe as passing through critical stages of adjustments. Furthermore, NICDCD (2016) and Leigh (2009) suggest that some parents may get devastated by the news and react differently by deserting their families, divorcing and many other reactions. Thus, Beazley and Moore (2012) and Nolan and Tucker (1988) emphasise the need for psycho-social support and counselling for hearing parents and their deaf children. Furthermore, Beazley and Moore (2012) emphasise the need to exploit the social model and its applicability in a coherent way to arm the concerned parents with appropriate child caring and management skills. Considering these facts, principles of the ubuntu philosophy are seemingly applicable to the study. According to Hintermair (2006)'s study it is vitally important to identify factors that promote successful coping with the faced demands imposed by the impairment or cochlear implantation. Although this study did not address cochlear implantation issues, Hintermair (2006)'s study also inspired the development of this study.

Basing on my experiences as an educationist, the discovery of children's impairments seem to cause a lot of disequilibrium in families and societies to the extent of creating instability and promote the surfacing of many uncomfortable issues. Such cases could be reduced if people maintained the ubuntu philosophy as human-beings. According to Mutswanga's study (2016), *ubuntu* is both a concept and a philosophy which regulates behaviours of a community or society. The study therefore encourages us, Zimbabweans to take the matter to the drawing board for a postmortem. In support, Nolan and Tucker (1981) assert that, when news is disclosed to parents that their child has been diagnosed as deaf, they feel crushed, let down of their expectations, empty and alone despite their prior suspicions and how they may have prepared selves for the news. Against this background, the study investigated the experiences and reactions of parents when their children's congenital deafness is discovered with a view to get insights as to how Zimbabwean parents could be empowered in improving their children's educational needs and caring styles. The lessons learnt from the experiences are expected to pre-arm parents-to-be and the parents currently struggling with the discovery of their child's congenital deafness. The study is guided by the following research questions: 1) What are the parenting reactions of parents to the birth or discovery of a child with congenital hearing impairment? 2) How can the after effects of the discovery of a child's congenital deafness be improved to help the parents cope with the situation? 3) What lessons can be learnt from the revealed experiences? Considering preceding facts, how then, can parents with children with congenital hearing impairment be assisted to handle the discovery of their disability skillfully for better parenting, education and child caring?'

The significance of the study is therefore to ensure that parents with children with congenital HI are skillfully armed with appropriate ammunition in handling their children's social, psychological, spiritual, educational and medical issues. Parents are expected to develop positive relationships with both educationists and health services. This should also help to create awareness on where and how to get various provisions for the affected children. The study aims to make parents with children with HI more knowledgeable of how to express and obtain their rights from various sectors in society. The findings further aim to be an eye opener to community members, the government and policy makers. Guided by the *ubuntu* philosophy and its principles the findings from the study are also expected to transform the society at large in managing the concerns of parents with children with HI and as well make the diagnosed persons more assertive. The findings are further expected to transform the mindsets of parents and the population at large so that people with congenital HI are seen as people first who can equally contribute to sustainable livelihoods regardless of their missing hearing.

1.2 METHODOLOGY

Using the phenomenology design, the study qualitatively explored the experiences of parents to the birth or news of the discovery of a child's congenital hearing impairment to give insights to the phenomenon understudy from the insiders' perspective. The approaches allowed the parents to freely narrate their reactions to the discovery of a child's congenital deafness in a natural setting. These approaches were therefore the best in eliciting very rich information with verbatim presentations. In support Mutswanga (2014) describes both approaches as complementing each other and not diametrical opposites but fitting very well in this study. According to Groenewald (2004) and Ploeg (1999) the phenomenological design and qualitative research are complementary as means to the truthiness of the findings. In support Al-Busaidi (2008) defines qualitative research as an umbrella term covering an array of interpretative techniques seeking to describe; decode; translate and come to terms with meanings of naturally occurring phenomena and not quantities, statistics or frequencies as is the case with quantitative research.

The study's population focus is on a minority population of parents or care givers with children with congenitally HI in Harare urban. The study could not find the statistics of parents with children with congenital

HI [born deaf] in Zimbabwe. Furthermore, the statistical periodic analysis lacks specifics since most statistics are presented as estimates. This study criticizes the systems for poor statistical analysis of PWDs by disability type even though Lemacks, Fowles, Mateus and Thomas, (2013) generalizes that birth defects affected 1 (one) in every 33 babies which may need further studies to prove its applicability to Zimbabwe. Thus, this study encourages the policy makers and implementers to carry out surveys on statistical analysis of PWDs by disability type and classification to anchor meaningful planning and research work and increase the validation of equal opportunities and provisions to all citizens.

Purposive sampling was employed to select the four pairs of parents with congenitally deaf children who took part in this study. Snowballing helped in identifying these parents. The key informants from the association of people with HI played key roles in identifying the participants using a prescribed selection criterion. In essence, purposive sampling is a principle of phenomenology, thus was most suitable for the study. The exploration allowed the study to elicit rich experiences from these parents. Point of saturation determined the sample size when no more new data was received from the participants. In support Driessnack, Sousa and Mendes (2007) assert that, in qualitative research participants are purposively selected for their experiences and information rich about the phenomenon under study. Semi-structured interview questions were therefore instrumental in collecting data for the study.

Instruments are the data collection tools used to collect information for the study. Information was elicited from the six in-depth interviewees and two narratives. Where-need-be probes were used to gain insights into ongoing observed behaviours. The interview questions were continually improved as data collection took place. Data collection was therefore triangulated and that enriched and augmented the findings. In support, Patton (2009) considers narratives as personally told or written stories of participants' lived experiences. Both tools helped to understand lived human experiences on the phenomenon. That then, made the used instruments appropriate for the study.

Data collection procedures included explaining the purpose of the study to the participants and verbally seeking the consent of the participants. It was made known to the participants that the collected data was going to be used for the particular study without actual names of participants for confidentiality and ethical reasons. Participants were also told that their participation was voluntary and that they were free to withdraw at any time. Standard interview procedures were adhered to according to the qualitative perspective. While in-depth interviews were ongoing and individually probed, the narrators also wrote down their lived experiences on the phenomena with the guidance of the semi-structured in-depth interview questions. These were guided by the questions; *Could you please narrate how you felt when news about your child's congenital deafness was first disclosed to you? How did you react? What could be done to reduce the felt impact/experiences?* Notes were made on parallel margins to highlight any noted clarified issues or areas requiring clarification. Point of saturation determined the adequacy of the information and also the sample size. Before considering the collected data for analysis it was read several times to cross check for meaningfulness and focused-ness on the study.

The thematic analysis approach was employed to analyse the collected data. Data collected through in-depth interview was analysed first followed by the narratives while observational notes gave it more insights. Margin notes emerging from probes were aligned to the corresponding data. After being satisfied by the collected data, emerging patterns and themes were proposed and continually revisited to establish their appropriateness and relevance to the phenomenon under study. The collected data was re-read and inserted under corresponding theme codes on margins to make it easier to merge together information supporting the themes. Each theme was then discussed taking into account the research question it addressed while supporting related literature review where possible.

1.3 EMERGING PATTERNS AND THEMES

The experiences of parents in caring for children with congenital HI were analysed and placed into patterns and themes which were further discussed and supported with related literature. The extent to which research questions were answered was also discussed. Three key patterns emerged from the study namely; *Blame Shifting Tendencies, Misunderstandings and Misconceptions* but a pattern of *Milestones seems prevalent* in every family as noted in most participants' disclosures.

1.3.1 Blame Shifting Tendency

These excerpts reflect high tendencies of blame shifting as follows:

We had stayed for 15 years without a child. When I conceived I was the happiest woman in the world ... When I gave birth to a baby boy, my husband was excited and loved me more than ever before [Parent 1, wife, Narrator].

The excerpt from *Parent 1 [wife, a narrator]* entails the happiness that the birth of a child brings to a family. As expressed by this participant, the happiness is doubled or trebled after episodes of bareness. However, this study reveals that in most instances this same happiness is short lived by the discovery of the child's disability as expressed by the same participant:

... but little did I know that it was the beginning of further unhappiness and marriage challenges [Parent 1, wife, Narrator]. The same narrator confirmed further:

My uncle had a deaf child so my husband pointed fingers at me suggesting that the tragedy that had fallen us was from my family's side because we were a cursed family where few girls were married.

Reported [Parent 1, wife Narrator].

The findings therefore reflect high tendencies of blame shifting develop amongst families when a child's impairment is discovered. Married partners and their families seem to deeply reflect on their past and what they know or have heard about their in-laws' past to try and come up with answers or causes of the misfortune before them. The families always look forward to a healthy baby as evidenced by Parent 1 [wife, Narrator] but when it fails the husband shifts blame towards the wife and her relatives. All these are indicators that families with children with disabilities need all forms of support when a child's impairments are discovered.

1.3.2 Misunderstanding and misconceptions

The collected data further revealed misunderstanding and misconception as paving way for faced challenges in managing the disclosure of a child's HI as demonstrated below:

I did not divorce my wife when we got a deaf child but still our marriage became unstable with a lot of blaming, shouting at each other and always brought in the issue of the birth of the deaf child into our misunderstandings [Parent 3, husband].

Another participant complained:

My husband drinks beer but his drinking rate abnormally increased when I gave birth to our 3rd child who is deaf. I have tried to make him realise how the behaviour was a way of running away from the responsibility towards our deaf child but this has always resulted in me receiving blows from him [Parent 4, Wife].

The findings seem to reflect a high need for all related institutions to help clear the misunderstanding and misconceptions faced by parents with children with HI. The findings reflect that a lot of misunderstandings and misconceptions surround the birth of a child with congenital HI. In most instances the study shows that wives are generally beaten and pointed fingers at by their husbands as responsible for the birth of a child with hearing loss. Immediate counselling intervention and education are therefore necessary when a child's disability is revealed as suggested by the majority of participants in this study.

1.3.3 Faced milestones

Generally, the findings revealed that nearly every family experienced some form of milestones to the birth of a child with impairment as exemplified below:

Other relatives suggested that the evil curses of bearing many deaf children was from my 'maiguru's' family the sister-in-law's side, [the mother of the deaf children's family], thus most of my close relatives still today call this 'muroora' [sister-in-law] a witch and many other names that reference her as a mother of deaf children 'zvimumumu'. Surely stigma and discrimination has no boundaries. Though I am educated as a teacher I had negative attitudes towards all people with disabilities and always thought a family with a child with a disability was a cursed family [Parent 2, husband's relative].

The voices of parents of children with hearing impairment expressed high need to give the affected families the desired support to help minimize the impacts of the milestones. The birth of a child with congenital deafness brought with it instability in families. Most husbands found the world harsh and to have robbed them of 'a normal' child as portrayed by the majority of husbands in proceeding sections. Thus, most husbands reacted violently towards their wives as a way of retaliating against the reality or discovered anomaly. Family support and counselling are further emphasized.

1.4 Emerging Themes

Several themes emerged from the study and many more emerged but this study only selected the most related ones from the obtained testimonies. However, because of expected size of the document, this study only came up with seven themes, namely: *lack of parental support; victims of ignorance and bitterness; genetic impacts as root causes; isolation; absence of intervention; education, parental support and care giving ammunition.* Lessons learnt were also highlighted with a view to transform families' negative ways of managing the birth of a congenitally deaf child.

1.4.1 Impact of the discovery of a child's disability

Excerpts below reflect how news about the discovery of a child's impairment impacted on the family:

Though at first I was disappointed by staying for years without a child, the birth of a boy-child relieved me [Parent 1, husband, telephone shared information]. The wife further expressed:

However, when he continued to babble without any other utterances I suspected something to be wrong with his speech development and I further noticed the absence of hearing. I panicked and became thinner each day as I did not know how to say what I suspected to my husband and the in-laws [Parent

1, wife]. The wife mourned further:

He later on took me to my family and asked them to rectify the problem after which I could only return to him with a hearing and talking child. I also begin to hate the child as being responsible for my divorce and all the suffering I was going through [Parent 1, wife].

I was greatly disappointed by the birth of a deaf child after struggling and shopping around to get a child [Parent 1, husband, telephone shared information].

I have not been supporting my first marriage child. I cannot sign thus I have not bothered to learn sign language because I rarely have anything to share or ask from my deaf child and I always point to the mother to attend to his requests. Generally my marriage feelings have been hate [Parent 1, husband, telephone shared information].

I am the sister of the man who has 3 deaf children. I am currently working as an infant teacher at one of the schools in Harare. Since I stayed with my brother and his wife while going to school I witnessed the birth of all their children. The 3 deaf children were never liked even by their own mother. [Parent 2, husband's relative].

The above excerpts evidence that the discovery of the birth of a child with disabilities equally impacts on both parents although its impact seemingly doubled for the married women. The excerpts of women in this section indicate how the news of a child's impairment makes them hopeless and instills fear on how to break the news to their husbands and in-laws, fear to be accused and to be violently victimised.

After giving birth to a deaf child I cried every day and night until I became too hopeless to prepare for the family's upkeep [Parent 3, Wife].

It was fortunate that our deaf child could not hear because he would have heard our daily misunderstandings and felt unwanted [Parent 3, husband].

The collected data expressed high need for supportive interventions since the discovery of a child's impairment brought with it lots of negative impacts on the family as highlighted by preceding excerpts.

1.4.2 Lack of parental support

With the advent of the diminishing extended family bonds such changes are likely to expose families to meet their own challenges as individual entities which is the opposite of ubuntu. As a result the collected data reflected high lack of parental support to the birth of a child with impairment from the immediate family members; the community and the government as evidenced by the following excerpts:

I was in it alone and nobody came to my rescue [Parent 1, wife].

I am a mother of four children, from which 3 are deaf. I was screened into the at risk register at the hospital so I managed to get advice, guidance and assistance and was referred to Jairos Jiri school for the deaf where one of the teachers volunteered to assist me in handling the matter [Parent 2, Wife, Narrator].

The findings revealed high lack of parental support since out of the eight participants only one expressed to have benefited from the received external support. The study reports lack of parental support as compounded by lack of early interventions on most needed support to reduce coping challenges. The excerpts in proceeding sections confirmed:

But parents need early support when the impairment is discovered because without it, they may not know where to start from about their deaf child's needs, education and future [Parent 2, Wife, Narrator].

I hated being alive. I grieved alone and almost died of stress and depression [Parent 3, Wife].

The majority of parents in the study saw little need to live after being robbed of a hearing child. That could possibly be the reason why the majority of men in this study could not face the discovery of their children's impairments, thus reacted by either neglecting/deserting the family or divorcing their wives. It is probably because of these reasons that the majority of parents emphasized the need for early intervention policies and strategies as one of the ammunition in managing the discovery of a child's deafness.

1.4.3 Victims of ignorance and bitterness

The study further reported that lack of parental support contributed to most parents' ignorance and bitterness when news about a child's impairment was disclosed. This is supported by the following excerpts:

The discovery was a bigger blow to my husband [Parent 1, wife].

I also begin to hate the child as being responsible for my divorce and all the suffering I was going through [Parent 1, wife].

When we got a deaf child I was not prepared to shop around again to have his hearing restored but since we did not have a history of deafness in the family I divorced my wife... [Parent 1, husband, telephone shared information].

Due to the numbers of children the father fled to Botswana where he has since remarried and is providing us with once a while little support [Parent 2, Wife, Narrator].

For years I have not gained interest in learning sign language. After noticing that these children had a

promising future I slowly began to show interest in them and learnt a few signs [Parent 2, husband's relative].

I used to steal my husband's money to take the child to the hospital, prophets and traditional doctors but that never helped, instead I received blows from my husband for both stealing his money to try and solve an issue which according to him I was responsible for and for bringing the curse to his family members [Parent 3, Wife].

However, it was only my wife who actively participated in everything because I found it too demanding. I gave my support in form of cash. We now have a second child and is a hearing boy [Parent 3, husband].

I am a heavy drinker and my wife always brings in issues of my over drinking as responsible for the deafness of my 3rd born [Parent 4, husband].

The participants reported that their ignorance to child's deafness was compounded by panic; bitterness; lack of knowledge and a shoulder to lean on. The insights from the study revealed unstructured and unclear supporting strategies to the discovery of a child with congenital HI. The situation exemplifies a western individualistic philosophy rather than the communal principles that most Africans are known to subscribe to. Due to such observations the study encourages Africans, especially Zimbabweans who are the focus of this study not to take the issues understudy for granted but urges them to go back to the drawing board to make sure that issues of PWDs are regulated to principles of ubuntu they subscribe to.

1.4.4 Genetic impacts as root causes

The study revealed that most parents had partial knowledge about genetic influences on HI as expressed by the following excerpts:

...fear that I was going to have a chain of deaf children since there were gens of deafness from my wife's family. To my surprise when I remarried we got a deaf boy-child but I took this as a curse from my first wife and I am still confused how it came about but my second wife deliberately quickly became pregnant and gave birth to a hearing girl-child [Parent 1, husband, telephone shared information].

...and she is always talking about my aunt who is deaf as the reason why we had a deaf child. I get so annoyed by all this and it is for these reasons that I spend more hours outdoor than home [Parent 4, husband].

The study emphasizes the relevance of helping parents understand the influences of genetics on deafness and how such information could help parents make informed decisions about their situations and the future.

1.4.5 Isolation

The fact that society considers the spoken language as a communication pre-requisite contributed to the isolation of people with HI since that excluded them from family and societal conversations especially where one is born to hearing parents. This is validated by the excerpts:

I had no shoulder to lean on because friends and in-laws deserted me [Parent 1, wife].

I feel so isolated as neighbours call me all sort of names and always point fingers at me as a mother of 'zvimumumu' that is deaf children. Neighbours laugh and clap hands behind my back each time I go out of the gate. When I had two deaf children I used to withdraw from surrounding people and wept until tears stopped [Parent 2, Wife, Narrator].

I always looked into the clouds as a person from a Christian family, hoping that one day God was going to descent and solve my problems since my in-laws and husband isolated me and my deaf child [Parent 3, Wife].

My wife has noticed that I have no time for this child and she is ever complaining that I am isolating the deaf child [Parent 3, husband].

Me and my deaf daughter feel so isolated and lost. We are lost in the sense that the hearing world seems not to acknowledge our existence [Parent 4, Wife].

A person who is deaf is a person first before one notices his/her conditions. However, the preceding excerpts reflect that most people with HI and their families are labelled and called names relating to their impairments and that seems to have isolated most them from the hearing world.

1.4.6 Absence of interventions

The study continues to reveal that the discovery of the birth of a child with HI is marked by high absence of support and early intervention strategies as earlier on reflected:

My own family members did not know how to help me because they equally mourned [Parent 3, Wife].

I sign with the child and play with her but the father does not even put effort to talk to her as periodically as he engages in conversations with hearing siblings. I don't know what could be done but am affected [Parent 4, Wife].

The findings imply that there is need to plan early parental support services to arm them with appropriate ammunition in managing the discovery of a child with congenital hearing loss. The insights forewarn Africans, not sparing Zimbabwe, not to take issues presented by this study for granted because the highlighted experiences

portray that disclosure of a child's impairment brings with it several husband and wife relationship challenges. Furthermore, the regulated purpose of an African family is damaged and compromised as exemplified by the findings and that indicates the need for urgent action to address the situation.

1.4.7 Education and Care giving ammunition

As reflected below the study shows that lot of care giving ammunition, counselling and education are required to arm the concerned parents:

One of my children received speech training which later helped her to articulate though severely hearing impaired while the other two were helped to sign and speechread [Parent 2, Wife, Narrator]. Fortunately, one day a friend of mine invited me to a workshop for parents and deaf children. It was through presentations, group counselling, question and discussions that I learnt to manage my situation. The workshop empowered me. I learnt to accept my situation and fend for my children from the little cash I demanded from my husband. Through buying and selling and vending I have managed to look after my children and even send them to special boarding schools for the deaf where they are doing very well and have acquired more English vocabulary than their hearing siblings. One of the deaf girls is now married and has 2 hearing children while one of the 2 boys is into sculpturing overseas and has asked his young brother to join him. These boys are living independently and they have also managed to buy themselves a house each in one of the subs [Parent 2, Wife, Narrator].

Their mother only started to like them after receiving some guidance and counselling from the special school for deaf where she also saw deaf models. I feel village health workers should be empowered to be the first support givers when a child within the community is diagnosed as disabled [Parent 2, husband's relative].

The opening of a resource centre for the deaf brought light into my situation because I was engaged in afternoon discussions where my deaf child enrolled and that helped me to understand my child and made me aware that it was hearing that was missing but she could do all things other school children were taught. I was taught basic sign language and that helped and made me come closer to my child and attend to her needs. Feelings of being loved made her love me too and improve in all areas of life. I feel it is important to support parents when they give birth to a child with disabilities. One needs support from immediate family members, the village health workers, medical staff, educationists and even from the government itself [Parent 3, Wife].

A family friend introduced us to the service centre in Harare where we later on took our child to have her tested and seek her placement and had a hearing aid fitting. It was only at this level that peacefulness began to prevail in our home and we secured placement for our child and started to train her to speechread while she taught us basic signs [Parent 3, husband].

At least the neighbourhood school came to our rescue by consulting us and my husband agreed to have our deaf daughter placed in a resource centre. My husband openly pointed out that this placement was good riddance of the child because she disturbed my household chores as a wife since I paid too much attention to her. Despite all that, I was pleased when my husband agreed to our child's placement. Our child is now in the resource centre where she has learnt to socialize, sign and speechread [Parent 4, Wife].

The collected data highlighted early parental support and counselling as necessary ammunition which could help parents come to terms with the hearing loss conditions of their children.

1.5 DISCUSSIONS

The section collapsed the four research questions and discussed them as: 1) *Parents' Experiences after the disclosure and its impact*; 2) *Possible coping mechanisms*. The discussions were supported with related literature review where possible.

1.5.1 Parents' experiences after the disclosure and its impact

The collected data revealed that the majority of parents anticipated high excitement to the birth of a non-disabled child such that the reverse created varied challenges as equally noted by Webber (2011); Van Riper (2007); Heward (2010) and Trute and Hiebert-Murphy (2001). According to Ritchie (2013); Cohen (2008); Kandel and Merrick (2003) and National Information Center Children and Youth (NICHCY) (2003) the initial exuberance is muted by the birth of a child with disabilities as already exemplified by the preceding excerpts in this study. The findings revealed that, high disequilibrium occurred between husbands, wives and in-laws as most shifted the blame of the discovery of a child's congenital hearing loss to women (their mothers). Furthermore, all the parents who took part in this study expressed fear in meeting their children's communication, educational and caring needs as equally noted by Cohen (2008). For example, most parents who took part in this study expressed emptiness and fear about how their children with congenital deafness were going to operate in society and school environments where the spoken language is a pre-requisite.

Furthermore, the majority of parents expressed that they ran short of ideas and information about where

to get services for their children. Through other participants' learnt experiences readers may obtain insights to their challenges as narrated by *Parent, 3 husband and Parent, 4 wife*. Marriage partners of most of the participants lamented and continually questioned why their relatives blamed their marriage partners for the birth of a child with congenital deafness without giving them any help. The same participants were further alarmed by the news that most of their neighbourhood schools refused to admit some children with HI because some parents were against the idea of their children learning side-by-side PWDs and additionally some teachers could not admit them due to lack of skills and resources. These are good enough sign-posts (indicators) for the need to reconsidered improved parental ammunition in caring and educating children with HI.

Additionally, a sense of desperation is reported by the majority of the participants. Some of the specific parental experiences included confusion, disbelief, disappointment, and uncertainty which are equally reported common in related studies as noted by Hintermair (2006) and Nolan and Tucker (1981). The question is why is it that reports of parental failure to cope with the discovery of a child's impairment continue to be a pertinent issue in the field of disability? As reported by the majority of the participants the country's poor screening, lack of firm policies and follow up procedures were reported as attributors. Thus, most participants argued that, child screening gaps were caused by late diagnosis which was further compounded by late interventions. In other words, the country needs to carry out a survey on support received by the parents after disclosure of a child's impairment. The survey could equally help inform the policy makers, health and education systems. Lack of parental support after the discovery of a child's impairment was reported as compounding any other challenges encountered in upbringing a child with congenital deafness.

The findings further revealed lack of clear ammunition policies and early interventions before and after the discovery of a child's impairment as also heavy attributors. All these measures attributed to the existing coping challenges experienced by most parents in Zimbabwe and probably in most regions in Africa. Some parents criticized the unclear relationships between the Ministries of Education and Health to be another contributing factor. The majority of participants complained that personnel from the health sector only visited schools to control outbreaks but never or rarely on missions of following up on screened children. The burden was left to parents despite their affordability. The majority of participants further emphasized that the relationship was supposed to be reciprocal but this was absent in the Zimbabwean system. The participants further complained that when they reported their children's suspected conditions, some health practitioners challenge them instead of examining the suspected area or issues and is probably one of the reasons why some parents sought medical attention only when the condition looked obvious.

These experiences relate to care professionals' actions and communication styles and the child's functional evolution. Early care interventions could benefit from coordinated transition between phases and parent support throughout the care trajectory including professionally disclosed news about a child's hearing loss (National Research Council (2004). The findings showed that the discovery of a child's congenital hearing impairment triggered a range of emotional responses in parents and across family systems (Trute and Heibert-Murphy, 2001) as eluded by *Parent 2, husband's relation* and subtly by the majority of participants. According to Hintermair (2006) research on parental experience with deafness and research on the socio-emotional development of the children must always be combined and studied in the context of resource availability.

Patterns of blame shifting tendencies, misunderstanding and misconceptions emerged. Other common indicators were that most parents faced milestones in caring and educating their congenitally deaf children. Indicators from this study are that the diagnosis of a congenital hearing loss is a critical life event for parents which can raise high stress experiences (Scorgie, Wilgosh, and McDonald, 1998). Giuliop, Philipov and Jaschinski (2014) propose that, fathers of children with disabilities are likely to have fewer emotional exchanges while the mothers suffered more in terms of social contact. Probably, *Parent 1, husband*, took it as a genetic cause from the wife's side who had an uncle with a deaf child but all the same experiences of women in this study seem to portray that women go through more hard times than men. Another indicator emerging from this study is that women need more support than men when a child's impairment is diagnosed. In support Giuliop *et al* (2014) reveals that in most instances it was mothers of children with disabilities who either gave up their jobs in order to look after the child while those who continued to work were reported to be regularly absent from work most of the times in order to attend to the child with an impairment's needs. All this compounded the amount of stress on women with children with disabilities in general. However, some of the stated experiences sound familiar and known but this study aims to remind readers, policy makers, educationists and the public that it is time these taken for granted issues are addressed because of the reflected damages they continue to cause to the affected families and their children with disabilities and how that reduces the sustainable economic development of a country.

In support, Young (1999) argues that both perspectives co-exist in parents since they can feel both hopeful and fearful about a child's discovered condition. Young (1999) further explains that some parents can simultaneously experience enjoyment and pride to the birth of a child but sorrow is likely to build up when a child's impairment is discovered. The participants in this study anonymously described the period of a child's

impairment as requiring ammunition in the form of parental support. According to my experiences as an educationist, this seems absent; taken for granted or not well coordinated where it is claimed to prevail. In other words there is high need to consider parental support when the news about a child's congenital hearing loss is disclosed.

In support Giulio *et al* (2014) assert that feelings of emptiness, loneliness and rejection were felt more by mothers with children with disabilities than fathers. Generally, having a child with a birth defect such as, HI negatively impacts on the whole family (Lemacks *et al*, 2013). However, Lemacks *et al* (2013) propose that the misunderstandings and misconceptions are further compounded by the way health care professionals communicate the news of the discovered impairment to the parents because the news is in most cases reported without focus to assist the affected parents but for the sake of it without even the way forward or follow ups plans. In support Postance (2009) argues that, instead of giving the news with support, in most instances parents reported that the news greeted them with a mass of confusing and contradictory information from professionals with varied agendas where some would propose use of Sign Language, articulation or speech only with a deaf child. On the other hand, some may suggest that the child needs visual communication and/or that teaching the child signing would hinder language development and many other controversies. Such information is likely to make parents with congenitally deaf children more confused. Furthermore, Postance (2009) suggests that the period of diagnosis presented most parents with a *showbag* full of dry and unexplained medical terminologies which they were left to deal with alone at home without direction. The insights encourage health professionals to always make sure that they explain the circumstances surrounding the diagnosis to make sure that their understanding is at the same wave-length with the affected parents so as to enable the child to receive informed support from both ends.

1.5.2 Possible coping mechanisms

Other studies and this study acknowledge that the discovery of a child's congenital HI brings with it a lot of challenges to both the affected child and his/her family. In support Zaidman-Zait (2007) asserts that the identification of a child's hearing loss is a distressing time for parents, often eliciting intense emotional responses to the diagnosis. Guided by the principles of ubuntu the study seeks to transform attitudes of both parents and the medical practitioners to consider the discovery of a child's impairment with mutual understanding and empathy through information sharing, guidance and counselling and providing any other support the family or the concerned child may require. The study urges all concerned parties to treat the discovery of a child's impairment with justice and compassion by giving the situation the most needed attention that can help the affected parents cope. The family and its structures, which include the extended family and surrounding communities, are expected to receive the news of the impairment with empathy and see the child as a child despite the discovered impairment. In other words, the study encourages the family circles to maintain their collectivism ethos towards the family struggling to accept the news of a child born with HI come to terms with it. In support Hintermair (2006) proposes that coping with a hearing loss must not degenerate into battling against a defect; it must instead reinforce what is available, healthy, and strong to promote the quality of life of persons with HI. Positive attitude change and accepting PWDs as equal future productive partners could further assist in reinforcing their quality of life.

The study suggests that the preceding suggested changes are likely implementable in an organized and focused country. This calls for clear supportive legislation where Africans are collectively mandate driven to support the affected families. Such policies are likely to fight against negative caring towards PWDs which is currently driving most PWDs into the streets. If this is taken collectively the country is likely to minimize or completely rule out the use of streets and corners as dwelling places for beggars. In other words, the study calls for a purpose driven multi-disciplinary approach with tangible actions and results but not a for the sake of it solution. According to the study findings, this should further be reinforced by pro-active systems where early screening, detection and interventions are reinforced by clear policies. The National Research Council (2004) confirms that such early detection generally also leads to earlier care intervention because according to Ritchie (2013); Cohen (2008) and Hintermair (2006) where care and support was reduced most parents experienced confusion, disbelief, disappointment, and uncertainty which further developed into stress and hopelessness.

However, in order not to compound the existing crisis, National Research Council (2004) stress that, all assisting authorities and institutions should make sure that they positively guide the affected families to help them cope with news of the discovery and further continue to help them positively and informatively meet the challenges. In support the National Research Council (2004) proposes that, early care interventions could benefit from coordinated transition between phases, parent support throughout the care trajectory, and a broad approach to deafness in professionals' communication. The findings also emphasized the need for a resource-oriented approach to the education and caring of persons with HI. To achieve all this Hintermair (2006) argues that parents greatly need to be supported when their children's congenital HI is discovered because they have to play a central facilitator role towards a child's primary social, emotional, and cognitive experiences. Thus, Hintermair (2006) conclusively considers early diagnosis and intervention as the best prevention strategy against stress for

the parents with deaf and hard of hearing children. This is further expected to increase the child's self-concept because rejection is likely to prevail if latently intervened. In other words, early detection and interventions are likely to bring about positive child upbringing and development despite the challenges that the impairment brings.

The study portrays the majority of parents feeling inadequate in communicating, caring and making educational decisions for the child's discovered HI and is likely to increase behavior and poor emotional adaptation as noted by Hintermair (2006). Considering preceding discussions parents' decision making are paralyzed by the challenges the congenital HI brings to the family. Thus, Zaidman-Zait (2007) proposes that parents must undergo a process of adaptation to the various challenges uniquely associated with raising a child who is deaf, which includes modifying communication strategies, becoming involved in the medical and educational decision making, working with professionals across a range of disciplines, learning about technological supports, obtaining appropriate intervention programmes and services, and dealing with additional financial and child-care pressures. That therefore implies that parents with children detected as congenitally HI will require continued guidance and counselling to help them cope with considerable anxiety and fear prior to and during their child's amplification or surgery. The findings further proposed that all these factors could further receive positive regard from affected parents if they received adequate information about their child's diagnosis; what needed to be done; how it was to be done; where it was to be done; by who and how cost effective it was?

The majority of parents proposed that, there was need to hold discussion forums where the Ministries of Education and Health gain insights into existing ways which could help parents cope with the discovery of a child's congenital HI. To cope with the discovery of a child's HI Zaidman-Zait (2007) and Hintermair (2006) propose that parents needed to adapt their communication behaviour. In support Giulio *et al* (2014) asserts that the risks and cost of caring for a child with disabilities can be a less burden if states provided better services and greater support. In other words, the country and its citizens need to re-activate the application of the ubuntu principles in issues of disability. Such implementations are likely to promote the affected parents' productivity and improve their socio-economic functioning and further promote the child's social, emotional and educational outcomes. Nolan and Tucker (1981) sum it all when they propose that, parents are the only people who can help their child in his early steps towards communication with further help from skilled educationists and counsellors.

1.5.3 LEARNT LESSONS

There are a lot of lessons to learn from the lived experiences of parents when their child's deafness is discovered as expressed by the following excerpts:

It was only when a friend came to my rescue that I attended a workshop where parents with children with disabilities went through group counselling session... This was the turning point of child's future because other parents' stories and how their children had achieved independent living through education helped me understand that deaf people were educable. ... My story is long. [Parent 1, wife].

I have discovered that deaf people are very talented in practical work and they need social and spiritual support as they grow. They also need patient parents who take interest in both sign language and speech-reading as a language for deaf people. I have learnt... [Parent 2, Wife, Narrator].

I at first supported the idea of my brother's fleeing and remarrying but I have recently known that it was bad to do so because every child, hearing or deaf is just a child. I also learnt that early education is very important for every deaf child. Deaf children also need to be exposed to sign language and any other intervention strategies [Parent 2, husband's relative].

I think there is need to have systems in place where men with deaf children meet to discuss their experiences and solutions other men took about their situation besides educational and medical support [Parent 3, husband].

She teaches me sign language and am closer to her each day while the father continues to distance himself though he recently acknowledged the progress she was making at school [Parent 4, Wife].

... I feel as a family we need technical support outside the family support in order to manage the birth of a deaf child in our marriage [Parent 4, husband].

The findings also reflect that the discovery of a child's impairment impacted negatively on the extended family. Generally, the excerpts reveal the importance of significant others in the family structures which equally supports the ubuntu philosophy adage guiding this study which says *a person is a person because of others*. This is an indicator that the discovery of a child's impairment is likely to be a serious burden for a single family without other team members' interventions. That may further bring instability and contribute to family divorces despite the peace and relief the extended family members are generally expected to bring to the African family. In other words, the dissemination of the news of a child's impairment should make attempts to involve interested parties from the extended family so that they are together in it as early as possible. Systems seem to take disclosure as relief granting tool for parents yet it brings with it varied packages of milestones. This is a taken for granted effect yet very powerful in destroying family relations and dreams. It means early intervention is

necessary to both the parents and their child with congenital HI to help them cope and manage the situation. Thus, through principles of ubuntu families with children with disabilities and their communities are reminded to communally manage the situation. The affected families are expected to learn that they should not close in and out their children from the hearing world in order to receive community support because according to Lemacks *et al* (2013) parents are often suppressed due to embarrassment, shame and guilt. It is for these reasons that the study urges health community workers to stay aware of all happenings in their Wards so as to engage early, give informed guidance and give helpful follow ups.

1.6 CONCLUSION

The study emphasizes that the emergence of a child's disability is an unplanned journey as equally noted by Brown, Goodman and Kupper (2014) and Reichman, Corman and Noonan (2008). Main issues emerged between married families when the disclosure of a child's congenital deafness was made. In some families that brought darkness and robbed their happiness whereby some divorced; separated; created sour relationships and/or instability. However, the study notes with great concern that not even one family reported receiving early screening or detection interventions. The implications are that nobody came to the rescue of parents when they needed support after the disclosure of a child's deafness. These are indicators of a great gap. The emphasis here is that, supportive interventions should address parenting concerns of all parents whether rich, poor, uneducated and educated for a country to sustain its economic and social developments. The majority of the participants proposed that Ministries of Education and the Ministry of Child Welfare and Health Care should work together mainly to support the parents with children with disabilities. The study proposed that parental support be guided by the principles of ubuntu. There is also need to establish within reach counselling centres. The findings suggest that the principles of ubuntu are instrumental in helping most parents with children with congenital deafness.

1.6.1 RECOMMENDATIONS

The following recommendations emerged from the study:

- There is need for the government to design early screening and intervention policies where follow-ups are emphasized and reported to the appropriate centres by community health workers for onward decision making by Schools Psychological Services (SPS).
- There was need for a wheel framework of communication to enable a multi-disciplinary approach towards the discovery of children's impairments to help arm the parents with appropriate ammunition in meeting the needs of persons who are deaf and their families.
- That the government develops and provides strong early parental support systems to families with children who are deaf or PWDs through provision of ward or village counsellors where individual and group counselling sessions are encouraged.
- There is need for the government to make sure that transparency and health communications prevail between Ministries of Education and Child Welfare and Health Care and that communication is maintained through transparency on child's expected health interventions
- That communities and wards be mandated to establish neighbourhood community centres for parents and their children with hearing impairment for support, knowledge sharing, referrals and counselling to help parents and the concerned child cope with the situation
- There is need for the government to mandate the teaching of Sign Language as one of the early intervention strategies so that persons who are deaf acquire language early and are not disadvantaged when they start school.
- That the government creates a parent support budgetary fund for parents with children with hearing impairment for parents' workshops, counselling and care support and needed provisions.
- There is need to skill all stakeholders involved in making parents with children with hearing impairment cope with congenital impairments.

1.6.2 The study considered the following as requiring further studies:

- 1) how to create close collaborative relations between the Ministries of Education and Child Welfare on Health Care issues of children with disabilities
- 2) how to implement mandated early screening and detection and design effective early intervention strategies which are not lip-serviced
- 3) key players' experiences in managing a child's discovered impairments.

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