

Developing a Practice Guideline for Enhancing Communication in Hearing Families with Deaf Children

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Abstract—Deafness coupled with a lack of support and resources in developing countries poses a serious threat to the well-being of children. The mismatch between the needs of persons with disabilities and the resources available to them is a key factor in service provision in resource constrained contexts. Furthermore, deafness in children is the most common childhood sensory disorder in developing countries, and as such seriously affected with regard to resource constraints. This paper discusses the issues and research protocol for a Ph.D. study that aims to develop a practice guideline that is contextually sensitive and includes an interdisciplinary approach that will improve the outcomes of learners and the relationships in hearing households with deaf learners in rural areas of the Eastern Cape, one of the poorest provinces in South Africa. The guideline developed will consider the lived experiences of deaf children and their hearing families on the impact deafness has on their relationships and communication at home. Ethical clearance for the study has been obtained. The methodology is a mixed-methods approach in the form of a survey using questionnaires and semi-structured interviews with deaf learners in primary and high school and their hearing parents to get their perspective on the impact deafness has on their relationships and communication at home. The study is conducted using adolescent learners from Grades 7 to 12 (excluding learners younger than 12 years and older than 21 years). An audiologist, teachers, and support staff will also give their views on how the intervention is currently done and possible suggestions on how management can be done differently. Data collection will be conducted in isiXhosa by the researcher, as isiXhosa is dominant in this region. The interviews will be conducted in South African Sign Language by the sign language interpreter for deaf learners and educational professionals. An expected outcome for this study is the development of recommendations and a practice guideline for deaf children diagnosed late from rural or under-resourced environments. To ensure the implementation of the findings, in the end, professionals will be given feedback on the outcomes of the study so that they can identify areas within their practices that require updated knowledge. The developed guideline is expected to have an impact on the Department of Education policies both regionally and nationally, providing recommendations for a strategic management plan and practice guidelines for this vulnerable and marginalized population. The IsiXhosa specific context could be generalized to other similar contexts.

Keywords—Deafness, family-centred approach, early identification, rural communities.

I. INTRODUCTION

IN South Africa, a low to middle income country with resource constraints affecting a large part of the population, disability prevalence is estimated between 5.2% and 6.4% in

children below the age of 9 years [1]. It is estimated that 798 000 babies are born annually with early onset bilateral or congenital hearing loss [2], [3]. Reference [3] further estimates that in South Africa, there is a prevalence of 6 in 1000 babies born with a permanent bilateral hearing loss in the public sector compared to the 3 out of 1000 babies born within the private sector. Deafness in children is the most predominant childhood sensory disorder in developing countries estimated to affect 62 million children below the age of 15 years worldwide [4]. According to the World Health Organisation (WHO), deafness is one of the most neglected disabilities and is worse in developing countries [5]. The neglect could be the result of the large gap between the needs of the disabled and the resources available to them [1].

The degree of the child's hearing loss influences the age at which the hearing loss is discovered and the age at which the child and parent gain access to intervention services [6]. Parents mostly detect hearing loss between the ages of one year and five months to two years and the average age for a diagnosis is almost two years with intervention commencing at over two and a half years of age [5], [3]. The age from infancy to the age of five years is the period of the most dynamic transformation in human development [7]. This is when critical language development happens [8], [9]. However, there may be delays to a diagnosis and intervention services as a result of the lack of knowledge on the available services to parents, fragmentation of services as well as due to poor socioeconomic conditions and resource limitations [5], [3], [10].

Children in rural areas and children with disabilities have access to lower quality services compared to those in middle-class suburbs which further delays the age at which a diagnosis is made [11]. Furthermore, [11] mentions that the long distance and high transport costs may limit access to services although the services may be available for free. As a result, in rural areas of the Eastern Cape, children sometimes get to be seen and diagnosed around the ages of eight and ten years, resulting in late placement in a special school. Subsequently, these children become vulnerable, not only due to the degree of their impairment but also due to the lack of participation in society as well as increased risk of poverty as a result of their disability [12].

This paper focuses on data collected during the pilot study which is critical in shaping the study further. The purpose of the

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study was to investigate the views, experiences and the feelings of deaf learners and their hearing parents and the impact deafness has on their relationships and communication at home and in their communities. A practice guideline will be developed based on the findings which can be used by undergraduate students, professionals and educators in promoting early identification and early intervention for deaf children. The tool developed will have to be family centred, culturally relevant and specific to the needs of the children from rural and low socio-economic backgrounds such as the Eastern Cape.

II. METHODOLOGY

A. Study Design

The pilot study used a qualitative approach in the form of a semi-structured interview. This approach was used to understand a situation or experience from the participants, narrating their perspectives or experiences [13].

This main study uses systematic and interpretive approaches using both a quantitative and qualitative approach (mixed method). The resident audiologist, teachers and support staff are not included at this stage and will give their views on how the intervention is currently done and possible suggestions on how management can be done differently.

The study is planned in three phases. Phase one of this study is a descriptive survey design using a quantitative method in the form of a self-administered questionnaire. Phase one is near completion as 80% of the target has been covered. Phase two is in the form of qualitative research design in the form of semi-structured interviews and a target of 10 parents and 10 learners have been covered. Phase three will be the development of the tool as well as validation of it.

The pilot study for phase 1 has been conducted to gather parental and deaf learners' responses on the challenges they face in establishing communication within the home context of families living in rural contexts. Conducting the pilot study helped with adapting the data collection tools as the researcher was able to assess the appropriateness of the instruments as well as the data collected for the main study. The pilot study was conducted in the form of semi-structured interviews, with four deaf learners and their hearing parents. Interviews were audio-recorded for parents and video-recorded for learners.

B. Participants

The study is conducted using samples from Grades 7 to 12 learners, with exclusion of learners younger than 12 years and older than 21 years.

The pilot study was conducted on a group of four parents and their four deaf children, using purposive sampling. Participants selected for the pilot study were parents and their children enrolled at a district office and who met the selection criteria of the main study. The pilot study was conducted with the assistance of a sign language interpreter who had to assist with communicating with deaf children. The researcher first explained the purpose of the study to both the parents and learners verbally and through an information document with the

assistance of the sign language interpreter. Consent and assent were obtained from parents and learners before the study began.

C. Description of Participants

Table I summarizes the description of parents and learners who participated in this study. All participants were females and isiXhosa language speakers between the ages of 36 to 58 years. Their deaf child is the only deaf person within their families. Only one of the learners had a comorbid condition, reported to be physically challenged, has muscle weakness on her right side diagnosed as Cerebral Palsy which at times becomes a challenge for her. The families have large households of between five to seven members. The age at which the child was diagnosed was on average two years. Three of them fall behind the Grades they should be in considering their ages and the fact that they started school early as one indicated that the child started at four years and the other three at the age of five years at a school for the deaf. The four learners who participated were between the ages of 15 years to 21 years, and all were female.

TABLE I
 DEMOGRAPHICS OF PARTICIPANTS

Characteristics	P 1-L1	P 2-L2	P3-L3	P4-L4
Relationship	Mother	Mother	Mother	Grandmother
Age	36	37	44	58
Number of people in household	5	5	7	7
Education background	Diploma	Degree	Diploma	Grade 11 or less
Employment status	Full time	Part-time	Part-time	Housewife
Home Language	IsiXhosa	IsiXhosa	IsiXhosa	IsiXhosa
Household income	R4501-R12500	R4501-R12500	R4501-R12500	Less than R4500
Gender of the child	Female	Female	Female	Female
Age at diagnosis	3 years	2 years	2 years	4 years
Other medical conditions	No	No	No	Yes (Cerebral Palsy)
Grade of child	10	12	7	8
Current age of child	16 years	21 years	16 years	15 years

Parents 1-4 = P-4, Learners 1-4 = L1-L4

D. Data Collection Tools and Procedure

Data collection was conducted in isiXhosa, as isiXhosa is dominant in this region. The interviews were conducted in South African Sign Language by a sign language interpreter for deaf learners.

The interview questions were open ended. The open-ended questions allowed for the researcher to discuss the topic of deafness and their experiences in depth. The researcher had personal contact with the participants, adhering to COVID-19 regulations in terms of maintaining social distancing. The interviews were audio recorded for parents and video recorded for learners and permission was sought before conducting the interviews. Parents and children had some of the questions in common, and few were not. An interview guide was used consisting of ten open ended questions. The questions were then refined and finalized in preparations of the data collection of the main study.

All interviews were conducted in isiXhosa for parents by the researcher and for learners in South African Sign Language

with the assistance of the interpreter. Parent interviews were audio-recorded and learner interviews were conducted in video recording. Recording the interviews allowed the researcher to listen to the conversations at a later stage and start with the process of transcribing. As a result, we were able to listen and concentrate on the interviews allowing for a flow of discussion. As the interpreter was giving direct translations we were able to probe and request for clarification when needed.

E. Data Analysis

The data analysis process started soon after the interviews were conducted and the interviews were transcribed verbatim as they were gathered and analysed. Transcripts were then analysed using thematic analysis. Initially we used interpretive analysis which is the process of decontextualizing and recontextualizing data [14]. In the process of decontextualizing data, we separated data from original context of individual interviews and assigning codes to the units of meaning in texts [14]. The codes were then examined for patterns, organized and reduced to subthemes and themes as a result, relationships were drawn across all the narratives given in the interviews. The process worked well for the analysis.

F. Ethical Considerations

Ethical clearance from the University of KwaZulu-Natal Biomedical Research Ethics Committee was obtained prior to conducting the research (BREC/00000012/2019).

III. RESULTS AND DISCUSSION

The purpose of this pilot study, in addition to testing the data collection methods, was to conduct preliminary data analysis to describe the challenges faced by hearing families and their deaf children in establishing communication and relationships in their home contexts. To gather information on their challenges one had to first get an understanding of what their perceptions about deafness are as well as the challenges that they came across in accepting the child as being deaf. Quotes from the data were sorted into categories and eight themes were identified and combined from both parent and learner data.

A. Experience of Having a Deaf Child/Being Deaf

All four parents indicated from the interview that they struggled to accept their child's deafness. P1 "It took me a while for me to accept but eventually I accepted." This concurs with what is highlighted by [8] that parents often experience feelings of guilt, denial, anger and grief when their child is diagnosed as being deaf. On the other hand, the experience shared by deaf children was positive as they indicated that they had no negative experience. L1: "Being deaf for me has not brought any challenges for me. I socialize with people. I take myself as everyone else, there is no difference".

B. Perceptions about Deafness

All parents had no prior knowledge about deafness and the diagnosis of their child was as a result shocking and hard to accept as they could not understand what exactly that meant for their children and the impact it is going to have on their future. P1: "I had no knowledge about the deafness before. I was

devasted and worried about that the child's future and the stigma from the community." Parents often face challenges such as education concerns, communication issues, technology challenges as well as difficulties relating to the concerns about the safety of the child as well as finances [15]. This is shown by the quote from P1 who has concerns about her child's future and about the child being stigmatized in the community. Three learners on the other hand indicated that being deaf is a normal thing to them. However, one indicated that she gets angry and is not happy with the terms communities use when referring to them.

C. Communication at Home

Both parents and learners indicated that families cannot communicate with their deaf children. P1: "The family cannot communicate with the child, we do want and wish we can sign, but it is a struggle. We are dependent on writing, but due to the age, the child sometimes misses important areas as her level of English is not good." L4: "Some struggle to communicate with me, there are challenges but somehow we find a way of meeting them." This is reflected in [6] which states that over 90% of deaf children have hearing parents and the majority of them cannot use sign language or lack the skill to use it. The challenge in communication needs to be addressed for effective communication to happen between deaf children and their hearing families.

D. Challenges Faced by Families

Reference [16] states that families are not only faced with the challenge of communication, but they also must deal with other challenges such as ignorant neighbours, socio-economic challenges, and limited intervention options with no parent-to-parent support. This has also been noted in this pilot study. All families indicated that they cannot talk to their children about the adolescence stage which is very critical as children need guidance and support from their parents. P1: "I cannot communicate with her regarding reaching adolescence. I am dependent on what she is being taught at school." L1: "My mother, I struggle to talk to her, I find a way of looking for assistance from the school. Some things I do try to talk to her and she would get me."

E. Treatment from the Communities

All parents interviewed felt that their communities had accepted their deaf children but indicated that they cannot communicate with the deaf child, and the child is often not included as a result. P3: "The community loves her, she is however treated as though she is younger, for instance a younger one would be sent to do something because she cannot hear. They then assume even her brain functions below normal range." P4: "The community at first did not understand her, they used to think she is bullying others or aggressive towards others as she used to get frustrated when they could not understand her. Because she is now at school, she spends less time in the community. She is loved." On the other hand, when learners were asked about the treatment they receive from their communities two learners indicated challenges with inclusion, the other two are not feeling excluded. L2: "I don't spend much

time at home, but there are few times I cannot really tell if I get included or not.”

From the parent responses it has been noted that there is also a tendency of assuming that just because the child is deaf, they are also somehow affected mentally and in some cases being treated as though they are younger than their actual age. Thus, apart from the need of introducing sign language to families there is a need of educating communities about deafness as well as introduce sign language so that communities are able to include children in everything.

F. Sign Language Training

Both parents and learners indicated that families cannot sign and were never offered sign language classes or support by the Department of Education or the schools. P2: “We have never been offered sign language training.” P3: “We cannot use the formal sign language, we use home signs.” One learner raised that she wishes that her mother could at least use basic fingerspelling so that she can be able to fingerspell words if the mother is not getting what she is trying to say. As was noted by [16] sign language training remains a challenge as parents only have access to it during parent’s meetings or through the deaf child. Therefore, the department of education and the deaf schools need to make provision to capacitate parents in South African Sign Language.

G. Positives about the Deaf Child

Parents had something good to say about their deaf children, mentioning their strengths and what they like about them. P1- “She is a brilliant child and does take instructions.” P2: “My child is very respectful, she likes to be hands-on assisting with house chores.” Learners also had good experiences or moments that they cherish about being deaf or having been part of their families. L2: “When I was growing up I used to be scared as I could not hear but as time went on I understood and accepted my deafness. I went to a mainstream school initially, but I could not grasp what was being taught. Then my mother managed to find a school for me at St Thomas. I was then happy and felt now I belonged to a community.”

H. Suggestions on How Things Can Be Done Differently

All four learners wish that they can communicate with the families and have a better relationship with them. L1: “My wish is for my mom or my family to know that I have a book. I am willing to use it to teach them. Sign language is a visual language not verbal, so pictures would also help. They can point at a picture and I would then show them how to sign for it.” L2: “My wish is to help my family to learn fingerspelling alphabets as it would make it easy for me to interact. As that would give me an idea of what the person is trying to say.” One learner voiced her wish that the government would make sign language an official language and provide sign language classes for families. Another learner also pointed her mother’s negative attitude towards sign language and suggested it could be the reason she is not learning sign language from her.

Parents wish to be capacitated in sign language and for deaf people to be accommodated in all platforms. P1: “My wish is for government to take it seriously the training of parents, and

communities at large to use sign language and that can only happen if they open centres for trainings in different communities. It should be a priority.” P4: “I wish there could be information packs or pamphlets teaching about sign language for families to learn sign language. I want to be able to communicate freely and share jokes with them.”

IV. STRENGTHS OF THE STUDY

Conducting the interviews in isiXhosa with parents and utilizing the services of a sign language interpreter was a strength for this study. It allowed an opportunity to be able to engage with their children as in the end an informal focus group was done and parents were able to engage with their children through the Sign language interpreter.

V. LIMITATION OF THE STUDY

The study is looking at families in the rural context but these challenges may be happening even across urban contexts.

VI. RECOMMENDATIONS

A recommendation from the pilot study which will be implemented in the main study was to have an additional question where parents and learners could share if they know or have been provided with career guidance. Also, a request was made by parents and learners to sit in during the interviews as this gave parents an opportunity to ask for clarities through the assistance of the sign language interpreter on issues raised by their children as well as to acknowledge their mistakes. This arrangement will also be considered in the main study.

VII. CONCLUSION

This pilot study has shown that hearing parents and their deaf children are facing major issues in dealing with deafness and deafness has a negative impact on communication and relationships at home as families and communities cannot communicate with their deaf children. There is a need to offer sign language classes for families and communities and also ensuring that there are sign language interpreters in different departments so that deaf individuals receive the services that they need optimally.

The main study will look in-depth into these issues and recommendations made will assist with the development of the guideline needed to enhance communication between deaf children and their hearing families.

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