

Lived Experiences of Parents of School-Aged Children with Hearing Impairment in North Trinidad

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Abstract

Aim: *The aim of this study was to explore the lived experiences of parents living with hearing impaired children in north Trinidad. This study emanated as a result of the researchers' cursory observation in dealing with the parents of the children with hearing impairment.*

Methods: *An exploratory phenomenological study was undertaken to document the unique experiences of these group of parents. An institution of the hearing impaired was identified and parents of the children within school-aged were engaged in the study. Triangulation of different strategies namely 3 focused group interviews and 3 face-to-face interviews was utilised to collect data from 25 parents. The data was audiotaped, transcribed and organised in themes.*

Results: *The organized themes represented the main findings of the study. The emerging themes include reliance on spirituality to cope, communication challenges, and need for supportive environment among others.*

Discussion: *The implications of the results were discussed in particular reference to literature and policies in Trinidad and Tobago.*

Keywords: *Caribbean, Hearing Impaired, Lived experiences.*

I. Introduction

A hearing threshold in both ears of 25dB or better means that hearing impairment is present [1]. UNICEF (2003) estimates that hearing loss is about 10% of the world population (120 million) indicating that about 10% of China's population has hearing loss estimated at about 10 million with 1.71 million children of school age with hearing loss.[2]. This picture is perhaps the same for other countries.

The children who cannot hear in the classroom may seem to be a distraction to the other students, and might be labelled as such. Currently in Trinidad and Tobago, these students are identified during the screening for hearing activities in schools, a function of the School Health Programme [3].

The families with children with hearing Impairment (HI), especially the parents face a number of challenges. A number of studies reported the various levels of involvement of the different parents, including fathers, mothers, grandparents etc. [4]. However, "mother power" was reported by Organization for Economic Cooperation and Development (OECD, 1997), a phrase denoting the greater involvement of mothers in the care of the children with HI [5]. This level of involvement includes assisting the children with school work, anticipating the other needs of the children, and noting that the children lacked the communication skills compared with other children [6, 7, 8, and 9]

Parents look forward to their children's successful academic outcomes while some parents had high expectations of their children. However, all parents expected they would need some additional support [10]. The "No Child Left Behind" (NCLB) Act of 2001 in the United States, has four basic principles that govern that Act that should be followed by all states are:

- Increased flexibility and local control
- Stronger accountability for results
- Expanded options for parents, and
- An emphasis on methods that have been proven to work.

Since the NCLB Act of 2001 and the amendment of the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, the number of children with special needs in the same social, academic and community environments has increased [11, 12, and 13]

The investigators observed that parents living with school aged children who are hearing impaired in north Trinidad show signs of frustration, anger, and pain. There is paucity of information pertaining to the hearing impaired or deaf school children in Trinidad and Tobago, but the researchers believe that the parents would expect their children to become academic achievers with a bright future. In Trinidad and Tobago, it is not a common place that children who are handicapped in any way are allowed the privilege as children who are

physically normal. Trinidad and Tobago has four (4) schools for the hearing impaired located at various regions of the Island country aimed at ensuring that the HI children are not denied the compulsory education as contained in the Education Act of Trinidad and Tobago Ministry of Education [14]

Like normal hearing children, deaf and hard of hearing children must be educated. These children have speech delay because of the deafness [1]. They are taught how to sign using the sign language alphabet so that they will be able to communicate. This teaching takes place in institutions specially designed and staffed for the facilitation of the education of deaf and hard of hearing children [15]

It was observed that some of the strategies as outlined in the Caribbean Charter for Health Promotion of 1993, are applicable to the behaviours and needs of some of the parents, including, "Formulating Healthy Public Policies", and "Creating Supportive Environments" [16]. The researchers envisaged that in order to inform policies appropriately on matters related to the HI, the experiences of these special group of parents should be brought to the table.

Purpose of the Study

This study sought to determine the lived experiences of parents living with school-aged children who are hearing impaired in North Trinidad. To this end it sought to investigate the coping strategies of the parents, the type of support they had, if any, and how they managed their children's change from childhood to adolescence.

Objectives:

1. To determine the coping strategies/mechanisms parents of school-aged children with hearing impairment used.
2. To ascertain what support parents of school-age-children have in the care of their wards
3. To ascertain how the parents of the school-age-children fared in caring for their children from birth to adolescence.

The Research Questions

What are some of the coping strategies employed by parents of school-aged children who are hearing-impaired in North Trinidad?

1. What coping strategies/mechanisms did you use in attending to your child?
2. What type of support did you have, if any?
3. How did you manage the change from childhood to adolescence?

II. Methodology

The Research Design

The researcher opted to use an exploratory phenomenological study aimed describing the lived experiences of parents with children with HI. This type of study allows researchers to gather data that are subjective and are of substance, meaning, rich and thick, while focusing on the lived experiences of people. This action taken will help to fully elucidate the nature of the phenomenon. In this case, it will serve as a first step to identifying important and relevant factors pertaining to the feelings of parents of school-aged children who have hearing-impairment. This phenomenological approach will use in-depth interviews and observations [17, 22].

The Sample

The sampling strategy was purposive based on the information needs. The respondents had to know the subject, be articulate, reflective, and willing to talk with the researcher [17]. To this end the researchers decided to use the parents of the children who were all of school age, of the Cascade School for the Deaf, who were able to give rich information as required. This population consisted of 33 children with hearing impairment in north Trinidad. We expected that altogether about 66 parents. All were invited to be respondents in the sample. Of that number, 33 attended the first session, but a number of them were not interested in sharing, or were unable to attend for various reasons. Twenty five (25) were the respondents in the interviews. However, 3 preferred to be interviewed individually. Both parents of one child participated. There were only two fathers in the sample. Although the sample was small, we believed that very valid and informative data can be obtained through relatively small samples [18].

Prior to the interviews, meetings were held with the school principal and the researchers to inform her of the study and to seek her permission to meet with the parents, to conduct interviews with them, and to use the Cascade School for the Deaf as a base for some of the interviews. Having had the permission from the school's principal, the parents were sensitized by both the researchers and the principal on the Monday following, which was a convenient day because the parents usually met on Mondays to learn sign language and to support one another. Besides, that particular Monday was "Open-Day" for the school as a result, the maximum number of

parents were expected. The principal lent her support in arranging for the researchers to meet with the parents, by giving the researchers the parents' contact numbers.

Data Collection Strategy

The approach to data collection was triangulation, as more than one method was used to collect and interpret the data. The methods used for this same phenomenon were focus groups interviews, individual interviews, and observation. We believe that this triangulation method would promote data validity and reliability [17, 18].

The interviews were conducted over the period February 2015 to April 2015. There were three focus group interviews. The first focus group interview took place at the Cascade School for the Deaf because that location was convenient for that group. The other two (2) focus group interviews were held in one of the offices of one of the researchers which was accessible to the other parents and where there was privacy and comfort. Two individuals were also interviewed in the researcher's office, and one in the comfort of her own home. They were parents of a 17-year old male, an 11-year old female and a 13-year old male. The respondents were placed into the focus groups according to the age range of their children. Two groups were parents of hearing impaired children aged 5-11 years, and one group were parents of hearing impaired children aged 12-17 years. There were three individuals interviewed face-to-face alone (Table 1)

Table 1: Distribution of Respondents

Groups/Individuals	No. of Respondents	Age range of children
Focus group 1	10 (1 father included)	5-11 years
Focus group 2	6 (1 father included)	5-11 years
Focus group 3	6	12-17 years
Individual 1	1	17 years
Individual 2	1	11 years
Individual 3	1	13 years
Not interested	3	
Unable to attend	5	

Respondents were given details pertaining to the research including obtaining their informed consent for the interview and the need to audiotape their responses. Anonymity and confidentiality were assured by letting them know that their names would not be used, thus making identification of parents absolutely difficult, and that their responses will be kept in confidence.

The interviews were conducted on four different days and according to the availability of the parents. The first focus group (FG1) was conducted in February 2015 at the Cascade School for the Deaf, before the day's activities for "Open Day" as was arranged before. The interview for one individual (Ind.1) was conducted one afternoon in February also, at the respondent's home where she was comfortable and felt free to speak. The second and third focus groups (FG2 and FG 3) were conducted one morning in April 2015 at 9.30 am and 11.30 am, respectively, in the researcher's private office. The other two individual interviews (Ind. 2 and Ind. 3) were conducted on another morning in April 2015, at 10.00 am and 11.00 am respectively, also at the researcher's office.

Demographic information pertaining to age and gender of the children were provided with the help of the school principal, before the interviews were scheduled. The information of the parents pertaining to age, education, and employment status were provided by the parents prior to the group interviews.

It was appropriate to use the same research instrument for all the interviews. The group interviews lasted approximately one and a half hours for FG 1, one hour for FGs 2 and 3 and the Individuals lasted approximately forty minutes each. The responses were recorded, transcribed and analyzed at a later date.

The group members were allowed to introduce themselves before the interviews, although they were familiar with one another from meetings at the Cascade School for the Deaf. The researcher asked the questions and allowed them to respond, interjecting with follow-up questions as were necessary. The focus groups respondents and the individuals met only once for the interviews, and responded to questions. The responses to the questions formed the basis of the qualitative analysis. The record was played back to them, ensuring that they heard what they said. Many thanks were extended to them for their time and information, and they were assured of the safety and protection of the data collected.

Particular focus was on the philosophical elements as the respondents narrated some of their lived experiences. The researcher observed and noted their expressed feelings while articulating information during the interview and that explained the epistemological perspective of the interview. Ontological data underlying truth assisted the researcher to interpret and analyze the narrative that the respondents gave bearing in mind that whatever they said at that time was needed and personal and indeed valuable. Value, however, has two aspects, intrinsic and extrinsic. It was interesting at that time to know how much value they put on their lives seeing that frustration was a major part of their feelings [19].

III. Data Analysis

Arrangement of Transcripts

After the interviews the data collected on the audio recorder were played back a few times to get a clear understanding of the responses. They were then transcribed verbatim.

Three (3) transcripts were made for each of the focus groups (FG 1, FG 2, and FG3). Similarly three (3) transcripts were made for each of the 3 respondents who were interviewed separately (Ind. 1, Ind. 2, and Ind. 3).

Each transcript has the responses for all of the questions asked during the interviews. Three main questions – 1, 2 and .3 were asked. After the responses from questions.1 and 2 there was one (1) follow-up question each, but after the responses from question 3, two (2) follow-up questions were asked. All the questions were aligned to answer the main research question, what are some of the coping strategies / mechanisms employed by the parents of school-aged children who are hearing-impaired in North Trinidad?

Within each transcript, codes were underlined with the “tract change and comment” function on the computer. In that way the researcher was able to identify similarities in the underlined codes for each question more easily.

All the identified codes for the responses from the three focus groups and the three individuals for the same question were grouped into categories from which themes emerged. From each emerging theme, there was a sub-category derived at to enable the researchers to be better able to address the research questions as stated.

IV. Results and Discussions

The results and discussions are presented according to the research questions.

Question 1 – What coping strategies / mechanisms do you use in attending to your child?– the themes that emerged were:

Spirituality – trusting in God gave strength and hope to all. This theme gave a sense of developed self-reliance based on spiritual beliefs. This was what the respondents seemed to hold on to when faced with a difficult situation

Communication challenge – They mostly expressed ineffective communication from their children.

Question2 –What type of support did you have, if any? The theme that emerged, and its sub-category was:

Supportive environment - an awareness that support is vitally needed in mentally traumatic conditions such as having a HI child.

Question 3 – How do you manage the change from childhood to adolescence? The themes that emerged were:

Psychosocial – many changes in adolescents / the multiple roles of parents / identity and attitudinal change / empowerment of adolescents.

Fear of the unknown – heightened parental fear because of children’s HI as well as the lack of effective communication with their children.

Educational success – education is key to job security.

The themes that emerged were listed according to the question number, to further answer the over-arching question – *What are the lived experiences of parents living with school-aged children who are hearing-impaired in North Trinidad?*

The researchers chose to interpret and discuss three (3) of the emergent themes namely:

- *Communication challenges*
- *Supportive environment, and*
- *Psychosocial*

Interpretation of Findings

a. Communication challenges

The findings revealed that the parents were more challenged in the area of communicating with their HI children. From looking at both focus group and individual responses, the lack of effective communication was a major “red flag” that redounded to challenges in the relationships between parents and their HI children. It is painful enough to learn of the diagnosis of the hearing impaired but when a parent realizes the difficulty to communicate verbally with their precious child it is disastrous. One parent said “it was really hard and I used to cry.” Another said “you make your child love your child, care for your child, and can’t talk with your child.” With the major challenge being signing, it was incumbent upon parents to learn the sign language alphabet along with their child so that they can communicate. It is interesting that a number of studies pointed to this challenge [15].

b. Supportive Environment

From close observation of the responses given by the respondents and the individuals with respect to the type of support that they would have had, most of them said they had some form of support. In fact this

question got the most responses even though some of them thought they could have had more support, but the support was generated from all areas hence the reason the theme was *a supportive environment*.

Every focus group mentioned they had support from either the child's grandparents, or aunts to assist with nurturing their HI child, and the support was continuous, in most cases it was their parents (the children's grandparents) who were there for them. This help caused the grandparents, particularly the mothers to develop mechanisms to communicate with the children. It was also a good practice because it allowed for great support for the parents of the deaf child. This is similar to Chinese families as mentioned in the literature review. The family was extended sometimes up to five generations with many children, grandchildren, and great grandchildren living in the same dwelling house. However, the interpersonal relationship among themselves seemed to augment the lapses as some of the respondents projected that within themselves and with each other they were able to grow enough to help in the situation [2, 4, and 8].

c. Psychosocial

Parents in this study expressed the observed lapses in their children's development. The children's condition challenged them from making and maintaining friendships as with the normal children. These impacted on the communication as well as on other developmental processes [19 and 20]. All in all, the parents expressed the need for professional help mainly from the school teachers as they were limited in their knowledge of certain responsibilities and their nuances [21].

V. Recommendations

It is obvious that this study is a new area to us in this region because of the scarcity of written information on the topic. Most of what is written came from the respondents in the study, but in order to bring improvement to the parents' situation some recommendations ought to be made:

- Research on the topic should continue since there seems to be no recorded information on parents experiences living with hearing-impaired children in Trinidad and Tobago.
- More involvement of fathers in the interviews.
- Financial support for parents with such disabled children because of their overhead costs for speech therapy and the likes. Some parents have expressed that need. Transportation costs could be a burden, therefore specially marked transport should be made available.
- Parents experience pain, guilt, shame and go through a period of denial before becoming resilient. Recommendation is therefore made for counselling parents for a period after the initial shocking news that their child is hearing-impaired.
- The Ministry of Health (MoH) Audiology Services has proposed New-born Hearing Screening (NBHS) as a practice in every hospital in Trinidad and Tobago where babies are born. This practice is essential within the first 2 to 3 days after birth to alleviate the impact the infamous news will have on parents when it is time for speech acquisition. It is said that when the impairment is diagnosed early the child has a better chance of acquiring normal speech. It is therefore recommended that the MoH ensures NBHS practice comes on stream at the earliest opportunity.

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