

Innovations

The Lived Experience of Child Rearing Practice of Parents' having Children with Deaf

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Abstract

The major objective of this study was to explore the lived experience of child rearing practice of Parents' who have children with Deaf in Ahurie Kebele. In this study qualitative approach within phenomenological research design were employed. The findings were based on the snowball sampling technique of 9 hearing parents having deaf children were selected. The tool selected for to collect data was semi-structured interview. As it was informed in the finding, hearing parents' experience was founded to a deaf child can affect parents, siblings, and family members in various ways. That is, it was founded presence of a deaf child may affect family life in terms of family interaction, family resources, parenting style, and access to support for the child. Moreover, parenting stress affects parent-child relationships and important child outcomes. In higher levels of parenting stresses have been related to poorer social and emotional development in both deaf and hearing children. They further didn't aspire that their children will get married and have children through leading their independent life. Based on the finding of the study, the involvement of the concerned federal ministries in promoting and coordinating interventions needs to be available for parents and children with deaf.

Key terms: 1. Experience, 2. Rearing practice, 3. Deaf

Introduction

Over ninety percent of children with hearing impairment are born to parents who are hearing; who do not even recognize the child's hearing impairment or his or her attempts to a manual language (Kirk, Gallagher & Anastasiow, 2006). In case, the majority of these parents have had no meaningful interaction with people who are deaf before the birth of their child. They struggle with understanding what it means to be visually oriented in a world that is itself audio logically based. Parents' first thoughts may be about their child's inability to hear sounds. They may later or never shift to a cultural perspective that allows them to think visually about day-to-day interactions. Hence, Parents' first experience of deafness usually comes when their child is "diagnosed" as deaf within the medical system. All of this focuses on disability that emphasis on the medical model of response and the unfamiliarity with deafness often results in parents becoming uncertain about their abilities to parent their deaf child (Allen, 1986). The parents are shocked and even traumatized by the diagnosis of their child's hearing impairment. This entirely different view and experience of the parents often leads to difficulties in parent-child communication. Due to this, Mayer, (2007) states that they usually fail to support the child's efforts in language acquisition yet it is generally understood that parents must play an active role in their children's language development. While some hearing parents have adopted non-auditory means of communication, the vast majority lack the skills to communicate effectively with children with hearing impairment children.

In support this; children with hearing impairment with hearing parents do not commonly receive essential exposure to language-driven interaction during early developmental stages. Besides, hearing parents often express feelings of

failure or sorrow related to a child's deafness they may view as a handicap (Meadow, 2007). In a case, Scott & Dooley, (1982) has emphasized that to effective parenting promotes the physical, emotional, mental and social well-being of deaf children as well as provided personal care to their deaf children, the support services available to them and the challenges they faced.

With this all, this study was conducted to bridge the existing information gap that from literature by studying the lived experience of child rearing practice of parents having deaf children was tried to conduct. But, no study has been conducted in the area of lived experience of child rearing practices of parents having deaf children in this place.

Statement of the Problem

Parents always wish to provide their children with the best living and learning environment to nurture them to achieve success in the future. With early identification and support, children with hearing impairment may adapt to everyday life and the learning environment and develop their potentials. However one of the major stresses of a family is the caregiving responsibility of the child which takes on both parents and other family members. Concern and anxiety towards the child's future is also a factor as confirmed by (Gupta & Singhal, 2004). Besides, it is also observed that lived experience of hearing parents with their deaf child has trouble with questions like "How will my child live when I get old and cannot do much anymore?" or "How will my child support himself/herself when I pass away?" are a parent's and a primary care giver's main concern. Many parents feel deeply concerned, and fear that their child will enjoy fewer opportunities in life. Their influence on parenting stress has not been determined. Therefore, researcher identifies this incidence issue and has tried to answer the following research questions.

- What is the lived experience of parents' who rearing children with deaf?
- How do parents cope up challenges when they rearing children with deaf?
- What are the lessons can be drawn from the parental lived experience of rearing children with deaf?

Objectives of the Study

The general objective of the study was to explore the lived experience of child rearing practice of parents' having children with deaf.

- To explore the lived experience of child rearing practices of parents' who have children with deaf.
- To identify coping mechanisms of challenges facing when parents rearing children with deaf.
- To learn the lesson that parents draw their experience in rearing children with deaf.

Significance of the Study

The researcher believed that, study is significant information to be delivered for hearing parents and deaf children that the lived relations of both ways. It is also, held that the support services for parents of children with hearing impairment could be provided with the help of such data. Researches directed at understanding what it is like to be a parent of a child with deaf. The results of the study are helpful for parents of having new diagnoses children as hearing impairment to learn from other parent's experiences. Also, gives additional insight for schools and deaf center so that they can employ various means and options to encourage parents and professionals to come together to work on the gaps and insufficiencies that they have.

Moreover, it is helpful for special needs educators and other professionals in understanding the unique experience, struggles, and needs of parents as well as nationally and internationally. Following this, it also serves as a reference for a governmental organization, non-governmental organization, program developers, organizations like policymakers, international organizations, and deaf centers, to facilitate opportunities for the parents regarding awareness-raising, counseling, and providing income-generating activities.

Delimitation of the Study

All Keble were not included. Children with hard of hearing and their parents were not include. Thus, the study was delimited only deaf children and their hearing parents at Ahurie Keble.

Research Methodology

Design of the Study

The design of this study was phenomenological design. In this study qualitative approach were employed. The rationale for using qualitative approach is that found to be applicable to the study. Due to, the issue needs to be more explore and also, this approach can be used to better understand any phenomenon about which little is yet known.

Population and Sampling Techniques

The data sources of this study were all hearing parents of deaf children. To select the participants from the target population non-probability sampling technique were employed. Sample and snowball sampling technique employed to select participants (Ahurie Kebele lived hearing parents). Moreover, purposive sampling technique was employed to select area that hearing parents lived residence.

It is believed that small sample sizes are the norm in phenomenological research design (Collins & Nicolson, 2002). Hence, for this research, all of 9 hearing parents of children with deaf were selected by snowball sampling technique in this study. Snowball sampling is a technique whereby the researcher starts with one member of a group that in turn refers the researcher to another member (Creswell, 2014).

Data Collection Tool

Interview

In order to collect relevant data from hearing parents of deaf children interview (semi-structured interview guide was employed. Semi-structured interviewing gave room for probing for clarification and further discussion of important and relevant issues that arose during the interviews. Face-to-face interviews enabled the researcher to read non-verbal communication and reactions, which proved to be helpful in the analysis of data. The interviews were audio smartphone records and later transcribed.

Data Gathering Procedures

The procedure of data collection was done in the following ways. First, develop and made ready for administration letters of cooperation from the department of special needs and inclusive education was presented to concerned bodies of the study area Ahurie Kebele Administrative office. Following that the researcher explained the objective of the research to the administration. The researcher went to the areas where they interacted with the parents in their natural settings. Two visits are made. The first visit was done for purposes of seeking permission to conduct the study from the authorities and also to meet with participants face to face for purposes of acquainting them with the study and also asked them to take part in the study. A convenient date for participants to be interviewed was decided on that day. Individual face to face semi-structured interviews conducted on the second visit. Parents are requested to give a detailed description of their experiences.

Procedures for the Interview Process

Interview Preparation -the first step of the researcher was 12 interview questions administered to 9 participants. This may seem obvious to say but the fact is that preparation is the most overlooked part of the entire interview process. When preparing for an interview the first thing to do is find a location to interview without interruptions. Second, Starting the Interview-arrive three minutes early for the interview and be sure to start on time. Start with introductions and a discussion of the goals of the interview.

Thirdly, Asking the Questions -the goal of asking interview questions is to elicit information from the participants. This information should be addressed your concerns about moving forward with the participant. Fourth, Closing the Interview-after the candidate has thoroughly answered all of your questions open up the floor for the candidate to ask questions of their own. At this point, the "closing of the interview" stage begins.

Allow enough time for the participants to ask questions and address any concerns they may have and keep answers brief and to the point and the last Assessing the participants -Remain as objective as possible when assessing

participants. Don't ignore gut instincts, as they can be strong tools when reading other people but don't rely on them alone.

Method of Data Analysis

Qualitative method of data analysis was employed. Due to this, in depth explanations, narrations and interpretations were used. The data collected through open-ended questions was critically analyzed and interpreted by using thematic analysis.

Results and Discussions

Parents Experience In Rearing Children with Deaf

Parents having deaf child were in the midst of the grief process experience a variety of emotional responses. Anger is one of these possible emotional responses to having a deaf child. Raising deaf children is difficult for all parents, families, and neighbors because it is new to born deaf children in families. However, parents rearing children with deaf together with their hearing siblings and peers. Children with deaf cannot communicate or sign with their families because it lacks sign language both families and children. Their response in line with Jackson,(2008) states that families' develop negative experiences to raise their deaf children, because challenges faced by parents; lack of information, communication, inadequate social supports, limited access to services, and limited access to funding.

According to participant one description

To raise his deaf child he faced so many problems like tension, depression, and feeling of fear when a new child was born. He said that, in what case God gives child with deaf is the obstacle to rearing his child with deaf. To reduce the severity of the problem he goes to different churches in a different place but his child cannot cure from hearing problem.

This implies that raising deaf children in families was difficult. It faced so many challenges in families like communication barriers between families and deaf children, financial problems, anxiety, depression, and feeling of fear.

Parents Expectation about the Future Life Career of Children with Deaf

The question delivered to respondent parents focused on investigating their insight about the future life career of their deaf children the response of research participant parents indicated that although their deaf children are too young, they deeply worry and ponder about the implication of deafness for their children about their future life career. All participant parents were asked about their aspirations regarding the future life of their deaf children.

Among the study, participants did hope that the deafness of their children will be cured by spiritual remedy including miracle and the use of holy water. They further did aspire that their children will get married and have children through leading their independent life. But children did not cure by spiritual remedies like holy water and miracle cannot lead their independent life. Their response in line with Merawi, (2013) states that parents did not believe that their deaf children lead their functional independent living being integrated into the life of local communities.

According to Participant four description

There is no aspiration about his child with deaf marriage affairs. The future life of his deaf child is dark because his child is illiterate in this case how he exchanges ideas and information to live together within the communities. If God is allowed his child will be cured of his deafness he lives independently, without this it is difficult to think about his child's future life.

The implication of the above statement is that deaf children's cannot lead their life independently and parents haven't hope about their child's future life career and there is no aspiration that their children cannot marry in case of deafness.

Challenges Faced by Parents in Rearing Children with Deaf

Financial Problem

The question delivered to respondent parents focused on parents get support from the communities and local government the response of the research participant stated that they did not get financial support from the government and non-governmental organization. The child was supposed to go for another medical operation like life in the town to attend the child in a special school as his feet were not well. Due to financial problems, we could not take him to the hospital for the second operation that is why he is just like this. If we can get some financial assistance we can take him to the hospital.

“I have fewer challenges at home because the family members help me in the upbringing of the child; the only challenge is the financial problem. I raise the question that governments give support to hearing parents of deaf children. This is what I said Wow the other children love him; they help him with any help he needs”(participant 5).

This indicates that participant parents faced financial problems to take their children to the hospital and parents did not get support from communities, non-governmental organizations, and government. Parents not supposed to go for another operation like life in town to attend special schools due to financial problems.

Communication

Almost all parents stated that the biggest impact on the family was not the hearing loss itself which is an invisible disability but that natural vocal communication between parent and child was unacceptable. Looking for a way out several parents reported inventing their means of nonverbal communication but that was only a temporary escape from a real solution to the problem. Families interact with their children only by leap reading and gesture without knowing or understanding. Deaf children want something it is difficult to understand easily. Hearing parents of deaf children tend to provide insufficient explanations for their decisions in the family and do not express their feelings about their relationships with their deaf children, due to communication barriers.

“He comes to me to know something and he signed away and I don’t know what he is. And I have to keep asking him “what? What? What?” kind of gets upset because he can’t get his point across to me, and I’m trying to get a point across to him and we are struggling”(participant 2).

This implies that the biggest impact on the families was communication between parent and child. Families interact with their children only by leap reading and gesture without knowing or understanding. When children want something it is difficult to understand easily. Hearing parents of deaf children tend to provide insufficient explanations for their decisions in the family and do not express their feelings. The response in line with Marschark (2007), states that although a decision about the best mode of communication required time, parent-child relationships and language acquisition could not be put on hold.

Psychological Problem

The parents feeling and reaction to the discovery of children with deaf. In their response, all respondent parents noted that they observed the strange problem of their children was identified by others such as neighbors, families, and friends. The gravest feeling experienced by parents was despair, sadness, anxiety, feeling of depression, and being overwhelmed by the news. Explained the situation of how she observed or be aware of the unfamiliar problem on my child and my reaction after the diagnosis and the approach of the professionals in the hospital as follows:

“While my child was one year old, I have detected a strange problem on my child which was different from his siblings. I have tried to share my concern with my husband regarding the problem that I have observed on our child. Unfortunately, my husband couldn’t share my worry arguing that he is a child that he may exhibit such strange behavior which is a common characteristic of young children. Regardless of such an argument of my husband, I have decided to take our child to the health center and find out the appropriate response and support for my worry and the problem of my children respectively from the right physician. The result of the diagnosis depicted that my child has severe hearing problem. When I was informed by the doctor about the real problem of my child, I found in a dilemma on the way forward. I understand that I

had suspicions about the problem of my child before the diagnosis, but when I was informed by the doctor about the situation of my child, it was really painful and difficult to accept the reality. We had a diagnosis but we had nothing else, absolutely nothing else. We weren't being referred on to anywhere else. We were just being told our child had this condition and that was it. And they couldn't tell us how it was going to progress. They couldn't tell us how they were going to treat it"(participant 2).

The implication of the above statement is that the gravest feeling experienced by parents was despair, sadness, anxiety, feeling of depression, and being overwhelmed by the news.

Societal Problem

The question delivered to the participant focused on the social support from the community towards deaf children. The answer of the respondents indicated that the societal response both negative and positive.

Accordingly, 7 participants of the study did feel that they experienced a positive response from the community towards their deaf children. They further argued that the community they lived in inconsistently showing sympathy and love to their deaf child. They did believe that the treatment of the community in favor of their deaf children through various cultural norms had a positive message to them against the existing negative attitude of the society towards the deaf child.

"I didn't face a serious challenge that the community didn't offend me concerning the situation of my daughter deafness. no one negatively treated my daughter or affected my feeling and emotion advertently or inadvertently. Especially my neighbors were highly cooperative in assisting and encouraging me in treating my deaf daughter. They even played a leading role in integrating my daughter with their hearing children and play with her peers in harmony and a sense of intimacy" (participant 6).

Finally, she confirmed that this situation enabled her to develop confidence and hope for the future career of her deaf daughter. However concerning the other aspect of the response/social support from the local community's towards deaf children, the remaining one respondent argued that they have been experiencing painful discrimination and exclusion of their deaf children in the local community they live in.

I often assume that people may mistreat my deaf child, and for this reason, I prefer to keep my child at home. I had never allowed my child to attend social events with fear of negative response and prejudice of the community to disability in general (participant 7).

This indicates that generally there is no discrimination and exclusion in the local community that deaf children live in. The treatment of the community in favor of their deaf children through various cultural norms had a positive message to them.

Parents Coping Mechanism to Rear Children with Deaf

Acceptance and Adaptation

All of the participant parents described accepting and adapting to their deaf child's to provide the best life for their child and this acceptance and normalization is an important part of these parent's experiences that facilitated their ability to cope with their child.

Even if my daughter is necessarily developing at the rate of other children and she is doing things easier that led her able to cope with things better and get satisfied with every little progress that my daughter is making because it's like another difficulty that overcomes (participant 8).

The implication of the above statement is all participant parents described accepting and adapting to their deaf child's to provide the best life for their child.

Religion

One of the most used coping mechanisms by being reported in all parents' interviews was religion. Religion was the most coping mechanism for all participants' of the study. All research participants stated that they engaged in

spiritual beliefs and used spiritual healing methods such as holy water and prayer to their children and themselves to decrease the problems of their children and to cope with the challenges they faced. Dutton, (2004) shows that parents facing major difficulties in their lives used prayer as a coping strategy and religious organizations may provide positive support and tend to understand disability through the lens of religion and they may see disability as God's gift or will.

"I go to church and I began to pray a lot and I used to drink holy water, let my son drink the holy water too. Afterward, God answered my prayer and decrease my stress, anxiety, and tension to raise my deaf child (participant 3). My stress level is lower when I participate in a Bible study regularly and pray. I am trying to teach my families at home by getting advice from a good friend of mine that I met at the church. I have met more friends at the church who seem to have better understandings in children and tend not to be judgmental instead they can just act normal with you"(participant 4).

It implies that the most coping mechanism that participant parents were used religion.

Conclusions and Recommendations

Conclusion

Based on the finding obtained the following conclusions were made.

According to the lived experience of the participant parents had numerous negative experiences caused by a lack of sufficient knowledge about the experiences that parents raise their deaf children. All participant parents are affected emotionally. Parents often struggle with guilt; they feel as though they somehow caused the child to have deaf. The parents of deaf children faced several challenges including financial constraints, psychological problems, and difficulty communicating with the children. The parents overcome the challenges by finding comfort in God and working hard to meet the needs of the children.

Among the participant parents didn't hope that the deafness of their children will be cured by spiritual remedy including miracle and the use of holy water. They further didn't aspire that their children will get married and have children through leading their independent life. Parents did not get financial support from the government and non-governmental organizations. The child was supposed to go for another operation like life in the town to attend the child in a special school as his feet were not well. Due to financial problems, we could not take him to the hospital for the second operation.

The biggest impact on the family was not the hearing loss itself which is an invisible disability but that natural vocal communication between parent and child was unacceptable. Participant parents state the most salient feeling experienced by parents was despair, sadness, anxiety, and feeling of depression.

Recommendations

Based on the findings obtained and the conclusions drawn the following recommendation were made. The government and non-governmental organizations should be support for hearing parents of children with deaf financially to rear their children with deaf. And also Encouraging sign language among families and in the community.

Parents of having children with deaf, should be to promote their social relationships, their lived experience, sharing information about how to rear their children deaf and to reduce the psychological stress that parents faced. Further, considering the communication challenges faced by parents of children with deaf sign language should be funded by Woreda and region for all children with deaf and their families.

References

1. Adams, J.W. (1997). *You and Your Deaf Child: a Self-Help Guide for Parents of Deaf and Hard of Hearing Children*. 2nd edition. Washington: Clerc Books.
2. Äsberg, K., Vogel, J., & Bowers, C. (2008). Exploring correlates and predictors of stress in parents of children who are deaf: implications of perceived social support and modecommunication. *Journal of Child and Family Studies*, 17(4), 486-499
3. Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36(5), 685–695.
4. Bodner-Johnson, B. (2001). Parents as adult learners in family-centered early education. *American Annals of the Deaf*, 263-269.
5. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
6. Brown, E. (2012). *Loss change and grief. An educational perspective*. London: David Fulton Publishers.
7. Buyisile, H (2015). Lived experiences of parents' of children with disabilities in Swaziland. *Journal of Education and Training Studies*, 3(4), 206-215.
8. Charanjeev, P. (1985). A study on parental attitudes towards hearing impairment in children. *Hearing Aid Journal*, 1993, 8(3).
9. Collins, K., & Nicolson, P. (2002). The meaning of satisfaction for people with dermatological problems: Reassessing approaches to qualitative health psychology research. *Journal of Health Psychology*, 7, 615–629.
10. Creswell, J. W. (2014). *The selection of research approach Research Design*. California: London: Sage Publication.
11. Creswell, J.W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd edition.), Thousand Oaks, CA: Sage
12. Dutton, K. T. (2004). Relationships between Home-Environment and Scholastic Behavior of a Disadvantaged Population. *Journal of Educational Psychology*, 69 (6), 754-760.
13. Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication disorders quarterly*, 29(2), 82-98.
14. Kirk, S.A; Gallagher, J.J., and Anastasiow, N. J. (2006). *Educating Exceptional Children*. New York: Houghton Mifflin
15. Marschark, M. (2007). *Raising and educating a deaf child: A comprehensive guide to the choices, controversies, and decisions faced by parents and educators*. Oxford University Press.
16. Marshall, M. (1996). Sampling for qualitative research. *FamilyPractice*, 13(6):522-525
17. Mayer, C.(2007). What matters in the early literacy development of deaf children. *Journal of Deaf Studies and Deaf Education* 12, 4, 411-431.
18. Meadow-Orlans, K. P. (1995). Sources of stress for mothers and fathers of deaf and hard of hearing infants. *American Annals of the Deaf*, 352-357.
19. Meadow-Orlans, K. P., Mertens, D.M. & Sass-Lehrer, M. (2003). *Parents and Their Deaf Children: The Early Years*. Washington, D.C.: Gallaudet University Press.
20. Merawi, A. (2013). *Autism and Family: problems, prospects, and coping with the disorder*. Unpublished manuscript, Addis Ababa University, School of Graduate studies. 67-71

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