



“Parents Whisper: Lived Experiences of Parents of Children with Special Needs”

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ABSTRACT

This paper investigated the lived experiences of parents with special needs children using the phenomenological qualitative research approach. Ten parents of children with special needs from Mambusao Elementary School Mambusao, Capiz, Philippines were chosen as informants of the study based on the children with special needs enrolled at MES. The data were gathered through interviews using a semi-structured questionnaire. To delve deeper into their personal experiences as parents with SN children. Colaizzi's method was used to collect, record, and analyze data. The researcher formulated three themes from the results: 1) Self-Denial, emotional breakdown, and financial struggle were the challenges encountered by parents of children with special needs, (2), Parents' coping Mechanism to the challenges they encountered was through family support, optimistic outlook, and Faith in God. (3) Improving the life of the children with special needs was the parents' aspirations in life, and (4) Any support from LGUs or government entities. They narrated how these experiences impacted their lives as parents of children with special needs. This experience greatly affects their mental and emotional health and even impacts their life. Causes, inferences, and recommendations based on these findings were discussed.

Keywords: emotional breakdown, financial constraint, faith in God

Introduction

Childbirth is generally associated with feelings of joy, but parents who have children with special needs (SNs) face many challenges in bringing up their children (Zablotsky B. et al., 2017). They face stress in managing the behaviors and needs of their children, and the overall family life changes while dealing with the different needs of children with SNs. Long-term burden means stress often spreads across every aspect of life and may even lead the person to show non-functional responses (Auerbach E. et al., 2019). It emphasizes the need to understand the beliefs of parents about their child's disability as their belief system guides them to take necessary actions about the management of such children's mechanisms (Siklos S. et al., 2006).

Each family has its own set of coping strategies to manage the stress. Not all strategies help all parents as they have diverse personalities and characteristics. Being the primary care-taker and



by virtue of spending more time with the child, mothers play the most important role in managing such children (Hockenberry MJ. Et al., 2007)

According to a study by Margalit M. et al (2007), parents of SN children have a heightened stress level compared to parents of typically developing children as these parents face extra stress while dealing with children's diverse and challenging needs. Therefore, they feel overburdened and face more challenges in handling daily-life problems. Parents' stress also affects their own well-being, health and child's adjustment.

Another study of Shin J. Y. Et al, (2009) found that parents with SN children with cognitive delay face more stress compared to other disabilities. There are many other factors which can be a predictor of stress in parents, like low level of mother's education, fathers' poor health, poverty and less social support.

A study of Twoy R. et al., (2009) who identified strategies, including seeking guidance and help from others, sharing with friends, dependence on positive sources found in families, thinking about one day at a time, trying to learn the vocabulary about the child's disability, learning to handle natural feeling of rage, frustration and bitterness, keeping their outlook positive, finding the related and helpful management problems, accepting the situation and feeling responsibility for their child and identifying the fact that they are not alone in this endeavor.

Parents' interpersonal relationship, their financial adjustments and their professional growth together influence their adjustment in terms of handling their SN child. Parents use different coping strategies, such as developing and maintaining a healthy relationship with their child, giving equal love to the child and developing a close relationship with the family (Sivberg B. et al., 2002).

This study aimed to focus on the experiences faced by parents of children with special needs.

More specifically, it sought to answer the following questions.

1. What are the challenges encountered by parents of children with special needs?
2. What are the coping Mechanisms of the parents of children with special needs?
3. What are the aspirations in life of the parents of children with special needs?
4. Any support from LGUs or any Government Entities by the parents of children with special needs?

Design, Tools, and Participants



This study was undertaken using a qualitative research approach, specifically drawing an understanding of phenomenology. It was utilized Giorgi's descriptive phenomenological method in describing the lived experiences of parents of children with special needs. It started with expression and description of their lived experiences so that the phenomenological story, which Giorgi calls —life text, could be created.

Participants in this research study included parents of children with special needs who were enrolled in SPED classes at Mambusao Elementary School.

Ethics

The study ensured anonymity, confidentiality, privacy, and the right of participants to withdraw. Participants was aware of the scope of the study and I asked them to share their views and experiences as parents of children with special needs. This study adhere to the Ethical Guidelines for Education Research (BERA, 2018), acknowledging the ethical implications of the study.

Data Analysis

In-depth interviews were conducted with ten (10) parents regarding the experiences they encountered in rearing their children with special needs. The informants' confidentiality was given priority and their names were concealed to hide their identity. The 10 informants were coded A, B, C, D, E, F, G, H, I, and K.

A researcher-made interview guide questionnaire was used as an instrument of the study and was subjected to validation by experts in sociology, philosophy, psychology, education, language, and research.

To analyze the data, Giorgi's descriptive phenomenology method was used as follows: transcribing the responses from the recorded interview, reading the transcriptions to get a sense of the whole responses by each informant, establishing the meaning units, transforming the meaning units into psychological sensitive expressions, and determining the structure or descriptive language and phenomenon.

The thematic analysis enabled the researchers to identify, analyze, and report on themes that emerged from the qualitative interview data.

RESULTS AND DISCUSSIONS

The emerging themes from the parents of children with special needs in the in-depth interviews include (1) The Challenges encountered by parents of children with special needs, (2), Parents' Coping Mechanisms to the Challenges they Experience. (3) Parents' Aspiration in Life. (4) Any Support from the LGU or Government Entities.

1. CHALLENGES

Three sub-themes emerged: 1) Self-Denial 2) Emotional breakdown, and 3) Financial Struggle

1.1 Self-Denial

Based on the responses of the parents of children with special needs, they have self-denial of the situation of their children diagnosed with special needs. They were worried about the



situation of their child and they didn't know what to do with their life. They were stressed mentally and physically. They have the feeling of shame of what people would say about them. As reported by some of the participants, they experience difficulty of accepting the truth. In addition, they have a negative attitude towards their children with special needs.

These findings have been highlighted in the study of Durand et al., (2013) revealed that some children with special needs pose particular challenges because of developmental needs and behaviors that require specific parenting skills or actions not required for children who are developing typically.

1.2 Emotional Breakdown

Despite their concern and queries, the participants were able to experience an emotional breakdown in life since the parents of children with special needs perceive more problems in themselves and their families. Furthermore, they experienced parenting a child with special needs increases stress in the areas of everyday management of disruptive behaviors, heavy caregiving responsibilities, and concerns about the future of the child when the parents are no longer able to care for him or her. Participants experienced that most of the time they cried because they did not know what to do with the situation of their children with special needs. Our participants were united in saying that having children with special needs was life-changing in the sense that it required major adjustments in their lives.

In connection with the study of Woodman, (2014) revealed that parents, and indeed family members, of children with special needs experience challenges that differ from those experienced by parents of typically developing children.

It conforms to the study of Margalit, (2006) reveals that parents of SN children have a heightened level of stress compared to parents of typically developing children as these parents face an extra level of stress while dealing with child's diverse and challenging needs.

1.3 Financial Struggle

During the interview, the participants shared that they encountered financial shortages in attending their children with special needs classes to improve their reading and writing skills. They revealed they were anxious about their means of transportation since they were not financially stable to support their education. During the interview, the first of these adjustments concerns the toll of disability on the family's financial and human resources.

2. The Parents' Coping Mechanism to the Challenges They Experienced

Two subthemes emerged: 1) Family Support, 2) Optimistic Outlook, and 3) Confidence in God

2.1 Family Support



Despite their struggles, the participants were able to reflect on various ways of coping in this time of struggle in raising a child with special needs through the help of their members of the family. They learned to adjust to their situation to survive by praying to God for guidance and hoping that their child became a normal individual member of society. They narrated that the continued support of family and relatives mitigates the burden or challenges experienced that sustain in improving the life of the children with special needs.

2.2 Optimistic Outlook

Despite the challenges they experienced, they have a positive outlook on life to overcome. Looking at the brighter side of things has helped them adjust to challenges, rejection, self-blame, and feelings of stress. The participants experienced relief when the children improved or developed their self. They realized everything that God had a reason why they had a child with a disability. Participants realized everything and were able to overcome the painful feeling and feeling of shame.

The findings of the study coincide with the result of Tway, et al. C. (2007) revealed the identified strategies, including seeking guidance and help from others, sharing with friends, dependence on positive sources found in families, thinking about one day at a time, trying to learn the vocabulary about the child's disability, learning to handle the natural feeling of rage, frustration and bitterness, keeping their outlook positive, finding the related and helpful management problems, accepting the situation and feeling responsibility for their child and identifying the fact that they are not alone in this endeavor.

2.3 Faith in God

Based on the interview, they were motivated and learned to overcome their challenges with their strong faith in God. They keep on praying to God for guidance and believe that they will be able to overcome their daily needs until their children with special needs improve their lives. They believe in the power of prayer that they will overcome everything to survive and provide everything to their children.

3. Parents' Aspiration in Life

3.1 Improve Life

Based on the responses, the participants expressed their deep motivation to improve the lives of their children with special needs so that they will not be discriminated against but instead be understood and accepted by the community as members of society. They narrated that their ulterior aspirations are to develop their children's behavior in dealing with others and improve their reading and writing skills.



4. Any Support from the LGUs or Government?

During the interview, some participants revealed that they received Php 350.00 pesos once a year from DSWD and groceries from their Barangays. However, some participants did not receive any assistance from the government. They appeal to the Local Government Unit or other Government entities to provide financial assistance to those rearing children with special needs. They narrated that with the support and encouragement they receive from the people in the community, they feel less alone.

Conclusions

The study concludes that parents of children with special needs are greatly affected and experience challenges. This study on the phenomenon of the experiences among parents of children with special needs increases public awareness about their self-denial, emotional breakdown, and financial struggles in rearing their children with special needs. Despite the challenges encountered, they were able to cope up due to family support, an optimistic outlook and strong faith in God which made them strong and compassionate mothers. Furthermore, parents have an ultimate aspiration to improve the lives of their children with special needs and nurture their reading and writing skills. Moreover, they did not receive sufficient financial support from LGUs. Despite these tough circumstances, parents remain hopeful and resilient that their children with special needs will improve their lives as well as their reading and writing skills to become productive members of society to evade discrimination.

Recommendations

Local Government Units or DSWD may provide accessible mental health services, including counseling and support groups, specifically tailored for parents of children with special needs.

Governments and nonprofit organizations may offer more comprehensive financial support, including subsidies for medical care, therapy, and special education services.

Schools may organize public education campaigns, workshops, and community outreach programs focus on fostering understanding and acceptance of children with special needs.

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