



## **Lived Experiences of Parents Parenting an Adolescent Child with Special Needs**

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### **ABSTRACT**

The essence of being a parent is demonstrated in the day-to-day experience, the most ordinary circumstances, in trivial matters, likewise, in most significant events like birthdays, moving ups, graduations and other special occasions. Yet, it makes one wonder if parents exhibit the same enthusiasm when their child is born with special needs, when developmental disabilities are apparent, when milestones are not met, and when lifestyle is compromised due to parenting a special child who is now an adolescent.

The journey of the parents parenting an adolescent child with special needs, from the Socksargen Center for Adaptive Intervention in General Santos City, were interviewed with the use of a validated questionnaire, and described what came out as a positive response to parenting, negative impact of parenting, and significant factors related to parenting an adolescent child with special needs. This qualitative health search utilized a descriptive phenomenology. The reason that a descriptive phenomenological approach was applied in this study was to examine subjective human experience. In view of the aims underlying the use of descriptive phenomenological approach, this method better suited the experiences of parents parenting an adolescent child with special needs. The use of a descriptive phenomenological approach gave rise to the three emergent themes such as Virtuous Gains in Parenting, Specks in Parenting, and Merry-go-round Challenges in Parenting. Virtuous gains in parenting spoke about acceptance, love and compassion, humility, positive attitude, good decision making and family support. Specks in parenting expressed parents fear, deprived social life, and poor nutritional pattern of the children. The merry-go-round challenges in parenting were that of unskilled health professionals handling special children as well as the need for exploration for further studies and breakthrough in parenting adolescent children with special needs.

In conclusion, parents were able to adapt their child's medical condition as well as tolerated their behavioral issues and learned the art of disciplining a special child. To deal a special child entails tolerance, deep affection, concern and with a humble heart. Struggles were real especially with keeping with the child's nutritional pattern, the unfavorable opinions of other people, and fear of the child's future.

This research will provide valuable information regarding the care of parents as well as the impact of the nurses and other health professionals on how to manage children with special needs. The findings may be useful in creating awareness in the city, support the community and possibly generate consciousness to all parents and promote a support group in the locality to encourage one another, and empower the parents to live a worthy life despite the setbacks and challenges.

Keywords: Lived Experiences, Parenting, Special Needs, Adolescence

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### **Introduction**

Special needs refer to a child's limitations, such as unmet milestones, banned foods, and denied experiences. These disadvantages can impact families and make the term "special needs" seem devastating (Mauro, 2016). Research focuses on understanding the adolescent stage of parenting a child with special health care needs, examining stress and functioning levels of parents influenced by coping behaviors (Hastings, 2005), depression (Dale, E., Jahoda, A., & Knott, F., 2006), and personality (Duarte, R., Bordin, I., Yazigi, L., & Mooney, J., 2005). However, this research often overlooks the family's evolving life experiences of children with special needs, focusing on the child as a stressor and negatively affecting parents' psychological well-being.

Around 7-18% of children and adolescents in the US have chronic conditions causing limitations in activities and requiring special care (Willis, 2005). These individuals are at risk for nutrition-related health problems. Parenting a child with special needs can be challenging and frustrating, with financial concerns exacerbated (Willis, 2005). In the Philippines, parents of children with developmental disabilities from larger families have lower employment rates. This study aims to explore how parents perceive and experience their child's disability, focusing on how it impacts their family life and health and well-being.

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## Methodology

This chapter discusses how the study was conducted to arrive with valid and reliable information. It specifically elaborates the research design used, the locale where the study was conducted, as well as the number and the nature of the participants of the study. A purposive sampling was appropriately employed in the conduct of the study. Moreover, data gathering procedure was laid down emphasizing the instrumentation used as well as the process of organizing and analyzing the data that were gathered in the study.

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## Summary of Findings

These were the salient findings of the study. In this stage of parenting an adolescent child with special needs, it was well-accepted by all participants with regards to the medical condition as the child becomes an adolescent. In handling the child's behavioral issues, it was with patience and understanding by all participants. Also the parents have to reprimand when needed. It was noted that the child's condition affected the family and also their social life to some degree. In terms of perspective of parents in parenting the adolescent child with special needs, the attitudes developed were that of patience, love, compassion, mercy, and humility. In coping a difficult child especially the health care needs such as the nutritional pattern and the like, half of the participants or the parents experienced difficulty with the nutritional pattern of their child because they were picky eaters and the other half were good because they have outgrown that stage already. The experience of handling the adolescent child with special needs affected their decision making in general in terms of their daily activity, events or occasions to be attended as well as the education of their children. The experiences of the parents with the nurses were generally pleasant and professional in nature but two participants had a not-so-good experience in their previous encounter with them.

Factors that promote adaptation were parents accepting the situation and condition of the child, feeling of love and mercy, being understanding and responsible, hopeful about the future. A positive outlook was also a factor and the support of the family. The presence of God was also part of the success. Factors that contribute to dysfunction were people around who were unaccepting or judgmental, feeling of self-pity and the experience of crisis in the family. There was also this fear and discouragement about the child's future.

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## Conclusions

From the findings that were emphasized in this section, the research revealed the following conclusions:

That all parents parenting their adolescent child with special needs have adapted well the medical condition of their children in this stage. The behavioral issues were tolerated and parents became considerate as well. Some parents admonished their children for wrong behavior; that the parents' standpoint in dealing their adolescent child with special needs were of tolerance, deep affection, concern and with modesty. There were struggles for parents whose children were very selective about what they eat. Parents take discretion in the decision making for their children's well-being; that parents find nurses under their care considerate and pleasing, while impolite and ill-mannered when not being earlier informed about the children's condition; that parents adapted the situation well as they developed deep affection and compassion for their children and other children with similar condition. They became considerate and accountable for their children's welfare. Maintaining good perspective and trust in God, bring hope for their children; that parents find unfavorable opinions from people a cause for apprehension; and that their children's condition somehow contributed to despair, worry and anxiety over what lies ahead for their children.

From the findings and conclusions that were presented, this research recommended the following points that may contribute to other people's deeper appreciation of the conduct of phenomenological studies with emphasis on the parents parenting an adolescent child with special needs vis-a-vis the field of nursing:

That parents will have an avenue such as an active organization based in General Santos City that will cater to their state or condition, that of handling children with special needs in order to draw out support from one another. The objective of which is to provide a community with a good cause, an extended family that promotes a sense of comradeship and respect for each other's plight; that the government of General Santos City will provide a concrete program for the welfare of the children with special needs. The objective of which is to make treatment plan accessible and affordable to the parents and family, to reduce the burden of parenting a difficult child by eliminating financial constraints that go with therapy, intervention and education in the development of the child with special needs; that the health professionals such as nurses will acquire the skills, knowledge and attitude in dealing or handling a child with special needs apt for nurses as care providers. Nurses who implement nursing care based on a sound knowledge, scientific principles and developmental theories, and a documented therapeutic plan. Likewise, nurses who promote optimal wellness, integrate ethical provisions in all areas of practice and maintain professional practice standards by providing nursing interventions that meet individual needs and are consistent with the total rehabilitation program; that a Facebook account or similar social media sites will be created and initiated by parents with special children to form a support group that will address issues and concerns about parents and their children; that a similar study may be conducted using the same phenomenological approach in gathering and treating qualitative data among parents lived experiences in a setting that will focus on adult with special needs; that a similar study be conducted using a similar approach among professional nurses on how they provide care to those who are with special needs; and that the future researchers are encouraged to conduct similar studies in a broader scope, like it is not limited only to SCAI in General Santos City, but widened the investigation to General Santos City and eventually national in scope.

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**Citations**


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