

# A Phenomenological Study on the Lived Experiences of Parents of Children with Special Needs

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**Abstract:** *This research paper provides various related studies that analyze the live experiences of parents of children with special needs and the possible ways to empower and recognize their remarkable strength and patience. The purpose of this research is to render knowledge and data of the live experiences of parents of children with special needs, to study the concepts, challenges, and struggles they're facing, for acknowledgement, understanding to the scholars, people and researchers that being a parent of a child with special needs is more than what meets the eye and to give recommendations to further improve their status. An interview questionnaire under the qualitative phenomenological approach was conducted; a research method that focuses on describing the live experiences of people and how they have suffered from these experiences.*

**Keywords — Experiences of parents of children with special needs, Phenomenological-qualitative study**

## 1. INTRODUCTION

Only a few people would understand how heavy the demand of raising a child is until they themselves become a parent. But in rare circumstances it is more difficult and complex to raise a child with special needs. This study examined the outlook of parents of children with physical, behavioral or intellectual disability.

For a long time, there has been lots of awareness made by people affected by the discrimination towards children with special needs. These people might be relatives, friends, siblings, and most especially the parents of these children with special needs. People became aware of how their words towards these children may affect their lives and the lives of the people around them. Everyone took care in what they say and their actions towards these children. To avoid making them feel sad, bullied, and different.

The burden of the children with special needs is what their parents had to withstand and endure. Parents of children with special needs are often tired and exhausted, some frequently become problematic that leads to depression. Their time and assets for self-care are decreased more than those of parents of typical children.

Parents of children with special needs undergo emotional breakdown. They tend to worry and dwell on the negativity they or their child might encounter in the future. [1] But despite the pessimism, children with special needs bring new hope, happiness and a whole new experiences to the lives of their families [2] [3] [4]. Acknowledge that parents know their child best and the possibilities are endless.

## 2. RELATED WORKS

Parents had almost reached the point of emotional breakdown. It described the worry and anxiety they experience about the future [1]. Studies have shown that parents experience psychological distress, frustration, insomnia, and lack of control [5]. These experiences highlight the impact of providing care, including the pervasiveness of fatigue and exhaustion [6][7][8][9][10][11]. Taking care of a child with a disability in the family can cause an increase in care giving demands and burdens [12]. Parents experienced anger, denial, defiance, bargaining, depression as well as trauma [13]. Parents often report that children's behavior problems are the most challenging part of raising a child and that feeling efficacious as a parent occurs more readily in the absence of children's maladaptive behavior [14].

On the other hand, children with disabilities bring joy, new experiences, and challenges into the lives of their families [2][3][4]. For parents with a child with special needs, there is a scope for hope, joy, and delight in their ordinariness [15][16]. Having a child with special needs had helped them put life into perspective. Another related study stated that raising a child with a disability can pose different challenges to a family. While other families successfully adapted to giving care giving demands and view their child as a positive contributor to their family and their quality of life [17]. When the child with a disability receives a positive affirmation, it boosts the parents' overall feeling and helps them to be more positive [18][19].

However, parents of children with disabilities face challenges that vary with the nature of the child's disability [20].

## 3. STATEMENT OF THE PROBLEM

To investigate the lived experiences of a parent of a child with special needs, specifically, this study will seek answers to the following questions:

1. What is the idea or concept of being a parent of a child with special needs?
2. What are the challenges/issues and problems that a parent of a child with special needs encounter?
3. How do the respondents cope up with the challenge and problem being encountered?
4. What are the recommendations based from the respondents in order to further improve their status?

#### 4. METHODOLOGY

The research method for this study was a qualitative phenomenological approach. This approach focuses on describing the lived experiences of people and how they have suffered these experiences. It also focuses on the similarity of a lived experience within a particular group [21].

The researchers explicated the data gathered instead of analyzing it. The explanation process referred to has five phases or steps: (1) bracketing and phenomenological reduction, (2) delineating units of meaning, (3) clustering of units of meaning to form themes, (4) summarizing each interview, and (5) extracting general and unique themes from all the interviews and making a composite summary in the form of a grounded theoretical framework.

To get the information imperative for this study, the researchers used interviews and observation method in data gathering. A letter of request has been given to the participants by the researchers that signify their agreement with the interview. The researchers then interviewed the selected respondents.

The respondents of the study consist of parents of children with special needs who are residents in the province of Bulacan, Philippines. To determine the respondents of the study, the researchers used the purposive sampling technique. This sampling approach is a strategy where "Members of a sample are chosen with a purpose to represent a location or type concerning the criterion" [22]. The benefit of this approach is that it gives the researchers the ability to think critically and define the scope of the population that needs to be studied at an early stage [23].

In this study, the researchers created a criterion which they used to select the respondents. The respondents have to meet these criteria for them to be qualified as a respondent in

this study. These are the criteria for this study: first, a parent of a child with special needs; second, a parent of a child with special needs who is a resident at the province of Bulacan; third, the parent had taken care of the child for at least one year. Considering these general criteria, five parents qualified for the study.

To gather the information for this study, the researchers made interview questions. These questions describe the issues and experiences of the parents in taking care of their children. We sent emails to the respondents to schedule an interview with them. Another reason for this is to inform and prepare them about the topic at hand and prepare them to tell their lived experiences as parents of children with special needs. The guide questions served as stimuli to get the perceptions of the respondents on the issues.

The guide questions were:

1. For you, what is being a parent of a child with special needs?
2. What are the problems and issues do you encounter as a parent of a child with special needs?
3. How do you cope up with those challenges?
4. What can you recommend in order to improve your status?

The thematic coding technique was used in the analysis and interpretation of the narratives of the respondents. It is a type of qualitative analysis that involves recording or identifying group of words which are connected to a common subject or idea which will allow you to categorize these words and establish a "framework or thematic ideas about it" [24]. The data processed were triangulated and checked by the respondents.

The following methods have been thoroughly followed by the researchers for the fair evaluation of data collection: (1) The researchers informed the participants on the study and told them that participation was voluntary. They were offered a choice whether or not they wished to be part of the study. (2) The researchers formed a questionnaire by using Google Forms web platform consisting of 4 questions to be answered in essay form. (3) The researchers wanted to be informative and as a result, the questionnaire was given to the participants ahead of time to help them prepare themselves. It helped provide information-rich responses, as the participants had time to prepare for the questionnaire. (4) Every form was recorded. By making use of Google Forms, the researcher can capture fully and precisely what was answered, rather than take notes of versatility in answering questions.

#### 5. RESULTS AND DISCUSSIONS

## **Ideas and Concepts of Being a Parent of a Child with Special Needs**

### **A. A Lifelong Journey**

Almost half of the researchers' respondents believe that being a parent of a child with special needs is a lifelong journey. Parent 3 used the words "lifelong work" to describe the long and challenging process parents go through with their child. Parent 5 supported the idea as Parent 5 answered "It's a long journey". This just shows that being a parent of a child is a lifelong journey. This doesn't just apply to the parents of children with special needs, but to every parent who loves and dedicated their lives, to raise their child.

### **B. Be Adaptable**

Parent 2 answered "I should be able to adapt to my child's way of communicating so I would know his needs and make him feel that he is loved, important, and someone that provides happiness to the family". Parent 2 explained that one of the hardest parts of being a parent of a child with special needs is communication; you need to be adaptable so that you can connect to your child and know your child's needs. This was supported by Parent 4, Parent 4 said that one of the concept of being a parent is to provide the needs of their child. A study revealed that the parents of a child with special needs encounter challenges such as failure to cope with the children's disability and financial challenges. Since communication is often a problem this study suggested the development of training programmes which will empower parents and provide them with knowledge for the benefit of their child. This way, parents can slowly adapt to their child's way of communication with the help of the knowledge they learned from the proposed programme. [25]

## **Challenges and Problems Being Encountered by Parent of a Child with Special Needs**

### **A. Lack of Patience**

One of the things you need to have when you become a parent is patience, but it gets more challenging for the parents of children with special needs. Parent 3 and Parent 5 both started their answers with patience, and then proceeded to mention other factors. This was explained by Parent 2 as the parent said "and there are times when it's difficult to control him from excessively doing the things he wants to do." Parent 2 shared an experience as a parent of a child with special needs and this just shows how much patience they experience on a daily basis that it becomes a problem or a challenge for them.

### **B. Financial Needs**

Being a parent is both tiring and expensive. You have to provide your entire child's needs which is challenging for the respondents of this study as their child has special needs. Parent 1 answered "My child has special needs and financial needs" which shows how providing these needs are really challenging for the parents. Parent 3 and Parent 5 also mentioned that one of their main challenges or problems as a parent is that they struggle financially.

## **Coping Mechanisms Employed in the Challenges and Problems being Encountered**

### **A. Family Support**

Being a parent of a child with special needs is really hard but by getting support from your family makes your work less stressful and much easier. Both Parent 1 and Parent 2 answered that they get support from their family. Parent 2 explained that "His siblings help to take care of him". Parent 4 shared that she helps her child in his studies to make it easier. This explains that getting support from your family is really helpful especially if you are a parent of a child with special needs.

### **B. Having a long patience**

Having a long patience is a must especially if you are a parent of a child with special needs. Parent 5 answered that having a long patience and by working hard is how she coped up with the struggles that she experienced by being a parent of a child with special needs. Parent 3 answered similarly "take one day at a time", which shows how vital patience is when you have a child especially when your child has special needs.

## **Recommendations based from the Respondents in order to Further Improve their Status**

### **A. Time, Patience, Effort, and Faith**

Being a parent of a child with special needs takes a lot of time, patience, and effort. You have to really prepare yourself. Parent 1 suggests that you should allot more time, patience, and effort. While having a strong faith is a notion that some parents of a child with special need hold onto in tough times. Parent 3 recommends to have strong faith, sound mind and body to carry on and keen understanding of what's to come.

### **B. Moral Support**

When you give moral support, you help encourage a person especially a person with special needs. Parent 4

suggests always giving moral support to your son or daughter, and always being at their sides as parents.

### C. Acceptance

The first time you figured out that you are going to be a parent of a child with special needs, acceptance is the first thing that you need to do. Parent 5 recommends to accept his/her condition and accept that this is a lifelong process.

### D. Seek Government Assistance

In the Philippines, there is a Comprehensive Program for Persons with Disabilities that aims to promote services to all types of PWDs 0-59 years of age. The program focuses on areas of disability prevention, rehabilitation and equalization of opportunities. Parent 3 recommends seeking government assistance because this is the right of every person with disability. And by seeking help, this can certainly help you in some ways and make your life as a parent, a little bit lighter.

## 6. CONCLUSIONS

The conclusions attained by the researchers are based on the findings of the research. First, the idea or concept of being a parent of a child with special needs classified as a blessing and a lifelong journey which conveys that being a parent of a child with special needs is having a feeling of contentment and sacrifice ; second, the challenges, issues and problems that they encountered as a parent of a child with special needs varies from untiring patience, their child's communication and learning disabilities and financial needs that manifest in a tremendous hard work ; third, the data analysis indicates that taking one day at a time with help, support and prayers from their family along with patience they were able to cope up with the challenges and problems they've encountered; fourth, they were able to provide recommendations to further improve one's status as a parent of a child with special needs by having more time, patience and effort, strong faith, mind and body, understanding and moral support to their children and acceptance; lastly, the researchers concluded that being a parent of a child with special needs isn't easy, in fact it is a hard challenge as it takes all your energy and well-being to hard work.

## 7. RECOMMENDATIONS

Based from the conclusions of the study, the following are hereby recommended:

1. The concept of being a parent of a child with special needs is lifelong work. Parent should treat their child as a blessing and not as a burden. This mindset gave parents the patience and understanding they need to cope up with the needs of their children with special needs. A long journey awaits these parents. Adapting to their child's way of communication will help them provide the love, care, and happiness their child needs.

2. As a parent of a child with special needs, challenges are always encountered. According to the respondents, parents find it hard to teach these children life skills. The researchers concluded that the parents take one day at a time to help their children learn slowly but surely. In addition, by showing moral support and giving more effort, the parent understood more what their child needs and learning how to cope up with the challenges they face every day.

3. The respondents recommends parents of a child with special needs to have a strong faith that their child could make it, to have keen understanding of what's to come and to accept their child for who they are. The researchers came to the conclusion that acceptance is the key to fulfilling the role of a parent of a child with special needs.

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