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## **The Impact of Autism on Parents' Lived Experiences**

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## Abstract

The study sought to understand and describe the lived experiences of parents raising children with autism, comparing the experiences of mothers and fathers. The study employed a phenomenological qualitative research design, conducted at Cebu Kid's Center for Autism Foundation, Mandaue City. Using snowball sampling, nine parents of children aged 3-12 participated in semi-structured interviews. The study found that parents often face significant stress and challenges, including financial strain, lifestyle changes, and lack of support from healthcare providers. Additionally, parents primarily sought information online rather than from doctors, highlighting a gap in the patient-provider relationship. The study also revealed shortcomings in public special education schools, such as inadequate facilities and an unfavorable student-teacher ratio. The study concludes that comprehensive support systems are essential for parents of children with autism, including better healthcare communication, improved educational resources, and family-centered mental health interventions. The study recommends that healthcare providers create therapeutic relationships with parents, governments improve working conditions for special education teachers, and mental institutions offer family-focused interventions. Increasing public awareness about autism and providing continuous support for parents are also crucial steps to enhance the overall well-being of families affected by autism.

**Keywords:** *Autism, Lived Experiences, Phenomenological Research, Parental Stress, Support Systems*

## 1.0 Introduction

This study aimed to understand and describe the lived experiences of parents raising children with autism and to compare how the experiences of each parent differed from the other. The research aimed to provide insight into how parents with children with autism experienced the pre-diagnostic phase, how they were able to cope up with their activities of daily living and other concerns related to the future of their child.

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With the rise of Autism both globally and locally, people are seeking greater awareness of the condition's complexities. This research study will help educate and support affected parents to guide their children develop towards independence and improve their quality of life. It will also help educators in special education schools and other therapists to understand what parents with Autistic children go through so they can better know how to involve them in the upbringing of their children to be able to attain maximum levels of independence. Parent's participation in their children's development and implementation of intervention increases the ability of a child to learn and use skills quickly: if teachers and therapists develop and implement interventions that are not supported or implemented at home the skills are likely to be absorbed slower, and the likelihood of having long-term benefits are small (Eve, 2012).

This study will benefit children with autism by helping their parents gain a deeper understanding of their world, thereby improving the children's overall development and future prospects. It emphasizes the significant role parents play in shaping their children's lives, highlighting that parents can profoundly influence their children's outcomes (Stephens, 2007). The findings will prompt hospitals and assistive services to better address the needs of both parents and children, recognizing that mothers often experience higher stress levels than fathers, particularly when their children are young (Davis & Carter, 2008). Additionally, the study will guide these institutions to enhance existing support and develop new services. Mental health institutions will gain insight into the challenges faced by parents, leading to the provision of therapy for both the children and their parents, as the well-being of parents is crucial to the well-being of their children.

## **2.0 Review of Related Literature and Study**

There is limited related literature on knowledge first-time parents have regarding developmental stages through early years of life; however a study conducted by Willian, Pearce & Devine (2013) showed that first-time mothers seek knowledge on communication milestones from friends. The findings of the study indicated the need for increased information provision to first-time mothers regarding early communication development. Parents play a big role in their children's life especially in molding who they become in the future and are to be blamed for what their children turn out to be (Stephens, 2007). Knowledge about autism empowers parents by providing the opportunity to participate in decision-making and problem-solving process to meet the needs of individuals with ASD.

At the sign of any weird or incomprehensible behavior parents with a child with autism should immediately seek help (Eve, 2012). Staying the child at home with the hope that the child will outgrow the problem is a great mistake that should never be done by any parent. A child with autism can better thrive if treatment is started early (Eve, 2012). Overcoming the challenges that come with having a physically challenged child and being emotionally strong puts a parent in a better position to cater to his/her child's needs, dismissing evidence and being in denial does not make the situation any better (Erjona, 2013).

Doctors play a crucial role in diagnosing, treating, examining, and educating patients about their diseases, with the delivery of information being especially important in critical conditions (Kozier, Erb, Synder & Berman, 2007). Patients require full disclosure about their illness, including its nature, expected outcomes, treatment options, risks, and benefits, as well as other relevant information (Kozier, Erb, Synder & Berman, 2007). Parents, in turn, have the responsibility to

ensure their children's safety by either being present at home or adjusting their schedules to accommodate their children (Christensen, Schneider & Butter, 2011). However, working parents often find it challenging to spend sufficient time with their children due to workplace structures that hinder supervision. Parents in autonomous jobs have more flexibility to communicate with their children during working hours compared to those in monitored communication roles (Christensen, Schneider & Butter, 2011).

Children with autism function best with routine and schedules. It is the duty of the guardians to establish these routines so the child can be able to follow and find meaning in his life through completing a task. Having a child with autism has changed the parenting roles of most parents in a sense that it requires them to develop an increased sense of parenting that is intense in both quality and quantity of behaviors (Woodgate, Ateah, & Secco, 2008).

A study conducted by Davis & Carter (2008) on parenting stress in mothers and fathers of toddlers with autism spectrum disorders, indicates that mothers get more stressed than fathers about their child with autism. The same study also shows that high levels of stress are present in mothers when their children are quite young.

Parent support groups that emphasize sustaining couples' relationships during times of is beneficial for families with children with ASD (Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015) especially when children exhibit more intense behavior problems and are difficult to control.

The study conducted by Santoso, Ito, Ohshima, Hidaka, & Bontje, (2015) on resilience in daily occupations of Indonesian mothers of children with autism spectrum disorder showed that parents' greatest concern was for their children's future. The results of this study further shows that creating and re-creating accepting conditions such as support from family members and other people from the environment, involvement of father in the child care and understanding of the child's condition among extended family members is fundamental to mothers' resilience by easing their emotional and practical burdens (Ohshima, Hidaka, & Bontje, 2015).

A study conducted by Smith, Hong, Seltzer, Greenberg, Almeida, & Bishop, (2010) on Daily experiences among mothers of adolescents and adults with autism spectrum disorder indicates that, mothers of adolescent and adult children with ASD spent significantly more time caring for their children and doing household chores than did mothers of children without disabilities.

Parents with children with autism are at an increased risk for acute to chronic stress as compared to children with other disabilities and parents of children without disabilities (Bluth, Roberson, Billen&Sams, 2014). A study conducted by Phetrasuwan& Miles (2009) on Parenting stress in mothers of children with autism spectrum disorders indicated that managing demanding behaviors and upset feeling, discipline, and managing the behavior of their child with Autism in public places were the highest sources of overall parenting stress. Mothers also reported stress related to not having time for their activities and needs and difficulty in giving themselves permission for such needs (Phetrasuwan& Miles 2009). When compared with parenting children with other disabilities, parenting a child with ASD is associated with greater parenting since they warrant attention and intervention, which can be overwhelming to parents (Bluth, Roberson, Billen&Sams, 2014).

Fathers have unique interaction styles that make important contributions to the language and symbolic play development of their typical children; though fathers with children with autism

spectrum disorders are underrepresented in both early intervention and research, they can make similar contributions to their children with autism (Keller, Ramisch, & Carolan 2014).

A study conducted by Lickenbrock, Ekas, & Whitman, (2011) showed that maternal perceptions of the child with an ASD were directly related to marital adjustment; specifically, mothers who reported higher levels of positive perceptions of their children also reported higher levels of marital adjustment. Focusing on the positive accomplishments helps to promote positive family outcomes.

Having a child with autism has both positive and negative impacts on the other typical children. Siblings tend to develop a sense of maturity and take pride of greater sense of responsibility faster than their peers. They take pride in the accomplishments of their brother and sister and develop a strong sense of loyalty. Siblings of ASD children are usually more tolerant of differences in people and show the compassion for others with special needs. However, many siblings feel resentment at the extra attention the child with autism receives, and some feel guilt over their good health. They may also feel burdened with what they perceive as parental expectations for them to be high achievers. Many feel anxious about how to interact with their brother or sister, and feel rejected by the lack of reciprocity. Often there is a feeling of resentment at having to take on extra household chores, coupled with restrictions on social activities. A study conducted Griffith, Hastings & Petalas (2014) demonstrate that both mothers and fathers rated siblings of children with autism as having significantly more emotional problems and lower pro-social behavior than the normative population.

### **3.0 Research Methodology**

This study employed a phenomenological qualitative research design to understand the contexts within which parents of children with autism engage with their experiences. Conducted at Cebu Kid's Center for Autism Foundation in Mandaue City, the study used snowball sampling to recruit nine informants (six females and three males) with autistic children aged 3-12. Data were collected through semi-structured face-to-face interviews, with questions formulated to guide the conversation and allow informants to express themselves openly. A pilot study ensured the validity of the research instrument. The researcher practiced bracketing to manage personal biases, and informants were contacted and interviewed in English at their preferred venues. The interviews, lasting 30-40 minutes, were recorded for transcription, and data saturation was reached by the ninth informant..

This study utilized Colaizzi's (1978) phenomenological data analysis process, which involved transcribing participant narratives from audio-taped interviews, extracting significant statements related to the phenomenon, and formulating general restatements for each significant statement. These formulated meanings were then grouped into theme clusters, leading to the development of an exhaustive description through synthesis. The researcher conducted interpretative analysis of symbolic representations, identified the fundamental structure of the phenomenon, and returned to participants for validation to ensure the accuracy of their intended meanings. Data collection ceased upon reaching saturation, where no new information emerged, making further data collection redundant (Polit & Beck, 2004).



#### 4.0 Results and Discussions

This chapter describes the findings of data generated from the respondents about their experiences parenting a child with autism. Experiences that were common to all the respondents, as well as distinctive experiences of individual respondents are also presented. Using content analysis, four primary themes were found to be most prominent from the data were; (1.) Bitter Reality; (2.) Challenges Parenting a Child with Autism, with eight subthemes, lack of financial resources, lifestyle changes, difficulty recognizing atypical behavior, impact of autism on family and social system, uncertainty about the future of the child, delayed diagnosis, difficulty finding appropriate schools, parents frustrations; (3.) Need for Social Support System; (4.) Blessings amidst Difficulties.

##### Theme 1: Bitter Reality

The diagnosis of autism is devastating to parents; no parent is ever prepared to hear that their child is anything other than healthy (Davis & Carter 2008). It is every parent's dream to deliver a normal child but when they discover that their child is special and that their parenting journey is to take a different path than they had expected then they become overwhelmed (Schieve, Blumberg, Rice, Visse, & Boyle 2007). Parents in this study, when asked how the period of diagnosis was for them, had different reactions. Havana, who is in her mid-thirties upon receiving the diagnosis, broke into tears; the diagnosis brought sense hopelessness to her life, but she was again grateful to know what was happening to her son. Havana said that;

*"When the diagnosis was finally passed I broke into tears, I was hopeless, and the future seemed bleak though I was grateful to know what exactly was happening to my son" SS4*

Diagnosis made it possible for parents to understand what they were dealing with and were able to start therapy these results are similar to Matange (2012), where parents were relieved upon knowing the condition of their child, because they were able to explain their child's behavior.

No matter the vast information Cha had about autism she was in denial. She was scared about her son's diagnosis and hoped that it was something else other than autism. Cha reported that:

*"When I received the news I was in denial, I hoped that the doctor had made a wrong diagnosis and that my son was suffering from something else. Though I had read a book on autism and everything that was written in it in regards to Autism was manifested in my son's character I was scared, the news was unbearable"*

Luda upon receiving the diagnosis was devastated. Like Havana, she cried and questioned God for what she was going through. The diagnosis, however, helped her begin therapy as it was seen in Havana's case.

*"Upon receiving the information I was so devastated, I cried and asked God what I had done to undergo so much than I could handle, the diagnosis, however, helped us start therapy for my son" as verbalized by Luda (SS4)*

Lovers were depressed by her son's diagnosis and like Luda she questioned God for what she was going through. She reported that;

*"When I discovered that my child was for sure autistic, and there was no cure for it, I got depressed for days and asked God endless questions" (SS5).*

Ben's life shattered into pieces upon receiving the diagnosis. He reported that;

*"My son was diagnosed as having autism at the age of 3. When I received the news, my life became hopeless" as verbalized by Ben (SS1)*

Most parents expect to deliver a healthy child, to have a posterity that will succeed them and be exactly like them or even better (Grohol, 2015). When the bitter reality of a different outcome takes a toll on their lives, they despair as they try to find meaning in their child's condition (Grohol, 2015). The results of this study are similar to those of a study by Rivard et al. (2014), which showed that both mothers and fathers reported higher levels of stress after the diagnosis.

## **Theme 2: Challenges Parenting a Child with Autism**

Parents who care for a child with autism face many issues and challenges on a day to day basis. The needs of a child with autism complicate relationships, between family members, causes parents to work extra hard, and change their lifestyles to accommodate the child with autism.

### **Subtheme 1: Lack of Financial Resources**

This refers to the inability to avail different therapies to the child with autism and other treatments necessary to attain a certain level of independence. Raising a child with autism is very demanding financially, it requires parents to work extra hard if they are to avail therapies and all the necessary treatment for their child. Parents in this study were affected financially by raising a child with autism. Havana was not able to see an occupational therapist and a speech therapist every day as she reported that:

*"Tom's education is very expensive; I cannot afford to see an occupational therapist and a speech therapist every day" SS8.*

Cha's expenses on her son's education were so grand that other family members had to step in to help. This was her response when asked what problems emerged after the diagnosis:

*"Kim's expenses are so grand that other family members come in to help us. We spend 100,000 pesos per month on his education" SS9.*

Tim, a father of two, reports that they have to work extra hard as a family to make ends meet and to educate their child with special needs. This was his response to the problems they encountered after diagnosis;

*"Since my child was diagnosed with autism it has greatly impacted on our finances, we have to work extra hard to raise the money needed for therapies and our expenses at home" SS8*

Parents with Autistic children spend fortunes on therapies and treatment (Bashir, Khurshid, Qadri, 2014) that even the most affluent parents go bankrupt. The expenses weighed greatly on the parents because of a couple of things which included; 1) Loss of one parent's income since one parent had to quit work making the other parent work extra hard to provide for the family, 2) Specialty of schooling; these children had to be taken to special schools that catered specifically for their needs, had several teachers and used sophisticated equipment that were expensive 3) Lack of health coverage; health insurances do not cater for children with autism for they consider it more of educational than medical.

### **Subtheme 2: Lifestyle Changes**

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The diagnosis of autism impacted on the careers of parents. One parent had to quit a job to care for the child with autism. Parents have the responsibility of caring for their children; it is therefore upon them to create time to be with their children especially when they have jobs that are demanding (Christensen, Schneider & Butter, 2011). In the statement below Cris reports that the wife had to stop working to care for the child with autism.

*"My wife had to stop working to care for our special child" as verbalized by Cris*

Like Cris's wife, Dida, Cha, and Loveres had to quit their jobs too to care for their child with autism as seen from their responses below;

*"When my son was diagnosed with Autism I had to quit my job so I can fully attend to his needs. I've been a stay home mother for 14 years. I put my son's needs above everyone else, his happiness is my joy" as verbalized by Dida (SS5)*

*"Kim is my first born child. When I was pregnant with him, I decided to be a stay home mother, so I could have enough time to care for my kid" as verbalized by Cha (SS1)*

*"When the diagnosis was made I quit working to care for John" as verbalized by Loveres*

For most families, it was the mother who had to quit the job to care for the child with autism, one family, however, had the mom working and the dad caring for the child with autism. Tim is a stay home dad who cares for his child with autism while the wife works.

*"I'm a stay home Dad when Rony was diagnosed with Autism we had to decide with my wife who will stay with Rony because he needed attention" as verbalized by Tim. (SS3).*

In families where both parents were working, two house help were hired, one specifically for the child with autism whereas the other for the other normal children and household chores. This is seen in a statement below made by Luda

*"Since I'm a working mother I solely depend on yayas to take care of my kids. I have a special yaya for Gabe so he can concentrate on him alone" (SS9).*

Caring for a child with autism is very demanding; unlike the normal children a child with autism requires constant monitoring. It is, therefore, the duty of parents to ensure that these children are safe and should give up whatever could be preventing them from fulfilling their parental roles (Christensen, Schneider & Butter, 2011).

Having a child with autism affects how the family functions this is basically because much time is directed to the child. Havana and Tim say that they hardly have adequate together as a couple as a result of having a child with autism as seen from their statements below:

*"Our time together as a couple is affected since we cannot go out often as we did before Tom was born" as verbalized by Havana*

*"Our time as a couple has also been affected, we do not get adequate time together since we have to do extra work to make ends meet and live a comfortable life. We also have a lot of misunderstanding as a couple in regards to finances that have led to many quarrels." as verbalized by Tim*



Not only did having a child with autism affect family bonding but it also affected friendship. Tim recounts not having gone out with friends in the name of having fun for the past two years, much of his time is directed to his family and especially on the child with autism. This was the response of Tim when asked .how having a child with autism has impacted his life;

*"I have no much time with my friends as I did before Rony came to our lives. The last time we sat down with my friends in the name of hanging out together was two years ago" as verbalized by Tim.*

Children with autism can be difficult to control and may cause embarrassment in public places. Cha is one of the parents that stopped going to church with her child because he cannot settle in one place.

*"Our priorities and the family routines changed after my child was diagnosed Autistic. We stopped going to church together since Kim would not sit down for more than an hour without causing distractions." as verbalized by Cha.*

Tim avoided public places so he could avoid explaining his child's condition to everyone. He had less time for friends and worked extra hard.

*"I avoid going to social gatherings with my special child for the fear that I will have to explain for every one of his mischief" as verbalized by Tim.*

All parents in this study had to adjust in one way or another to accommodate their child with autism. The new shift in family functioning caused anxiety, most parents found it impossible to maintain a normal life, everyday activities had to be modified and the child with ASD given extra attention. Activities that the family did together before the diagnosis such as going to church together or social gatherings stopped due to uncontrollable behaviors of their son. The time couples spent together bonding was also limited as a result of the demanding needs of the child with autism. Though change is part of life some changes that do not allow normal functioning can cause stress, managing the child's behavior in public will enable parents to live a normal life (Phetrasuwan& Miles 2009).

The findings from this study revealed that change was inevitable. Parents avoided going places where their child would be a source embarrassment, and if they were to go, they would leave their child behind. These changes have had an impact on their careers, finances, and lifestyles. Though these adjustments are necessary, their well-being should be put into consideration. Joining social groups will help them learn from other parents who share the same burden.

### **Subtheme 3: Difficulty Recognizing Atypical Behavior**

Parents in this study were often unaware of atypical behaviors in their children with autism, mistaking signs like delayed speech and lack of eye contact as normal. It usually took an outsider to identify these abnormalities. For example, Luda only sought medical attention for her child after an accident, leading to the discovery of autism symptoms

*"When Gabe was two years and six months, he fell from the second floor to the ground and had a cut on his head. When we went to the hospital, we were told that Gabe will be ok even without stitching the cut and were asked to return for assessment after some time. When we returned, the doctor noticed that Gabe had no eye contact and could not speak. The Doctor*

*directed us to a developmental pediatrician who diagnosed Gabe as having developmental delay" (SS3)*

Parents were unaware of autism spectrum disorder. The diagnosis of their child sent many parents to seek for knowledge. Their major source of information was on the internet. Few parents confronted doctors to understand the condition affecting their child fully. The stress parents went through after learning the condition of their child explains why they did not confront the pediatricians immediately. The relationship between helping professionals and parents is important as it enables the parents open up their concerns and fears to them (Ahern, 2000).

Loveres compares the feeling of not knowing what autism was to the struggle of finding a way out in a dark room. She stated that:

*"I had no knowledge about autism, and I didn't know what to do with my child. It was as though I was in a very dark room trying to find my way out. I looked for knowledge everywhere. "I surfed the net every day to advance my Knowledge on the disorder."*

Gutu like Loveres sought knowledge from the internet. She went to a different doctor to confirm her child's condition.

*"The news of my child did not come to me quite well. I spent the whole night crying. I had no knowledge of the condition, so I went to the internet to educate myself. With the hope that my child could be suffering from something else other than autism I went to another Neurodevelopmental doctor to seek a second opinion that wasn't different from the first."*

Parents need to be enlightened about the disorder that affects their child so they can be in a better position to decide which intervention and treatment are better for their child. Knowledge about autism empowers parents by providing the opportunity to participate in decision-making and problem-solving process to meet the needs of individuals with ASD (Murray, Curran, & Zellers, 2008)

Health care providers play a very vital role in our lives. They can recognize the symptoms associated with autism better than the parents. It is, therefore, important that doctors be mindful enough to educate parents about the disorder their child is suffering from. Patients are entitled the right to information (Muse, 2011) and should be fully informed about their diagnosis.

#### **Subtheme 4: Impact of Autism on Family & Social System**

The impact of autism on family & social system is often the strong and negative effects brought about by having a child with autism in the family. Some parents reported abandonment of their extended family members and spouses. These parents had to carry this heavy burden of rejection as all the blame for their child's condition was shifted upon them by the family members. Loveres, who had just had her second baby at the time of the interview, had undergone a lot then she could handle with her first child who is autistic. The extended family members treated her bad. Her relationship with the husband crumpled soon after the diagnosis that she considered separation. Thus, she decided to go back to her biological parents to seek solace. This is her response when asked about her marital life after the diagnosis of her child:

*"My relationship with my husband was affected by my child's diagnosis. He became distant and cared less about the child. My in-laws treated me bad as though I am the cause of John's condition. The pressure was too high that I was considering separation. When it did not work, I went back to my parents to stay with them"*

Gutu was in tears as she narrated to the researcher how she had to struggle alone with her child after the husband abandoned her. She stated that;

*"My relationship with my husband quickly changed. He started blaming me for my child's condition and stopped sending us money for our needs yet he was the breadwinner in the family and worked abroad"*

For Ben their romance stopped, and he blamed the wife for his son's condition as seen the statement he made below:

*"Our romantic life ceased, I blamed my wife for our son's condition" as verbalized by Ben.*

Rejection is a bitter pill to swallow; it is even worse if it is from the people you expect to stand by your side during difficult situations. Having a physically challenged child is enough stress on its own that other negative energy such as rejection should be eliminated.

Parents with more than one child reported that the other siblings to the child with autism complained about the too much time accorded the child with autism. These children felt deprived of attention and love from their parents. Dida a mother of three from time to time had to make the other normal children understand why she accorded the child with autism too much time. This is what she had to say when asked about her experience raising a child with autism:

*"When my children were young his other siblings would ask me why I spend more time with their young brother than I did with them; which I responded by telling them that their brother was special. In their young minds, they couldn't understand what that meant and with innocence they asked if they were not special. So what I did in their childhood was to make them understand their brother's condition"*

Luda's other normal children became envious of their brother and would even fight him for he was favored by their parents more than them.

*"When my child was diagnosed with autism his other two siblings got envious of their brother. And would fight him often because he was favored" as verbalized by Luda (SS12).*

Siblings to the child with autism are deprived of attention and love from their parents for much attention is directed to the child with autism. A study conducted by Griffith, Hastings & Petalas (2014) reveal that extra attention given to the child with autism causes resentment in the other children.

Parents stated that the siblings to the child with autism had grown to be responsible and protective as seen in the statement below which made by Dida:

*"I have trained my other children to treat their younger son as special. I Slowly tried to inform them when they were little that it is their responsibility to care for him and now that they*

*are old they have become so protective of him, which gives me assurance that our son will be safe even after we leave this earth"*

Luda's normal children at the grade one had understood their brother's condition and were choosing careers that will help them manage their brother's condition in future. Hardly do you see grade one students think for their brother with autism.

*"The twin sibling of my child with autism are now in grade one. They now understand their brother more than they did when they were young. One twin says he wants to be a banker so he can pay for his brother's therapies and the other one wants to be a doctor so he can be the one treating his brother" as verbalized by Luda.*

Siblings of children with autism often mature more quickly and develop a stronger sense of responsibility due to the caregiving role imposed by their parents (Griffith, Hastings & Petalas, 2014). Autism impacts all family relationships, including those with non-affected children, often leading to feelings of neglect among siblings (Boushey, 2001; Roth, 2001). To prevent resentment and rivalry, special attention must be given to nurturing parent-child relationships within the family, ensuring that all children feel valued and supported (Meyer, Ingersoll & Hambrick, 2011).

#### **Subtheme 5: Uncertainty about the Future of the Child with Autism**

Parents were concerned about the future of their children, especially when they cease to exist. The thought of death instilled fear, worry and panic in parents. Parents acknowledged that they were not immortal and in one way or the other they will die. Since children in this study were dependent on their parents, most parents thought of training the siblings to the autistic child to be responsible so they could care for their brother in the present and the later days. When asked about the problems they have encountered after the diagnosis, parents' responses were as follows;

*"I'm scared about my child's future, especially after I die. I will not live forever to care for him, and that worries me"*

Cha was worried about the diagnosis and had started training the sibling of the child with autism to be responsible.

*"I'm worried about my son's future, but I started to teach her sister though she is young that his brother is special and should be cared for. The sister is also responding and has learned to cherish and protect her older brother" as verbalized by Cha.*

The thought of the future causes Lovers to panic, like Cha she hopes to train the siblings to the child with autism to take responsibility for their brother.

*"I panic at the thought of my child's future. I wish I were immortal, so I could care for him forever. I will raise my other kids to know that it is their responsibility to care for their elder brother" as verbalized by Lovers.*

After diagnosis parents recognize that their children may not live a normal life other healthy children live (Altieri & von Kluge, 2009). They were not going to have a carefree childhood, university studies or even get married (Altieri & von Kluge, 2009). This realization contributed to anxiety about the future (Ogston, Mackintosh & Myers, 2011)

Dida, who is in her 50s, is seeing the results of her effort in training the other children to care for the child with autism. She states that the siblings have turned out to be protective towards their brother; this gives her the assurance that the child will be safe in the hands of his brothers when she dies.

*"I have trained my other children to treat their younger son as special. I slowly tried to inform them that it is their responsibility to care for him and now that they are old they have become so protective of him, which gives me assurance that our son will be safe even after we leave this earth" as verbalized by Dida.*

Parents who had only one child contemplated upon giving birth to another child who will take care of the child with autism in the later years. Havana, who had only one child, was advised to give birth to another child as seen in her statement below;

*"My family has been advising me to give birth to a second child, so he can take care of Tom when I age".*

Due to the responsibilities placed upon the siblings to the child with autism they grew to be more mature and more sensitive to the needs of their brother with special needs. The kind of expectation parents have in their other unaffected children such as to be high achievers makes them feel burdened (Griffith, Hastings & Petalas 2014).

#### **Subtheme 6: Delayed Diagnosis**

The average age at which Autism is diagnosed worldwide is four years though autism could be diagnosed as early as age two (Bios, 2014). In this study, reasons that led to late diagnosis included misdiagnosis by the doctors; most doctors gave the initial diagnosis of delayed development or delayed speech. It also emerged that parents dismissed evidence that would have led to an early diagnosis. At Kim's initial visit the doctor diagnosed language delay, it took a period of one year for the proper diagnosis to be made.

*"When Kim was five years we took him to a pediatrician who diagnosed Kim as having language delay when we went back after a year it was certain that Kim was Autistic" as verbalized by Cha.*

Parents such as Havana were just afraid to know what it was their child was suffering from. As in the case of Havana, the relatives even had to insist for her to take her son to the hospital.

*"Though it was evident that Tom had something wrong with his behavior, gestures, and how he interacted with other people it took me long to visit a pediatrician for the fear of the unknown but when he was 2.9 my relatives insisted that we should visit a pediatrician and when we finally sought medical Tom was diagnosed with Autism" as verbalized by Havana. (SS3)*

Being in denial and dismissal of other people's opinions and evidence that would have led to diagnosis were other factors that led to delayed diagnosis. Though the atypical behavior was evident in Havana's son, she disregarded her aunt's advice to visit a doctor.

*"When Tom was two years old we went to the province. That's when my Aunt noticed that Tom was not like any other kid. I didn't want to believe her though I could see him behave differently from other kids; he could not talk, or look at someone who is talking to him, he made weird sounds too" as verbalized by Havana (SS2)*



Misdiagnosis can delay the diagnosis and treatment of autism, which is currently based on DSM criteria observed by medical and psychological professionals (Chew, 2012). This delay hinders addressing a child's educational and other needs promptly. Early diagnosis and intervention are crucial for managing autism effectively, as starting treatment early promotes better overall functioning and independence in children by enhancing their communication, social, adaptive, behavioral, and academic skills (Eve, 2012; Erjona, 2013). Early therapy benefits the entire family by fostering the child's independence.

### **Subtheme 7: Difficulty Finding Appropriate Schools**

Parents were dissatisfied with the services they received at the public schools, leading them to seek more advanced schools that dealt solely with autism. Though they were expensive, all parents said it was worth since they could see significant improvement in their child. Tim, a father of two walked the rough road of looking for that school that will help nurture his child as seen in his statement below;

*"Getting an education for my son has been difficult. The special education school I first enrolled my child in, grouped all children with disabilities in one class yet each had different needs depending on his/her disability. I've been hopping from one school to another looking for the best school. The school my child is right now is simply the best, unlike the first public school my child started in where students are many and teachers few, the recent school offers quality services".*

From Tim's statement, it is evident that he was satisfied with his son's education in the private school, unlike in the previous school where the ratio of student to teachers is not ideal. Teacher's lack of supervision affects the performance of children. Luda observed this negative attitude in the teachers that handled her son as seen in her statement below;

*"In the public school where I enrolled my child, teachers that handle children are not passionate; they end up not bringing out the best out of our kids. They do whatever they do for money and not to help the pupils".*

Education plays a big role the life of every child, more especially in the life of a child with autism (Wilson, 2015). Therefore before choosing a child's education, it's important to consider the criteria that make an appropriate school fit for a child with autism (Wilson, 2015). Centers that care for the autism and the entire family will be of great benefit because autism affects the whole family at large (Matange, 2012).

### **Subtheme 8: Parent's Frustrations**

Most parents did not get over their depression quite easily; there were episodes where they vented their disappointment to their child and treated them badly. Since life takes a different direction than most parents expect after the diagnosis, parents became stressed and overwhelmed by their child's condition. This period is critical for parents that they need to be supported and educated about their child's conditions so they can accept the child with autism (Hayes, & Watson, 2013).

Havana, Cha, and Tim are often faced with periods where they lose their patience especially when they are overwhelmed by circumstances around them, and instead pour their anger on the child with autism as seen in the statements below;

*"I haven't gotten over my depression, I'm still angry with God, and when I'm agitated especially during my periods, I vent my anger on Tom" as verbalized by Havana.*

*"I find myself shouting at John when he does not listen to me yet I have other things to do. Especially now that he is older, I expect him to follow instructions" as verbalized by Cha.*

*"When I am overwhelmed with things around me I find myself shouting at Rony when he does not follow instructions" as verbalized by Tim.*

Autism is described as a condition with a greater number of stresses than any other disability (Bashir, Khurshid, Qadri, 2014). The findings of this study show that it was not an easy experience for parents to accept the reality as it presented. They struggled with frustration, rejection, and so many other challenges. This shows that parents with children with autism need support. The findings suggest that early interventions are crucial, both for the child with autism and their parents. Early intervention for parents will help prevent a potentially destructive build-up of anger that may lead to depression or possible abuse of the child (Matage, 2012).

### **Theme 3: Need for Social Support System**

Having a child with a disability is challenging, the hardships that parents go through as they try to find meaning in their child's condition bring them close together (Lickenbrock, Ekas, & Whitman, 2011). Parent's perception of the child's disorder determines marital adjustment; families that focus on positivity rather than negativity more social support is crucial during this time because it will help parents stick together (Lickenbrock, Ekas, & Whitman, 2011)

For Havana, having a supportive husband helped her through her depression as seen in her response below:

*"I have a very supportive and hardworking husband, who is helping me get through my depression and provides for our needs especially after I stopped working" .*

Cha like Havana was able to move on with the support from her husband.

*"I have a very supportive husband who has been with me throughout the challenges and despite how hard it was for me to move on after my child's diagnosis, he became the shoulder to lean on" as verbalized by Cha.*

Cris reported that their marriages became stronger due to facing challenges of ASD together.

*"Having a special child has strengthened our relationship with my spouse, I feel more attracted to her now than I ever did, the bond between us even strengthen with trials" as verbalized by Cris .*

Some families had members from the extended family come to help financially. Luda when asked about the positive and negative aspects of raising a child with autism replied by saying;

*"Taking care of Gabe is expensive as compared to the other kids that the extended family come to help when I'm defeated here and there"*

Yaya's (House helps) through their support in caring for the autistic child made it possible for couples spend time together. Cha stated that;

*"We still have enough time for my husband as a couple; this has been possible for us since we have had good 'yayas' that have helped us care for Kim during our dates" (SS11).*

Parents who spend time together are in a better position to deal with challenges, and their relationship becomes even stronger Santoso et al. (2015).

Parent support groups that emphasize sustaining couples' relationships during times of stress (rather than just focusing on their roles as parents) are beneficial for families with children with ASD. Support from family members and other people from the environment, the involvement of the father in the child care and understanding of the child's condition among extended family members is fundamental to mothers' resilience by easing their emotional and practical burdens Santoso et al. (2015).

Dida whose child with autism is 11 years had joined a support group. She says her circle of friends after diagnosis has widened to include parents with a child with autism.

*"My circle of friends widened after my child was diagnosed with autism to include parents with autism, we have formed supportive groups, and they have helped me a lot regarding coping" as verbalized by Dida.*

Joining a social support group will enable parents to share ideas with other parents with the same condition as theirs thus enabling them to increase in knowledge about the disorder and to pick up some of the positive attributes that have benefited other kids with the same condition as their child (Davis & Carter 2008).

#### **Theme 4: Blessings Amidst Difficulties**

No matter how disheartened each parent was by their child's condition, there was still one reason to smile, that one attribute in their child that kept them going, the rose among the thorns that lit up their spirit whenever they looked at their child with autism. For Gutu, her son is a blessing from God, which alone kept her positive as seen in her statement below:

*"I consider my child a blessing from God though the challenges are pressing I'm always positive" Gutu*

Havana and Tim developed positive virtues such as endurance and patience. Tim like Gutu considers his child with autism as a gift from God as seen in their statements below:

*"Endurance has become a virtue after raising my child with autism" as verbalized by Gutu*

*"My child has taught me to be patient, a virtue I would not have developed had I not been gifted with him" as verbalized by Tim*

Dida was pleased by the idea that his son will always be there with her since he won't be involved in any relationship as seen in her response below:

*"My son will be here to stay with me forever. Since he won't get married, he will forever remain mommy's boy" Dida chuckled*

As the saying goes, every dark cloud has a silver lining all parents saw something positive in their child with autism. They said he was a blessing from God; they turned to God to teach them how to live one day at a time no matter how pressing the situation around was.

## 5.0 Summary

The study found that focusing on the lived experiences of both mothers and fathers with children with autism addresses a gap in the literature, as most studies predominantly focus on mothers. It highlights the critical needs of these parents for information and emotional support, emphasizing that informed and sensitive nursing care can significantly benefit them. The research reveals shortcomings in public special education schools in Cebu City, Philippines, particularly a lack of facilities and an unfavorable student-teacher ratio. Many parents sought information online rather than consulting healthcare providers, indicating weak relationships between them. The study underscores the need for ongoing support for parents, especially during diagnosis and therapy, due to autism's lifelong nature requiring continuous intervention. It also identifies lack of knowledge, parental attitudes, and misdiagnosis as major factors leading to delayed diagnosis..

## 6.0 Recommendation

The study recommends that nurses and other healthcare providers focus on creating therapeutic relationships with parents of children with autism to facilitate open communication and the sharing of vital information. This approach will help parents comfortably express their fears and struggles, enabling healthcare providers to offer relevant and effective interventions. Continuous support from nurses during healthcare visits can prevent the build-up of anger in parents and protect children with autism from potential abuse.

To provide quality care in public schools, the study recommends that the government improve the working conditions of teachers by hiring more staff to meet the needs of enrolled students. This includes opening more classrooms and training additional teachers to specialize in educating children with autism. Addressing these issues will enhance the educational experience and outcomes for children with autism.

The study also recommends that mental institutions recognize the daily challenges faced by mothers of children with autism and understand that autism affects the entire family, including siblings. Therefore, interventions should target the whole family rather than just the affected child. Increasing public awareness about autism is crucial, and hospitals should distribute leaflets highlighting early detection and appropriate management. This broader awareness and understanding will benefit parents, families, and society as a whole.

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