

Journal of **Medicine, Nursing & Public Health**



ISSN Online 2706 - 6606



Stratford

Peer Reviewed Journals & books

Experience of Parents with Children with Autism in *Mandaue City, Philippines*

**Valerie Chepngetich, Chepketer Lily Ng'eno & Philip
Kimutai Sanga**

ISSN: 2706-6606

Experience of Parents with Children with Autism in *Mandaue City, Philippines*

¹*Valerie Chepngetich, ²Chepketer Lily Ng'eno & ³Philip Kimutai Sanga

¹Student, University of Kabianga, Kericho, Kenya.

^{2,3} Lecturer, University of Kabianga, Kericho, Kenya.

*Email of Corresponding Author: valerie8977@gmail.com

How to Cite this article: Chepngetich, V., Ng'eno, C., & Sanga, P. (2022). Experience of Parents with Children with Autism in Mandaue City, Philippines. *Journal of Medicine, Nursing & Public Health*, 5(1), 68 - 84. <https://doi.org/10.53819/81018102t6012>

Abstract

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. The study provided an understanding of the condition parents with a child with autism are in, and points out their greatest needs, which include the need for information regarding autism and emotional support. Nurses after knowing the challenges parents and the child with autism go through will be more sensitive and therapeutic when rendering care. The support that nurses extended will be more appreciated by parents with a child with autism, especially during their vulnerable times. Finally due to the limited knowledge parents have at the time of diagnosis nurses will be there to educate parents on the nature of the disorder and to answer their concerns. Nurses together with other health care providers should focus on creating therapeutic relationships with parents with a child with autism to open up channels for interaction and sharing of vital information. This way parents will be comfortable to open up their fears and their struggles with ease that will aid in giving relevant interventions. To be able to provide quality care in public schools, the government should work on improving the working condition of teachers by employing more teachers who meet the need of the enrolled students. More classrooms should be opened and more teachers trained to help children with autism.

Keywords: *Experience of Parents, Children with Autism, Mandaue City, Philippines*

1.0 Introduction

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).

The children with autism will benefit from this study since they will gain understanding from their parents in the world they live in. 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).

Hospitals and other assistive services will adjust their services to meet better the needs of both parents. Mothers and fathers react differently to parenting a child with autism; mothers tend to become more stressed than fathers (Davis & Carter 2008). They will also be more sensitive to the needs of parents whose autistic child is younger than they are to parents whose child with autism is older because high levels of stress are present in mothers when their children are quite young (Davis & Carter 2008). Hospitals and other assistive services will also be aware of the current available assistance to those affected, as well as services to be developed in future.

Mental institutions will understand the struggles parents with a child with autism go through and will start therapy not only for the child with autism but also for their parents. The well-being of parents dictates the well-being of their children, so their needs are of paramount importance as is for their child. However, there is limited related literature on the experiences of parents with children with autism.

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).

Parents have the responsibility of ensuring that their children are safe and must either care for them at all times or alter their schedules in such a way that they are home when their children are at home (Christensen, Schneider & Butter, 2011). Working parents find it impossible to spend adequate time with their children. The structure of the workplace especially today makes it impossible for parents to supervise their children's development, it is possible however for parents within autonomous jobs to communicate with their children during working hours as compared to the employees whose communication is monitored (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 and 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 of 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 and 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).

2.0 Research Methodology

This study used phenomenological qualitative research design. Phenomenology qualitative research is conducted to comprehend the contexts within which informants engage with an issue (Polit & Beck, 2004). The study was conducted at Cebu Kid's Center for Autism Foundation, Mandaue City along BasakLabogon road close to Basak Elementary school.

Snowball sampling was the sampling technique used in this study. An occupational therapist directed the researcher to some of her clients with children with autism who further introduced to the researcher to other parents who had a child that suffered from autism. This means that the subjects were recruited from existing acquaintances. The informants who were willing to participate in the said research shared their experiences without coercion. This sampling technique

led the researcher to nine (9) informants that were difficult to assess. The researcher stopped getting more informants because at the 9th informant data saturation point was reached. The researcher got the informants from Cebu kids Center in Mandaue.

Parents with autistic children ages 3-12 were recruited. Any parent (father/mother) that was willing to participate in the study and spoke English, irrespective of their educational attainment or socioeconomic status was included. The study excluded the siblings and the house help of the children with autism. Data was collected through the use of semi-structured face-to-face interviews. Formulated questions were used to guide the conversation. The informants were audiotaped to aid later in the transcription phase. The questions formulated were open-ended and provided the research informants an opportunity to express better themselves. A pilot study was conducted before the actual research that served as a trial run of the developed instrument (Polit & Beck, 2004) which yielded similar results to the actual study. Pre-testing the questionnaire helped ensure the validity of the study by making sure the questions are clearly understood. Research informants that participated during the pilot study were not included in the actual study.

The researcher did bracketing before data gathering. She examined her personal biases, experiences, past knowledge about the research topic to a fellow researcher. She later wrote all these biases down and kept a journal during interviews writing down every bias that arose.

The researcher requested an occupational therapist to refer her to some of the parents of her clients with Autism that met the criteria established by the researcher. The informants were contacted telephonically by the researcher to obtain consent and set up appointments. The researcher went to the venue suggested by the research informant that the interview should be conducted. The interviews were conducted in English depending on what the research informant was comfortable with. The researcher explained the nature of the study to the participants, including the risks and benefits that could arise as a result of their participation, they were then given the consent form to read and encouraged to ask questions on areas that they didn't understand before signing the consent form. Interviews that lasted for 30-40 minutes commenced after the consent form was signed. The questions allowed the participants to reflect on their experience. After the interview both the research informant and the researcher agreed on when the next interview will be.

Nine (9) informants were interviewed, six (6) female, (3) male. At the time, the researcher had finished interviewing the 9th informant she had already reached the saturation point, and there was no need for further data collection.

The following steps, representing Colaizzi (1978) process for phenomenological data analysis were utilized: (1) Transcribing all the subjects' descriptions. In this part of the analysis process, participant narratives were transcribed from the audio-taped interviews held with each. According to Colaizzi's (1978) process, the narratives do not need to be transcribed verbatim, as long as the essence of what the participant was communicating is caught in the transcription. Individual transcriptions of the interview are then validated by the respective participant on the date the researcher and the informant would have agreed upon; (2) Extracting significant statements by leaving out statements that do not directly relate to the phenomenon under investigation. Colaizzi (1978) noted that any statements in the participants' narratives that relate directly to the phenomenon under investigation are considered significant. Significant statements are extracted from each of the narratives and numbered; (3) Creating formulated meanings: In this stage of analysis, Colaizzi (1978), recommends that the researcher attempts to formulate more general restatements or meanings for each significant statement extracted from the participant's narratives;

(4) Aggregating formulated meanings into theme clusters: Colaizzi (1978) suggests that the researcher assign or organize formulated meanings into groups of similar type.

In other words, the formulated meanings are grouped into theme clusters; (5) Developing an exhaustive description. A comprehensive description is developed through a synthesis of all theme clusters and associated formulated meanings explicated by the researcher; (6) Researcher interpretative analysis of symbolic representations from the articulation of the symbolic representation (which occurred during the participant interview); (7) Identifying the fundamental structure of the phenomenon. The fundamental structure refers to 'the essence of the experiential phenomenon as it is revealed by explication' through a rigorous analysis of the exhaustive description of the phenomenon; (8) Returning to participants for validation. A follow-up appointment is made between the researcher and each participant for the purpose of validating the essence of the phenomenon with participants. Any alterations are made according to participant feedback to ensure their intended meaning is conveyed in the fundamental structure of the phenomenon. Integration of additional information provided by participants for inclusion into the final description of the phenomenon occurs at this point.

The researcher stopped gathering data once data saturation was reached, which was determined when themes and categories in the data become repetitive and redundant such that no new information could be obtained by further data collection (Polit & Beck, 2004).

Moral standards were maintained throughout the course of the study by putting careful attention to issues of recruitment, written consent, confidentiality, anonymity, potential vulnerability, and sensitivity. The purpose of the study was thoroughly explained; informants answered questions that they were comfortable with, without any element of force, fraud, deceit, duress, an ulterior form of constraint or coercion. Each informant was oriented to the research and informed that the interview will be in two sessions the second session will be after data transcription and was basically for validation. The informants were also informed about the benefits and risks of the study before being asked to sign the consent form.

It was possible that the informants could elicit mild psychological distress as the process of sharing their journey in raising an autistic child will bring to memory some memories they would rather avoid sharing. The informants were asked to take breaks between the interviews in case they became overwhelmed with sadness. Informants, whose distress level became intolerable, were referred to a psychologist. The informants benefited from this study in the sense that through sharing of their experiences and feelings they were able to examine themselves and accept their children with special needs. Through sharing, they gained insights into their feelings and how it affected their care to the autistic child. This helped them deal with their difficulties and learn to accept the challenges in taking care of a child with special needs.

To maintain anonymity, the researcher gave each informant a pseudo name for each informant to protect their identity. Only the researcher was able to access the recorded and the written information shared by the informant. The researcher was true to what they agreed with her research informants; that was to dispose properly of any data gathered after her final defense. Removal of data from the USB, memory drives, and written accounts were kept with utmost anonymity and confidentiality. All the data were completely deleted in all storage drives after the researcher had presented her final defense.

3.0 Results and Discussions

This section 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, two 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.

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 take them, to be exactly like them or even better (Grohol, 2015). When the bitter reality of how things have turned out takes a toll in 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 the results of a study by Rivard et al. (2014) which showed that both mothers and fathers reported a higher level of stress after 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

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

Atypical behavior is the irregular or abnormal behavior that is seen in children with autism. Parents in this study reported being unaware of the abnormal behavior in their child. First-time mothers and fathers thought some of the behaviors such as delayed speech and lack of eye contact were normal; it took someone different to point to the parents the abnormality in their child's behavior. In Luda's case, the doctor realized the atypical behavior after the child fell from the second floor. This finding indicates that were it not have been for the accident; Luda wouldn't have sought medical attention concerning symptoms that related to autism. When asked how she became aware of Gabe's condition this is what she had to say;

"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 and Petalas (2014) revealed 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 tend to develop a sense of maturity and take pride of greater sense of responsibility faster than their peers because of the responsibility placed upon them by their parents to care for the child with autism (Griffith, Hastings & Petalas, 2014).

Autism disorder impacted all family relationships, including parental ones with non-affected children in the family. These results are similar to other studies such as; (Boushey, 2001; Roth, 2001) where informants felt that they were neglecting their other children because of the attention accorded the child with autism. Special attention needs to be given to parent-child relationships within the family to avoid feelings of resentment and rivalry towards the child with autism that may affect the sibling relationship, as well as to nurture a parent-child bond for all children (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 (Altiere & von Kluge, 2009). They were not going to have a carefree childhood,

university studies or even get married (Altiere & 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 is a potential problem of delayed diagnosis (Chew, 2012). Scientists are seeking a biomarker for autism, but currently neurodevelopmental disorders are diagnosed based on the observations of a team of medical and psychological professionals according to criteria in the Diagnostic Statistical Manual (DSM) (Chew, 2012). Later diagnosis leads to delay in addressing a child's educational and other needs (Chew, 2012).

Early diagnosis is vital for managing autism, a child with autism can better thrive if treatment is started early (Eve, 2012). Although there is no cure for autism, the goal treatment is to improve the overall functioning of a child by promoting the development of communication, social, adaptive, behavioral, and academic skills as well as lessening maladaptive and repetitive behaviors (Erjona, 2013). Findings showed that starting therapy early is crucial for the entire family; children get to attain a certain level of independence that allows them to function on their own.

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).

Implications and Recommendation

This research has contributed to the gap in the literature by focusing on the lived experience of both mothers and fathers with a child with autism since most studies have focused mainly on mothers. It also provides an understanding of the condition parents with a child with autism are in, and points out their greatest needs, which include the need for information regarding autism and emotional support. Nurses after knowing the challenges parents and the child with autism go through will be more sensitive and therapeutic when rendering care. The support that nurses extended will be more appreciated by parents with a child with autism, especially during their vulnerable times. Finally due to the limited knowledge parents have at the time of diagnosis nurses will be there to educate parents on the nature of the disorder and to answer their concerns.

Nurses together with other health care providers should focus on creating therapeutic relationships with parents with a child with autism to open up channels for interaction and sharing of vital information. This way parents will be comfortable to open up their fears and their struggles with ease that will aid in giving relevant interventions.

To be able to provide quality care in public schools, the government should work on improving the working condition of teachers by employing more teachers who meet the need of the enrolled students. More classrooms should be opened and more teachers trained to help children with autism.

Mental institutions that deal with different mental disorders should be aware of the challenges mothers face from the day to day basis. They should know that autism affects the entire family including siblings; therefore interventions should focus on the entire family rather than the affected child only.

REFERENCES

- Ahern, K. (2000). "Something is wrong with my child": A phenomenological account of a search for a diagnosis. *Early Education and Development*, 11, 187-201. https://doi.org/10.1207/s15566935eed1102_4
- Altieri, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors in parents of <https://doi.org/10.1007/s10826-008-9209-y>
- Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report (MMWR)*. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w
- Bashir, A ,khurshid, S , &Qadri, F . (2014) Awareness and problems of parents of children with autism spectrum disorders.*International journal of interdisciplinary research and innovations* (2). pp. 42-48
- Bluth,K. Roberson,P.Billen,R.and Sams,J.(2014) A Stress Model for Couples Parenting
- Boushey, A. (2001). The grief cycle-one parent's trip around. *Focus on Autism and Other Developmental Disabilities*, 16, 27-30. <https://doi.org/10.1177/108835760101600107>
- Chew, K. (2012). Autism diagnosis often delayed for African-American children. *Care2*. Retrieved from: <http://www.care2.com/causes/autism-diagnosis-often-delayed-for-african-american-children.html>
- Children With Autism Spectrum Disorders and the Introduction of a Mindfulness children with autism. *Journal of Child and Family Studies*, 18, 83-92.
- Christensen, K., Schneide, B., & Butler D, *Parent roles in their children's lives: Supervision content/uploads/2014/11/Autism-Worldwode-2012.pdf*
- Davis. N. O. & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278-91. doi:<http://dx.doi.org/10.1007/s10803-007-0512-z> <https://doi.org/10.1007/s10803-007-0512-z>
- Ekas, N.Timmons, L.Pruitt, M. Ghilain,C. &Alessandri, M.(2015) The power of positivity:
- Erjona, D. (2013). Parental stress in families of children with disabilities.*Journal of educational and social research*. 3(7) <https://doi.org/10.5901/jesr.2013.v3n7p579>
- Eve, G. (2012). Catching autism early.*American psychological association*. Retrieved from: <http://www.apa.org/monitor/2012/10/autism.aspx>
- Griffith, G. M., Hastings, R. P., & Petalas, M. A. (2014). Brief report: Fathers' and mothers' ratings of behavioral and emotional problems in siblings of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(5), 1230-5. <https://doi.org/10.1007/s10803-013-1969-6>
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism

- spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629-42.
<https://doi.org/10.1007/s10803-012-1604-y>
- Intervention.HHS public access. <https://doi.org/10.1111/jftr.12015>
- Matange, B. (2012) .An Exploration of the Lived Experiences of Mothers Raising Children with Meyer, K. A., Ingersoll, B., &Hambrick, D. Z. (2011).Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 1413-1420. <https://doi.org/10.1016/j.rasd.2011.01.027>
- Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children parenting stress. *Gateway*. Retrieved from:http://pediatrics.aappublications.org/content/119/Supplement_1/S114
- Phetrasuwan, S., & Miles, M. S. (2009).Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing*, 14(3), 157-65. Retrieved from http://search.proquest.com/docview/195757733?account_id=141440 <https://doi.org/10.1111/j.1744-6155.2009.00188.x>
- Polit, D.,& Beck, C. (2008) *Nursing research: generating and assessing evidence for publishing*. Predictors of relationship satisfaction for parents of children with autism spectrum disorder. *Journal of Autism and disorders*, 2015; 45 (7): 1997 <https://doi.org/10.1007/s10803-015-2362-4>
- Rivard, M., Terroux, A., Parent-boursier, C., & Mercier, C. (2014).Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609-20. <https://doi.org/10.1007/s10803-013-2028-z>
- Roth, P. H. (2001). A mother's account. *Focus on Autism and Other Developmental Disabilities*, 16, 17-19. <https://doi.org/10.1177/108835760101600105>
- Santoso, T. B., Ito, Y., Ohshima, N., Hidaka, M., &Bontje, P. (2015). Resilience in daily occupations of indonesian mothers of children with autism spectrum disorder. *The American Journal of Occupational Therapy*, 69(5), 1-8. Retrieved from<http://search.proquest.com/docview/1711617458?accountid=141440> <https://doi.org/10.5014/ajot.2015.017566>
- Schieve L, Blumberg S, Rice C, Visser S, & Boyle C (2007) The relationship between autism and Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167-78. <https://doi.org/10.1007/s10803-009-0844-y>
- Stephen, K. (2007). Parents are powerful role models for children. *Parenting exchange* Retrieved from: <http://www.easternflorida.edu/community-resources/child-development-centers/parent-resource-library/documents/parents-powerful-role-models.pdf>