

ANALYSIS OF THE LIVED EXPERIENCES OF FILIPINO PARENTS OF CHILDREN WITH ASD

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ABSTRACT

Parents having a child diagnosed with Autism Spectrum Disorder (ASD) face a lot of challenges thus making them more susceptible to experience higher levels of stress and deal with more complex situations. This research aimed to investigate this context in a Filipino setting and as well as classify the uniqueness of their parenting style compared to typical counterparts. The phenomenological approach of qualitative research was utilized to explore the lived experiences of underprivileged parents who have ASD children. This study was participated by three Filipino underprivileged mothers with ASD children. In-depth interviews were conducted; thematic analysis was utilized. Three major themes in their experiences have been derived namely: parenting caught off guard, parenting strains and struggles of ASD childcare and parenting the unique spectrum. Implications for future research to parenting education, the fields of education and mental health have also been discussed.

Keywords: Autism Spectrum Disorder, ASD Parenting, Parents, Children

INTRODUCTION

Parenting has been a challenging task due to its complexities in rearing a child, yet it is twice as much to those who have children diagnosed with ASD. Having to care for a child with special needs can affect the equilibrium of the family's state. Parents have difficulty balancing work and their family life.

Compared to other conditions, parents who take care of ASD children reported a higher degree of stress unlike with other disorders. This has been attested by the findings done by Ren et.al. 2020, when analyzed with typical children; with down syndrome (Hastings et al. 2005a) and other disabilities (Perry et al. 2005) as cited in the study of Lyons and associates (2010).

Additionally, having to care for a child with special needs is quite demanding and stressful for families, especially for the parents (Akturk & Aylaz, 2017). Their source of stress can be from the condition itself or the additional financial demands

(Bitsko, et.al., 2016) as a child with ASD requires a special type of care and attention that typically developing children may not need and requires additional expenses for the child's treatment and maintenance.

Some studies also mentioned that parenting an ASD child is complex in nature. Ventola and colleagues (2017) had explained that there is a complex history that lies beneath ASD parenting. This has been caused by referencing the theory of Kanner (1943) that mothers were to blame why children have ASD. Stating the notion of the theory, it was presented that autism is due to "refrigerator mother", a mother who is cold and unemotional.

Family dynamics and equilibrium are often considered as struggles because of the unique needs of a family member with ASD (Ślifirczyk, et.al., 2016). Some members, especially mothers give up work or are likely to work lesser hours to cater the needs of their child with ASD (Morris, 2014).

The American Pediatrics Academy is recommending that universal screening be implemented by ages 18-24 months (Christensen et.al., 2016) however, since not every family have access to a specialist nor a professional health care provider, some children may get delayed or even non-confirmation of this diagnosis at all. Socio- economic differences can be a factor in delayed diagnosis as those belonging to higher income families tend to be more acceptable of mental health conditions and clinicians are more likely to refer a child for diagnosis if the child belongs to this type of family (Houtrow, et al., 2014) thus it has been found that delayed ASD diagnosis are more prevalent in racial and ethnic minorities (Jo,et.al., 2015), lower income families, and those living in under-resourced or rural areas (Daniels & Mandell, 2013). This implies that the additional financial, emotional, and social demands of having a child with ASD can be particularly more difficult for families with limited resources (Kerns, et.al., 2017). Research have shown that social support provides positive influence on the family caring for a child with special needs, particularly on better relationship quality (Yamaoka, et.al., 2015) and helps in accepting the child's condition (Kilic, et.al., 2013). It has been highly recommended that these families' level of support be assessed and encouraged to strengthen and be further developed such as in the form of parental support groups (Paynter, et.al., 2013) as most parents feel there is a lack in community support for their type of family (Jovanova & Radojichikj, 2013) and many are turning to the internet for information and emotional support (DeHoff, et.al., 2016).

It has also been found that given the opportunity to access family treatment sessions, families with children with ASD will participate and continue treatment regardless of demographic background (Carr & Lord, 2016; Carr, et.al., 2016). Families with higher income were also found to have lesser difficulties in accessing services and treatments compared to families with lower income (Hidalgo, et. al. 2015).

Given these, this paper focused on highlighting the different experiences of selected parents of ASD children, particularly in the Philippine setting. More so, it provided additional information on to what extent the level of care thus

these parents provide as compared to rearing a typical child including unique challenges and how they go about it.

OBJECTIVES OF THE STUDY

This study was conducted to 1) identify the experiences of ASD parenting in the Filipino context; 2) examine the challenges and demands experienced by parents in child rearing; and 3) determine the unique parenting capabilities of parents of children with ASD.

METHODOLOGY

In this study, the phenomenological approach of qualitative research methodology was utilized to explore the lived experiences of underprivileged parents who have ASD children. The participants of this study are three (3) mothers and married. Two of them are working while taking care of their child with ASD and the other one is a full-time housewife and earning is below the poverty threshold in Metro Manila. All of them voluntarily agreed to participate in the interview which was conducted during their most convenient time and schedule.

A demographic profile questionnaire and an interview guide question were formulated prior to the start of the interviews. Different practitioners and experts on the field of Autism Spectrum Disorder and research validated these prior to the start of the data. The instrument was translated in Filipino for the participants' better understanding of the questions.

Then, a consent form and assurance of confidentiality of the participants were obtained prior the interview session. The participants were not coerced to answer any questions which they found uncomfortable to answer. All the interviews collected and transcribed for analysis.

After transcribing all interviews, the researchers reviewed and analyzed similar and unique experiences of the participants. The researchers coded these data along with a description in a tabular form. Next, these were identified in two categories: (1) *challenge/demand* and (2) *capabilities*. These categories were based on Patterson's (1988) model on family adjustment

and adaptation. Within these two categories, the codes were further identified into subcategories. These codes and data were constantly reviewed and checked to ensure correct classifications, reliability, and cohesiveness of the subcategories.

Anonymity and confidentiality were strictly observed. There were also no monetary rewards given to the participants and engaging in this research is purely voluntary.

RESULTS AND DISCUSSION

In this paper, three (3) major themes and seven (7) minor themes were derived from the observed patterns in the responses. The major themes provide the overview and summary of the experiences of a mother in a poor household raising an ASD child. The following themes are presented herewith:

1. Parenting caught off guard

All parenting journeys disclose beautiful stories of carrying a child inside the mother's womb, noting all milestones and keeping tabs of the development of the child until they finally grow into a young adult. But not everyone has normal parenting experiences especially when the parents need to attend to the special needs of their child. The first theme discusses the beginning journey of the mothers' life having an ASD child: their extraordinary experiences of seeing their child, learning about their child's condition and accepting the condition as a lifelong journey for them, as parents.

Minor Theme: (Mis) Assuming the typical parenting role

Like any parents, the participants also have a story to tell during the time before they become mothers. They were living a normal, yet simple life and making the most out of it by fulfilling their dream career, being productive and enjoying their single life to the fullest with their friends. One mother has to say, "simple, typical na single, nagwowork may friends" (simple, typically single, working and with friends). This shows that even though they are not financially stable, living a simple and normal life gives them happiness.

This statement is said to be a typical response from these mothers due to the unnoticeable nature of the disorder that leads to poor understanding the problem for both children and parent thus affecting family life and more exposure to crises. (Pisula & Porebowicz-Dorsmann, 2017).

Minor Theme: (Mis) Assuming the typical child

This minor theme exposes how the mothers observed their child with ASD prior to knowing the specific condition that their child has. One mother told us that before she realized that her child has ASD, she said that her child projects positive behaviors before, she has to say, "napakabit, simple na bata, wala ka nang hahanapin sa kanya, masunurin, trying hard makasurvive sa case niya" (very kind, simple child, there is nothing I could ask for my child, obedient, trying hard to survive the case). The other mother said that her child looks just like other kids and smart, except that she sensed that her child has problems in dealing with others, she had to say, "Kung titignan siya, walang makakaisip na may ASD sya. He looks good (physically). He's a smart boy except hindi sya masyado nagsasalita to socialize" (At a glance, no one will think of (the child) has ASD. He looks good (physically). He's a smart boy except he is not talking much to socialize.) In this minor theme, it was shown how some mothers see their child's observable behaviors as typical. However, there were some behaviors which directly affect the child's social behavior which call the parent's attention and seek professional help and advice.

As parents, they cannot get away with what challenges are given to them, especially when it comes to their children. One of the parents of an ASD child initially wishes that what they are experiencing is just temporary. The feeling of denial did not leave them up to now, one mother has to say, "denial nung una na sana lagnat lang, pag uminom ng gamot, wala na. 15 years, in denial ako, pero tuloy lang yung therapy. Tanggap namin siya pero may denial pa din, ayoko dahil ginawa ko naman lahat" (Denial at first, hoping that it is just a fever that when you take medicine, it will be cured. Fifteen years, I am in denial, but we continue the therapy. We accept it but denial is still present, I

do not agree because I did everything). However, when reality strikes to them, they do not have any other choice but to accept the challenge and embrace parenting to their ASD child with their whole heart, one of the mothers has to say, *“in denial at first then acceptance.”* This journey is never easy for them, or for anyone. But with the right mind set, acceptance and faith in God, they were able to embrace it.

Minor Theme: Gripping the parenting journey

In this theme, mothers shared their experiences upon knowing that their child has a condition, and it was ASD. One of them slowly began comparing and observing other behaviors of their child with other children of the same age. One mother has to say, *“akala ko nung una, late magsalita lang; at age of 2, wala pa siyang napronounce na word”* (At first, I thought it was just delayed speech; at the age of 2, still (child) had not pronounced a word). Apart from that, these parents see some differences such as having delayed speech, no or limited eye contact, has their own world, does not socialize and has poor communication skills which were common characteristics of a child with Autism Spectrum Disorder (ASD). Upon knowing from the developmental pediatrician, the parents do not have any other course but acceptance.

This finding is supported by the reason that the difficulty in adjustment for parents may be compounded because the children rarely receive a diagnosis before the age of 4 (Pisula & Porebowicz-Dorsmann, 2017).

2. Parenting strains and struggles of ASD childcare

This theme focuses on the concerns, challenges and problems the mothers of ASD children have encountered along their parenting journey. Parenting is not an easy life to choose. It requires love, passion, devotion and everything that one is willing to give from those couples or people who chose this path of life. However, the already difficult life becomes more difficult when the usual parenting challenges are added with the lifetime needs and demands of the child with ASD.

These challenges do not just involve personal or societal challenges, but also financial difficulties.

Minor Theme: Blocks to Treatment

Autism spectrum disorder (ASD) is a set of neurodevelopmental disorder characterized by a limited social behaviors and nonverbal interactions that can be observed in the first three years of life. (Park, H. et. al., 2016). Moreover, there is no known medication that cures this condition which makes it difficult to handle (CDC, 2022). For this reason, it affects the quality of life of the family, specifically, the parents because their child requires different kinds of treatments that cost so much. Parents, no matter how difficult it would take on their part, would sacrifice their time, effort, and money to make their child live a normal life as they grow older through the help of treatments. Treatments that are commonly required for children with ASD are medication, and occupational and speech therapy. The treatments which include several times visiting the Occupational therapists and Speech therapists for a week costs the parents a lot, a mother has to say, *“tatlong sessions of occupational therapy per week at isang session of Speech Therapy per week”* (Three session of occupational therapy every week and one session of Speech therapy every week.) One parent had to sacrifice her job to attend to her ASD child’s treatment.

Minor Themes: Regret and guilt

Parents of ASD, like other parents, are also human. And even if they are caring and rearing their own child, who keeps on trying to give their best to support their child, they themselves can also be a source of challenges and difficulties. As human beings, they feel negatively with what their child became, denial, pain, and regret covering their hearts, as one mother has to say, *“Nanghihinayang ako”* (I regret.) As time goes by, their ASD child required more from them and one is more attention and being more careful in handling their child, one mother has to say, *“Mas naging maingat ako sa kanya at mas nabigyan pa ng atensyon na kailangan niya”* (I became more careful to him (child), and I gave attention he

needs.) ASD children need longer patience as they have slower ability to grasp and understand what is being told to them. Parents of ASD children change and develop into a person needed by their child even to the point of losing themselves in the process.

These findings are supported by Gau et. al (2010) as cited in the study of Ventola, and associates (2017) that parents of ASD children are less affectionate and more psychologically controlling compared to their typical counterparts.

Minor Theme: Financial Challenges

Becoming aware of the child's condition is not easy to handle. But being a less fortunate parent gives an additional problem in their journey. The parent's financial status is being challenged because of the additional expense required from them to raise an ASD child while they are merely capable of providing for their basic needs, one mother has to say, "*mas naglaan kami sa mga pangangailangan niyang pinansyal*" (*prepared for the financial needs*).

These responses are supported by the findings done by Parish and colleagues (2015) wherein they had identified that families were shown to spend more out-of-pocket expenses related to their child's condition compared to other families. Likewise, the diagnostic and treatment of ASD is costly among behavioral and neurodevelopmental conditions (Durkin, et. al, 2017).

3. Parenting the unique spectrum

This major theme reveals that the parenting journey of a mother with an ASD child does not stop when the parent finally realizes the condition of their child and provides the needs and treatment of the child. It is still a very long journey of parenting, raising, rearing and caring for their ASD child. It is unending. Parents of ASD children continue with their duties and responsibilities of teaching their child the necessary life skills. Parents also realize that their life is unpredictable, so they find ways and other support for their child with ASD even after their time has passed on earth.

Minor Theme: Similar but unique parenting strategies

In the interview, one parent said that it is a "*gift*" to rear a child with ASD. This is because it teaches one extraordinary lesson in life that not everyone is given a chance to experience. Teaching specific task to a child with ASD is quite challenging and needs longer patience and attention. One example is when explaining something, "*Pag eexplain lang kay Boy X (the ASD child), kailangan paulit ulit, dun sa isang anak, isang sabi lang*" (*When explaining to Boy X, it has to be repeated several times, unlike with my other child who could understand it in just one saying.*) Mothers tried their best to give equal attention to each one of their children in the family, but to no avail, they end up giving more to their child with ASD, To minimize jealousy among other siblings with the special attention she gives to the child with ASD, the mother explains to them the needs of their sibling with ASD and maintain equality. No matter how they tried to give fair and equal attention to their normal children and the child with ASD, mothers cannot help but still give more attention and care, "*Mas maatensyon na pag aalaga at pagtingin sa kanya.*" In other words, rearing a child with ASD requires specialized attention, care, and patience.

This is attested by the findings by Ku, Stinson & MacDonald (2019) citing the research of Baker et al. 2010, that responsiveness, nurturance, affection are components in rearing their ASD children and had been found out that it is also similar to their typical counterparts.

Minor Theme: Importance of support to parenting

This theme explains that part of the parenting journey is their vision of their ASD child's future, as part of their moving ahead of their experiences. In this part, mothers greatly recognize the role of support in the life of their child with ASD. Support which may not just come from them, as parents and immediate family members, but also support coming from the expert and professionals and from other relatives, like grandparents, *tito* and *tita*. They look for the support from the teachers and therapist to help the child with ASD develop better. They also reach for the support from other relatives to provide for the help needed by their child with ASD in their

absence, one mother has to say, “*magtulong-tulong pa para maalagaan at masuportahan at maibigay and mga pangangailangan niya*” (We are helping each other in looking after and providing support and needs.) Mothers with ASD children, lean on their husband or partner in terms of financial support and companion.

It has been inferred that parent have become more aware and involved in their child’s condition, treatment and may serve as the primary delivery of treatment (Ventola, et al., 2017).

CONCLUSIONS

This study identified that Filipino parents with ASD child experience challenges when it comes to detect its occurrence at the early onset of child rearing. Evident factors that parents experience is guilt, regret and not detecting early the condition. Moreover, the parenting takes time for parents who have children with ASD. Lastly, the uniqueness of ASD parenting, specifically in the Filipino context involves treating the child as a special gift and importance of continuous support from relatives.

RECOMMENDATIONS

Based on the collected responses from the participants, its patterns and articulated themes, the researchers formulated the following recommendations:

Education. Parents must expand their knowledge in parenting not only with typical child but even with children diagnosed with developmental disorder. Thus, it shall allow them to adapt easily and can provide opportunities to anticipate future problems and identify possible resources to address the concerns. Furthermore, this must be also well-emphasized in the curriculum to be aware of the different relevant issues on parenting to both typical and atypical children.

Counseling and Psychology. Given this context, practitioners shall design preventive and intervention programs to parents in alleviating negative feelings of parenting especially with ASD

children. The programs must include stress coping strategies, available social services, basics of ASD and other developmental disorders, and maximizing competencies of being a parent. Moreover, more extensive counseling sessions shall also be established in order to have easier way of adapting to the situation for both the child and the parent.

Extensive Social Services. With collaboration to local and national government units, this paper can be a basis for reviewing or crafting relevant policies in intensifying social services to parents and children with ASD. This can be in a form of programs related to accessibility in health and basic social services, psychological and physical safety, and human rights and social justice advocacy programs.

Research. Published research and literature about the lived experiences of parents with ASD children were limited in numbers and future studies are required to validate the findings from this study. Therefore, additional research this topic and other disabilities would be beneficial as this literature is very limited.

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Angelbert Z. Hernandez, MA., is a registered psychometrician, a registered guidance counselor and a licensed teacher. He also earned certifications such as Certified

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Marilou B. Francisco, Ph.D., is a graduate of BS in Psychology from St. Paul University, Master of Arts in Psychology, and Doctor of Philosophy in Guidance and Counselling from the University of

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Ma. Laarni D. Buenaventura, MAEd., is a graduate of BS in Psychology from La Consolacion College Manila as one of the recipients of Drilon Academic Scholarship where she graduated

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Melchor S. Siena, Jr., is a graduate of Bachelor of Arts in Psychology at the National Teachers College. He is currently writing his thesis for his degree of Master of Arts in Special Education with specialization on Autism and Mental Retardation at the University of Makati. At present, he works as a Values Education Teacher at Potrero National High School where he also serves as the Coordinator for Testing Programs.



Red Honeylee G. Valencia, is currently working as a Technical Assistant in Philippine Normal University, where she graduated Cum Laude with a degree of Bachelor of Secondary Education

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