

A phenomenological study of the lived experiences of families of children with autism in the Philippines

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ABSTRACT

Based on the data provided by the Autism Society of the Philippines (2018), it is estimated that around 1.2 million Filipinos, constituting 01 out of every 100 individuals, are affected by autism. This high prevalence poses significant challenges, particularly for parents who are raising children with autism, as they grapple with the lifelong developmental issues associated with the condition. Recognizing the pressing need for support, the Philippine Senate has taken notice of this matter, and senators have proposed the establishment of a National Center for Autism (Torregoza, 2023). In light of this context, the present study aims to delve into the lived experiences of family members, including parents, grandparents, and other relatives, who provide care for children with autism. The study aims to capture the critical experiences of families raising children with autism, focusing on stress, burden, ambivalence, and hope through qualitative interviews. By analyzing narratives within the framework of intensive motherhood ideology, this paper delves into caregivers' lived experiences and how they relate to these themes. The study incorporates seven participants whose interviews are recorded and transcribed. Codes are then derived from the transcriptions, and subsequently, themes are developed. The findings of the study reveal the resilient sense of hope that families maintain despite the numerous struggles, burdens, and ambivalent emotions they encounter in their journey with autism.

1. Introduction

Data from the Autism Society of the Philippines estimates that 1.2 million Filipinos, or 01 in 100 individuals, are affected by autism (Autism Society of the Philippines, 2018). This high prevalence poses significant challenges, particularly for parents who are raising children with autism, as they grapple with the lifelong developmental issues associated with the condition.

A comparison between parents of children with autism and parents of typically developing children revealed that those with autistic children experience greater levels of physiological stress (Costa et al., 2017). Also, previous studies reveal that mothers of children with autism reported being overloaded with emotional and physical burdens, experiencing helplessness and even depression (Aguilar & Ponde, 2019; Hall, 2011; McStay et al., 2014). Woodgate et al. (2008) categorized the stressors encountered by parents of children with autism into two: stress directly linked to the inherent challenges of raising a child with autism, while the second category of

stressors pertains to the social isolation and stigma that parents often encounter. Dunn et al. (2001) provided a comprehensive source of stress, which includes financial strain, limited support from family and friends, difficulties in accessing services for their child, and challenges related to their child's behavior and communication. Carr and Lord (2016) explored the challenges and experiences of Filipino parents raising children with autism. Also, they found out that the journey entails confronting financial strain and emotional toll, including feelings of guilt and regret for not identifying the condition soon, which can lead to stress and anxiety. According to Mabena et al. (2015), having children with autism can also impact family dynamics. For instance, parents experience isolation and difficulties communicating effectively with their children. At the same time, siblings may encounter relationship challenges and feelings of neglect due to the attention directed toward the child with autism. Parents of children with special needs may undergo emotional reactions akin to those associated with bereavement, and some may even experience enduring grief (Benderix et al., 2007).

The quality of life of children with autism and their parents is affected by the experience of stigma and poor understanding of their children's condition (Carr & Lord, 2016). Parents of children with autism experience being unfairly judged or criticized for their child's behavior, and they could struggle for acceptance and support from others (Woodgate et al., 2008). Caring for a child with autism also impacts the social relationship of caregivers because of the substantial amount of time commitment required in caring for their children with autism (Walga & Yohannes, 2023).

Despite the social condition of children with autism, their family draws hope from the availability of support from relatives to help them cope with their problems (Carr & Lord, 2016). Social support is essential for families raising children with autism to access interventions such as behavioral and speech therapies that may help improve the child's development progress (Catubigan, 2023; Mabena et al., 2015; Siklas & Kems, 2007). Research has shown that maternal stress tends to be reduced with increased levels of social support, whereas lower levels of social support are linked to higher levels of emotional stress (Pepperell et al., 2018). Since the journey of mothering children with special needs necessitates the availability of social support, Portuguese mothers confronted this challenge. They crafted the script of mothering to include advocating for recognizing children with autism as children of equal worth (Lo Bosco, 2021).

Families of children with autism use a range of strategies to manage the stress associated with their child's condition. According to Woodgate et al. (2008), these strategies include preserving healthy relationships with their partner or spouse or allocating quality time to their other children. In addition, Pepperell et al. (2018) found out that mothers of children with autism report more significant use of emotion-focused coping strategies characterized by managing the emotional aspect of stress, while fathers use problem-focused strategies that include methodological intervention strategies. On the other hand, when parents use particular coping strategies, such as distancing and escaping in dealing with the stressors they face, they may instead experience higher levels of depression and social isolation, especially when they perceive their control of the situation as limited (Dunn et al., 2001).

Portuguese mothers of children with autism approach the issue from a distinct perspective. They acknowledge the significance of diagnosis in managing their children's needs, extending their efforts from personal coping. They believe that raising a child with autism entails mastering the complexities of navigating public welfare and healthy bureaucracy, as well as understanding educational programs and special education services (Lo Bosco, 2021).

Prior research has outlined the myriad stressors caregivers of autistic children endure, affecting their well-being, social ties, and family coping. A phenomenological approach extends this, considering contextual elements like family dynamics and socio-economic status. This inquiry also examines how the “good motherhood” ideal influences caregivers’ experiences, framing their roles within an idealized motherhood construct.

This study investigates the experiences of caregivers of autistic children, exploring their journey from diagnosis onward. It emphasizes challenges, coping strategies, and hopes for the future within the framework of intensive motherhood ideology.

2. Theoretical basis

The “good mother” concept historically and culturally shapes women’s identities, practices, and decisions profoundly (Ross, 2016). This ideology expects good mothers to provide nurturing and caring responsibilities toward their children (Barlow & Chapin, 2010). Hays (1996) coined intensive mothering theory, framing women’s behavior and role expectations within good mothering ideals. Critics find the standards unattainable, socially constructed, and fulfilling a perceived intrinsic calling (Gajardo & Otienza, 2017). Ennis (2014) defines intensive mothering as a cultural ideology demanding mothers invest substantial time, energy, and resources into childrearing. This framework aligns with “new momism”, where a woman’s fulfillment relies on her maternal role.

This study explores caregivers’ experiences with autistic children, focusing on their perceptions of caregiving in the context of mothering. Caring for special needs children adds complexity, compounded by behavioral challenges, financial constraints, and societal stigma. Their nuanced mothering understanding will be analyzed to uncover factors shaping their caregiving experiences.

A phenomenological approach investigates caregivers’ experiences with autistic children, offering insight into their lived realities. Employing Moustakas’s (1994) empirical phenomenological method, detailed descriptions are gathered to analyze subtleties and interpretations within the context.

The study, using a phenomenological approach, delves into Filipino families’ experiences with autistic children, highlighting socio-cultural influences on findings. It emphasizes the essence of living with autism but confines its scope to the Philippine context, showcasing only a partial aspect of their reality, limiting broader generalizations.

3. Methodology

Using qualitative descriptive research, the study explores experiences of parents or caregivers raising children with autism from a phenomenological perspective.

Furrukh and Anjum (2020) used a phenomenological approach to study Pakistani mothers of autistic children, uncovering challenges, coping strategies, and social support. Similarly, Woodgate et al. (2008) explored Canadian parents’ experiences with autistic children, employing a hermeneutic phenomenological approach to delve into their lived realities. Smith et al. (2009) utilize phenomenology to uncover the significance of daily experiences. With a small participant group, this method reveals unique individual experiences through in-depth interviews, exploring their interpretations and emotions.

The study involves seven voluntary participants from diverse social backgrounds, referred by others. They include mothers, grandmothers, and sisters, showcasing the gendered

aspects of caring for autistic children. Interviews, conducted via phone, online, and in-person with consent and recording, were adjusted for spatial constraints. Originally intended as a focus group, scheduling conflicts due to childcare challenges led to individual interviews at participants' convenience.

Participants' anonymity and privacy were safeguarded by not collecting identifying information. Shared experiences of having autistic children fostered rapport. Standard background procedures reassured participants, promoting trust and ease. Interviews were transcribed and analyzed for common themes. Researchers, as well as parents of autistic children, ethically framed questions, recognizing potential sensitivity among participants.

This phenomenological study provides insights into caregivers' experiences with autistic family members, mainly focusing on maternal narratives from grandmothers and sisters. Expanding informants beyond mothers poses challenges, as some families may struggle with acceptance. Homogenous backgrounds among informants could have facilitated a more focused exploration of their experiences.

Narratives underwent structured processing, starting with multiple reviews of transcriptions. Individual narratives were crafted to explore contextual factors. A matrix was constructed to examine details of caregiving journeys, forming codes and overarching themes directly related to the study's objectives, capturing caregivers' experiences.

4. Result and discussion

The initial section presents the narratives of the participants. Subsequently, we will delve into their challenges, along with their experiences of ambivalence, fear, and hope.

4.1. Result

A mother's journey of raising a child with autism: The case of Lisa

At just one year and 08 months old, Lisa's son received an autism diagnosis, prompted by family observations of speech delays and behavioral indicators like toy lining and tiptoeing. Initially in denial, Lisa accepted the diagnosis when confirmed by a doctor. While she was not devastated, knowing professional help was available, acceptance did not erase moments of sadness. She shared that:

“Upon receiving the autism diagnosis, I clung to hope that my child was not autistic, attributing delays to other causes. However, when the doctor confirmed it, acceptance began gradually. Though not devastating, sadness occasionally surfaced. He is distinct from my other children, yet acceptance gradually eased the journey.”

Their middle-class background facilitated their son's evaluation by a developmental pediatrician, enabling early intervention and therapy sessions for him.

“Therapy is both challenging and costly, with speech therapy alone costing 500 pesos per hour, requiring perseverance to continue.”

They enrolled their son in a private school owned by a relative for his schooling, not tailored for special needs. Despite the mainstream environment, he completed high school and began college. However, due to academic stress, he required assistance to finish. Lisa proudly notes his talent for cartooning, his passion, alongside skills in cross-stitching and other arts.

Following her son's autism diagnosis, Lisa chose to prioritize him over her career, a decision she does not regret. She takes pride in her mothering ideals, observing that paid caregivers frequently substitute mothers in therapy centers for autistic children. Early intervention aided in her capacity to manage her son's condition. As a mother of an autistic child, Lisa encountered challenges, including her son's habit of opening others' bags. Despite therapy and guidance, she felt offended at a gathering when the host closely monitored her son, contradicting claims of affection yet expressing concern over his behavior.

She reassured her friend about her son's behavior, questioning her own sensitivity. Recalling a spa visit where she sensed murmurs about her son's condition, she felt scrutinized and indirectly discriminated against. Handling her son's meltdowns, often triggered by reprimands, proved challenging, with her husband displaying more adeptness in these situations.

Despite being non-verbal, Lisa's son displays no eating or toilet training issues. At 28, he handles household tasks independently, bringing Lisa joy. She perceives individuals with autism as honest and obedient, lacking negative behaviors, akin to having an angel in the family. Despite her care, Lisa regrets hindering her son's independence post-accident.

Lisa entrusted her son to teachers at school, facing initial challenges due to his wandering habit. However, his behavior improved over time, benefiting from interactions with peers. Therapy alongside regular schooling enhanced his demeanor. Lisa is reassured about his future as her other children are prepared to care for him, deeply loving their brother, ensuring his safety and well-being in their absence.

Embracing the journey: Parenting twins with autism

At one year old, the twins ignored their names when called, prompting their mother to seek answers online and from acquaintances. She said, *"Most children respond to their names by age one, but my twins showed no reaction, prompting worry. I sought advice from acquaintances and struggled with complex online information."* Despite complex online information, acquaintances reassured her the twins were just delayed, advising patience, interaction, and finding playmates. At three, their behavior intensified, leading to an ASD diagnosis. She added, *"The developmental psychologist confirmed my twins have autism, clarifying my concerns. As their care becomes more challenging, therapy enrollment is likely recommended."* The psychologist advised occupational and speech therapy, which halted after a year of the pandemic. With the father in Manila, the mother solely cared for the twins, even tending to basic needs like bathing and diaper changes. Occasionally, the sibling-in-law assisted when school was not in session. According to her, *"I am their sole caregiver despite them still in diapers at six. Expecting a baby, while their father works in Manila. Thankfully, my sister-in-law supports me."* Currently, the twins attend SPED but lack friends and need constant maternal presence, especially as their mother expects another child. Despite her not working, she prioritizes their care. Their family, including the father and sibling-in-law, see caring for them as God's will, accepting the challenge with love. She further added that, *"Though challenging to care for, their presence is welcomed as a divine gift. If we were to predecease them, their sibling would assume responsibility for their care."*

Nurturing unconditional love: A mother's journey with her daughter's autism

After Rizza's husband passed away, her daughter stayed with her mother-in-law while Rizza worked. Understanding the situation, the mother-in-law offered to care for her granddaughter, which Rizza gratefully accepted. She said, *"Due to my deceased husband being an only child, my mother-in-law cares for our autistic daughter, yet I still visit her occasionally."*

Rizza noticed developmental concerns in her daughter at age three, including delayed speech and unresponsiveness, yet she followed commands. She enrolled her in free special education classes and paid therapy sessions, yielding positive behavioral changes from hyperactivity to improved communication. Rizza noted her mother-in-law's spoiling tendencies, leading to anger and physical outbursts, which she manages patiently.

Upon discovering that her daughter had autism, she initially felt disheartened. Rizza said, *"Enrolling her in daycare initially, the teacher's inability to handle her caused distress. With her father alive, the emotional pain intensified, realizing she did not fit in like other children."* Once unruly, her daughter progressed, responding well to reprimands. With her parents-in-law's financial and emotional backing, covering therapy costs, and aiding school attendance, her daughter's behavior improved, showing the family's steadfast support.

She vigilantly supervises her daughter's interactions with other children, fearing misunderstandings due to her autism. Concerned about potential conflicts, she cautiously allows her daughter to socialize, mindful of encouraging diverse interactions. A past incident where her daughter inadvertently harmed a neighbor's child reinforces their cautious approach, opting to avoid situations where her condition may not be understood.

Acknowledging the sadness of having an autistic child, she initially struggled to comprehend the situation, leading to occasional frustration and disciplinary actions. Believing in exposing her child to fear and avoiding spoiling, they maintain a structured routine, including simple chores, to foster independence.

While facing the trials of raising an autistic child, she refuses to see her as a burden, attributing no blame to her for her disability. One notable challenge is toilet training, requiring extensive patience due to her daughter's difficulty grasping and following commands, necessitating repeated teaching sessions for understanding.

Aware of her daughter's lifelong condition, therapy offers hope for improvement, but they're prepared to accept it if no change occurs. Fearful of her wandering into danger, such as highways, they remain vigilant about her safety outdoors. Proactively sharing their child's situation, they feel no shame. Interactions are met with understanding and concern. Despite autism's challenges, finding joy in her daughter's happiness and comforting moments like her affectionate hugs with her and her younger sister bring solace.

Embracing differences: Ranz's journey with mild autism

Ranz diagnosed with mild autism at one, received prompt therapy and assessments. His grandmother and aunt assist in his care without viewing him as a burden. Her grandmother said, *"Ranz, under my care since infancy, has mild autism. His parents abroad, we accompany him to therapy sessions based on assessments."* Enrolled in SPED, Ranz, now seven, is independent and friendly, not needing constant supervision. His parents have been Dubai since he was two, his grandmother and aunt care for him. Initially challenging due to his wandering and behaviors, therapy sessions twice weekly have been helpful. According to her grandmother, *"Caring for him is tough. He wanders, once nearly hit by a tricycle. Initially, he could not communicate restroom needs."* In third grade, Ranz attends classes with regular students. His parents, despite being only childless, find solace in cousins who would care for him if needed. They consider Ranz a source of luck in their lives.

Making sense of having a child with autism: Lerma's journey

During Lerma's pregnancy, complications arose, including oxygen deprivation, leading to her daughter's brain oxygen deprivation. Preeclampsia forced early delivery, and by age one, her daughter experienced frequent seizures, requiring anti-seizure medication. Lerma's father suggested she care for her daughter due to her medical needs, suspecting autism was triggered by her condition. Sacrificing her job, Lerma prioritizes her daughter's care, despite occasional regrets about leaving her career.

Her 17-year-old non-verbal daughter, though well-behaved, posed challenges with balance and communication. Leaving her job, Lerma took on full caregiving responsibilities, including feeding. Therapy center enrollment led to self-feeding within a month, addressing both balance and communication issues. Lerma fosters independence, encouraging her daughter to handle manageable tasks autonomously. Enrolled in therapy, Lerma's daughter overcame picky eating and improved toilet training, now using the restroom independently. The only hurdle remains dressing after restroom visits. Lerma is cautious about her daughter's safety around males, ensuring she wears modest clothing for protection.

Despite challenges, she views her daughter with autism as a divine gift, questioning how parents could not love their special-needs child. While no parent wishes for such challenges, acceptance is crucial. Nonetheless, concerns about her daughter's future persist, reflecting typical parental worries. She faces indirect discrimination due to her daughter's condition. People's reactions to her daughter reflect their attitudes. She explains promptly to foster understanding about her daughter's behavior, taking a proactive stance due to her unique needs.

Concerned about her daughter's future, Lerma hesitated to have more children after her first, fearing her daughter's care needs. It took six years to decide on a second child, advised to expand the family for additional support. They have trained their younger children to care for their older sisters, preparing them for potential future responsibility.

Amidst challenges of raising an autistic child, she finds joy in her daughter's minor achievements, valuing each success. Emphasizing acceptance, she relieves both parent and child from societal pressure. Contrary to misconceptions, she proudly notes her daughter's cautious nature, debunking assumptions about autistic children's capabilities.

Transforming challenges: Timothy's journey with autism and ADHD

Timothy did not speak, had no eye contact, had no focus, and could not be fed until he was almost two years old. When he had a check-up at Manila (University of Sto Tomas Hospital), they found out he had autism and ADHD. Her mother said, *"I was puzzled then, unlike other children, Timothy did not speak, lacked focus, avoided eye contact, and hardly ate until he was two. When we had him checked at the University of Sto. Tomas in Manila, they said he had autism and Attention Deficit and Hyperactivity Disorder (ADHD)."* His father was in New Zealand, so his mother was the only one caring for him. His diet is fried chicken, pork chop and spaghetti only. His mother further added, *"He refuses to eat. He only wants spaghetti, pork chop and fried chicken. He often stays near things that are spinning, like a fan. He is often in front of electric fans or anything that spins. He also opens and closes doors repeatedly, mixes soy sauce, vinegar, and oil, throws spoons, forks, plates, chairs, shoes at the river behind their house."* He was enrolled in a private school at SPED Muñoz and SPED San Jose, but he did not finish his school year because he distracted the other students too much. He sometimes hurt other students and was not cooperative. His therapy sessions, regular

assessments, and home-schooling continued until his behavior slowly changed. Eventually, he became calmer and spoke words he often heard like mother, father, uncle, aunt, and others. She said, *“Perhaps his behavior has gradually improved because of the therapy. We have obtained a Certificate of Independency.”* When his family managed to get a certificate of independency for New Zealand, they are all currently abroad, and he is currently studying there. He has a sibling that can take care of him anytime.

Navigating the challenges of raising a child with autism in a dysfunctional family: A sister’s story

Carla, the eldest of three, faced her parents’ separation early on. Initially, with their mother, financial constraints led them to live with their father, better able to support them. With her mother’s youth and a significant age gap with her father, Carla entrusted them to their paternal grandmother’s care, as their father worked abroad.

At 22, Carla, a year older than her autistic brother, noticed his speech delays and behavioral problems early on. These were associated with an incident where he slipped from their mother’s grasp during parental arguments. His speech is limited, often saying “no,” resorting to pointing when expressing desires.

He displays typical autism behaviors when happy, such as jumping and hand-flapping. Enjoys music but struggles with sleep, sleeping late and waking early, leading to irritability, according to his sister.

Despite living with their paternal grandmother, she feels she carries more emotional and caregiving weight than her grandmother. Their relationship is not close, partly due to the grandmother’s resentment towards their mother, which extends to them. Speculating that her grandmother has unresolved personal issues, she believes until resolved, they won’t truly feel her grandmotherly love.

She perceives her family as dysfunctional due to ongoing parental conflict, including physical violence. Following their parents’ separation, they rely on their paternal grandmother and reside in a troubled neighborhood, close to an uncle with a history of drug addiction and incarceration. These challenging circumstances likely contribute to her brother’s aggressive behavior, compounded by his autism.

Carla struggles with her autistic brother’s challenging behavior, especially when he harms himself. She links his behavior to discontinuing therapy after two years, which he did not enjoy. Their family initially sought evaluation at a developmental pediatrics center when he was younger but ended therapy due to his lack of enjoyment.

Caring for her autistic brother, just a year younger, poses challenges as she also needs parental care. As the eldest, she shoulders caregiving duties but admits struggling at times, losing her temper and resorting to physical discipline.

During the pandemic, she confronted the complexities of caring for her brother with autism. Researching, she learned patience is crucial; violence is not the solution. Understanding their limited comprehension, she advocates for support and guidance. Living near their uncle, who struggled with addiction, her brother picked up destructive behaviors. Despite leaving him in their uncle’s care during absences, she does not fault herself, recognizing the importance of a nurturing environment.

It would have been better if her father repartnered so that there would be someone mothering them, but she mentioned that her father never had a long-term partner because he might have his attitude issues, which is why his relationships did not last. Despite this, her father transcended his role as a provider because whenever he arrives in the country, he inquires if they have the time to eat out together. Their bonding time is limited because their father often has other errands to attend to.

They do bring her brother to restaurants, but it is a struggle, and she manages. Sometimes it is difficult because her brother might suddenly have a meltdown. She usually takes her brother to a quiet place where there are no people and tries to calm him down. Sometimes, she massages her brother. Sometimes it works, but at times, her brother resists. She also rubs his back to soothe him. One time, they were eating out, and her brother had an outburst. Everyone was looking at them, and their only reaction was to explain to people that her sibling has autism, apologize, and then leave the restaurant. Although there were no direct statements of discrimination, she could feel they were discriminated against because of her brother's actions. There are times when her brother has a tantrum, and his mouth foams even though he does not have epilepsy. She feels that her brother adopted the behavior from their uncle who has been looking after their brother for a long time, when they were at school and no one was home. The way her uncle disciplined and raised her brother has yet to be effective.

Another challenge they encountered was when her father took her brother to a grocery store. Because their father was afraid that her brother might have a meltdown in the store, he left them inside the car. To their surprise, when their father returned to the car, her brother was no longer inside. They went back home, and that was when they saw her brother running back towards the house, which was five to ten minutes from the store. Fortunately, her brother was unharmed and remembered the way back home.

There was also another incident when they were on a trip, and her brother suffered from motion sickness and was vomiting, and she could sense that the bus passengers were disgusted.

Despite her brother's behavioral challenges, she mentions he can hum tunes independently. He enjoys watching TV commercials and can hum the melodies for them. He is also able to obey simple commands. Also, he can take a bath independently, although it takes about three hours to complete the task. They have two bathrooms, so they can use the other one while her brother is still bathing. Sometimes when they are getting ready to go somewhere, they allow her brother to bathe ahead of them.

Her family is also planning for the future of her brother. Since she will be graduating next school year, she talked to her father about their setup and the need for her to start working. Her father is also nearing retirement. It was agreed upon that when she and her other sibling are both working, her father will be the one to take care of her brother. They believe that the life of those with autism is not necessarily long, so they also prepare for it. Her brother also hurts himself during meltdowns, so they are afraid that it might have an impact on his health. If her brother outlives them, they have already spoken with their step-siblings, explaining their brother's condition and even asking them to care for him.

She also has moments of ambivalence towards her sibling, whom she did not understand until the pandemic hit. As the older sister with no parents, she sacrificed her study time to care for her brother. During this time, she often thought that if her brother had not had that unfortunate incident when he was a child, maybe he would be okay now. Perhaps she would not

face such hardships. If only their parents had not separated and they had lived in a happy family, her brother might have grown up in a less violent environment. Her brother's mannerisms and behavior might have been different. During the pandemic, she saw videos of families in similar situations who were functioning normally. There were also news stories of high school seniors with autism graduating. She believed that if her brother had not grown up in such a dysfunctional family, having autism might have been okay for her brother.

4.2. Discussion

4.2.1. Struggles and difficulties

The struggles faced by families of children with autism, as depicted in their narratives, are multifaceted and can be clustered around the following themes: 1) diagnosis and acceptance, 2) financial difficulty, 3) behavioral challenges, 4) parental sacrifices, 5) educational challenges, and 6) social stigma and discrimination.

Researchers who study familial stress find that parents with ASD children are at an increased risk of high-stress levels (Mancil et al., 2009). Many families go through the challenging process of accepting the autism diagnosis. Simangunsong et al. (2023) found that stay-at-home mothers, due to their availability and caregiving responsibilities, demonstrate a greater acceptance of their children's developmental condition, particularly in cases of autism.

Initially, they may be in denial or hope the development delays are temporary. Some mothers perceive their children with autism as simply experiencing speech delays and delays in certain developmental milestones. There are hints of denial as they consider their children to be typical kids with delayed speech that necessitates intervention. According to her Lisa,

“Of course as a mother, there was denial. I told myself that even though they were saying that, I thought it was delayed. Nevertheless, when I saw the signs of autism like lining up, tiptoeing, delayed walking, no eye contact, and he had problems with speech. I decided that I need to have him checked.” - Lisa, has a 28-year old son with autism.

One of them associates the delays with an incident in which her brother accidentally slipped from their mother's grasp during a heated argument between their parents. They only embraced the diagnosis after consulting with a developmental pediatrician. She said, *“But there was an accident that happened. At first they thought it was just because of that accident. It turns out he already had autism. It was like my parents were fighting during that time. My brother was only two months old when he fell.”*

Accepting the diagnosis became a critical step towards seeking early intervention and appropriate support. As early as their children turned 01 to 02 years old, an assessment by a developmental pediatrician occurred. Autism therapy interventions are pretty expensive. The availability of classes for special children became an alternative venue where children could learn. The majority of participants in this study come from middle-class backgrounds, with two having relatives who are Overseas Filipino Workers (OFWs). These families have the financial means to send their children to private schools and to consistently access occupational and speech therapies. Generally, families need to invest significant financial resources for the early intervention of their children. The cost can be a considerable burden, particularly for those with limited financial resources.

The main challenges encountered by families with autism stem not from financial constraints but from the behavioral issues manifested by their children with autism. Children with

autism may exhibit challenging behaviors such as meltdowns or self-injury, which can be emotionally and physically taxing for mothers and caregivers. Managing and understanding these behaviors can be a significant challenge. Meltdowns are the most difficult to handle. Caregivers believe that when their children become upset due to unmet desires, receiving commands, or experiencing frustrations, they tend to react with outbursts, and tantrums, which can eventually escalate to meltdowns. Children with autism are also hyperactive. Some make it a habit to throw things in their house. Some manifest annoying behavior such as repeatedly opening and closing doors, mixing soy sauce, vinegar, and oil, screaming, and hurting others and themselves.

Many of the mothers and caregivers of children with autism make significant sacrifices. These sacrifices are crucial in upholding an idealized image of a “perfect mother.” In the case of caring for a child with autism, societal norms demand that mothers prioritize their children’s needs above all else, reinforcing the expectation of child-centered mothering practices as a benchmark for being perceived as good mothers. Some quit their jobs to provide full-time care and support for their child, which can impact their career. Their middle-class background enabled them to dedicate themselves full-time to caring for their children instead of pursuing paid employment to contribute to the family’s material resources. This choice often comes from a deep commitment to their child’s well-being. Those who quit their jobs harbor no regrets in prioritizing their children over their careers, as they believe that they have successfully raised their children and take pride in their ideals of motherhood.

During the period when one of the participants’ husbands worked in Manila, she was solely responsible for the care of their twin children with autism. She had to bathe and feed them on her own. Even when the twins reached the age of six, the mother continued to change their diapers as they were unable to communicate when they needed to use the bathroom. One participant candidly discussed the challenges she encounters in caring for her younger brother with autism, who is just a year younger. Despite her own need for parental care, as the eldest in the family, she has taken on the role of caregiver. She admitted experiencing moments of difficulty with her situation.

Mothers and caregivers of children with autism consider it an educational challenge accessing appropriate education for children can be a struggle. In some cases, finding a school environment that meets and integrates the child’s needs with regular students can take time and effort. The middle-class status of the participants facilitated their children’s attendance at therapy sessions. One participant was able to send her son to a regular school and socialize with other students, ultimately leading to his successful completion of high school because of their close relationship with the school owner. Others are able to send their children to special education classes. Other children only attended therapy sessions, while others showed disinterest in schooling and therapy sessions.

Mothers and caregivers often face judgment, misunderstanding, or discrimination from others in social situations. This can be due to their child’s behavior or because of a lack of awareness about autism. Sometimes, it can be emotionally distressing to defend their child or explain their condition repeatedly. Mothers of children with autism are particularly attuned to how their children are treated, whether by close friends, relatives, or acquaintances. For instance, one mother felt offended at a gathering when the host continuously monitored her son, seemingly concerned that he might accidentally break something. These mothers often grapple with internal questions, wondering whether they are overhearing hushed criticisms about their children’s behavior or if their worries are causing them to become overly paranoid about how

others perceive their children. When people are gazing at their children because of their behavior, mothers, and caregivers employ a proactive approach of explaining their children's medical condition.

4.2.2. Children with autism are gifts, not burden

Mothers embrace their children as divine gifts, especially when facing the challenges of raising a child with autism. They find joy in this unique journey, appreciating their children's honesty, obedience, and pure hearts, contrasting typical kids' behaviors. Even when alone in caregiving, they cherish their twins with autism as blessings needing love and nurturing, regardless of the father's absence due to work. One mother refuses to see her child with autism as a burden despite challenges, firmly believing they should not be blamed for their disability. Even the sister caring for her brother shares this view, attributing his aggression partly to their dysfunctional upbringing. These findings contrast previous studies where mothers reported overload, helplessness, depression, and physical burden, consistently highlighting caregivers' positive appraisal of their autistic children (Aguilar & Ponde, 2019; Hall, 2011; McStay et al., 2014).

4.2.3. Fears

One mother, haunted by her experience, regretted not granting her son the opportunity for complete independence. Her excessive protectiveness stemmed from a traumatic incident where her son was hit by a vehicle at the age of four. This distressing event prompted her to confine her son to the home, driven by her overwhelming fear for his safety. In hindsight, she deeply regretted the extent to which her fear had made her overly protective. In contrast, another mother grappled with ongoing apprehensions and concerns regarding her daughter's interactions with other children. Her worries primarily revolved around the possibility of her daughter unintentionally causing harm to other kids. These concerns were rooted in the fact that her daughter's autism was not readily apparent in her facial features, making it challenging for others to comprehend her daughter's medical condition. Additionally, a sister responsible for her younger brother's well-being faced her own fears when their father inadvertently left her brother behind in a local grocery store, forcing him to walk alone.

4.2.4. Hope

With the behavioral and educational challenges their children are confronted with, mothers and caregivers grapple with the long-term care and support needs of their child with autism. Planning for their child's future has been done, especially when they are no longer around. They focused on the upbringing of their younger children with the idea that they would bear the responsibility of looking after their siblings should anything happen to them. They have also been instructing their other children to look after their older sister, who has special needs. Families of children with autism draw their hope on the availability of close relatives who will continuously provide nurturing, loving, and caring tasks for these children. Furthermore, this sense of hope may stem from the family's financial stability, which enables them to meet the basic and educational needs of their children with autism.

5. Conclusions & recommendations

Embracing the intensive motherhood ideology proves to be beneficial for families raising children with autism. When mothers view caring for their children with autism as their primary and essential role, the nurturing and childcare responsibilities do not feel burdensome, even in the face of challenging behavior and meltdowns these children experience. Their strong desire to

be exemplary mothers and caregivers to these children leads them to have more modest expectations and find contentment in even the most minor achievement of their children. They willingly exit the workforce as a testament to their dedication to being exceptional mothers to their children. Raising a child with autism requires caregivers to center their daily lives around the welfare and safety of their children. In this context, these children are seen as precious gifts, and their caregivers rarely experience ambivalence in their roles, despite the challenges they face. However, caring for children with autism is not always a positive journey, as some informants feel that they feel exhausted by the task of caring for their sibling with autism.

This phenomenological study explores the experiences of caregivers, specifically mothers, grandmother and sister. It highlights the significant social pressure to fulfill the roles of a good mother or caregiver, particularly in a situation where children have developmental disabilities such as autism. Despite the considerable burden, societal expectations compel caregivers to wholeheartedly accept the challenges of caring for children with autism. However, this expectation is challenged when a sister's life is disrupted due to assuming the responsibility of caring for her brother in a dysfunctional family.

The study's findings highlight the internalization of motherhood ideology not only by mothers but also by other female caregivers within Filipino families. It underscores the strong family bonds among Filipinos, who view children as blessings from God regardless of whether they have special needs. In the context of caregivers originating from middle-class backgrounds, prioritizing career over caregiving duties is discouraged as it may be perceived as failing to fulfill their roles as "good" mothers, grandmothers, or sisters. Consequently, when children require additional support due to developmental needs such as autism, the pervasive ideology of intensive motherhood compels these caregivers to prioritize providing care or support for the affected children.

Given the limitation of this study, it is strongly suggested that future research may look into the following: (1) the lived experiences of fathers or male caregivers in families of children with autism to be able to compare the struggles and difficulties encountered by men in this context. Furthermore, it will provide insights into how men negotiate parental roles; (2) to conduct a longitudinal study to understand mothering in the various life stages of children with autism.

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