# Paternal Resilience in Time of Pandemic: A Phenomenological Inquiry on the Experiences of Fathers of Children with Autism

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#### Abstract

This phenomenological research was conducted to inquire into the experiences of fathers of children with autism during the COVID-19 pandemic. This qualitative study was explored because there is a dearth of studies focusing on paternal involvement and a lack of local autism research. Nine participants, who were chosen using purposive sampling, individually participated in an unstructured interview. The van Kaam method popularized by Moustakas was used to analyze the data gathered. Five major themes emerged: recognizing the child's needs, surviving hardships, enduring exhaustion, encountering silver linings, and moving forward. The findings showed that fathers of children with autism encountered challenging and fulfilling events during the pandemic with resilience. Fathers of children with autism prioritized familial needs, especially of the child, and increased their presence in the household. A strong paternal character builds up fathers' resilience in coping with the difficulties of raising a child with autism in a precarious time.

Keywords: Special Education, fathers of children with autism, COVID-19 pandemic, phenomenology, Philippines

#### 1.0 Introduction

Fathers play an important role in the upbringing of a child with autism (Rankin et al., 2019). From their perspective, they feel the need to be responsible to attend to their child's daily care routines (Potter, 2017) as much as mothers do because they are aware of the demands brought by the disability.

Autism has been defined by the Diagnostic Statistical Manual 5th edition (American Psychiatric Association, 2013) as a neurodevelopmental disorder characterized by impairments in social and communication skills and restrictions and repetitions of behavior. Parental involvement plays

a significant part in ensuring that intervention is provided especially during the early years (Pasco, 2018). As such, support from fathers is as relevant as the support from mothers in the child's progress (Burns-Darden, 2019).

Parental involvement was even more needed when the coronavirus (COVID-19) outbreak happened. The pandemic brought a sudden change to the routines of children with autism, including the loss of access to school and other support services. According to the United Nations Educational, Scientific, and Cultural Organization (UNESCO), school closures have high economic, educational, and social costs to all people, but the

impact is more severe for persons with disability and their families (Robbins, 2020). In the ASEAN region, parents and their children with autism find it difficult to adjust to the changes brought by COVID-19 (Lim et al., 2020). The economic crisis that arose affected society, especially the family (Minas, 2020), as children were obliged to stay at home (Wang et al., 2020). Households struggled with the demands required in distance learning (Association of South East Asian Nation [ASEAN], 2020). Parents of children with special needs demanded more support to combat mental distress (Chen et al., 2020). In the local context, strict rules were implemented to prevent the spread of the virus, including school closure and stay-at-home protocols for children. Parents of children with autism confronted these sudden changes (Colizzi et al., 2020; Mutluer et al., 2020; Narzisi, 2020).

Unearthing these challenges pushed the investigation of the pandemic experiences of fathers of children with autism as they equally provide support like mothers. Fathers' perspective in rearing children with autism was recommended to be studied (Burrell et al., 2017) since they are often overlooked in research (Rankin et al., 2019) and have not been explored (Suhaimi et al., 2020). Recent studies on autism parenting focused on parental emotional well-being and anxiety levels (Alhuzimi, 2021; Chen et al., 2020). Some studies explored the experiences of families during the lockdown or quarantine (McDevitt, 2021; Stankovic et al., 2022; Latzer et al., 2021).

In the Philippines, recent autism parenting research focused on strategies for managing children at home (Cahapay, 2020a), ushering children with disabilities into the "new normal" (Cahapay, 2020b), and the effect of parental involvement on the academic performance of children with autism (Nillos, 2019). In the local

context, research on the difficulties, challenges, and techniques of parents of children with autism was recently explored (Bodoso, 2019).

However, there is a dearth of studies that specifically address the role of fathers and their experiences of the pandemic. Hence, this study sought to address the gap by exploring the lived experiences of fathers of children with autism during the pandemic.

# Literature Review Autism Spectrum Disorder

The concept and definition of autism spectrum disorder have gone through many changes over the years, from its early accounts of diagnosis to the many studies that increased understanding and innovated care and treatment. A psychiatrist named Eugen Bleuler first coined the word autism in 1911 to describe people withdrawing from their inner world (Rowland, 2020). He described autistic children as wanting to be on their own and isolated from society. Years later, Leo Kanner studied 11 highly intelligent children who shared similar characteristics consistent with the definition of autism. In 1944, medical professor Hans Asperger studied four young boys whom he considered to have autistic personalities because of difficulties with social interaction (Fitzgerald, 2019). In 1952, the Diagnostic Statistical Manual (DSM) of Mental Disorders of the American Psychological Association (APA) first mentioned autism as childhood schizophrenia. After a series of modifications, the latest 5th edition of DSM released in 2013 defined autism as a neurodevelopmental disorder that adversely affects a child's educational performance and is characterized by having deficits in social communication and restricted and repetitive patterns of behavior (Rosen et al., 2021). The 5th edition of DSM is currently used as a

basis for the diagnosis of autism by developmental pediatricians. Recent demographics show a global increase in the rate of children with autism (Qiu et al., 2020; Özerk & Cardinal, 2020). In the Philippines, more than one million children have autism (Lambatin, 2018), and some are not identified and diagnosed.

# The Pandemic and Its Impact on Children with Autism

The outbreak of the novel coronavirus started in December of 2019 in Wuhan, China, where cases of acute respiratory diseases increased death tolls rapidly. It is termed SARS-CoV 2 or better known as COVID-19. The virus eventually spread to other countries until it reached a point wherein it was classified as a worldwide epidemic. This led to strict implementation of social distancing, wearing protective gear (e.g., face masks, face shields, personal protective equipment), and lockdowns (Yuki et al., 2020). The world was forced to go into lockdown for a while to prevent infection. But this particular move brought changes in routine, socioeconomic difficulties, and adjustments in family dynamics.

It is a significant negative life event for children with autism as well. The main difficulties of the lockdown include abrupt changes in routine, lack of special education services, limited physical space, and issues in daily living. Children were observed to transition into a worsened behavioral and social state because of the aforementioned factors (Latzer et al., 2021). Specific research on the impact of the pandemic on Asian American families with children with developmental disabilities shows that the primary concern was the disruption of children's education and therapeutic services (Dababnah et al., 2021) in which parents tried to provide the best that they can.

Commitment from parents was needed to face the challenges during the pandemic. According to studies, parents of children with autism experience dissatisfaction and stress in dealing with limited support services for their children (Franz & Kelly, 2021, Corbett et al., 2021). On top of that, the severity of the pandemic increased parental anxiety about a virus infection, healthcare access, quality of life, financial instability, and future concerns as a family. It had a psychological impact not only on children with autism but also on their caregivers. Even before the pandemic, parents already experienced stress from the challenging behaviors of their children. In the local context, a study found that parents of children with autism encounter varied problems and difficulties (Bodoso, 2019). The main impacts of the disability on the family are continual stress, the need for constant assistance, and worry for the future. According to Althiabi (2021), both fathers and mothers of children with autism have greater anxiety during the pandemic compared to before it happened.

# Fathering a Child with Autism

The role of fathers is rarely included in research about autism parenting (Rankin et al., 2019). Most studies focused on mothers, and little research has been done to investigate fathers (Di Renzo et al., 2020). It is to be noted that, generally, modern fathers wanted to be recognized as good fathers by their children, partners, and surroundings (Hakoyama, 2020). Unlike decades ago, the societal norm of being a good father was simply the head of the household, a provider, and a safe keeper. Now, fathers are overwhelmed in performing various roles. The challenge remains of being a good listener and friend to his child.

According to a study on stress and depression

levels of fathers of children with autism, the biggest fear that they have is the future of their children (Jagan & Sathiyaseelan, 2020). As they try to meet the needs of their child, there is an increase in mental health problems. Their thoughts about their child's future, social survival, and independence are the main sources of their stress. Looking at the paternal side of parental stress during the pandemic, fathers' anxiety levels increased because of restrictive measures and home confinement (Trumello, 2021). Stress was found to worsen the father-child relationship because there was an increased demand for fathers to create new routines and rules that were not present before the pandemic. According to Blake (2021), fathers tend to look at the positive traits of their children to cope with the deficits of the disability. The extent of fathers' involvement and desire to focus on their child's progress brought by circumstances such as the pandemic show how the paternal role continually evolves and thus needs more support from society.

#### 2.0 Methods

This study utilized the descriptive phenomenological research design. The use of phenomenology was appropriate for exploring the lived experiences of fathers of children with autism during the pandemic since this paper focused on exploring the personal and individual experiences of the participants (Lichtman, 2014).

Nine participants were identified using the purposive sampling technique. Purposive sampling refers to the random selection of samples within a given population that can best match the purpose of the study (Campbell et al., 2020). Inclusion criteria were used to determine participants: the father has a child or children who is or are medically diagnosed with autism and who is or are enrolled in a public special education school and must be receiving modular/online education during the pandemic, and the father is residing in the same house as the child/children and affirms parental responsibility for the child/children. Parental responsibility refers to the awareness of the participant of his responsibility in taking care of the child.

All nine participants fit the inclusion criteria and were presented with informed consent to orient them to the research objectives and secure the confidentiality of their identity. An unstructured in-depth interview was used as the research instrument to deeply extract the essence of the phenomenon (Creswell, 2016). General ethical principles of respect for persons, beneficence, and justice were expressed to ensure the ethical soundness of the study.

In the analysis stage, the modified van Kaam methodology described by Moustakas (1994) was utilized. This method includes seven interrelated steps that cluster and categorize related data of the participants to form a general concept. The seven steps are horizontalization, reduction and elimination of data, clustering and thematizing, validation, construction of textural description, construction of structural description, and incorporating the structural and textural description into themes.

The trustworthiness criteria set according to Lincoln and Guba (1985) were observed to ensure the validity and reliability of the analysis. The criteria include credibility, transferability, dependability, and confirmability. Findings were conveyed to the participants for validation, and thematized data were validated by two external auditors.

#### 3.0 Results

Five main themes emerged from the data and were organized as follows: recognizing a child's needs, surviving hardships, enduring exhaustion, encountering silver linings, and moving forward.

## Theme 1. Recognizing a child's needs

This theme is generated from two subthemes:
a) Distance learning, and b) Limited mobility. These subthemes provide the foundations for arriving at the theme.

The participants shared their experiences in handling the educational and intervention needs of their children during the pandemic. Most of the participants struggled because of the absence of direct school support during the lockdown. They further claimed that modular and/or online learning could not suffice the needs of their children. It was also difficult when other services such as speech therapy and occupational therapy were inaccessible. Outdoor movement of their children was likewise recognized by the participants as a necessity that they could not fully provide because of community restrictions.

Distance learning. Concern for the child's development was a big factor for the participants. The fathers who participated in this study all expressed disappointment towards distance learning. The implementation of distance learning was not as effective as the actual classes held in schools or therapy centers, according to the participants. As one put it:

"His therapy stopped when the pandemic started. I felt that there would have been a great improvement if he had just continued his therapy. It felt like we prolonged the chance for him to be normal. Also, I prefer face-to-face classes because his teacher can

focus on him and he can also focus in class" (Participant 5, personal communication, September 25, 2021).

Moreover, they experienced difficulty with home education now that they become the primary teacher and source of education for their children. One participant shared:

"It is more difficult now that we are hands-on with his education. His lessons are based on the teacher's instructions to us" (Participant 4, personal communication, September 25, 2021).

Limited mobility. Limited mobility was also a concern for the participants. Fathers in this study showed anxiety towards their children's social isolation and the consequences that await knowing that interaction is an essential part of improving their social skills. Their statements showed that they had no choice but to conform to community restrictions. Some expressed:

"We want to take her out, but we cannot do anything because of the pandemic" (Participant 8, personal communication, October 22, 2021).

"We do not go for check-ups because of the risks. It would be better if she can go out, but what can we do? There's COVID right now" (Participant 2, personal communication, June 10, 2021).

## Theme 2. Surviving hardships

This theme encompasses the challenges of fathers as providers of their families during the pandemic. Shared experiences revealed that the main difficulty experienced was the lack of finances. Most of the fathers in this study experienced

difficulty sustaining their sources of income. The participants differed in employment positions; three are employed, three are self-employed, and three are under job order contracts. But most of them receive minimum wages. Those who are under job order contracts needed to wait for job opportunities since there was less demand for their services. Instead of losing confidence and feeling unproductive, they diverged into small businesses and sought part-time jobs just to maintain their economic needs.

Overcoming deficient income. Some fathers were challenged when their work and salaries changed due to the pandemic. The salary is not enough to keep up with their families' needs, especially the needs of their children. As a coping mechanism, the participants shared that they encourage themselves to be diligent and withstand financial difficulties by finding sources of income:

"During the pandemic, we were very badly off. So, we go around selling bread. Aside from bread, we sell shrimp paste and dried fish. We do earn from a little profit of one peso or two pesos for a piece of bread. Fortunately, we can spend for our needs at home from our income" (Participant 8, personal communication, October 22, 2021).

"I sell fish. If I won't sell fish, I won't have any source of income. Before the pandemic, my income was good because I sold fish, we had a sari-sari store, and I had a computer shop. The computer shop was a good source of income. But now, there is no income" (Participant 9, personal communication, October 28, 2021).

# Theme 3. Enduring exhaustion

The theme is generated from three subthemes which are: a) Caregiving fatigue; b) Communication struggles; and c) Stretching patience.

The way that fathers endured the challenges of having children with autism during the pandemic is built on their acceptance of the diagnosis. Since they spent more time at home during quarantine, they became more involved in the rearing of their children. The Hiligaynon word "kapoy" which means tired and "budlay" which means difficult uniformly appeared in the participants' verbatim responses because of how they often experienced these situations. But then, fathers added that they had no choice or that they accepted that exhaustion is part of the demands and challenges of dealing with persons with disabilities.

Their coping mechanism also showed when they mentioned how they adapted to their children's inability to communicate. Their way of connecting is through reading their children's actions, observing routines, and interpreting changes in behavior.

Patience was also found to manifest in the way fathers cope with the behaviors of their children. Their awareness about autism spectrum disorder lowered their tendency to be angry and reprimand their children. Some fathers expressed that they regretted the way they discipline their children, knowing that children with autism do not have full knowledge of what they are doing-whether right or wrong. Although, in some circumstances, getting angry cannot be avoided especially at the height of exhaustion.

**Caregiving fatigue.** Since children with autism are unable to develop self-care and daily living

skills as fast as typically developing children, there is a demand to monitor constantly their actions and train them repeatedly. Over the years, the participants were involved with taking care of their children. Due to the increased time at home during the pandemic, fathers found it tiring to tend to their daily needs and deal with the behavior of their children. It is a team effort for both the father and mother. For them, acceptance was key to continuing their responsibility. As one put it:

"It is tiring. My time revolves around her. Taking care of her is the difficult part because she doesn't know how to take care of herself. We just help each other. If one is working, the other one will watch over her. It's us two who need to tend to her. You just need to accept that she's special" (Participant 2, personal communication, June 10, 2021).

Communication difficulties. The participants also expressed that they were challenged to communicate with their children. They worry over their children's inability to ask for help verbally when the need arises. Although this has stressed and emotionally affected fathers, they were able to find ways to connect with their children. Some participants described their experiences:

"We struggle when she gets sick because she cannot tell us. I just know that she is not feeling well when she gets into a tantrum. If she cries and behaves differently, that is when I get it" (Participant 2, personal communication, June 10, 2021).

"She is non-verbal. It's difficult to communicate with her. I make codes out of her actions. It is always trial and error for us" (Participant 3, personal communication, September 20, 2021).

Stretching patience. This is one of the challenges that the participants faced in nonchalantly handling their children's behaviors. Some fathers regretted the way they discipline their children, knowing that a child with autism does not fully know what he or she has done wrong. One recalled his experience:

"Sometimes I'm upset when I spank her. I feel bad when my patience runs out because of her stubbornness. But it is very seldom that I do that. I just usually act as if I am about to spank her so that she will get scared and she would not misbehave. I just try to control my emotions when I do that" (Participant 2, personal communication, June 10, 2021).

"There are times when I am tired that I get irritated with her tantrums. I get irritated, but I control it because I know that she cannot control it" (Participant 8, personal communication, October 22, 2021).

#### Theme 4. Encountering silver linings

By metaphorical definition, a silver lining is a positive aspect that happens within a time or in a place of hopelessness. Despite the difficulties and threats faced during the pandemic, the fathers adapted to the state of quarantine with their families and have increased opportunities for spending time with their children. Consequently, the increased time spent with their children showed how both personas give affection to one another. Fathers shared that the time mostly spent at home was the positive aspect brought by the pandemic.

The subthemes that substantiate the theme are a) increased time with family, and b) father-child affection.

Increased time with family. An increased time with their families was the advantage of the pandemic for some fathers. Fathers found it a significant time to bond with their families because it was difficult to do that when everyone was always preoccupied before the lockdowns happened. The situation presented a time to see and bond with their children. They shared:

"I am just happy that they are all here. It is better than not having them here. I like to see my children together in one room" (Participant 5, personal communication, September 25, 2021).

"We bond every night. During this pandemic, we have that daily routine. When he woke up, we would go around within the perimeter of the house. I am happy that my child became closer to me in this time" (Participant 6, personal communication, October 16, 2021).

"I enjoy our bonding. It is usually when I rest, and she would lie down next to me" (Participant 3, personal communication, September 20, 2021).

Father-child affection. Due to changes in work schedule and a change in routines for both parent and child, there had been more time spent at home. Fathers shared how their love for their children continued to give them happiness during the pandemic. They were vocal in expressing their affection for them:

"I am happy when he is sweet to me. Even though he cannot speak, when I see that he is trying to be affectionate and he grabs my attention, it makes me happy" (Participant 9, personal communication, October 28, 2021). "She makes me happy, and she takes my stress away sometimes. Even though she is not in the mood, she obeys and gives me a kiss. It takes away my anger" (Participant 8, personal communication, October 28, 2021).

## Theme 5. Moving forward

This theme is generated through the subthemes: a) accepting reality, and b) bracing for life's eventualities.

As the pandemic challenged fathers in rearing their children with autism, optimism and a strong religious spirituality sustained them to be positive and be in a hopeful disposition. Fathers similarly shared anxiety for the future of their children because of their incapability of living independent lives. All fathers expressed their commitment to support their children in any way they could to uphold the quality of their lives.

Accepting reality. Fathers expressed that the history of knowing their children's diagnosis until the present time was difficult for them. But eventually, they were able to accept it. According to the participants, having a strong spiritual belief and gaining more knowledge about the disability helped them cope with the situation. Some fathers opened that it was a plan of God for them to have children with autism. Hence, they have no right to question God but only to accept it. This notion gave them the strength to face reality. Here are some examples:

"That's why sometimes, I question if indeed God is fair. I thought we are all equal but why do I have a child like that. But now I just let it be. There's nothing I can do. I cannot blame God. God has plans for us" (Participant 2, personal communication, June 10, 2021).

"I'll continue to bear the suffering. God wouldn't give her to us if we weren't capable of handling her" (Participant 8, personal communication, October 22, 2021).

Bracing life's eventualities. Because the viral infection of COVID-19 can cause severe illness or sudden death, the participants thought about the future of their children. Most sentiments expressed were those of worry and fear. Since autism is a lifetime condition, they were concerned about the life of their children as they grow older. A similar plan among fathers was to pass on the responsibility to the siblings of the children. But fathers still expressed hope that given the right support and intervention, their children caould be independent. One said:

"I want him to continue school so that he'll learn daily life skills, proper behavior, and how to go about life. It's better rather than we will continue carrying him until he is old" (Participant 4, personal communication, September 25, 2021).

#### 4.0 Discussion

During the pandemic, fathers of children with autism recognized the children's needs, survived hardships, endured exhaustion, encountered silver linings, and moved forward. Resilience dynamically emerged as they faced the challenges of the pandemic. For instance, the first theme showed how fathers expressed their parental concern over the absence of educational support, therapy services, and outdoor movement for their children during the pandemic. This is a demonstration of how fathers secure the needs of their children. They have a sense of responsibility and commitment to be more hands-on in facilitating these needs. The second theme depicted resilience in terms

of being the breadwinner of the family. Having limited to no means of income stimulated fathers of children with autism to be resourceful so that basic needs could still be provided. Financial instability is the main source of stress that they were able to manage despite the difficulty of job security. The third theme encompassed how fathers prioritized caring for their children despite the stress they feel from dealing with their disabilities. It is evident in how they continually took full responsibility for their children and understand the behaviors brought by the disability. Moreover, fathers were innovative in breaking communicative barriers by using symbols and gestures and observing their children's routines. The fourth theme described how fathers found positive experiences in the pandemic which was their increased time spent with family. It was evident in their statements how affection towards their children became a source of optimism for fathers during the pandemic. The fifth theme revealed how the events of the pandemic caused fear and anxiety about the future of their children. But despite the uncertainty of independence and stability after the pandemic, fathers remained hopeful that their children could learn through proper support and intervention. Acceptance was found to be important to adapt to both present and future situations as fathers of children with autism.

A study in Malaysia showed that parents of children with autism develop resilience from being exposed to both risk experience and protective experience (Ilias et al., 2018). Risk experiences include the traumatic events like finding out the diagnosis while protective experiences include the environment where parents learned how to cope with the situation. Resilience is a product of a long process of developing acceptance and adapting to the reality of having a child with autism. Moreover, a study conducted in the United States revealed

that having either a good or bad disposition can influence how parents of children with autism build resilience (Hashimoto, 2020).

Based on the data analyzed, certain characteristics have emerged from fathers' experiences that built their resilience during the pandemic. These paternal characteristics are the strength of character, courage, optimism, love, and acceptance. All these characteristics appeared in specific events in their lives during the pandemic. The experiences during the pandemic as a parent

of a child with autism, which was both challenging and fulfilling for fathers, as well as their experiences as a father before the pandemic enabled them to become resilient in continually performing their roles.

Figure 1 shows an illustration of how the experiences and characteristics of fathers of children with autism develop resilience during the pandemic. This conceptual model specifically shows the paternal resilience of fathers of children with autism.

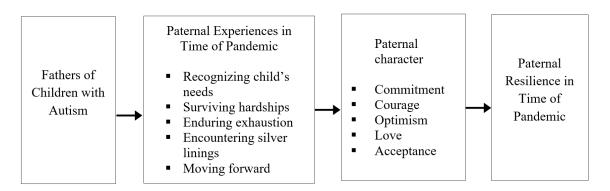


Figure 1. A Conceptual Model on Paternal Resilience in Time of Pandemic

#### 5.0 Conclusion

Fathers of children with autism have encountered both challenging and fulfilling events with resilience during the pandemic. The pandemic was when fathers of children with autism prioritized familial needs, especially of the child, and increased their presence in the household. A strong paternal character builds up fathers' resilience in coping with the difficulties of raising a child with autism in a precarious time.

This phenomenological study explored the lived experiences of fathers of children with autism in Negros Occidental. The study involved only nine fathers of children with autism who fit the criteria and were willing to participate; thus, it did not represent the whole population of fathers of

children with autism. It is recommended to further explore resilience in fathers of children with autism with a larger number of participants.

Other suggestions for future research may also be carried out. First, a similar study may be conducted, focusing on mothers of children with autism. The maternal perspective would provide meaningful insights into autism parenting in the locale. Second, a comparative study of similar purposes may enlighten the differences between paternal and maternal involvement in raising a child with autism in the Filipino context. Lastly, this explorative study may contribute to the development of initial interventions and psychosocial support focused on parents of children with autism.

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