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Challenges and Opportunities for Children with Autism Spectrum Disorder during the Pandemic: Parents' Views in the Limelight

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ABSTRACT

The Covid-19 pandemic has disrupted many facets of human existence, including the experiences of the most vulnerable members of society. This study aimed to explore the lived experiences of children with autism spectrum disorder (ASD) during the pandemic through the lens of their parents. It specifically aimed to delve into the challenges and opportunities these children encountered during these trying times. Using a phenomenological inquiry, six purposefully selected parents whose children have ASD were interviewed and observed to generate rich and detailed information about the phenomenon, which was fortified by the participants' shared photographs by virtue of the photovoice methodology. The analysis brought out five themes from the gathered data; three focused on challenges: (1) putting up with the unavailability of special services, (2) catching up with the demands of modular education, and (3) running into emotional breakdowns. Meanwhile, two themes focused on opportunities: (4) increased time for family bonding and (5) acquisition of new life skills. The study's findings highlight significant implications to government and educational leaders on the interventions and programs needed by children with ASD as they thrive in the midst of the pandemic.

INTRODUCTION

The Covid-19 pandemic outbreak has brought enormous destruction to world health and has been identified as a significant contributor to an increasing number of deaths in almost all countries. Not only has it affected day-to-day human concerns, but it has also caused devastating financial and political catastrophes in the nations that have been afflicted by it (Alam et al., 2022). In addition to the fact that Covid-19 is a threat to the entire planet, it has also been highlighted as a significant element in the unequal distribution of resources and the stalling of human progress (Mishra et al., 2020). Indeed, such an unexpected phenomenon has generated serious and unprecedented impacts worldwide.

As many difficulties come to hold with all the changes caused by the pandemic, one group, in particular, is vulnerable to this unexpected disruption: children with autism spectrum disorder (ASD). As people who are "unable to anticipate,

cope with, resist and recover from the impacts of a disaster" (Du et al., 2015; Van Zandt et al, 2012), children with ASD are considered defenseless during the pandemic due to their inherent characteristics and conditions. In the eyes of a child with ASD, the extreme effects of the pandemic are all the more afflicting; for these children, social interaction and communication are deemed as their difficulties (Brignell et al., 2018), which makes transitioning from one activity to another and focusing on details inevitable travails every day, even more so, during the pandemic.

A study conducted by Pachner and Aranyi (2021) showed that children with ASD exhibit vulnerabilities to mental health issues because of the loss of therapeutic services during the pandemic. Other services also suffer from a shortage of staff, closures of healthcare provider establishments, and reduced or drastically altered access to these specialized services (Eshraghi et al., 2020). Most of

the services needed by persons with ASD, such as the applied behavior analysis (ABA), are normally done face-to-face with the healthcare providers; however, these services have been held or changed into telehealth services because of the pandemic (Baweja, et al., 2021). According to the results of a study conducted in Spain by Lugo-Marin et al. (2021), the main sources of stress during the lockdown were the suspension of therapy treatments and the resulting behavioral issues experienced by children with ASD. The study furthered that individuals with ASD expressed that their needs were not adequately addressed because of lockdown measures, i.e., they experienced difficulties in accessing essential healthcare services and facilities. Other studies (see Amirova et al., 2022; Pachner & Aranyi, 2021; Mutluer et al., 2020) also substantiate that the pandemic was likely to have negative effects on children with ASD because it disrupted educational services. It has also been reported that the lockdowns caused them to lose their previously acquired skills (Amorim et al., 2020). Moreover, there is a significant indication that children with ASD are at increased risk for anxiety with worsening ASD symptoms and behavioral problems caused by their fear, depression, irritability, and impulsivity (Amorim et al., 2020; Baweja et al., 2021; Eshraghi et al., 2020).

Conversely, the pandemic has also brought relatively positive effects on children with ASD, as studies argue. For instance, Huang et al. (2021) report that some children with ASD have developed cognitive and language proficiencies during the lockdown with their parents. Likewise, these parents had more time to attend to their children and do more household chores and family activities (Hill et al., 2021).

As recent literature and studies delineate how the pandemic has undeniably affected the lives of children with ASD, research about the experiences of children with ASD in the Philippine context has remained underexplored, most especially when these experiences are viewed from the lens of the parents who are responsible for guiding, supporting, and caring for their children with ASD. It is argued that during this time of the pandemic, being a parent to a child who has ASD means navigating through some different processes and emotions, particularities of the impairment, its characteristics,

its progression, and natural adjustments (Roquette et al., 2021).

The above-described gap sparks research attention, hence the pursuance of this study. We argue that parents of children with ASD can view their children's experiences of difficulties in completing tasks, transitioning from one activity to another, changes in the delivery of instruction, and inability to access some essential services. With phenomenology and photovoice designs, this study explores the lived experiences of children with ASD from the lens of their parents who can give a clear picture of the reality of the pandemic's toll on these children. Implications of this research endeavor will shed light on what appropriate interventions can be extended by the government and educational institutions to help these children cope with difficulties brought about by the pernicious pandemic. From these well-elaborated perspectives, this study sought to answer the overarching research question: What challenges and opportunities do children with ASD have during the pandemic as viewed by their parents?

METHODS

This study employed phenomenological research design as a research method to explore the lived experiences of children with ASD. Phenomenology is both a research paradigm and a philosophy that investigate people's lived experiences of a particular phenomenon (Cerberne, 2014; Smith, 2013). Using this method, researchers can generate descriptions of how people make sense of the world around them (Neubauer et al., 2019). Hence, this design best suits the needs of the study towards shedding light on the study's research question. Moreover, this study made use of the photovoice methodology. It is a participatory method in which participants utilize photography, as well as stories about their images, to identify and express issues that are important to them (Plunkett et al., 2013; Sanon et al., 2014). The utilization of photovoice in conjunction with both the knowledge of the community and the evidence of best practice can lead to the development of successful and comprehensive methods to solve social issues in a manner that is also meaningful for the community that is involved (Sutton-Brown, 2014). In addition, photovoice is a form of visual research with the goals of promoting social change and investigating

a change in the level of empowerment in marginalized communities (Budig et al, 2018).

The participants of this study were six (6) parents whose children have ASD in Koronadal City, the capital of the province of South Cotabato in the Philippines. They were identified as the best source of information, considering that they have first-hand experiences with their children with ASD. These individuals were chosen on purpose to ensure that the data collected from them would be directly applicable to answering the study's research topic. Participants were selected according to the inclusion criteria: they had to be either the mother or father of a child with ASD, they had lived with their child before and throughout the pandemic, and they had to be willing to participate in the study for free. Sumalinog (2020) states that there should be between five and twenty-five witnesses to the phenomena until data saturation has been reached.

To commence data gathering, permission was secured from the main author's university. The prepared interview guide questions for the study were then subjected to content validation. A pilot interview also allowed us to go over the questions and decide which ones needed to be improved to acquire the necessary data. We then sought out potential participants who met the inclusion criteria. The participants willingly signed consent letters that outlined the purpose of the study and the nature of their involvement. Meanwhile, the in-depth interviews were conducted in Hiligaynon at the convenience of the participants, lasted 35-60 minutes each, and were recorded. All interview data were kept totally confidential and only we had access to them. To maintain confidentiality, we utilized pseudonyms rather than the participants' true names during the transcription and analysis. After the data had been transcribed and analyzed, interview transcript approval was sought from the participants. Onsite visits to the participants and their children were also conducted to triangulate the information gathered from the interviews; moreover, the participants were asked to contribute photographs that they thought were relevant to the data for the study. In compliance with health rules, we observed physical distancing and donned face masks at all times during these encounters.

In analyzing the data, we took into account the steps outlined by Moustakas as cited in Butler (2017). Hiligaynon responses were translated into

English, with the help of two native Hiligaynon speakers with doctorates in education. We then read the data multiple times to identify key points, then statements were categorized into meaning units, i.e., their meanings were derived from the lines of significance.

To supplement the thematic analysis of the interview data, we used the images that the participants had provided, and in this manuscript, these images were deliberately made blurry for ethical reasons. Three external research reviewers or peer examiners attested to the precision of the entire data analysis. On top of keeping an audit trail and keeping a reflective record, we also made sure the analysis was supported by solid theories and credible studies.

RESULTS AND DISCUSSION

Based on the analysis of gathered data drawn from the photovoice process and in-depth interviews, the following themes on the lived experiences of children with ASD as viewed by their parents during the Covid-19 pandemic transpired. These themes are described and discussed below.

Pandemic Challenges for Children with ASD

Children with ASD have experienced several challenges during the COVID-19 pandemic as viewed by their parents. These challenges include putting up with the unavailability of special services, catching up with the demands of modular education, and running into emotional breakdowns.

Theme 1: Putting Up with the Unavailability of Special Services

The pandemic has brought closures of special services such as services from a developmental pediatrician, occasional therapist, speech and language therapist, and counseling services. Hence, children with ASD had challenges in availing of these services. These services had caused some of the children to fall far behind for lack of the needed help and support. Parents expressed: *Sang nag lockdown, wala kapadayon ang akon bata sang iya sessions sa OT... Kabudlay gid iya mag travel kag strikto sato nga time. Damo sang mga health and safety protocols ng adapt sundon. Ti wala gid sya intervention.* (During the lockdown, my child was not able to continue his sessions with the occupational therapist because it was very hard to travel. There were a lot of strict health and safety

protocols that we had to follow. So, he did not have any intervention.) – Parent A.

Wala kami ka pa schedule sa developmental pediatrician kay perti ka budlay sadto nga time. (We were not able to have a schedule for consultation with the developmental pediatrician because it was very hard during that time.) – Parent B.



Figure 1. Photo D-1

Caption: *Tong nag pandemic. Wala na kami nakapa OT. Baw, kabudlay gid tana kay nagbalik ang dati nya nga behavior.* (When the pandemic started, my child was not able to go to his occupational therapist. It was hard for us because his previous behavior went back.) – Parent F

The shocks of the pandemic on business and jobs also hindered children with ASD from availing of the said services. Parents have voiced their family's financial constraints during this global emergency. This posed several problems and added burden to families of children with special needs, especially to those who just stay at home during the pandemic which resulted in a decrease in income (O'Hagan et al., 2021).

Tong nag pandemic... apektado gid amon income... nabudlayan gid kami sa kwarta Sir... Hindi na kami makapa-OT... (During the pandemic, our family income was greatly affected and we had financial issues. We couldn't afford to send my child to an occupational therapist.) – Parent C.

Baweja et al. (2021) contend that while there were global efforts to mitigate the risk of Covid-19, many of these measures (such as stay-at-home orders and social distancing) left people with disabilities in the United States without access to vital services and supports, making them even more vulnerable. Individuals with ASD, their families, carers, and other natural supports, as well as the

professionals who work with them, have felt the immediate effects of this catastrophe. Moreover, the reasons, why many individuals with ASD have experienced troubles with these services, are a shortage of staff, closures of healthcare provider establishments, and reduced or drastically altered access to these specialized services during the pandemic (Eshraghi et al., 2020). On that note, a survey conducted by Jeste et al. (2020) in the United States revealed that approximately 30% of children with special needs were cut off from all special services and support during the pandemic. Moreover, 74% of the children with special needs were deprived of access to at least one type of special service.

Theme 2: Catching Up with the Demands of Modular Education

The closure of educational institutions during the pandemic confronted the learners and their families with numerous challenges, especially those with ASD. The participants have expressed challenges experienced by their children about how they continued their education, particularly via the implementation of modular distance learning. These challenges include the difficulty of their child understanding the self-learning module in Mathematics written in Hiligaynon.

Di tana ka intindi ang bata ko sang Hiligaynon Sir... Ti gina translate ko lang. Di sya ya ka relate. (My child cannot understand Hiligaynon. I always translate what is written in the module into English for him to understand. He cannot relate.) – Parent D.

Wala kami choice Sir kundi answeran kay amo man ang ginhatag sa amon. (We do not have any choice but to answer because that was given to us.) – Parent C.

Denning and Moody (2013) explain that children with special needs and with ASD in particular need to have individualized and specialized learning materials and activities to address their individual needs and interests. They also have an obsessive interest in certain things and these interests vary from one child to another (Parsons et al, 2017). And so, the activities to be done in their modules have to be tailored fit to their identified interests. During the pandemic, parents have expressed their child's frustration with the tasks to be accomplished in the modules. There

were activities found in the modules which mismatched their interests, needs, and abilities.



Figure 2. Photo C-3

Caption: *Budlayan gid sya magintindi sa Hiligaynon. Gina translate ko lang na da. Pero after thirty (30) minutes, naan. Stressed na siya..* (My child has difficulty in understanding her activities in modules written in Hiligaynon. So, I just assisted her in translating the text. But after thirty (30) minutes of answering, she is already stressed.) – Parent B.

Di na sya kadugay answer ka module nya Sir ya... Ng lalo na pag damo sya sulatunon. (My child cannot stay long in answering the modules especially if she is asked to write a lot.) – Parent E.

Ambot ngaa damo tana sulatunon nila sa module Sir ah. Bal-an man na ni teacher nga natamad na sya magsulat. (I do not know why there are a lot activity that he has to write in his modules when in fact his teacher knows that he does not want to write.” – Parent C.

Baweja et al. (2021) explicated that throughout the pandemic, students with ASD who thrive with the help of a paraprofessional or one-on-one instruction in a classroom setting were suddenly being asked to complete schoolwork on their own time at home. Their parents or carers now had the added responsibility of helping them overcome educational obstacles while also maybe working to provide for the rest of the family and keeping the home in order. Parents typically have excellent insight into their children's talents and needs, but they may lack the knowledge and experience necessary to put those plans into action. This idea is in line with the findings of a study that was carried out by Pachner and Aranyi (2021). The authors found that children who have ASD had a very difficult time continuing their education during the pandemic, on top of the fact that they were unable

to adapt to online and distance curricula and cope with the difficulties associated with homeschooling.

Theme 3: Running into Emotional Breakdowns

Since these children with autism spectrum disorder (ASD) have experienced challenges in putting up with the unavailability of special services and catching up with the demands of modular education, their emotional and behavioral aspects were greatly affected. As expressed by the participants, their children have exhibited anxiety and frustration, leading to tantrums, and other violent behaviors. The changes in their routine have also contributed to these challenges.

Sang nag sige lockdown, wala na kami kapa OT... Nagbalik naman violent behavior niya. Mabudlay gid kung hindi sya maka session sa iya nga OT. (During lockdowns, we were not able to go to her occupational therapist. As a result, his violent behavior came back. It is really difficult if he can't have his sessions with his occupational therapist.) – Parent D.

Nag change gid iya routine sang nag pandemic Sir especially kay ara lang kami sa balay. Ti nag bag-o man iya behavior nadugangan pa gid sang mga activities sa iya modules nga hindi nya gusto himuon. (My child's routine has changed during the pandemic especially since we just had to stay at home. Also, she does not like to do her activities in her modules. There was also a change in her behavior.) – Parent B



Figure 3. Photo F-2

Caption: *Nag change iya routine sang nagpandemic. Wala pa gid sya naka pa OT. Nag sige naman siya tantrums. Gahibi na siya dira. Perti gid ya ka budlay sato nga time.* (The pandemic changed my child's routine. She also was not able to have her sessions with her occupational therapist. Because of these, she often had tantrums.

She was crying in this photo. It was really hard for us during that time.) – Parent E

Due to their challenges in social communication, children with autism benefit greatly from being immersed in surroundings that both provide loving support and gently push the limits of their social growth (often through school, play dates, and therapies). Since communicating with anyone other than immediate family is extremely difficult during the pandemic, the change in their behavior has been apparent. It has been shown that children with ASD thrive in structured, routine environments. The pandemic, however, has rendered such foresight impossible (Bellomo et al., 2020). This too corresponds to the study conducted by Amorim et al. (2020), which expounds those parents of children with ASD predominantly reported changes in their child's behavior, the negative impact of quarantine in learning, and issues on emotional management during the Covid-19 pandemic. In the same way, because of the pandemic, families of autistic individuals have reported higher levels of stress and a rise in the number of demands placed on them. This could have long-term adverse effects on the mental health of both the families and their children (Lee et al., 2021).

Pandemic Opportunities for Children with ASD

As expressed by the participants, children with ASD have also found opportunities during the Covid-19 pandemic. These opportunities include increased time for family bonding and the acquisition of new skills.

Theme 4: Increased Time for Family Bonding

The pandemic has offered more time for children with ASD and their parents to bond. The series of lockdowns has brought opportunities for them to be connected and enjoy while staying at home. This gave them enough time to do recreational activities that their child enjoys.

Nami man kay mas lawig na amon time mag bonding sa balay. Upod na kami maglantaw sang favorite nya nga TV show kag maupdan namon na sya mag-swimming. (I appreciate it because we had enough time to bond at home. We were able to watch his favorite TV show together and we were able to swim with him.) – Parent D.

Sadya kami sa balay ah. Gabulig siya sa akon prepare sang amon pagkaon. Gusto nya gid na magluto-luto. Happy gid ko nga may time na kami sa mga amo sini nga activity. (We enjoyed staying at home. My child enjoyed helping me in preparing food. He really likes to cook. I am very glad that we are able to have enough time to do this kind of activity.) – Parent F

In their Australian study, Evans et al. (2020) conclude that several families had adaptive and positive relationship functioning improved during the lockdown, in part because they learned to better communicate and resolve conflicts in the face of pandemic-related stressors. Some families have found value in the experience, try new activities, and cultivate admirable traits like gratitude, tolerance, and appreciation. It is in agreement with the study conducted by Huang et al. (2021) which revealed that with limitations because of safety and health protocols to stay at home, parents had more time to attend to their children and do more household and family activities.

Theme 5: Acquisition of New Skills

Because of the longer time that children with ASD spent at home during the lockdown, they acquired several skills. They were engaged in various activities and household chores which they were not able to do before the pandemic. As expressed by their parents, they learned how to arrange tables, wash dishes, prepare food, speak a new language (e.g., Bisaya), segregate/throw garbage, and even vlog.



Figure 4. Photo A-5

Caption: Tong nag pandemic, damo kami time para mag bonding kay di man kami ka gawas kay lockdown. Dira, naga swimming sya sa iya nga pool while ga meryenda kami ni Papa nya. (During

the pandemic, we had more time as a family to bond since we couldn't go out because of the lockdown. She is swimming that time while I and her father are having snacks.) – Parents E

Kabalo na mag obra akon bata sa sulod balay. Kabalo na sya maghugas pinggan... kag mag prepare table bag-o kami magkaon tapos limpyuhan nya man na ang table pagkatapos namon kaon. Sang wala pa pandemic, di nya ni bal-an kay hindi nya man ni mahimo tungod sa iya schedule sa school kag sa OT. (My child learned how to do household chores such as washing dishes, preparing the table before we eat, and cleaning right after. Before the pandemic, he does not know how to do household chores since he is preoccupied with his schedule in school and with his occupational therapist.) – Parent A.

Nag explore akon bata mag tiktok Sir... subong kabalo na siya ya mag vlog-vlog. Nakibot lang kami sina. Nalipay na siya mag vlog-vlog. (My child had more time exploring Tiktok, and now, he knows how to vlog. We are just amazed. Vlogging makes him happy.) – Parent D



Figure 5. Photo B-4

Caption: Damo sya nabal-an sang nag pandemic. Kabalo na sya magluto. Tapos ginabuligan nya ko kung mag bake ako. Sya man naga segregate kag haboy sang amon basura. (My child learned a lot of things during the pandemic. He can cook simple food now. He also helps me when I bake. He is also assigned to segregate and throw our garbage.) – Parent F.

He et al. (2021) explicated that during the lockdowns caused by the pandemic, many parents found themselves spending more time with their children at home. As a result, they needed to

reorganize their daily routines and activities to meet the new circumstances. Because of this greater time spent at home together, some parents and their children may find that they have more possibilities for learning and structured activities, which are beneficial to the development of both social and cognitive skills (Cabrera et al., 2020; Gregus et al., 2021).

CONCLUSION

Based on the findings delineated above, the study concludes that children with ASD have experienced challenges and opportunities amid the pandemic, as shared by their parents. Their challenges encompass (1) putting up with the unavailability of special services, (2) catching up with the demands of modular education, and (3) running into emotional breakdowns. Due to the possibility of aggravation of ASD symptoms, restricted access to therapy, and the necessity to adapt to changes in the environmental and educational settings, children with ASD are a particularly susceptible group of the world's population in the context of the Covid-19 pandemic. Future interventions and additional schemes of assistance for this population should take social and environmental adjustments into account without ignoring the therapeutic needs of those with ASD and their families. Hence, governments are called to bring their attention to the medical and social needs of these children, so services they need the most concerning their condition may be fully provided despite the pandemic. This is because if children with ASD are not provided proper guidance and help in adapting to a new, unfamiliar environment, detrimental impacts on their learning and behavior will arise. It must be noted that when it comes to the upbringing of a kid with ASD, parents require additional support from other people, particularly specialists who can assist and counsel them. Moreover, school leaders and administrators are called to sedulously take a look at the modular learning materials given to children with ASD. It must be assured that the said materials, covering the instructions and tasks, fit the needs and competencies of these children.

On the other hand, the study brings out that despite the pandemic, children with ASD have found opportunities like an increased time for family bonding and avenue for the acquisition of

new life skills. Hence, this study concludes that the pandemic is not after all a hellacious circumstance for everybody, as it is possible that during the Covid-19 pandemic, parents of individuals with ASD have seen how their children learned more about the values of family, trust, confidence, and determination.

Considering the limitations of this study, further research is recommended focusing on the pandemic experiences of professionals who have ASD. New perspectives and insights into the phenomenon may emerge concerning what challenges, opportunities, and coping mechanisms they hold that may bring enlightenment and inspiration to others with ASD and their concerned families.

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