



## Impact of COVID-19 Pandemic on Children with Autism Spectrum Disorder: A Qualitative Study of Mothers' Perspectives

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### ARTICLE INFO

#### Article History:

Received: 10 September 2023

Accepted: 01 November 2023

#### Keywords:

Autism Spectrum Disorder; COVID-19; Psychosocial impact; Coping mechanisms

#### Citation:

Hiruni Liyanage , Thilakshi Fernando, (2023). Impact of COVID-19 Pandemic on Children with Autism Spectrum Disorder: A Qualitative Study of Mothers' Perspectives. Proceedings of SLIIT International Conference on Advancements in Sciences and Humanities, 1-2 December, Colombo, pages 516-524.

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### ABSTRACT

The COVID-19 pandemic has had far-reaching global consequences, causing substantial changes in all aspects of daily life. Children with Autism Spectrum Disorder (ASD) are highly sensitive to the effects of the COVID-19 pandemic. The study explores the impact of COVID-19 on children with ASD by focusing on qualitative data obtained from their mothers. The study aimed to determine the impacts of COVID-19 on children with ASD, the challenges mothers of children with ASD faced during COVID-19, and the coping mechanisms they have used. A purposive sample of 6 mothers of children with ASD who fulfil the requirements of the inclusion criteria were recruited. Qualitative semi-structured interviews were conducted to obtain in-depth information. Thematic analysis was used for data analysis. Four major themes emerged: Pandemic's influence on the social development of kids with ASD, ASD children's psychological response to the pandemic, Motherhood struggles during the pandemic, and Adaptive responses to the challenges of COVID-19. The study findings indicate both positive and negative impacts of COVID-19 on children with ASD, particularly affecting their social skills. Motherhood struggles and adaptive responses during the pandemic are also discussed. Further research is necessary to identify interventions aimed at mitigating the effects of COVID-19 on children with ASD.

## 1. INTRODUCTION

The coronavirus disease 2019 (COVID-19), which was originally identified in December 2019 in Wuhan, China, quickly spread around the world and was declared a pandemic by the World Health Organization (WHO) on March 11, 2020 (WHO, 2020). Because of this pandemic situation, people faced extreme disruption and social isolation.

Children are the most vulnerable to possible impacts of the COVID-19 pandemic (Al-Balushi & Essa, 2020). Along with the issues that all children faced, children with Neurodevelopmental Disorders (NDD) faced additional hurdles because of the public health crisis. Especially children with ASD are at high risk of adverse effects from the pandemic due to their social interaction and communication challenges, restricted and repetitive patterns of behaviours, interests, and co-occurring behavioural and psychological symptoms (APA, 2013; Baweja et al., 2021). ASD was once thought to be a rare condition, but its global prevalence rate is rising, with a prevalence rate of 0.07% in Sri Lanka (Hossain et al., 2017).

The COVID-19 pandemic had a mixed impact on the mental health of children with ASD, with some experiencing increased anxiety and depression due to ineffective time management, unstructured activities, and disruptions to their routines (Amirova et al., 2022), while others reported feeling happier due to the absence of social stressors (Mumbardó-Adam et al., 2021).

Children with ASD face difficulties adapting to new situations such as lockdowns due to their inflexibility in thinking (degli Espinosa et al., 2020). Unexpected events can cause distress and behavioural issues in children with ASD, as they rely on routines and struggle with changes and transitions (Berard et al., 2021; Frankova, 2020). They may experience discomfort when wearing masks due to sensory sensitivities (Tamon et al., 2022). Additionally, the risk of infection spread

may be increased by challenging behaviours, such as scratching and biting, exhibited by children with ASD (Narzizi, 2020).

Social distancing policies during COVID-19 led to social isolation, loss of friendships, and increased loneliness, which was found to be preferable to children with ASD. However, this isolation was found to have negative impacts on the development and maintenance of social and communication skills in children with ASD (Cluver et al., 2020; Narzizi, 2020).

Prior to the pandemic, schools provided specialized support with facilities, teachers, therapists, and a structured curriculum for children with ASD (Roberts & Webster, 2020). However, the pandemic disrupted these services, necessitating home education as an alternative to school-based education, which posed challenges for mothers in meeting their children's educational and therapeutic needs (Amirova et al., 2022; Isensee et al., 2022).

Amirova et al. (2022) identified some parents who were happy with home education/therapies as it provided an opportunity for parents to spend more time with their children with ASD, leading to better understanding and increased closeness (Brooks et al., 2020; Mumbardó-Adam et al., 2021).

Reicher and Stott (2020) found that transitioning to online learning during the COVID-19 pandemic had advantages for students with ASD. Compared to face-to-face learning, students with ASD experienced less anxiety and benefited from the absence of overstimulation like loud school bells, shouting children, and changing classrooms.

To adapt to the increasing demands imposed on parenting when raising a child with ASD during COVID-19, parents have adopted both adaptive and non-adaptive coping skills such as behavioural strategies, changing routines, engaging in enjoyable activities during the pandemic and becoming

conscious of their children's hygiene (Meral, 2021; Neece et al., 2020). Tokatly et al. (2021) suggested that parents lacked knowledge and resources to meet their children's developmental needs during COVID-19.

The previous literature on COVID-19 pandemic suggest that it significantly impacted children with ASD and their mothers. Therefore, understanding and addressing the needs of parents are important as they are responsible for their children's well-being, education, and future. While there are studies on this topic globally, there is a knowledge gap specific to the Sri Lankan context. This study aims to explore mothers' perspectives on the impacts of the pandemic on children with ASD in the Colombo district, Sri Lanka. The findings will contribute to post-pandemic support interventions and future preparedness for pandemics concerning children with ASD.

The following are the research objectives that guided this study:

### **1.1 Research Objectives**

1. To identify the impacts of COVID-19 on the social skills of children with ASD
2. To identify parenting challenges faced when taking care of a child with ASD during COVID-19.
3. To identify coping mechanisms used by mothers to handle their child's ASD condition during COVID-19.

## **2. MATERIALS AND METHODS**

### **2.1 Design**

The present study is an explorative study which used qualitative semi-structured interviews. The study used Thematic analysis (TA) to systematically identify, organize, and offer insight into patterns of themes across the information gathered (Braun & Clarke, 2006).

### **2.2 Participants**

The researcher purposively selected six participants who met the inclusion criteria from a private special needs' institution. The criteria were mothers (1) who were aged 25 years to 45 years (2) with children with ASD aged between 5 years to 10 years and has attended school at any point and (3) currently living in the Colombo district.

### **2.3 Materials**

#### **2.3.1 Participant Information (PI) sheet and Consent form**

All participants were given a PI sheet which included information on the purpose of the study, eligibility criteria, impact of their participation, risks/benefits, confidentiality, whether the approval was given by an ethics committee, and whom they should contact for inquiries. Participants were asked to sign a consent form to confirm that they have read and understood the information given in the PI sheet and agreed to participate in the study.

#### **2.3.2 Interview guide**

The interview guide consisted of 13 main questions based on the objectives of the study. The questions were followed by prompts. The construction of the interview guide was formulated ensuring that the research questions were effectively addressed while allowing for flexibility in probing for rich qualitative data. This involved a thorough review of existing literature, identification of key research objectives, and a detailed outline of the topics and subtopics to be covered during the interviews.

### **2.4 Ethical Considerations**

Ethical approval was obtained from the SLIIT School of Psychology Pro tem Psychology Ethics Review before data collection, adhering to the APA 2017 code of conduct. The data was accessed only by the researcher and supervisor. Audio records were solely available to the researcher. Data was

securely stored in a password-protected computer folder and locked drawer. After five years, the data will be destroyed. Participants' anonymity was ensured as each participant were given an anonymity code which was the only recognition code used in each document or recordings of the research. They had the right to withdraw from the study at any time using their anonymity code. Interview questions were designed to be non-offensive, and participants were informed that they could skip any uncomfortable questions. A debrief sheet was provided, including contacts for available support services if participants experienced distress during or after the interviews.

### 2.5 Procedure

Data was collected only after obtaining ethics approval. Participants were invited to take part in the study through a volunteer requirement notice. The researcher purposively selected six participants out of a pool of participant who volunteered to take part in the study. The recruited mothers were asked to read the Participant Information sheet, which included information needed to make an informed decision about whether to participate in the study and sign the consent form to confirm that they have read and understood the information given and agreed to participate in the study. Interviews were conducted via Zoom or direct call at a convenient time and language. Each interview was digitally recorded and lasted 20 to 30 minutes. Participants were thanked and debriefed at the end of the interview.

### 2.6 Analytical Procedure

When analysing participant responses from the interviews, certain steps were taken to analyse the data. First, the recorded interviews were transcribed using verbatims. The data was then analysed using Thematic analysis (TA) to systematically identify, organize, and offer insight into patterns of themes across the information gathered (Braun & Clarke, 2006). The initial step involved familiarizing

oneself with the transcriptions and coding the data, which required significant time. By reviewing the transcripts multiple times and focusing on coding, themes and subthemes emerged from the data, important codes and corresponding quotes were documented. Finally, clustered themes were created using Microsoft Excel. And a coding framework was developed.

## 3. RESULTS

As mentioned, in the Methods section, a total of 6 participants partook in the study, and all participants' data were used to interpret the findings. The findings are presented in the sections below.

### 3.1 Demographic characteristics

Selected demographical information were collected for further reference and analytical process. These data were collected via the documentations of the institute in which the participants were taken. Table 1 below indicates a simplified version of the characteristics of participants and their children.

**Table 1:** *Information on participants and their children*

Information on Mothers			Information on Children with ASD					
Mother	Age	Profession	No. of Children	Child	Gender	Age	ASD Level	Education Level
P <sub>1</sub>	32	Housewife	1	C <sub>1</sub>	Male	10	Moderate	Grade 5
P <sub>2</sub>	38	Housewife	2	C <sub>2</sub>	Male	9	Mild	Grade 4
P <sub>3</sub>	37	Housewife	2	C <sub>3</sub>	Male	10	Severe	Grade 5

P <sub>4</sub>	26	Housewife	2	C <sub>4</sub>	Male	7	Mild	Grade 2
P <sub>5</sub>	32	Teacher	1	C <sub>5</sub>	Male	5	Moderate	Grade 1
P <sub>6</sub>	29	Housewife	2	C <sub>6</sub>	Male	5	Moderate	Grade 1

Adaptive responses to the challenges of COVID-19	Adapting to new life changes	5	"We go to school now, work with children, we visit relatives, we go shopping, so now it has become normal, to live with the pandemic." (P4).
	Being more aware and informed of the pandemic.	6	"... we have to take care about our health more than before, like from using sanitizer. Things vegetables also, washed before using because of COVID-19. Safety was the concern." (P4).
	Being more attentive to children's health and safety	6	"It all was a big challenge for me. (With sober voice) ..., and a child with autism can't express his feelings properly. I felt so helpless as a mother. I have run on the road holding my child in my hands to the hospital." (P6).

### 3.2 Qualitative Results

The TA was done using the transcripts obtained through all 6 interviews, exposed 4 overarching themes, including sub-themes for each main theme as outlined in Table 2.

**Table 2:** Table Representing Main Themes, Subthemes, Frequency, and Quotes of Interviews

Themes	Sub-themes	Frequency	Quotes
Pandemic's influence on the social development of kids with ASD	Improved interaction with family members	3	"He couldn't be with his peers, but he has his little brother, who is about 5 years old. They play together so they became closer than they were before the pandemic". (P4)
	Engaging in activities and spending quality time	4	"He always likes to make very big puzzles...14 plus, that kind of puzzles. He also makes Legos. During the COVID-19 period he had more time to do them than before." (P1)
	Adapting to COVID-19 safety protocols	5	"... he knows that he must wear a mask. He even gives us a mask when we go outside." (P2).
	Enhancing current skills and acquiring new skills	2	"Uhm... he has a verbal, difficulty; I think it has improved... he couldn't ride bicycles before, but after the pandemic he can now. He talks and communicates much more with us than before." (P5).
Lack of communication and social interactions	Lack of communication and social interactions	3	"My sisters' children also couldn't come to our house. He sometimes takes back the car key and said, "Let's go, Let's go on the car". We sometimes take him out also." (P5).
	Ineffective remote special education/therapies	6	"Uhm..., No. It's hard to do with online sessions. ....it's hard to children to understand" (P4).
	ASD children's psychological response to the pandemic	Experiencing stress and anxiety	3
Motherhood struggles during the pandemic	Withstanding the challenging behaviours of their children.	3	"They became more stubborn, .... Like those his hyperactivity was also increased, and still, it is the same". (P4).
	Enduring financial difficulties	1	"The COVID time was very difficult for us because my husband couldn't go to his job...Still, we haven't recovered to the financial status we were before the COVID-19 situation. So, it's very hard these days to pay for our son's therapy sessions." (P6)
	Providing home education	4	"I did not join any online sessions, But I did what I can do for him from home from our end." (P5).
Feelings of isolation and deteriorating mental health in mothers	Feelings of isolation and deteriorating mental health in mothers	3	"I felt that that my interest in everything decreased. I began to develop stress and anxiety and felt really hopeless during the entire COVID-19 period." (P6).

Overall, mothers of children with ASD shared their perspectives on the COVID-19 pandemic and how they think it has affected their ASD children, both psychologically and socially. Mothers shared that the pandemic brought upon many challenges and changes in their lives. From the mothers' perspectives, one of the common impacts on their children was staying at home with limited interaction with their family and peers, as well as the outside world. Mothers also shared that their children displayed symptoms of stress and anxiety, as well as feelings of isolation and loneliness due to the lockdowns. Regardless of these challenges, some positive changes were also noted. For example, some mothers noted that they had more time to engage with their child, and by doing so increased their bond, in addition to noticing an improvement in the child's critical thinking skills. In terms of the challenges brought upon these mothers, it was noted that the mothers found it challenging to tolerate the challenging behaviours of their children. Additionally, they experienced financial hardships, which made it difficult for them to manage their household finances as well as the costs for the child's therapy. This, in turn, brought upon mental health issues such as feelings of loneliness and stress for the mothers as well. Subsequently, mothers identified ways to cope with these situations by being more well-informed and aware of the pandemic and adapting their life to suit these changes to make their life and their children's life reasonably better and manageable.

#### 4. DISCUSSION

The present study aims to examine the impact of COVID-19 on children with ASD through the perceptions of mothers. Three research questions were explored: (1) the impact on social skills, (2) parenting challenges during COVID-19, and (3) coping mechanisms used by mothers. This section analyses the findings, their relevance to the research, and compares them to past studies. The results are based on semi-structured interviews with six Sri Lankan mothers of autistic children, and a thematic analysis was conducted.

In Sri Lanka, a collectivist country, social skills are prioritized over emotional regulation or behaviour in children. Hence, studying the impact of COVID-19 on children's social skills becomes crucial as it can significantly influence their future in Sri Lanka. While everyone has faced challenges due to the COVID-19 pandemic, children with ASD are particularly vulnerable. Isensee et al. (2022) highlights the numerous challenges faced by families with children who have ASD during the pandemic. The current study also supports this notion, revealing the psychological and social effects of COVID-19 on children with ASD. Lockdowns confined them at home, leading to increased stress and restlessness due to limited interaction with the outside world.

According to past research studies, education for children with ASD was typically provided in schools with the help of teachers, therapists, or psychologists competent in the field of special needs, and a specified curriculum with assessments and evaluations, where the effectiveness of the educational program reciprocated to the needs of the child; however, these services had to be discontinued and replaced with home or online education, which reduced the effectiveness of these special facilities (Roberts & Webster, 2020;, 2021). The current study supported this, as mothers preferred face-to-face learning/therapies and found online alternatives ineffective. Challenges

included lack of feedback, insufficient organization for individual differences, technical issues, and children's lack of attention. On the other hand, some mothers observed positive impacts, such as skill development and improved interaction with family members, resulting from the pandemic. Engaging activities like jigsaw puzzles contributed to new skills like critical thinking and being at home seemed to alleviate performance pressure and social expectations.

Contrary to degli Espinosa et al. (2020), who suggested that children with ASD struggled to adapt to the new lifestyle during COVID-19, mothers in the current study reported that their children adapted well and followed COVID-19 safety protocols without refusal or dissent.

According to the generally accepted diagnostic criteria, ASD is characterized by specific symptoms and qualitative or quantitative changes, along with repetitive behaviours (Bellomo et al., 2020). The current study supported this, as some parents described an increase in behavioural issues like restlessness and hyperactivity in their children.

Consequently, Alhuzimi (2021) highlighted that children with NDD already faced challenges and limited opportunities before the pandemic. The situation further deteriorated during the pandemic, impacting the mental health of both children with NDDs and their families, leading to unstable mental health and changes in mood and behaviour (Alhuzimi, 2021; Yazıcı et al., 2022). The current research findings supported this, revealing that both mothers and children with ASD experienced psychological effects, including feelings of loneliness, isolation, stress, and anxiety due to the lockdowns.

The current study highlighted the role of mothers as primary caretakers of autistic children during the COVID-19 period and the challenges they faced. Mothers expressed concerns about economic uncertainty, job loss, transportation

issues, and health concerns, all of which affected children with ASD. Financial difficulties, including difficulties in paying for therapy, were reported, aligning with past research (Cluver et al., 2020; Smile, 2020).

Consequently, previous studies (Neece et al., 2020; Meral, 2021) found that parents developed coping skills to handle their autistic children and became more conscientious about hygiene guidelines. The current study supports these findings, showing that mothers were more aware and informed about the pandemic and their child's health and safety.

#### **4.1 Limitations**

There are several limitations of the present study, such as only including English and Sinhala speaking participants and participants from selected geographical location. Another noticeable limitation is the fact that all participants' children were boys, and this limited the study to diversified gender which the results might have been affected. Also, all participants except one were housewives which may also have had an impact on the findings. Another limitation was that the sample was not geographically varied as it was limited to the Colombo district and from only one special needs institute. These limitations may have affected the reliability and validity of the results of the current study.

#### **4.2 Recommendations for research and practise**

The current study's results highlight important areas for future research. While mothers' perspectives on children with ASD have been extensively studied, it is crucial to also investigate fathers' perceptions of the impact of the COVID-19 pandemic. Additionally, further studies are needed to explore interventions that can mitigate the negative effects of COVID-19 or future pandemics on children with ASD. Recognizing that the mental health of mothers significantly influences the

well-being of children with ASD, it is essential to provide adequate support to mothers as well.

#### **4.3 Implications**

The findings of the study have the potential to affect educational policies and practices by calling for greater inclusion and flexibility to meet the needs of children with ASD during times of crisis. Insights from mothers' perspectives can assist in building programmes that target specific requirements of children, such as remote learning, therapy, and mental health care. Policymakers and public health authorities can use the research to enhance preparedness plans for future pandemics or emergencies.

### **5. CONCLUSION**

The study examined the impact of COVID-19 on children with ASD through the perspectives of Sri Lankan mothers. The results provided a comprehensive understanding of the research aim and addressed the research questions. Findings indicated that children with ASD are particularly susceptible to the effects of the pandemic, with both positive and negative impacts on their social skills identified. The study also highlighted the psychological impact on both children with ASD and their mothers. The challenges faced by mothers and their coping strategies were discussed, emphasizing their importance in helping ASD children adapt during the pandemic. The insights from this study will contribute to future pandemic preparedness, specifically in supporting parents of children with ASD.

### **ACKNOWLEDGEMENT**

The author wishes to thank everyone for their invaluable contribution and feedback to the present study.

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