

Impact of Covid-19 on the Stress level and Functionality of Autistic Children and their Parents: A Cross Sectional Study

Shimmaa Mansour Moustafa Mohammed ⁽¹⁾, Gihan Mohamed Mohamed Salem ⁽²⁾

(1) Assistant professor of Pediatric Nursing, Faculty of Nursing, Zagazig, University, Egypt

(2) Lecturer of Psychiatric and Mental Health Nursing, Faculty of Nursing, Benha University, Egypt Correspondence:

Shimmaa Mansour Moustafa Mohammed dr.shimamansour2020@gmail.com [Http://orcid.org/0000-0002-2956-610x](http://orcid.org/0000-0002-2956-610x)

Abstract

Background: The COVID-19 pandemic has an impact on everyone, but autistic children and their parents are particularly vulnerable. Parenting became even more challenging with the decreased access to schools, support systems, and intervening services. Researchers must thoroughly examine the problems and needs of diverse families in their home countries, in order to recommend the most likely interventions. The aim of this study to explore the impact of COVID-19 pandemic on autistic children and their parents' stress level and functionality. **Methods:** A descriptive cross-sectional study was conducted on purposive sampling of 80 autistic children and parents who used to get therapeutic services for their autistic children at three centres, in Zagazig city, Egypt. The collected data took place between June 2021 and September 2021 and included the characteristics of the autistic children and their parents, the impact of the pandemic on children and their parents' stress and functionality. **Results:** The study found that more than half (52.5%) of studied parents had severe distress, 47.5% of them had severe Parent-child dysfunctional interaction, and more than two thirds (70%) of them had difficulty with child, and more than two thirds (68.8% and 71.3%), respectively, the pandemic had a negative impact on their learning and personal development. **Conclusion:** The COVID-19 pandemic had a major negative impact on the stress level and functioning abilities of autistic children and their parents. The paucity of resources, particularly therapeutic ones, made the challenges parents and children faced in providing for them worse.

Keywords: Covid-19, autistic children, parents' stress

Introduction

People all over the globe have been impacted by the COVID-19 pandemic in their daily lives, socio-cultural structures, health and healthcare systems (Huang et al., 2021). Studies have shown that prolonged quarantines have harmful consequences on children's lives, including problems with learning, boredom, aggression, restlessness, anxiety, and loneliness (Al-Rahamneh et al., 2021; Imran et al., 2020). Despite the fact that fortunately fewer children than adults have COVID-19, it is evident that the pandemic is having a negative impact on them (Singhal, 2020). Children with Autism spectrum disorders (ASD) are especially susceptible to the more disruptive negative impacts of the COVID-

19 pandemic because of their special health concerns (Howard-Jones et al., 2022). ASD is a neurodevelopmental disorder that is marked by cognitive deficits, restricted social interactions, and repetitive behavior patterns and interests (Aysel et al., 2019; Wang et al., 2021). According to a recent Egyptian study the prevalence of ASD is 5.4/1000, and 2.8% of children are considered to be at high risk for ASD (Yousef et al., 2021).

Caring for a child with ASD puts more social, physical, psychological and financial strains on parents than any other condition because of: the disorder's severity, chronic nature, mental health comorbidities, rigorous therapies,

and difficulties accessing resources (Alhuzimi, 2021; Southey et al., 2021). Parents may need educational, psychological and social support for themselves and their children, to be able overcome their struggle with their negative mindset towards their experiences with the ASD (Aysel et al., 2019; Genova et al., 2021). Due to interruptions in critical services and therapies as well as other disruptions in day-to-day living, children with ASD may exhibit more autistic symptoms, a higher incidence of behavioral problems, and a decline in cognitive, mental and psychological wellness (Genova et al., 2021; White et al., 2021). Anxiety, speech issues, cognitive difficulties, seizures, immune system disturbance, are frequently seen in combination with ASD (AlSalehi & Alhifthy, 2020; Amorim et al., 2020; Dekker et al., 2022; White et al., 2021)

Furthermore, students, including those with ASD, were required to begin learning online from home as part of the COVID-19 program, which precipitated an immediate and maybe long-term negative impact on both the children and the parents (Zeglam & F Al-Ogab, 2022). Recent studies found out that the interruption. Of ASD children's routines and their preferences for sameness and repetition, could cause a number of malfunctions, such as an increase in behavioral outbursts, generalized anxiety, and aggression in children, as well as an increase in stress in their parents (Genova et al., 2021; Yilmaz et al.,

2021). Due to their demanding responsibilities, parents often experience high levels of stress, anxiety, burn out and general poor psychological and mental health functioning (Lugo-marín *et al.*, 2021). These responsibilities include: juggling their personal needs with those of their family, providing ongoing care, dealing alone with their autistic children's developing emotional, functional, and behavioral challenges by taking on the roles of therapists, caregivers, or educators (Aysel *et al.*, 2019; Lee *et al.*, 2021). Unsurprisingly, escalating parental stress, exhaustion, and maladaptive mental health functioning can in turn exacerbate their autistic children's behaviors and symptoms, worsen the mental and psychological health of the affected children and create a vicious process (Jacques *et al.*, 2021; Wang *et al.*, 2021).

Many recent research studies assessed the effect of Covid 19 on the emotional, mental and psychological health of parents and their autistic children, however it is essential to pay close attention to information pertaining to certain countries/communities as they have their own unique affects and demands (Genova *et al.*, 2021; Yilmaz *et al.*, 2021; Yousef *et al.*, 2021). Therefore, the aim of this study is to assess the impact of Covid-19 on the stress level and functionality of the autistic children and their parents, in Al-Zagazig Governorate, Egypt.

Aim of the work

This study aimed to explore the impact of COVID-19 pandemic on autistic children and their parents' stress level and functionality.

Research design: A descriptive cross sectional study design.

Subjects and Methods

Setting: The present study was conducted in the Speech therapy clinics affiliated to Zagazig university hospitals and El-Ahrar Hospital. Also, Center of Rehabilitation affiliated to disability science and rehabilitation, Zagazig university, Egypt.

Subjects

The study was conducted on autistic children and their parents who received care and follow-up at the previous mentioned setting.

Sample size and technique: This study was carried out by purposive sampling method (80 children and parents), the sample size was calculated using the MedCalc software program (www.medcalc.org/index.php) at 5% α error (95% significance) and 20% β error (80% power of the study), Inclusion criteria for children: Age:6-12 years, Sex: male and female and Autism diagnosed since 2-4 years. Exclusion criteria were having a severe neurological

disease, syndromic ASD, or a complex genetic syndrome.

Tools of Data Collection:

A validated Arabic-language questionnaire consists of four parts as the following was used for data collection.

Part I: Characteristics of children: this part was developed by the researchers and included age, gender, number of siblings, child ranking, age of autism diagnosis, and participation in online behavior modification programs.

Part II: Characteristics of parents: this part was developed by the researchers and included age, kinship, marital status, education level, occupation, residence, and income.

Part III: Parenting stress index (PSI): It was originally developed by (Abidin, 1995), and (Abidin, 1990). It used to measure the parenting-related stress. It consisted of 36 items classified into 3 subscales including: (Parental distress, Difficult child characteristics and parent-child dysfunctional interactions). Parenting Distress (How competent, constrained, conflicted, supported, and/or depressed parents feel in their role as parents), Parenting-Child Dysfunctional Interaction (How satisfied parents are with their child and their interactions with them), and Difficult Child (How a parent perceives their child to be, whether the child is easy or difficult to take care of). Each item scored depending on Likert scale as always, sometimes, and never 3,2,1 respectively. Total score ranged from 36 to 180 and categorized as mild if <50%, moderate if 50 to 70%, and severe if score >70%.

Part IV: Effect of pandemic on children: This part of the questionnaire was adapted based on that of (Amorim *et al.*, 2020). It included eleven items as days in quarantine, went out during quarantine, child's behavior change, impact of the quarantine in learning, child anxiety score, child adaptation to quarantine score.

Reliability & Validity:

The reliability of the tools was assessed using the Cronbach's alpha coefficient test in the SPSS software version 21. The internal consistency reliability (Cronbach's α) for the PSI-SF merged as excellent (.0905), while the "Effect of pandemic on children" emerged as good (0.823). Five pediatric and psychiatric nursing specialists evaluated the content's validity and provided feedback on the tools' structure, layout, uniformity, correctness, and

applicability.

Pilot study:

It included 8 parents of ASD children who represented 10% of the whole research group. It was done to assess the study's methodology, applicability, content clarity, viability, and time required to complete the questionnaire. Since the findings of the pilot study showed that there was no need to adjust the questionnaire, the participants were included in the study.

Data collection:

A review of recent related literature on the study's topic was conducted. To make the tools useable, the researchers prepared them and translated them into Arabic. Data collection took place between June 2021 and September 2021. Parents were informed about the goal of the study, how the data would be collected, and how to complete the questionnaire. All the parents agreed to participate in the study. The interview was conducted at the same speech clinics and rehabilitation center where the diagnosis of ASD was made and where families and children receive routine check-ups and follow-up care. After getting their informed agreement to participate, the parents were either talked to individually or in groups, depending on their comfort, readiness, and availability. It took 20 to 25 minutes to complete the questionnaire form. In order to avoid any missing information, the completed forms were collected on time and verified for accuracy.

Statistical Analysis:

The data were analyzed using SPSS version 21. The data's normality was assessed using the one-sample Kolmogorov-Smirnov test. The qualitative data were described in terms of numbers and percentages. Continuous variables were presented as means \pm standard deviation. Pearson correlation coefficient was used to measure the linear correlation between two sets of data. A linear regression model is a linear approach to modeling the relationship between a scalar response and one or more explanatory variables. The results were considered significant when the probability of error is less than 5% ($p < 0.05$) and highly significant when the probability of error is less than 0.1% ($p < 0.01$).

Results

1- Sociodemographic data of the studied parents and their Autistic children:

a. Parents: The mean age of parents was 34.06 ± 5.47 years, the majority (80.0%) of them were mothers, and more than half (55.0%) of them had a secondary education. In addition, more than half (60.0%) of the parents worked, 56.3% of them were from urban areas and the majority (80.0%) had

insufficient income (Table 1).

b. Autistic children: The mean age of children was 8.82 ± 2.35 years. Less than two thirds (61.3%) of the children were male, 56.3% of them were ranked as the second child and about half of them (48.7%) had one sibling. Additionally, 65.0% of children between the ages of 2 and 4 had been diagnosed as autistic. Less than a quarter (22.5%) of children participated in online behaviour modification programs (Table1).

2- Parenting stress:

Moreover half (52.5%) of the parents in the study experienced severe distress, and 47.5% of them had severe Parent-child dysfunctional interaction. More than two thirds (70.0%) of the parents reported difficulty with child. In terms of overall parenting stress, more than half of parents (57.5%) reported experiencing severe stress, while just about a third (32.5%) reported moderate stress. (Table 2).

3- Impact of the pandemic on the autistic children:

Table (3) showed that less than half (45.0%) of the children spent 10 – 20 days at home during quarantine, while (42.5%) of them were reported going outside while under quarantine. More than two thirds 68.8% and 71.3% of them were reported to suffer negative impact of pandemic on their learning and Personal development, respectively. Additionally, less than two thirds (62.5%) had severe anxiety, more than two thirds (67.5%) had limited adaptation to quarantine, and more than half (58.8%) had worsened changes in autistic symptoms.

According to Table (5), a high significant model was found using a F test value of 10.422 and a p value of $< .001$. With an R^2 value .601, this model can explain 60.0% of the variation in child anxiety. Also, explained that increasing child age and Days in quarantine had positive effect on anxiety level at p value .015* and .002**, respectively. While participation in online behaviour modification programs and adapting with quarantine had a negative impact on anxiety level at p value $< .01$ **. Additionally, going outside while under quarantine and having more siblings had a slight negative impact on anxiety level at p value $< .05$ *.

4- Correlation between the children's studied variables and parental stress:

According to (Table 4), there was a negative correlation between parent stress and the following variables: "positive change in behavior, positive impact of the quarantine on learning, and positive impact of the quarantine on emotion regulation" with a p value of $< .05$ *. Additionally, there was a

high negative correlation between parental stress and the following variables: “positive impact of quarantine in relation with relatives, adaptation to quarantine, better changes at autistic symptoms at p

value $< .01^{**}$. While there was high positive correlation between parent stress and child anxiety at p value $< .01^{**}$.

Table 1 : Sociodemographic Data of Parents and their Autistic Children

| Parents characteristics | No | Percent |
|---|------------------------------------|----------------|
| Age | | |
| 20-<30 | 21 | 26.3 |
| 30-<40 | 40 | 50.0 |
| ≥ 40 | 19 | 23.7 |
| M \pm SD | 34.06 \pm 5.47 | |
| Kinship | | |
| Mother | 64 | 80.0 |
| Father | 16 | 20.0 |
| Marital status | | |
| Married | 72 | 90.0 |
| Widowed | 2 | 2.5 |
| Divorced | 6 | 7.5 |
| Educational level | | |
| Illiterate | 0 | 0.0 |
| Read and write | 4 | 5.0 |
| Primary education | 4 | 5.0 |
| Preparatory education | 12 | 15.0 |
| Secondary | 44 | 55.0 |
| University education | 16 | 20.0 |
| Occupation | | |
| Work | 48 | 60.0 |
| Not work | 32 | 40.0 |
| Residence | | |
| Rural | 35 | 43.7 |
| Urban | 45 | 56.3 |
| Monthly family income | | |
| Sufficient | 16 | 20.0 |
| Insufficient | 64 | 80.0 |
| Autistic Children characteristics | No | Percent |
| Gender | | |
| Male | 49 | 61.3 |
| Female | 31 | 38.7 |
| Age | | |
| 6-<8 | 30 | 37.5 |
| 8-<10 | 28 | 35 |
| 10-<12 | 22 | 27.5 |
| M \pmSD | 8.82 \pm 2.35 | |
| Number of siblings | | |
| Non | 10 | 12.5 |
| 1 | 39 | 48.7 |
| 2 | 23 | 28.8 |
| 3 | 8 | 10.0 |
| Child ranking | | |
| First | 29 | 36.3 |
| Second | 45 | 56.3 |
| Third | 6 | 7.4 |
| Participation in online programs for behavior modification | | |
| Yes | 18 | 22.5 |
| No | 62 | 77.5 |
| Age of autism diagnosis | | |
| <2 | 16 | 20.0 |
| 2-< 4 | 52 | 65.0 |
| >4 | 12 | 15.0 |

Note. M \pm SD = mean \pm standard deviation

Table 2: Total Parenting Stress of the Studied Parents

| Items | Mild | | Moderate | | Sever | |
|--|------|------|----------|------|-------|------|
| | n | % | n | % | n | % |
| Parental distress | 10 | 12.5 | 28 | 35.0 | 42 | 52.5 |
| Parent-child dysfunctional interaction | 12 | 15.0 | 30 | 37.5 | 38 | 47.5 |
| Difficult child | 4 | 5.0 | 20 | 25.0 | 56 | 70.0 |
| Total | 8 | 10.0 | 26 | 32.5 | 46 | 57.5 |

Table 3: Impact of the Pandemic on the Studied Autistic Children

| Items | No | Percent |
|--|----|---------|
| Spent days in quarantine | | |
| <10 days | 16 | 20.0 |
| 10 – 20 days | 36 | 45.0 |
| >20 days | 28 | 35.0 |
| Going outside while under quarantine | | |
| Yes | 34 | 42.5 |
| No | 46 | 57.5 |
| Change in child's behaviour | | |
| Yes | 62 | 77.5 |
| No | 18 | 22.5 |
| If yes, behavioural changes were for: (n=62) | | |
| Better | 9 | 11.3 |
| worse | 53 | 88.7 |
| Impact of the quarantine on Learning: | | |
| Positive | 10 | 12.5 |
| Negative | 55 | 68.8 |
| Non | 15 | 18.7 |
| Impact of the quarantine on Emotion regulation | | |
| Positive | 6 | 7.5 |
| Negative | 62 | 77.5 |
| Non | 12 | 15.0 |
| Impact of the quarantine on Personal development: | | |
| Positive | 7 | 8.7 |
| Negative | 57 | 71.3 |
| Non | 16 | 20.0 |
| Impact of the quarantine on Relation with relatives: | No | Percent |
| Positive | 1 | 1.3 |
| Negative | 70 | 87.5 |
| Non | 9 | 11.2 |
| Child's anxiety level | | |
| Severe | 50 | 62.5 |
| Moderate | 23 | 28.8 |
| Low | 7 | 8.7 |
| Child's adaptation to quarantine: | | |
| High | 6 | 7.5 |
| Moderate | 20 | 25.0 |
| Low | 54 | 67.5 |
| Impact on autistic symptoms | | |
| worsen | 47 | 58.8 |
| Better | 5 | 6.2 |
| Non | 28 | 35.0 |

Table 4: Correlation between the Children's Studied Variables and Parent Stress (n=80).

| Items | Parental stress | |
|--|-----------------|----------|
| | r | p. value |
| Change in child's behavior "positive" | -.357 | < .05* |
| Impact of the quarantine on Learning "Positive" | -.402 | < .05* |
| Impact of the quarantine on Emotion regulation "Positive" | -.399 | < .05* |
| Impact of the quarantine on Relation with relatives "Positive" | -.601 | < .01** |
| Impact of the quarantine on Personal development "Positive" | -.362 | < .05* |
| Child's anxiety level | .721 | < .01** |
| Child's adaptation to quarantine "High" | -.640 | < .01** |
| Impact on autistic symptoms "Better" | -.538 | < .01** |

Table 5: Multiple Linear Regression Model for Child Anxiety (n=80).

| Items | Unstandardized | Standardized | T | P. value |
|--|----------------------|--------------|---------------|-----------------|
| | Coefficients | Coefficients | | |
| | B | B | | |
| Number of siblings | -.110 | .065 | 2.032 | .037* |
| Age | .178 | .134 | 3.600 | .015* |
| Impact on autistic symptoms | .211 | .156 | 3.897 | .012* |
| Child's adaptation to quarantine | -.286 | .217 | 6.012 | .003** |
| Participation in online programs for behavior modification "yes" | -.245 | .197 | 4.733 | .007** |
| Going outside while under quarantine | -.198 | .113 | 2.952 | .028* |
| Spent days in quarantine | .304 | .228 | 6.244 | .002** |
| Model | R² | Df. | F | P. value |
| Regression | 0.601 | 7 | 10.422 | .000** |

a. Dependent Variable: Child's anxiety level

b. Predictors: (constant): Number of siblings, Age, Impact on autistic symptoms, Child's adaptation to quarantine, Participation in online programs for behavior modification "yes", Went out during quarantine, and spent days in quarantine

Discussion

Few studies, particularly those that examine cultural, psychological, and socioeconomic factors, have specifically looked at how Covid 19 affects the stress level and functioning of autistic children and their parents (Jacques *et al.*, 2021; Mansour, 2021; Southey *et al.*, 2021; Yilmaz *et al.*, 2021). In the current study, we explore how Covid 19 has impacted the stress level and functionality of autistic children and their parents in Zagazig governorate, Egypt. In general, the findings of this study are in line with those of earlier studies (Chan & Leung, 2020; Genova *et al.*, 2021; Jacques *et al.*, 2021; Levante *et al.*, 2021) that showed that COVID 19 has a considerable negative impact on autistic

children as well as their parents.

The findings on the current study showed that two thirds of the children scored poorly on adaptation to quarantine, more than half had deteriorating autistic symptoms, and less than two thirds of the children suffered severe anxiety. These results are consistent with those of (Dekker *et al.*, 2022; Genova *et al.*, 2021) who suggested that the COVID-19 pandemic lockdown and confinement measures may have increased stress and exhibited emotional/behavioral symptoms in children with neurodevelopmental issues. The findings also shown how children's anxiety levels rose with age and the number of days spent in isolation. (Manning *et al.*, 2021) came to similar results

to ours, indicating a substantial correlation between ASD age and stress in ASD children. Additionally (**Genova et al., 2021**) revealed how COVID 19-related disruptions to education put autistic children at a higher risk for negative outcomes.

As well, our findings revealed that the pandemic has a negative impact on the learning and personal growth of more than two thirds of the study's autistic children. On the same line (**Colizzi et al., 2020; Manning et al., 2021**) described how the extended high levels of stress and insensitive environments experienced during the COVID-19 epidemic had a major impact on autistic children's physical, psychological, and mental development. In their study (**LeBlanc et al., 2020**) stated that, COVID-19 pandemic had an effect on how severe the children's ASD behaviors were. These results imply that the overall mental health especially that of parents influences how children perceive and experience their stress and anxiety (**Mansour, 2021; Schwartzman et al., 2022**). Similarly, (**Lee et al., 2021**) stated parents' mental health and wellbeing should be taken into account since they are linked to parent-child interactions, children's mental health and wellbeing, and family functioning as a whole.

Furthermore, the findings of the study showed that parental stress was significantly adversely impacted by the effects of the quarantine on the autistic children's learning, emotional regulation, behavior, relationship with relatives, development, adaptability, anxiety score, and autism symptoms. In accordance with the findings; (**Coyne et al., 2021; Crowell et al., 2019; Yilmaz et al., 2021**) reported a significant correlation between alterations in children's behaviour and parents' capacity for coping as a result of the pandemic's stress-inducing effects on parents' ability to care for both themselves and their children.

Additionally, more than half of the studied parents displayed severe distress, whereas in the total parenting stress score: more than half of parents had severe stress and about one third of them had moderate stress. These results are in line with those of (**Lee et al., 2021**), who reported how the pandemic's continuing

demands and the responsibility of raising autistic children led to high levels of stress and a range of mental health disorders.

According to recent studies. of (**Colizzi et al., 2020; Panda et al., 2021; Spinelli et al., 2020**) parents' stress levels increased as a result of a number of factors, including the length of the lockdown, unclear or lacking information, an increase in children's maladaptive behaviour, and employment insecurity/financial concerns.

The high level of stress among parents may be explained in part by the fact that most of the parents in the current study were female, the most had low incomes, and more than half had a secondary education. In an accordance with our findings, a study in Egypt that looked at how mothers raised children with ASD there found that: financial strain, emotional discomfort, social isolation, a lack of knowledge, poor education, treatment, and social stigma were some of the negative effects that mothers had to deal with (**Gobrial, 2018**). In keeping with this claim (**Acharya & Sharma, 2021**) explained despite the fact that experiences vary from one country and one place to another, mothers of autistic children typically tend to have lower health and wellbeing than mothers of children with other impairments. Moreover, (**Gobrial, 2018**) stated when there aren't enough social and personal supports, the ongoing stress that mothers of autistic children endure gets much worse. On the same line (**Miranda et al., 2019**) found in their study, that more than 50% of mothers declared that raising autistic child presents more challenges that make it harder for them to enjoy life. Additionally, more than two thirds of parents in the current study reported difficulty with their children while fewer than half of parents experienced severe parent-child dysfunctional interactions. The findings are in line with those of (**Lee et al., 2021**) who indicated that problems encountered during the pandemic, difficult behaviors in children, and parental stress have all increased the difficulty of parent-child interactions and family dynamics within a family unit.

Even though there weren't many of them, the parents who tried to cope with quarantine

and participated in online behavior modification programs while still taking their children outside reported less stress. Although the findings of the study imply that parents hardly adopted coping strategies, (Jacques et al., 2021; Lee et al., 2021; Yilmaz et al., 2021) in their studies stated that coping strategies had a consistent favorable impact on the stress levels of autistic children and their parents during COVID-19.

1. Strengths and limitations:

The strengths points as we study new variables and assess the relation between them by using one of important statistical test to predict these relations. Also, we conduct a cross-sectional study from different places.

According to limitation, the difficulty in collecting data from the parents due to time constraints, so a longer time was extended to conduct the study.

Conclusion:

According to the study's findings, Covid 19 could be negative to both the mental health and daily functioning of ASD children and their parents. By exploring the experiences of parents and children with ASD in Egypt, the current study adds to the body of knowledge on ASD. Sharing these experiences and knowledge would aid in developing a set of standards for understanding and addressing difficulties, challenges, and potential complications associated with ASD.

Declaration

Ethics approval and consent to participate:

This study was performed in accordance with the Declaration of Helsinki. The study was approved by the research ethics committee of the Faculty of Nursing, Zagazig University and was registered on the Open Science Framework (OSF); <https://osf.io/sfb74>. Written informed consent were obtained from parents who were informed about the aim of the study, the confidentiality of the data and their right to withdraw from the study at any time. All methods were carried out in accordance with relevant guidelines and regulations.

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