

Research Paper

Concerns and challenges faced by parents of children with autism spectrum disorder during the coronavirus pandemic in Indian scenario

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ABSTRACT

Introduction: The coronavirus pandemic has prevented children with autism spectrum disorder (ASD) from procuring clinical services which have led to changes in lifestyle and daily routines. Also, the parents of children with ASD were concerned regarding maintaining routines and introducing new experiences to their children during the pandemic. This is a cross-sectional study that explored the concerns and challenges faced by parents of children with ASD during the coronavirus pandemic.

Aim: The main objectives of this study were to profile the communication difficulties and environmental changes adopted by parents of children with ASD who did not have proper access to healthcare/rehab facilities during the pandemic in Indian scenario.

Material and methods: In total, 51 parents of children with ASD in the age range of 3 to 10 years participated in this study. They were asked to fill in a questionnaire (Google form) that had 20 close ended questions on their children's prelinguistic skills, communication behaviors, behavioral aspects, and emotional variations before and during the pandemic.

Results and discussion: The results revealed that children with ASD exhibited significant emotional and behavioral upheaval due to interruptions in routine connected to COVID-19. Depending on the severity of the disorder, children had difficulty in several tasks such as comprehension of simple commands and expression of daily needs. Also, the parents of children with ASD were concerned about maintaining routines and introducing new experiences to their children during the pandemic.

Conclusions: Individuals with ASD are a significant population who may require special assistance during the pandemic and future public health crises.

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1. INTRODUCTION

Autism is a neurodevelopmental disorder characterized by deficits in social communication, social interaction and the presence of restricted repetitive behaviors. Social communication deficits occur in various ways and can include impairments in joint attention and social reciprocity as well as challenges using verbal and nonverbal communication behaviors for social interaction. Restricted, repetitive behaviors, interests, or activities are manifested by stereotyped, repetitive speech, motor movement, or use of objects; inflexible adherence to routines; restricted interests; and hyper- and/or hypo-sensitivity to sensory input.¹ The coronavirus pandemic altered people's lifestyles all around the globe. It was especially challenging for parents of special-needs children. The consequences of the epidemic have created a significant disruption in their routine, which is a significant burden, for both the parents and children. Parents lost a key support network when special education systems were shut down, and they were forced to be the sole full-time caregivers, although often lacking the ability to cope with this new and frightening circumstance. The success or failure of these children were closely tied to how their parents dealt with the situation.

During the epidemic, the parents of children with autism spectrum disorder (ASD) encountered numerous challenges due to a lack of a network of services and sufficient guidance from therapists and educators. In a study done by Eshraghi et al.² revealed changes inhabit, a lack of special education programs, a lack of physical space, food, and sleep-related issues were the biggest barriers during the COVID-19 pandemic. As a result, many organizations that provide care or specialized educational programs had shuttered around the world, either voluntarily or due to federal mandates. Individuals with ASD receive fewer, if any, critical therapy hours and classroom time as a result of these closures.²

2. AIM

This study explored the concerns and challenges faced by parents of children with ASD during the coronavirus pandemic and profiled the communication difficulties and environmental modifications adopted by these parents while receiving no proper access to healthcare facilities during the lockdown in Chennai.

3. MATERIAL AND METHODS

3.1. Participants

The participants were 51 parents of children with ASD between 3 and 10 years of age. Those children with ASD who had received a minimum of 1 year of intervention and a maximum of 3 years of intervention, parents who were able to read and write English and had completed a minimum of 12th grade (higher secondary school) were selected for the present study. Those parents who did not satisfy these cri-

teria were excluded from the study. The parents were contacted through resources from various special schools and a few therapy centers in and around Chennai.

3.2. Procedure

This study was carried out using a cross-sectional survey method. A questionnaire was developed which comprised five sections. Questions were framed referring to the previous literature related to children with autism.^{1,3-5} Also, the questionnaire was validated for its content by four speech language pathologists who had clinical expertise of 5 years and above in the area of childhood language disorders and ASD. The final questionnaire was converted into a Google form and the weblink was sent to the parents after obtaining their consent. There were three questions on prelinguistic skills, seven in communication skills, five in behavioral aspects and five questions on emotional aspects (Annexure 1). The data was collected during the lockdown period in Chennai during 2021. The parents were instructed to respond to all the questions in each section. A total of 51 participants, of which 17 parents had completed their master's degree, 14 had completed their UG degree, and 12 completed 12th grade.

3.3. Statistical methods

The responses were analyzed for each skill based on the parents' responses of their child's behavior before and during the pandemic. The analysis was done by IBM SPSS. Mean and SD was used to summarize the data. The Chi-square test was used to test the significance of the difference between the distribution of the criteria among the groups. A *P* value of less than 0.05 was considered a statistically significant difference throughout the study. The effect size was kept at 20% which meant expecting a 20% difference in responses before and during COVID-19.

4. RESULTS

The responses of 51 parents of children with ASD are tabulated in Tables 1–3. The percentage scores of their children's pre linguistic skills such as, ability to maintain eye contact, paying attention during an activity and the ability to sit and attend an activity were assessed before and during pandemic. Almost 95% of parents reported that their children had a good ability to sit and attend to activity before the pandemic, whereas it reduced to 67% during the pandemic. The Chi-square test revealed that there was no significant difference in children's behavior with respect to the eye con-

Table 1. Prelinguistic skills. Results obtained before and during the pandemic.

Domains	Z value	P value
Ability to maintain eye contact	1.17	0.88
Ability to pay attention during an activity	0.17	0.57
Ability to sit and attend to an activity	0.80	0.21

Comments: Statistically significance if *P* < 0.05.

tact, attention and attending to an activity before and during pandemic (Table 1).

During the pandemic, it was observed that around 97% of parents reported that their children had good interaction before the pandemic, whereas during the pandemic it reduced to 76%. Around 91% of parents reported that their children were able to follow commands and comprehend gestures before the pandemic whereas during the pandemic 71% of parents have indicated that their children were able to follow commands and comprehend gestures adequately. Thus, there was a significant difference in children's behavior before and during the pandemic (Table 2).

Around 45% of parents responded that their child was able to greet or smile at a new conversational partner before the pandemic, whereas during pandemic 69% of parents indicated that their children had a poor ability to greet or smile at a new conversational partner. The child's ability to wait for his/her turn during an activity was reported to be satisfactory by 95% of parents, whereas during the pandemic it reduced to 61%. The change in the child's communication behaviors due to increased screen time was analyzed before and during the pandemic. Around 67% of parents reported that there was a change in the child's communication behaviors due to increased screen time before the pandemic whereas during the pandemic it increased to 79%.

The parents reported that, behaviors such as repetitive behaviors, temper tantrums, unusual reactions to sensory aspects, and emotion towards familiar people were almost the same before and during pandemic. In total, 36% of parents reported the presence of self-injurious behaviors before the pandemic whereas during the pandemic it increased to 83% with a significant difference ($P = 0.01$). The other behaviors did not show any significant difference before and during pandemic (Table 3).

The parents' stress levels during communication with their children with ASD were analyzed before and during the pandemic. The overall results indicated that during the pandemic 88% of the parents had anxiety/frustration/stress during communication with their children, whereas 12% of the parents indicated no anxiety/frustration/stress. There was no significant difference ($P = 0.12$) in children's behavior before and during a pandemic (Table 4). Almost 50% of parents of children with ASD reported that their routines activities were disturbed due to the changes in the child's behavior. Whereas, the remaining 50% of them did not have any effect on their routine activities. Also, it is evident from the Figure 1 that 69% of parents had difficulty in adopting the therapy techniques to follow at home during the pandemic. On the contrary, it was found that the 81% parents had spent quality time in interacting with their children.

5. DISCUSSION

In this study, the Covid-19 outbreak had an impact on children with ASD, resulting in a significant deterioration in their behaviors, which reflected their parents' concerns. Parents

Table 2. Communication behaviors. Results obtained before and during the pandemic.

Domains	Z value	P value
Interaction with his/her family members	2.07	0.01
Expression of his/her daily needs	0.17	0.57
Ability to understand the conversation	0.55	0.29
Ability to follow commands/requests and comprehend gestures	1.66	0.04
Ability to greet or smile at a new conversational partner	1.88	0.03
Ability to wait for his/her turn during an activity	2.45	0.00
Increased screen time due to pandemic	1.83	0.03

Comments: Statistically significance if $P < 0.05$.

Table 3. Behavioral modification. Results obtained before and during the pandemic.

Domains	Z value	P value
Repetitive behaviors	1.40	0.08
Temper tantrums	1.19	0.11
Self-injurious behaviors	2.17	0.01
Unusual reactions	0.25	0.40
Emotions towards familiar people	0.77	0.78

Comments: Statistically significance if $P < 0.05$.

Table 4. Emotional variations. Results obtained before and during the pandemic.

Domains	Z value	P value
Child's behaviours interfered with your daily routine	1.43	0.07
Anxiety/frustration/stress while communicating with your child	1.13	0.12

Comments: Statistically significance if $P < 0.05$.

adopted a few changes in their daily routine; such as reduced screen time and finishing personal tasks prior, so that they can spend as much time possible with their children. Parents have emotional and financial impacts as well. According to Mutluer

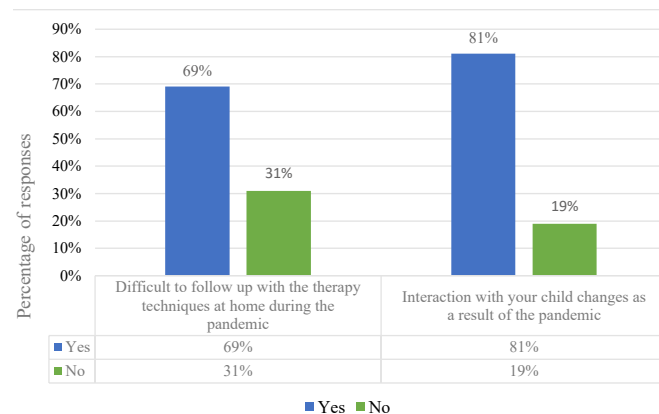


Figure 1. Responses of parents during pandemic.

et al.⁶ ASD-related behaviors, sleep quality, and hypersensitivity changed significantly during the pandemic compared to before the pandemic. The findings also point to an increase in parental concern. Another study reported by Colizzi et al.⁷ revealed greater difficulties managing regular life, including leisure time and education sessions, while less than half of the respondents said their children's behavior problems became more severe and frequent throughout the epidemic. Both of these studies explain a comparable response from the current study as in the Indian scenario.

6. CONCLUSIONS

- (1) The coronavirus pandemic has had various consequences on children with ASD due to a variety of situational variables. Due to the children's evolving communication needs and demands, offering continual and intense intervention is essential, especially for children with ASD.
- (2) Several parents have expressed feelings of concern, irritation, and stress while dealing with their children, and several parents have chosen a variety of environmental modifications to help them cope during this period.
- (3) The limitation of this study is that the parents who participated in the current study belonged to a wide range of ages and educational qualifications. A larger sample size would have yielded better findings that can be generalized.
- (4) This study emphasized the need for intensive intervention even in the absence of face-to-face therapy. With growing technological advancements, the demand for telecommunication has increased. In future, speech language pathologists must emphasize the need for various parent empowerment programs by offering continual and intense intervention for children with ASD.

Conflict of interest

No conflicts of interest, financial or otherwise, are declared by the authors.

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Ethics

The study was approved by the Institutional Ethics Committee SRIHER (DU) on 12 May 2021 (Ethical clearance ref no: CSP/21/MAR/92/308).

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