

## Increased Hyperactivity with Decreased Parental Perceived Social Support Among Turkish Children with Autism Spectrum Disorder during Coronavirus Disease 2019 Pandemic

### ABSTRACT

**Objective:** The aim of the present study is to investigate the change in emotional/behavioral problems of children with autism spectrum disorder (ASD) and the perceived social support of parents during the coronavirus disease 2019 (COVID-19) pandemic.

**Methods:** A total of 51 children with ASD aged between 6 and 18 years took part in the study. The Aberrant Behavior Checklist (ABC), the Strengths and Difficulties Questionnaire (SDQ), and the Multidimensional Scale of Perceived Social Support (MSPSS) were used to evaluate ASD symptoms, emotional/behavioral problems, and perceived social support, respectively. The cases were assessed before and 6 months after the pandemic.

**Results:** Our findings indicated that after the onset of the pandemic hyperactivity scores of children with ASD increased, whereas perceived social support of their parents decreased, compared to their pre-pandemic levels ( $P$ -value  $< .05$ ). The increase in hyperactivity and irritability levels among children were positively associated with the presence of a chronic illness in the family and medication discontinuation ( $P$ -value  $< .05$ ).

**Conclusion:** Quarantine in the COVID-19 pandemic may cause or worsen behavioral problems among children with ASD possibly due to problems related to poor medication adherence and lowered perceived social support among their parents. Clinicians working with children with special needs may be pro-active to assess and manage emotional/behavioral problems among this special population particularly during difficult times such as pandemic.

**Keywords:** Coronavirus disease 2019 pandemic, autism spectrum disorder, children, hyperactivity, social support

### Introduction

Autism spectrum disorder (ASD) is one of the most common neurodevelopmental disorders among children and is characterized by difficulties in social interactions, limited areas of interest, and repetitive movements.<sup>1</sup> ASD has an early childhood onset and is persistent over the lifetime with 1 in 56 children being affected with the disorder.<sup>1,2</sup> Stressful and traumatic events may cause or worsen emotional/behavioral problems among children with ASD, making them one of the "special vulnerable populations".<sup>3,4</sup> When the coronavirus disease 2019 (COVID-19) started in Wuhan, China, on January 30, 2020, the World Health Organization (WHO) declared COVID-19 as a "public health emergency of international concern" and following the rapid spread of the virus worldwide, declared as "a global pandemic" on March 11, 2020.<sup>5,6</sup> Since the beginning, which has been causing debilitating symptoms, 217 million people got infected and more than 4 million people died worldwide because of COVID-19.<sup>7</sup> In addition to increased mortality and morbidity, the psychosocial impacts of the pandemic are staggeringly severe for most people. Economic uncertainty, job losses, difficulty accessing health facilities and treatment centers, and the risk of infection have negatively affected the



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well-being and mental health of many people and especially those with existing mental health or developmental problems as in other epidemics and pandemics.<sup>8-13</sup>

Immediately after the onset of the COVID-19 pandemic, researchers argued that children with ASD, a vulnerable group in terms of mental health implications, will be more severely affected by disruptions in healthcare system and schooling, extended periods of lockdowns, delayed treatment sessions, and disruption of the daily routine.<sup>4,14</sup> Therefore, studies examining psychosocial impacts of the pandemic on children with ASD are of great importance.<sup>3,4,15,16</sup> The results of a recent meta-analysis indicated that behavioral problems faced by children with ASD are aggravated by the COVID-19 outbreak.<sup>10</sup> In line with this, a cross-sectional study revealed that half of the parents of children with ASD reported a higher need for healthcare assistance during the pandemic.<sup>17</sup> Recent research also reported detrimental effects of the pandemic on parental mental health.<sup>17</sup> Pattini and her colleagues showed that mothers of children with ASD were more vulnerable to stress compared to the unaffected population.<sup>18</sup> One of the main protective factors against pandemic-related distress is social support.<sup>19</sup> However, it is possible that quarantine periods negatively impacted social support among parents, which is not focused on by previous studies. Previous studies have indicated that health literacy and parental social support can be a goal of mental health and family health.<sup>20,21</sup>

The aim of the present study is to assess the emergence or worsening of emotional/behavioral problems in a clinical sample of young subjects with ASD as well as perceived parental social support among their parents during the COVID-19 pandemic.

## Methods

### Participants and Procedure

The present study was conducted between June 2020 and September 2020 in the child and adolescent psychiatry department of Istanbul University Faculty of Medicine. Subjects aged between 6 and 18 years old who had been referred before the pandemic period and diagnosed with a The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria were candidates (n=78) to be included in the study. Finally, 51 participants were included in the study based on the inclusion criteria, which consisted of (a) valid pre-pandemic scores on Strengths and Difficulties Questionnaire (SDQ), the Multidimensional Scale of Perceived Social Support (MSPSS), and

the Aberrant Behavior Checklist (ABC). Data regarding these scales were available for the pre-pandemic period (prior to 3-6 months of the pandemic) as these subjects were included in another previous study in the clinic, and (b) parents gave consent for their children to participate in the study. Twenty-seven cases were excluded due to either of the following: missing SDQ or ABC scores (n=11) could not be reached by phone (n=10), or lack of consent to take part in the study (n=6). During the initial evaluation, all subjects were assessed face-to-face before pandemic period by an experienced child psychiatry fellow as part of the routine clinical practice. Following a positive initial evaluation, patients were referred and presented to a board of faculty members to confirm the diagnosis of ASD.

Parents of the study subjects (n=51) were reached by phone or online interview programs to gather during-pandemic information, which was 6 months later from the start of the pandemic. After an initial informative session about the study, parents were administered SDQ, ABC, and MSPSS. Sociodemographic information was collected via a personal information form. In accordance with the Declaration of Helsinki, approval for the study was obtained from the Ethics Committee of Istanbul University on June 12, 2020 (number: 2020/785).

### Personal Information Form

This form was created for the purposes of the present study. Questions on demographics of participants such as age, gender, parental education level (in years), monthly income, and experience during the pandemic were included in the information form.

### Strengths and Difficulties Questionnaires

Strengths and Difficulties Questionnaire (SDQ) is an accepted instrument for assessing emotional and behavioral problems in the pediatric population and was created by Goldman and colleagues.<sup>22</sup> The reliability and validity of the Turkish version were tested by Guvenir and colleagues.<sup>23</sup> Strengths and Difficulties Questionnaire has 5 subscales (emotional problems, conduct problems, hyperactivity/inattention problems, peer-relationship problems, and pro-social behavior), which could be evaluated in itself and the total score is calculated as the sum of the first 4 subscales.

### Aberrant Behavior Checklist

This measure evaluates the behavioral problems observed in children diagnosed with ASD.<sup>24</sup> Sucuoğlu and colleagues confirmed the validity and reliability of the Turkish translation of the scale with 5 subscales assessing problems with hyperactivity, stereotyped behaviors, self-injurious behaviors, lethargy, and other behaviors.<sup>25</sup>

### Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support is a scale which is designed to assess perceived social support in 3 components. The scale measures the subjective evaluation of support level provided by one's family, friends, and the significant other. Total score is calculated as the sum of all subscales. Higher scores indicate greater perceived social support.<sup>26</sup> Çakır ve Palabıyıköğlü confirmed the Turkish version's validity and reliability.<sup>27</sup>

### Statistical Analyses

Statistical analyses were performed with SPSS for Windows, version 21.0 (IBM Corp, Armonk, NY, USA). Main test statistics included percentages, mean values, and standard deviations. Kolmogorov-Smirnov test was used to evaluate the normality of the distribution.

## MAIN POINTS

- Symptoms associated with hyperactivity increased during the coronavirus disease 2019 pandemic.
- Medication discontinuation and the presence of a chronic disease in the parents were positively related to the emergence or worsening of hyperactivity symptoms in children with autism spectrum disorder.
- Families perceived that they were getting less social support with the onset of the pandemic, while the decrease in perceived peer support of the families was the most significant.
- Telehealth-based psychiatric interventions and support from local psychosocial teams might be utilized in case of disasters and pandemics.

Pre-pandemic and post-pandemic scale scores were compared with paired samples *t*-test (vs. Wilcoxon test) for normally (vs. non-normally) distributed scale scores. The relationship between the discontinuation of treatment and the presence of a chronic disease in the family on hyperactivity symptoms in children with ASD was investigated by using multiple linear regression. Independent variables associated with hyperactivity scores, including discontinuation of treatment and chronic disease in the family, were computed (for all factors; absence: 0, presence: 1). The variance inflation factor (VIF) and tolerance were used to check for multicollinearity. Tolerance score was 0.987 and VIF score was 1.013 for both discontinuation of treatment and a chronic disease in the family. Normality assumptions were checked using histograms. *P*-values were not adjusted for multiple testing, and statistical significance level was set at  $P < .05$ .

## Results

In total, 51 cases took part in the study (46 males, 5 females) aged between 6 and 18 years old ( $11.45 \pm 2.72$ ). Table 1 shows the clinical and sociodemographic characteristics of the subjects.

The comparison of ABC and SDQ total scores showed that pre-pandemic and during-pandemic emotional and conduct problems were experienced to a similar degree among subjects. However, hyperactivity scores in both SDQ ( $t = -2.067$ ,  $P = .044$ , Cohen's  $d = 0.292$ ) and ABC ( $t = -2.490$ ,  $P = .016$ , Cohen's  $d = 0.349$ ) scales increased after the onset of the pandemic. Additionally, a significant increase was also found in the other behaviors subscale of ABC ( $t = -3.384$ ,  $P = .001$ , Cohen's  $d = 0.473$ ). (See Table 2 for the comparison of pre and during-pandemic scores on SDQ and ABC subscales.)

The MSPSS scores showed that perceived social support decreased significantly during the pandemic ( $t = -2.772$ ,  $P = .008$ , Cohen's  $d = 0.388$ ). A comparison between pre-pandemic and during-pandemic scores for each MSPSS subscale is reported in Table 3.

We ran a multiple linear regression analysis to examine the factors related to increase in SDQ-Hyperactivity and ABC-Hyperactivity scores. The results showed that treatment discontinuity was related to increase in SDQ-Hyperactivity ( $B = 1.42$ ,  $CI: 0.26; 2.59$ ,  $P = .018$ ) and in ABC-Hyperactivity scores ( $B = 14.35$ ,  $CI: 7.12; 21.57$ ,  $P < .001$ ). The presence of a chronic disease in family was also related to increase in SDQ-Hyperactivity ( $B = 2.12$ ,  $CI: 0.67; 3.57$ ,  $P = .005$ ) and ABC-hyperactivity ( $B = 9.78$ ,  $CI: 3.95; 15.61$ ,  $P = .001$ ). Standardized regression coefficients, confidence intervals and significance values were summarized in Table 4.

## Discussion

In this study, we examined the effects of the COVID-19 pandemic on emotional/behavioral problems in children with ASD as well as the level of perceived social support among their parents. It is important to state that there have been only a number of studies on this issue.<sup>14,17</sup> The current study yielded several findings that may have important clinical, social, and further research implications.

In an attempt to understand what kind of emotional/behavioral problems emerged or worsened during the pandemic in young subjects with ASD, we found that hyperactivity increased significantly after the pandemic, confirming existing research on the positive link between the COVID-19 outbreak and hyperactivity among this

**Table 1.** The Socio-demographic and Clinical Characteristics of the Participants

Variable	n (%) / Mean (SD)
Age in years (mean $\pm$ SD)	11.45 $\pm$ 2.72
Gender	
Female n (%)	5(9.80)
Male n (%)	46(90.19)
Mean duration of parental education y, mean (SD)	8.59 $\pm$ 4.02
Mean duration of parental age y, mean (SD)	40.94 $\pm$ 5.56
Family income status	
Minimum wage or lower, n (%)	25(49.01)
Above minimum wage, n (%)	26(50.98)
Chronic disease(s) in the parent(s)	
Yes, n (%)	10(19.60)
No, n (%)	41(80.39)
COVID-19 diagnosis in family environment	26(50.98)
Sources of information for COVID-19	
Social contacts n (%)	13(25.49)
Internet n (%)	22(43.13)
Television n (%)	47(92.15)
Social media n (%)	20(39.21)
Time spent to get info on COVID-19, h, mean (SD)	1.47 $\pm$ 1.51
Time since ASD diagnosis (years), mean (SD)	7.50 $\pm$ 3.74
Pre-pandemic schooling status	
Yes, n (%)	49(96.07)
No, n (%)	2(3.92)
During-pandemic schooling status	
Yes, n (%)	18(35.29)
No, n (%)	33(64.70)
Education	
Face-to-face, n (%)	2(3.92)
Online, n (%)	16(31.37)
Pre-pandemic medication use	
Yes, n (%)	43(84.31)
No, n (%)	8(15.68)
Medication status	
Monotherapy, n (%)	12(23.52)
Combination, n (%)	31(60.78)
Medication continuation during the pandemic	
Yes, n (%)	26(50.98)
No, n (%)	17(33.33)

AAP, atypical antipsychotics including aripiprazole, risperidone, olanzapine, and quetiapine; ATX, atomoxetine; MPH, Methylphenidate; MS, Mood stabilizers; SD, Standard deviation; SSRIs, selective serotonin reuptake inhibitors.

special population.<sup>28</sup> A recent meta-analysis revealed that the pandemic has exacerbated the conduct problems of children with ADHD and ASD.<sup>10</sup> Similarly, irritability and hyperactivity also increased among children with ASD.<sup>28</sup> In addition, another study revealed that during the COVID-19 pandemic, hyperactivity-related problems posed the greatest difficulty among children requiring mental health support.<sup>19</sup> Although these findings provide some insight into hyperactivity and irritability among children with ASD, factors worsening or improving these problems were not thoroughly examined. In the present study, we found that medication discontinuation was positively related to the emergence or worsening of hyperactivity. Most of the subjects in this study have been using one or more

**Table 2.** Types and Severity of Emotional/Behavioral Problems

SDQ and ABC Subscales	During-pandemic Mean ± SD	Pre-pandemic Mean ± SD	P
<b>SDQ</b>			
Total difficulties	19.70 ± 4.88	19.13 ± 5.62	.526 <sup>a</sup>
Emotional problems	3.00 (2.00-6.00)	4.00 (3.00-6.00)	.413 <sup>b</sup>
Conduct problems	3.00 (2.00-3.00)	2.00 (2.00-3.00)	.852 <sup>b</sup>
Hyperactivity/inattention problems	7.19 ± 2.41	6.52 ± 2.26	<b>.044<sup>a</sup></b>
Peer-relationship problems	5.47 ± 1.67	5.56 ± 1.76	.684 <sup>a</sup>
<b>ABC</b>			
Total scores	52.21 ± 21.79	44.52 ± 23.30	.070 <sup>a</sup>
Hyperactivity	21.66 ± 11.55	17.23 ± 9.45	<b>.016<sup>a</sup></b>
Stereotype behaviors	5.86 ± 4.67	4.82 ± 4.27	.162 <sup>a</sup>
Self-injurious behaviors	2.17 ± 3.11	1.70 ± 2.37	.195 <sup>b</sup>
Lethargy	0.00 (0.00-3.00)	0.00 (0.00-4.00)	.817 <sup>a</sup>
Other behaviors	6.09 ± 2.60	4.74 ± 2.76	<b>.001<sup>a</sup></b>

Values are presented as median (25-75%) or mean ± SD (standard deviation). ABC, aberrant behavior checklist; SDQ, strength and difficulties questionnaire. <sup>a</sup>Paired samples t-test; <sup>b</sup>Wilcoxon test. **Bold data**, *P* < .05 (significance).

medications over time that may include atypical antipsychotics, atomoxetine, SSRIs (selective serotonin reuptake inhibitors), methylphenidate, mood stabilizers, and alpha agonists. The type, number, and dosages of medications were used in a flexible manner according to the clinical picture and the needs of the subjects. These medications are usually used to manage behavioral problems mainly including hyperactivity/irritability, stereotyped, aggressive, or self-injurious behaviors in subjects with ASD.<sup>29</sup> Hence, it may not be surprising that discontinuation of these medications is related to the emergence or worsening of hyperactivity. Furthermore, we found that the emergence or worsening of hyperactivity was also associated with the presence of a chronic disease in the parents. According to current literature, COVID-19 results in higher mortality and morbidity for those with chronic medical conditions.<sup>30,31</sup> It may be possible that worry about infection risk might have kept those parents from visiting

healthcare facilities, which then may have impeded medication continuation among children with ASD. In addition, parents with chronic medical conditions may have more difficulty in managing behavioral problems and may perceive and report more negatively about the behavioral problems of their children with ASD.<sup>30,31</sup>

Finally, although autism spectrum disorder is approximately 4 times more common in boys than in girls, this rate was approximately 10 times higher in our study. Considering that hyperactivity and irritability symptoms are more common in boys than in girls, this may be a confounding factor.<sup>32</sup>

Several recent research reports the emergence or worsening of not only behavioral but also emotional problems among children with ASD during the pandemic.<sup>28</sup> However, there was no significant increase in emotional problems reported by the parents in our study. It may be possible that parents were more aware or in distress with behavioral problems in their children. In addition, emotional problems may also present or be reported by the parents as behavioral problems including hyperactivity/irritability among children with ASD. These findings from our study may prompt us to develop special intervention programs or tools for children with ASD and their parents. It is important to provide stable access to mental health services or experts during the pandemic. At this point, we should mention an important project developed and conducted by the Turkish Ministry of Health.<sup>33</sup> In this project, a comprehensive national model was developed for managing maladaptive behaviors in children with mental special needs during the COVID-19 pandemic that combines telehealth-based Applied Behavioral Analyses, psychiatric interventions, and support from local psychosocial teams. In this project, Dursun et al (2021)<sup>33</sup> reported that 347 individuals used the system

**Table 3.** Pre-pandemic and During-Pandemic Multidimensional Scale of Perceived Social Support Scores

MSPSS Scores	Pre-pandemic Mean ± SD	During-pandemic Mean ± SD	P
Total support	44.11 ± 18.77	40.56 ± 21.61	<b>.008<sup>a</sup></b>
Family support	16.45 ± 8.23	15.98 ± 9.19	.406 <sup>a</sup>
Significant other support	12.35 ± 8.81	13.49 ± 7.89	.108 <sup>a</sup>
Friends support	14.00 (4.00-21.00)	11.00 (4.00-18.00)	<b>.015<sup>b</sup></b>

Values are presented as median (25%-75%) or mean ± standard deviation. MSPSS, Multidimensional Scale of Perceived Social Support. <sup>a</sup>Paired samples t-test. <sup>b</sup>Wilcoxon test. **Bold data**, *P* < .05.

**Table 4.** Multiple Linear Regression Analysis for Predictors of Change in Hyperactivity Scores

	SDQ-Hyperactivity			ABC-Hyperactivity		
	OR	95% CI	P	OR	95% CI	P
Medication discontinuation	1.42	0.26-2.59	<b>.018</b>	14.35	7.12-21.57	<b>&lt;.001</b>
Chronic disease in the family	2.12	0.67-3.57	<b>.005</b>	9.78	3.95-15.61	<b>.001</b>

*R* = .507. *R*<sup>2</sup> = .257; *P* = .001 for SDQ-Hyperactivity scores. *R* = 0.625. *R*<sup>2</sup> = 0.390; *P* < .001 for ABC-Hyperactivity scores. **Bold data**, *P* < .05.

CI, confidence interval; OR, odds ratio.

\*Reference: absence (0), presence (1).

with mothers constituting the majority of applicants. The overall satisfaction of the system was 8.8/10. Several factors such as extended waitlist periods, lockdown, difficult transportation, and reluctance to go to the hospital due to infection risk may pose further difficulty to access mental health services and may result in medication discontinuation. Projects providing online services may help medication adherence among children with ASD and may provide social support for parents of children with ASD during difficult times such as the COVID-19 pandemic.

The parents of children with ASD experience a number of difficulties due to care for a child with a chronic mental health condition and coping with challenges in their individual lives.<sup>30,31</sup> During the COVID-19 pandemic, the severity of emotional and behavioral problems in children with ASD has been reported as increased, and their parents had to cope with it for longer periods of time due to restrictions, educational interruptions, and changes in home environment.<sup>14</sup> Hence, maintaining regular access to mental health services and ensuring treatment continuation may have caused significant distress among parents of children with ASD. Indeed, a brief report indicated that the large majority of families of children with ASD experienced moderate-to-severe levels of stress due to disruptions in the healthcare system during the pandemic.<sup>14</sup> Major determinants of heightened distress among parents were missed educational opportunities during a critical phase for their pre-school-age children, whereas the negative impact of comorbid ADHD, anxiety, and disruptive behavior disorders among school-age children was the main concern among parents.<sup>14</sup> Similarly, a large-scale multi-center survey among Turkish citizens revealed that the presence of a psychiatric disorder among children was positively associated with parental distress during the COVID-19 pandemic.<sup>19</sup> In addition, studies have shown that during the COVID-19 families experienced difficulties due to decreased communication with social contacts, reduced time in public spaces, increased concern about the well-being of their families, and a general feeling of lacking support.<sup>14,17,30,31</sup> However, previous studies have not focused on specifically perceived social support among parents of children with ASD. In our study, we have shown that families perceived that they were getting less social support with the onset of the pandemic, while the decrease in perceived peer support of the families was the most significant. While this finding is expected to some extent, it may be essential to document difficulties in getting social and friend support among parents of children with ASD during the pandemic. Clinicians and public authorities may be proactive in providing continuing social support for these parents.

In conclusion, children with ASD and their parents may be particularly vulnerable population to a number of emotional, behavioral, or social problems during the COVID-19 pandemic. Medication adherence may be an important protective factor against worsening or emergence of behavioral problems such as hyperactivity/irritability among children with ASD. This study has several limitations including a cross-sectional design, a relatively small sample size, a wide age range of the subjects, potential biases due to lack of randomization, and non-adjustment for multiple testing in the values.

**Availability of Data and Materials:** Data are available on request from the authors.

**Ethics Committee Approval:** This study was approved by the Ethics Committee of Istanbul University (approval number: 2020/785; date: June 12, 2020).

**Informed Consent:** Verbal consent was obtained from the parents/guardians of patients/patient who agreed to take part in the study.

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