The Impact of the COVID-19 Pandemic on the Educational Process of Children with Autism Spectrum Disorder and Effects on the Parental Quality of Life

COVİD-19 Pandemisinin Otizm Spektrum Bozukluğu Olan Çocukların Eğitim Süreçlerine ve Ebeveyn Yaşam Kalitesine Etkileri

Nihal YILDIZ[1], Nalan ÖZEN[2], Pınar ÖZKAN KART[1], Selman YILDIRIM[3], Serkan KARADENIZ[4], Çilem BİLGİNER[3], Gülnur ESENÜLKÜ[1], Sevim ŞAHİN[1], Elif ACAR ARSLAN[1], Tülay KAMAŞAK[1], Evrim ÖZKORUMAK KARAGÜZEL[5], Murat TOPBAŞ[2], Ali CANSU[1]

[1]Department of Pediatric Neurology, Faculty of Medicine, Karadeniz Technical University, Trabzon, Türkiye
[2]Department of Public Health, Faculty of Medicine, Karadeniz Technical University, Trabzon, Türkiye
[3]Department of Child and Adolescent Psychiatry, Faculty of Medicine, Karadeniz Technical University, Trabzon, Türkiye
[4]Department of Child Development, Faculty of Health Science, Avrasya University, Trabzon, Türkiye
[5]Department of Psychiatry, Faculty of Medicine, Karadeniz Technical University, Trabzon, Türkiye

ABSTRACT

Objective: After the pandemic period, the daily routines changed, and this caused a significant decrease in families' quality of life. We aimed to show how the pandemic period and closure of educational institutions influenced children with autism spectrum disorder (ASD) and their families' quality of life.

Material and Methods: The study is a descriptive type of research. The study population consists of families of children aged between 3 and 16 diagnosed with ASD who attended special education and rehabilitation centers and educational practice schools in Trabzon for at least 6 months before the pandemic, registered with the Trabzon Autism Association, and were followed at the Karadeniz Technical University Faculty of Medicine Child and Adolescent Mental Health and Pediatric Neurology Polyclinic.

Families were asked to complete the questionnaire we designed. The data was collected face-to-face prospectively. The questionnaire consisted of six parts: sociodemographic and personal characteristics of children and parents; education problems during the pandemic period; the effect of daily routines during the pandemic period on both children and families; the Quality of Life in Autism Questionnaire-Parent Version; and the Parental Burnout Scale.

Results: We contacted 169 parents. Mothers were more likely than fathers to complete the questionnaire (73.1% vs. 26.9%). School attendance decreased by 11.9%, while regular education availability fell by 8.1%. The pandemic has caused changes in the daily routines of families and children in many areas of life, such as decreased physical activity, changes in sleep duration and time, and deterioration in regular eating habits (p = 0.035; 0.001; 0.004; 0.001,

0000-0003-0989-842X : YILDIZ N
0000-0001-9238-3915 : ÖZEN N
0000-0001-5726-737X : ÖZKAN KART P
0000-0002-3344-9774 : YILDIRIM S
0000-0001-5109-3997 : KARADENİZ S
0000-0003-3375-3183 : BİLGİNER Ç
0000-0002-9423-6078 : ESENÜLKÜ G
0000-0001-5415-5874 : ŞAHİN S
0000-0002-3284-107X : ACAR ARSLAN E
0000-0002-5212-0149 : KAMAŞAK T
0000-0002-0734-5437 : ÖZKORUMAK KARAGÜZEL E
0000-0003-4047-4027 : TOPBAŞ M
0000-0002-1930-6312 : CANSU A

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Correspondence Address / Yazışma Adresi:

Nihal YILDIZ
Department of Pediatric Neurology, Faculty of Medicine,
Karadeniz Technical University, Trabzon, Türkiye
E-posta: nihalyildiz661@gmail.com

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respectively). The QoL of parents whose daily schedules changed decreased as a result. Our study found that their levels of burnout significantly increased, and the PBS total score and the QoLA scores had a moderately significant correlation (rs = 0.411, p<0.001).

Conclusion: In this study, we showed that the COVID-19 epidemic negatively affected the education process of children with ASD. In order to improve the QoL of families and reduce burnout levels, we suggest providing additional service opportunities (parks, playgrounds, hobby centers, etc.) and special psychiatric services for children with ASD during pandemic periods.

Key Words: Autism spectrum disorder, Burnout, COVID-19, Parenting, Quality of life

ÖZ

Amaç: Pandemi dönemi sonrasında günlük rutinler değişti ve bu durum ailelerin yaşam kalitesinde ciddi bir düşüşe neden oldu. Pandemi döneminin ve eğitim kurumlarının kapatılmasının otizm spektrum bozukluğu (OSB) olan çocukların ve ailelerinin yaşam kalitesini nasıl etkilediğini göstermeyi amaçladık.

Gereç ve Yöntemler: Çalışma tanımlayıcı tipte bir araştırmadır. Araştırmanın evrenini, pandemi öncesinde en az 6 ay boyunca Trabzon ilindeki özel eğitim ve rehabilitasyon merkezleri ile eğitim uygulama okullarına devam eden, Trabzon Otizm Derneğine kayıtlı, 3-16 yaş arası OSB tanısı alan çocukların aileleri ve Karadeniz Teknik Üniversitesi Tıp Fakültesi, Çocuk ve Ergen Ruh Sağlığı ile Çocuk Nöroloji Polikliniğinde takipli olgular oluşturdu.

Tüm OSB'li ailelere ulaşılması hedeflenmiştir. Ailelerden tasarladığımız anketi doldurmaları istendi. Veriler prospektif olarak yüz yüze toplanmıştır. Anket altı bölümden oluşmaktadır: çocukların ve ebeveynlerin sosyo demografik ve kişisel özellikleri; pandemi döneminde yaşanan eğitim sorunları; pandemi döneminde günlük rutinlerin hem çocuklar hem de aileler üzerindeki etkisi; Otizmde Yaşam Kalitesi Anketi-Ebeveyn Versiyonu; ve Ebeveyn Tükenmişliği Ölçeği.

Bulgular: 69 veli ile iletişime geçildi. Annelerin anketi doldurma oranları babalardan daha yüksekti (%73.1'e karşı %26.9). Okullara devam oranı %11.9 azalırken, düzenli eğitime ulaşılabilirlik %8.1 azaldı. Pandemi, fiziksel aktivitede azalma, uyku süresi ve süresinde değişiklik, düzenli beslenme alışkanlıklarında bozulma gibi hayatın birçok alanında ailelerin ve çocukların günlük rutinlerinde değişikliklere neden olmuştur (sırasıyla p = 0.035; 0.001; 0.004; 0.001). Sonuç olarak günlük rutinleri değişen ebeveynlerin yaşam kalitesi azalmıştır. Tükenmişlik düzeylerinin anlamlı düzeyde arttığı ve PBS toplam puanı ile QoLA puanlarının orta düzeyde anlamlı bir korelasyona sahip olduğu bulunmuştur (rs = 0.411, p<0.001).

Sonuç: Bu çalışmada COVID-19 pandemisinin OSB'li çocukların eğitim sürecini olumsuz etkilediğini gösterdik. Ailelerin yaşam kalitesini artırmak ve tükenmişlik düzeylerini azaltmak amacıyla, pandemi dönemlerinde OSB'li çocuklara ek hizmet olanakları (parklar, oyun alanları, hobi merkezleri vb.) ve özel psikiyatri hizmetlerinin sağlanmasını öneriyoruz.

Anahtar Sözcükler: Otizm spektrum bozukluğu, Tükenmişlik, COVİD-19, Ebeveynlik, Yaşam kalitesi

INTRODUCTION

The coronavirus disease (COVID-19) emerged in 2019 and has significantly impacted people's lives worldwide. Isolation and social distance strategies have been developed to prevent the virus's spread and protect against infection (1). During this process, schools throughout Turkey were closed, and most extracurricular activities for children and adolescents, which typically occur outside the home and in group settings, were canceled (2). Additionally, regular education schools for children with Autism Spectrum Disorder (ASD) were shut down.

Families worldwide have been grappling with the question of how to best support their children in these circumstances. The epidemic has been even more devastating for children who need special health care. The epidemic's disruption of these children's education was observed to have a negative effect on both their physical and mental health as well as their skill levels (3).

It has been emphasized that the pandemic and the measures implemented cause psychosocial distress that jeopardizes family stability (4). Such a stressor exacerbated the symptoms of the pre-existing mental disorder, caused stress on families and children, and caused anxiety and feelings of helplessness (5). The pandemic has altered the daily routines of families. The fact that children with ASD remain at home has increased the burden of educational responsibility on families. Families in this situation have differentiated themselves with actions such as altering their lives both inside and outside the home. The changing physical and mental health of families has affected both their quality of life and burnout levels.

ASD is a neurodevelopmental disorder that is characterized by difficulties in social communication and the presence of constrained, repetitive behaviors or interests (6). During the pandemic, there have been some changes in individuals with ASD at home, at school, in rehabilitation centers, etc. Their educational processes were interrupted, and their developmental characteristics were at risk. Children with autism have difficulty adapting to rules that do not fit into their usual routines and are more likely to have co-occurring psychiatric disorders and behavior problems. In addition to keeping up with the pandemic period and measures, parents are attempting to support their children who need additional care and time, such as the development of their physical, mental, and spiritual health, as well as their formal education at home.

This study aims to investigate how the pandemic period affected the behaviors, daily lives, and neurological development of children with ASD whose educational processes were disrupted by the closure of educational institutions. Another aim is to evaluate the family relationships of parents with children diagnosed with ASD, their sensitivity to both their own and their children's problems, their quality of life, and their burnout status as a result of the effects of the pandemic on both themselves and their children.

MATERIALS and METHODS

The population of the study consisted of families of children who were between the ages of 3 and 16, with a diagnosis of ASD, who were educated in the education and rehabilitation centers in Trabzon or were followed in the Child and Adolescent Psychiatric Health and Pediatric Neurology Outpatient Clinic of Karadeniz Technical University Faculty of Medicine. The Trabzon Directorate of National Education provided a list of schools that specialize in autism education. We visited every autism school in the heart of the city and spoke with the principals about the study. Families who agreed to take part in the research were enlisted. Because the study was descriptive research and intended to reach all families in the city center with children who had been diagnosed with autism, the sample size was not established. Families of 169 children with ASD were asked to complete the questionnaire we designed. Data were collected through face-to-face interviews with families without recording personal information, with the thought that families would express themselves more easily, provide reliable information, and reduce errors and ambiguity. Every participant who voluntarily answered the questionnaire was included in the study. The study did not include any families that did not volunteer. Surveys that provided incomplete answers to the questions in the data form were excluded from the study. Therefore, the statistical study was conducted on a total of 134 survey forms.

The questionnaire was divided into six sections, which were organized by the researchers after a review of the literature. In the first section, questions about some sociodemographic and personal characteristics of the child diagnosed with ASD, and in the second section, questions about some sociodemographic and personal characteristics of the parents were asked. In the third section, questions about the child regarding COVID-19 were asked. In the fourth section, there are questions for parents about COVID-19.

The Quality of Life in Autism Questionnaire-Parent Version (QoLA) was placed in the fifth section. The QoLA was a disorder-specific scale developed by Eapen et al. (8) to assess the quality of life (QoL) of parents of autistic children. Gürbüz B. et al. (9) conducted a Turkish validity and reliability study. It was divided into two parts. Part A includes 28 questions that assess parents' perceptions of their own QoL. Each question was scored on a five-point Likert scale from 1 to 5. Part B assessed parents' perceptions of how significant their child's autism-related difficulties were to them. There were 20 evaluation questions for this, which included the difficulties that children with ASD face. Part A of the questionnaire had a Cronbach alpha value of 0.93, and Part B had a Cronbach alpha value of 0.94. A high score indicated that parents had fewer issues with their autistic children's behaviors. The scale yielded a score ranging from 48 to 240; however, it was recommended that each section be scored and used separately.

The Parental Burnout Scale (PBS) was found in the sixth section. Kaner (10) created the PBS to assess the level of burnout experienced by parents in their marriage lives. Avşar A et al. (11) conducted a validity and reliability study of PBS in determining the burnout level of parents of children with ASD in 2019. It was a five-point Likert scale with 52 items and four subscales. The first PBS subscale was the "Negative Spouse and Marriage Relationship" subscale, which had 18 items. The "Emotional Burnout" subscale was the second, which had 17 items. The third subscale of PBS was "Sensitivity to Spouse and Children," which had 11 items. The final subscale of the PBS was the "Satisfaction with Marriage" subscale, which had six items (10,11). The scale score was proportional to the degree of burnout. Subscale Cronbach alpha coefficients were 0.94 for the Negative Spouse and Marriage Relationship subscale, 0.93 for the Emotional Burnout subscale, 0.84 for the Sensitivity to Spouse and Children subscale, and 0.89 for the Marriage Satisfaction subscale. As a result of the Cronbach's alpha internal consistency analysis performed on all of the scale's items, the scale's Cronbach's alpha coefficient was calculated as 0.89.

This study was approved by Trabzon Karadeniz Technical University (2021/383-19.11.2023).

Approval was received from the Ministry of Health, as it was a study conducted during the pandemic period, and from the Ministry of National Education, since access to the subjects and their families would be provided by schools. Informed consent was also obtained from families who volunteered to participate in the study.

For statistical analysis, SPSS 26.0 was used. Descriptive statistics of evaluation results were provided, including numbers, percentages, and mean, standard deviation, median, and minimum-maximum values for categorical variables, as well as mean, standard deviation, median, and minimum-maximum values for numerical variables. The normal distribution was tested using the Kolmogorov-Smirnov and Shapiro-Wilk tests. Measures that conformed to the normal distribution were compared using the independent t-test or ANOVA, while measures that did not conform to the normal distribution were compared using the Mann-Whitney U test, Wilcoxon test, or Kruskal-Wallis Analysis of Variance. The McNemar test was used to compare these proportions before and during the pandemic. The Pearson-Spearman correlation test was used to determine whether there was a correlation between the measurement variables. The significance level was set at $p<0.050$ in all statistical analyses.

RESULTS

One hundred sixty-nine volunteer parents participated in the study, but 35 questionnaires were excluded due to a lack of data. Of the 134 people who answered the questionnaire completely, 73.1% (n= 98) were mothers. Males constituted 83.6% (n= 112) of children with ASD. The mean age of the children was 9.1±4.1 (3–16). The age at diagnosis of ASD was 3.3 ± 1.4 (1–10).

It was stated that 35.8% (n= 48) of the children had diseases accompanying the diagnosis of ASD. Concomitant diseases were attention deficit and hyperactivity disorder in 58.3% (n= 28), epilepsy in 27.1% (n= 13), mood disorders in 10.4% (n= 5), disruptive behavior disorders in 8.3% (n= 4), an oppositional defiant disorder in 6.3% (n= 3), obesity in 4.2% (n= 2), Down syndrome gait disturbance, Duchenne muscular dystrophy, solitary kidney, hypertension, hearing loss, cleft palate-lip, bipolar disorder, Tourette syndrome, speech disorder, and an obsessive-compulsive disorder in 2.1% (n= 1). While 81.3% (n= 109) of children with ASD were receiving education before the pandemic, only 69.4 (n= 93) of them continued education during the pandemic period, and the difference was statistically significant (p= 0.027). Before the pandemic, 121 children received face-to-face education in schools; 92 children were able to continue their education face-to-face during the pandemic. On the other hand, while the rate of children receiving special education at home before the pandemic was 6.4%, it was 9.7% during the pandemic period. While the rate of students receiving online education was 0.0% before the pandemic, it was 9.7% (n= 9) during the pandemic period. The data on children's education and therapy status before and during the pandemic are shown in Table I.

When the status of mothers working in an active income-generating job was examined, 75.4% (n= 101) did not work both before and during the pandemic, 17.2% (n= 23) continued to work in their pre-pandemic job, and 3.7% (n= 5) left their jobs during the pandemic process. 21.6% (n= 29) of fathers did not work both before and during the pandemic, 56.0% (n= 75) continued to work before the pandemic, and 8.2% (n= 11) left their jobs during the pandemic. The monthly income of 29.1% (n= 39) of the parents decreased compared to the pre-pandemic period. 14.2% (n= 19) of the parents made a change of place for the education of their child with ASD during the pandemic period.

When it was evaluated whether there was a change in the relationship between the parents (separation/divorce status) during the pandemic period, it was determined that 3% (n= 4) of the parents experienced separation.

When the pre-pandemic and pandemic periods were compared, it was determined that there was a significant increase in the playing time of children at home (p<0.001). Those who used drugs for ASD during the pandemic (38.1%) were significantly lower than before the pandemic (45.5%) (p= 0.002). Data on children's daily routines before and during the pandemic are shown in Table II.

Information about children's and parents' daily routines before and during the pandemic is shown in Table III. Children (33.6%) who ate irregularly by skipping meals during the pandemic period were found to be significantly more than those (26.9%)

Table I: Children's education and therapy situations before and during the pandemic (n=134)

	Before pandemic n(%)	During pandemic n(%)	p*
Educational status			
Continue education	109 (81.3)	93 (69.4)	0.027
Regular	85 (78.0)	65 (69.9)	0.004
Irregular	24 (22.0)	28 (30.1)	0.004
Not pursuing any formal education	25 (18.7)	41 (30.6)	0.027
Receiving therapy[†] outside of education			
Receiving therapy	40 (29.9)	36 (26.9)	0.584
Not receiving therapy	94 (70.1)	98 (73.)	

Mc Nemar Test was used, [†]Speech/language therapy, play therapy, music therapy

Table II: Information about the daily routine of children before and during the pandemic period (n=134)

	Before pandemic	During pandemic	p[†]
Time spent on screen (television, computer, tablet, phone) excluding special education/therapy (hours)*	1.8 ± 1.6 (0-5)	1.6 ± 1.5 (0-5)	0.505
Time spent playing outside (garden, playground) (hours)*	1.4 ± 1.2 (0-5)	1.3 ± 1.1 (0-5)	0.009
Time spent playing at home (hours)*	1.9 ± 1.4 (0-5)	2.1 ± 1.4 (0-5)	<0.001
Drug use due to ASD[‡]			
Yes	61 (45.5)	51 (38.1)	0.002[§]
No	73 (54.5)	83 (61.9)	

Mean ± SD (min-maks), [†]Wilcoxon, [‡]n(%),[§] Mc Nemar Test was used, **SD: standard deviation*

Table III: Information about children and parents' daily routines before and during the pandemic period

	Children			Mother			Father		
	Before the pandemic*	During pandemic*	$p^{\dagger}$	Before pandemic *	During pandemic*	$p^{\dagger}$	Before pandemic*	During pandemic*	$p^{\dagger}$
Nutrition									
Eating regularly without skipping meals	98 (73.1)	89 (66.4)	0.004	106 (79.1)	101 (75.4)	0.383	109 (81.3)	100 (74.6)	0.093
Eating irregularly by skipping meals	36 (26.9)	45 (33.6)		28 (20.9)	33 (24.6)		25 (18.7)	34 (25.4)	
Physical activity									
Yes	88 (65.7)	89 (66.4)	1.000	74 (55.2)	66 (49.3)	0.057	69 (51.5)	63 (47.0)	0.070
No	46 (34.3	45(33.6)		60 (44.8)	68 (50.7)		65 (48.5)	71 (53.0)	
Sleep on time									
Sleeping on time	102 (76.1)	99 (73.9)	0.678	100 (74.6)	88 (65.7)	0.017	108 (80.6)	95 (70.9)	0.004
Not sleeping on time	32 (23.99	35 (26.1)		34 (25.4)	46 (34.3)		26 (19.4)	39 (29.1)	
Sleep duration									
Enough sleep time	103 (76.9)	97 (72.4)	0.031	101 (75.4)	92 (68.7)	0.049	117 (87.3)	105 (78.4)	0.002
Not enough sleep time	31 (23.1)	37 (27.69		33 (24.6)	42 (31.3)		17 (12.7)	29 (21.6)	

***** *n(%),* **†***Mc Nemar Test was used*

Table IV: Total scores of parents' parental burnout scale and quality of life in autism-parent edition sections according to the pandemic-related situations

	Parents' Parental Burnout Scale (n=132)		Quality Of Life Scale In Autism-Parent Edition Section (n=134)			
	Total scale score*	p	Part A*	p	Part B*	p
COVID-19 status of the child						
Infected	153.7 ± 36.3	0.443	88.1 ± 14.0	0.816	71.1 ± 19.6	0.248
Not infected	160.0 ± 24.5		89.8 ± 17.0		65.7 ± 16.9	
Quarantine status						
Imposed	155.8 ± 18.5	0.121	88.2 ± 15.9	0.595	65.7 ± 19.3	0.806
Not imposed	160.7 ± 28.5		90.2 ± 17.0		66.5 ± 16.5	
Changes in parental relationship (separation/divorce status) during the pandemic period n(%)						
Change in status	105.3 ± 46.1	0.009 (Posthoc p† 0.023)	83.5 ± 13.9	0.507‡	77.8 ± 12.3	0.365§
No change in status	161.4 ± 23.4		90.0 ± 16.6		65.8 ± 17.4	
Separation/divorce status before the pandemic	137.5 ± 21.9		80.3 ± 23.5		70.3 ± 11.7	
Neurological development of the child with ASD						
A regression	153.3 ± 26.8	0.079	83.5 ± 13.5	0.007	63.4 ± 14.7	0.164
No change or progress	162.3 ± 25.2		92.6 ± 17.4		67.4 ± 18.3	

*****_Score (Mean ± SD),_ **†**_(Bonferroni-adjusted p values) Posthoc Analysis Results Between_ Groups, **‡**_Kruskal Wallis. others Mann Whitney U,_ **§**_ANOVA._

who were fed irregularly before the pandemic (p= 0.004). According to the results of the bedtime evaluation, mothers who did not sleep on time during the pandemic period (34.3%) were found to be significantly higher than mothers who did not sleep on time before the pandemic (25.4%) (p= 0.017). A similar relationship was discovered for fathers. In terms of sleep duration, the rate of children, mothers, and fathers who did not sleep enough during the pandemic period was found to be significantly higher than before the pandemic (p= 0.031; p= 0.049; p= 0.002, respectively).

It was determined that 11.2% (n= 15) of children diagnosed with ASD were infected with SARS-CoV-2, and 28.4% (n= 38) of the parents stated that they were quarantined because they were infected or had close/heavy contact with someone who was infected.

The parents' mean PBS scores were calculated as 159.3± 26.0, the QoLA Part A mean scores were 89.6±16.7, and the Part B mean scores were 66.3±17.3.

When the PBS scores were compared based on the change in the relationship between the parents during the pandemic period, those with a change (separation/divorce status) had significantly lower scale scores (105.3±46.1) than those who did not (161.4 ± 23.4) (posthoc p= 0.023).

During the pandemic period, 32.8% (n= 44) of the parents reported that their child with ASD regressed in neurological development. Regression was reported in 52.3% (n= 23) of those who had language/speech, 22.7% (n= 10) who had motor movement, 77.3% (n= 34) who had social communication, 22.7% (n= 10) who had self-care, 43.2% (n= 19) who obeyed commands, 38.6% (n= 17) who made eye contact, and 40.9% (n= 18) who had attention/focus/adaptive skills.

Table V: Total score of parents burnout scale and quality of life in autism-parent version sections according to the daily routine of parents

	Parents' parental burnout scale total score (n=132)				Quality of life scale in autism-parent edition section (n=134)							
	Total Scare Score				Part A				Part B			
	Mother*	p	Father*	p	Mother*	p	Father*	p	Mother*	p	Father*	p
Sleep on time												
Sleeping on time	164.1 ± 25.2	0.004	164.1 ± 26.6	<0.001	93.0 ± 16.8	0.001*	92.7 ± 16.6	<0.001	69.4 ± 16.6	0.003*	68.2 ± 17.1	0.039*
Not sleeping on time	150.1 ± 25.3		148.0 ± 20.8		83.2 ± 14.5		82.2 ± 14.6		60.3 ± 17.0		61.5 ± 16.9	
Sleep duration												
Enough sleep time	161.9 ± 27.7	0.052	162.2 ± 24.3	0.022	92.9 ± 16.8	0.001	91.8 ± 16.7	0.001*	69.8 ± 17.1	<0.001*	66.8 ± 16.8	0.507*
Not enough sleep time	153.5 ± 20.9		148.9 ± 29.5		82.4 ± 14.1		81.7 ± 14.3		58.5 ± 14.9		64.4 ± 19.0	
Nutrition												
Eating regularly without skipping meals	165.0 ± 23.3	<0.001	162.7 ± 23.4	0.002	91.8 ± 16.8	0.001*	92.1 ± 16.1	0.004	65.9 ± 17.8	0.634*	67.1 ± 18.0	0.335*
Eating irregularly by skipping meals	142.3 ± 26.7		149.6 ± 25.7		82.9 ± 14.6		82.4 ± 16.5		67.5 ± 15.5		63.8 ± 14.6	
Physical activity												
Yes	157.8 ± 27.2	0.716	158.4 ± 27.4	0.868	89.5 ± 14.5	0.760	89.8 ± 15.3	0.625	68.7 ± 17.0	0.113*	69.1 ± 18.1	0.035
No	160.7 ± 25.0		160.1 ± 24.9		89.7 ± 18.6		89.5 ± 17.9		63.9 ± 17.3		63.8 ± 16.2	

* **Score (Mean ± SD),** *Independent T-test, others Mann Whitney U

Table VI: The results of the correlation analysis between the PBS total score and sub-dimension scores and the QoLA Part A and Part B scores

	PBS total score		PBS "Negative spouse and marital relationship" sub-dimension		PBS "Emotional burnout" sub-dimension		PBS "Sensitivity to spouse and children" sub-dimension		PBS "Dissatisfaction with marriage" sub-dimension	
	rs	p	rs	p	rs	p	rs	p	rs	p
QoLA Part A scores	0.411	<0.001	0.086	0.327	0.108	0.217	-0.013	0.886	-0.01	0.851
QoLA Part B scores	0.421	<0.001	0.138	0.111	0.015	0.861	-0.056	0.521	-0.061	0.482
Child's age	0.412	<0.001	0.249	0.004	0.083	0.343	0.047	0.587	0.031	0.724
Age at which the child was diagnosed with ASD	0.009	0.920	-0.107	0.219	0.066	0.446	0.101	0.245	0.027	0.757
Number of Siblings of the child	-0.117	0.180	0.120	0.132	0.087	0.323	0.022	0.804	0.077	0.382

QoLA**: Quality of Life in Autism Questionnaire-Parent Version,* ***PBS: *Parental Burnout Scale,* ***ASD:*** *Autism spectrum disorder,* ***rs:*** *Correlation Coefficient (Spearman)*

The QoLA Part A scores of parents who believed they had been regressed (83.5±13.5) were found to be statistically significantly lower than those who believed there had been no change or progress (92.6±17.4) (p= 0.007). The total scores of the Parent Burnout Scale and Autism Quality of Life Scale-Parent Edition sections based on the pandemic-related conditions of the parents are shown in Table IV.

The results of the PBS and the QoLA sections based on the parents' daily routines are shown in Table V. According to the findings of the time-to-sleep comparison, the mean PBS scores of both mothers and fathers who did not sleep on time during the pandemic period were statistically significantly lower (p= 0.004; p<0.001, respectively). Similarly, the mean scores of both mothers and fathers in QoLA Parts A and B were statistically significantly lower (p= 0.001, p< 0.001, p= 0.003, and p= 0.039, respectively).

The results of the correlation analysis between the PBS total score and sub-dimension scores and the QoLA Part A and Part B scores are shown in Table IV. The PBS total score and the QoLA Part A scores had a moderately significant correlation (rs= 0.411, p<0.001), as did the QoLA Part A score and the PBS "negative spouse and marital relationship" sub-dimension score (rs= 0.421, p<0.001). A moderately significant relationship was discovered between the QoLA Part A score and the "emotional burnout" sub-dimension score (rs= 0.412, p<0.001). There was no statistically significant relationship between the parents' total ADS score and the age of the child with ASD, the age at which the child was diagnosed with ASD, or the number of children the parents had.

DISCUSSION

Education is an essential part of life for children with ASD. In this study, we found that the closure of schools during the pandemic process, as well as the deterioration of the education system's continuity and sustainability, had an impact on the quality of life of not only children but also families. As a result of the interviews with the families, the parents, particularly those who were suffering from severe psychological depression during the pandemic, declined to participate in the survey. We observed that burnout increased in families that reported intra-familial conflicts and more intense childcare during the pandemic period. We believed that if they had also participated, our outcomes would have been even more striking. We discovered that there was little job loss among parents during the pandemic. In light of all of this information, we discovered that the change in the educational process has resulted in an increase in behavioral disorders in children as well as a decline in their neuromotor, social, and cognitive skills. At the same time, the pandemic and the measures implemented both exhausted the parents and had a significant influence on their daily QoL. Again, families reported a significant change in their QoL as a result of the difficulties faced by children who were unable to attend school during the pandemic. Closure and quarantine practices had a significant impact on daily life during the pandemic period. It has resulted in a reduction in children's sleep duration and a deterioration in their eating habits. The daily routines of the families changed as a result of this process, and this change consumed the families with mental and emotional functions.

It has been predicted that both families and children with autism may be affected during the pandemic period, and various studies and practices regarding the precautions to be taken in this process have been developed (12). However, studies examining the relationship between educational limitations, family quality of life, and mental burnout during the pandemic period were rare in the literature. Here, we aim to show the impact of the education process on autism spectrum disorder children and families during the pandemic period.

It is difficult for parents to cope with difficult children and adolescents independently because they lack the professional expertise to overcome these challenges and must frequently rely on schools and therapists for assistance (13). In our country, children with ASD were enrolled in school two weeks after their diagnosis to begin receiving an education. Their life skills and development were aided by 2 hours of individual therapy and 3 hours of group therapy per week. During the pandemic, ASD couldn't have the opportunity to attend these hours, and the continuity of education during the pandemic process was provided both at home with private trainers and online.

It has been well known that families play an important role in education, especially during times of crisis, such as the pandemic. In our study, we found that behavioral disorders increase blindly in ASD children whose parents were burned out and had a high level of emotional incapacity and who continue their education at home. Again, the parents' separation/divorce during the pandemic process resulted in exhaustion as well as difficulties adapting the children to their routines. Our research revealed that the pandemic had significantly reduced educational intensity, that families had become exhausted during this time, that their quality of life had declined, and that their children's emotional, social, cognitive, and motor development had suffered.

When asked what their biggest concerns were about the epidemic and the emergency, families mentioned the infection due to changes in daily routines (e.g., school absenteeism, kindergarten, the constant repetition of infected information, etc.) that increased/intensified, and the child's previously acquired or learned skills. It was stated that they were concerned about losing their health (7,14). Similar to the literature, it was found that among the areas where families had the most common problems with not being able to attend school, there was a fear of interrupting education during the pandemic and spreading it to their children when they went to school. Other reasons included being unable to spare enough time for the child, which existed before the pandemic, as well as transportation and financial problems.

Given that institutional interventions in environments such as schools, hospitals, and workplaces had changed entirely, it was thought that individuals with ASD who had difficulties in social interaction and communication might find it difficult to establish social relations from a distance and that this may even cause regression or hesitation in some skills acquired by staying at home during the epidemic. This was one of the most pressing concerns for families (14). According to the observations of the parents in this study, there were losses in the performance areas of the children during the pandemic period, with regression in the neuromotor developmental stages being the most common. Furthermore, families stated that their children were harmed in areas such as social communication, language speaking success, obeying commands, maintaining attention, and making eye contact during the pandemic. Throughout this time, the children's stagnation and regression in motor and cognitive achievements increased the family's stress and had a significant impact on their exhaustion. When we looked at the QoLA rating scale of families who noticed a decline in their children's performance, we saw that the burnout level of the families who thought that there was a decrease in performance was high.

Literature included habits about eating, nutrition, and sleep problems in ASD families and gave advice to use QoLA for daily routine activities (14,15,9). According to our findings, changes in the routine daily activities of the families, according to QoLA, caused a significant decrease in the families' quality of life. This demonstrates that the pandemic has had a significant impact on not only children's but also families' daily activities.

Given the possibility of education being disrupted in the future due to the emergence of different waves of the epidemic and similar situations (e.g., natural disasters such as earthquakes, floods, and so on), it was thought that better strategic plans for ASD may be required (3). As a result, it was critical to disclose the studies conducted by institutions directly dealing with ASD for these individuals and their families. It was necessary to emphasize the importance of continuity in the education of special children once more.

The number of participants was the most significant limitation of this study. The study's goal when it was created was to reach a larger audience. Some of the families did not want to fill out the form, thinking that such studies were not beneficial to their children or themselves and that the state did not care about such studies. In some families, they could not fill out the form even if they wanted to because their spouses did not give permission. Since the study was voluntary, the number of participants was insufficient. Since most educational institutions are in the center, transportation to the districts could not be provided due to both logistical difficulties and time constraints. Children with mild to moderate autism were included in the study, but because it was a survey study, a comparison of PBS and QoLA based on the children's autism severity could not be made to protect the data's confidentiality.

CONCLUSION

The COVID-19 pandemic has influenced all aspects of life. Children with ASD were reliant on routines and eager to improve their skills through education. Their patterns had an impact on both their families and themselves. Education was the basis of intervention for the clinical symptoms of autism. It was nearly impossible for a person with autism to survive without education. Even minor changes in this area could result in significant gaps in their world. To avoid deep gaps in cases such as pandemics, it should be ensured that services in the fields of education, social communication, and health care are provided continuously.

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