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How Did the Pandemic Affect Autistic Children and Their Families? Challenges and Psychosocial Impacts

Otizmli Çocuklar ve Aileleri için Pandemi Dönemi Nasıl Geçti? Yaşanan Zorluklar ve Psikososyal Etkiler

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ABSTRACT

Aim: Children with autism spectrum disorder (ASD) are especially vulnerable to the pandemic due to their need for routine and difficulty in adapting to change. The aim of this study was to evaluate the psychosocial impact of the Coronavirus disease-2019 (COVID-19) pandemic on children diagnosed with ASD and their families and the challenges they faced during this period.

Materials and Methods: We surveyed 85 parents of children with ASD aged 3-18 years, who were followed up in our clinic between the years of 2020 and 2021. We assessed ASD families' pandemic impact with the "Child and Adolescent Reactions to Stressful Situations-Autism Family Adaptation and Resilience" items. Parents answered the questionnaire online or by phone.

Results: The mean age of the children was 10.3±4.1 years, 65 were boys and 20 were girls. 10.6% of the families had a medical emergency during the pandemic. The most common behavioral problems were anger, difficulty in concentrating, and hyperactivity. 37.6% of the children could not receive educational support, 74.1% could not receive treatment, 31.1% had difficulty in reaching a doctor, and 7.8% had difficulty in affording treatment. Furthermore, 33% of the children spent more than 4 hours a day on screens. 61.2% of parents rated the pandemic quarantine process as more difficult than before.

Conclusion: The pandemic disrupted the daily routines, special education, rehabilitation, and health care services of children with ASD. It also increased their behavioral problems. Therefore, recognizing and addressing the psychological needs of children with special needs, such as ASD, will be an important part of the response to future disasters.

Keywords: Autism spectrum disorder, pandemic, COVID-19, child psychiatry, psychosocial

ÖZ

Amaç: Otizm spektrum bozukluğu (OSB) olan çocuklar, rutin ihtiyaçları ve değişime uyum sağlamadaki zorlukları nedeniyle pandemiye karşı özellikle savunmasızdır. Bu çalışmanın amacı, Koronavirüs hastalığı-2019 (COVID-19) pandemisinin OSB tanılı çocuklar ve aileleri üzerindeki psikososyal etkisini ve bu dönemde karşılaştıkları zorlukları değerlendirmektir.

Gereç ve Yöntem: 2020-2021 yılları arasında kliniğimizde takip edilen 3-18 yaş arası 85 OSB'li çocuğun ebeveynine, araştırmacılar tarafından hazırlanan anket formu uygulandı. OSB tanılı çocuğu olan ailelerin pandemiden etkilenme durumları "Stresli Durumlara Çocuk ve Ergen Tepkileri-Otizm Aile Adaptasyonu ve Dayanıklılığı" maddeleri ile değerlendirildi. Ebeveynler anketi çevrimiçi olarak veya telefonla yanıtladı.

Bulgular: Çocukların yaş ortalaması 10,3±4,1 yıl, 65'i erkek ve 20'si kızdı. Ailelerin %10,6'sı pandemi sırasında tıbbi bir acil durum yaşadığını bildirdi. En sık görülen davranış sorunları öfke, konsantrasyon güçlüğü ve hiperaktivite idi. Çocukların %37,6'sının eğitim desteği alamadığı, %74,1'inin tedavi göremediği, %31,1'inin doktora ulaşmakta zorluk çektiği ve %7,8'inin tedaviyi karşılamakta güçlük çektiği bildirildi. Ayrıca çocukların %33'ü günde 4 saatten fazla ekran başında vakit geçiriyordu. Ebeveynlerin %61,2'si pandemi karantina sürecini eskisinden daha zor olarak değerlendirdi.

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Sonuç: Pandemi, OSB'li çocukların günlük rutinlerini, özel eğitim, rehabilitasyon ve sağlık hizmetlerini sekteye uğratmış, ayrıca davranış sorunlarını da arttırmıştır. Bu nedenle, OSB gibi özel gereksinimi olan çocukların ruhsal ihtiyaçlarını bilmek ve karşılayabilmek, gelecek afet durumlarında yapılacak yardımların önemli bir parçası olacaktır.

Anahtar Kelimeler: Otizm spektrum bozukluğu, pandemi, COVID-19, çocuk psikiyatrisi, psikososyal

INTRODUCTION

In late 2019, a novel coronavirus was identified as the cause of pneumonia cases in Wuhan, China. The outbreak rapidly spread throughout China, and subsequently throughout the world, causing a rapid increase in the number of cases[1]. On March 11, 2020, upon the detection of the first case in our country, the World Health Organization declared the onset of the Coronavirus disease-2019 (COVID-19) pandemic[2].

To date, the virus has infected more than 370 million people worldwide and caused 5.65 million deaths[3]. The high number of asymptomatic infections has made it difficult to control the epidemic and serious measures have been taken worldwide to prevent transmission[4]. During this time, the government implemented several regulations, including the halting of education in accordance with the principles of controlled social life, a curfew for individuals under the age of 20 years, and periodic curfews throughout the nation[5].

These social measures and restrictions have significantly hampered the lives of people of all ages. According to reports, individuals under the age of 18 years, who are still in their developmental stage and unable to meet their needs independently, are at risk of developing mental health issues. Additionally, they have been greatly affected by the pandemic due to the transition to remote learning and curfews, which has kept them away from their peers[4,6].

It is known that crisis events negatively affect psychological well-being. Imran et al.[7] stated that anxiety, depression, sleep and appetite disorders, and impaired social interactions were the most common responses to crisis in children. Jiao et al.[8] (2020) conducted a study examining the behavioral and emotional distress experienced by children and adolescents following the COVID-19 outbreak. The study found that attachment to parents, distraction, irritability, and fear of family members contracting the disease were the most commonly reported problems.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that presents significant challenges related to social communication and interaction, restricted interests, and stereotyped behaviors. According to Diagnostic and Statistical Manual of Mental Disorders-5, children diagnosed with ASD experience difficulties with both verbal and nonverbal forms of communication, developing social relationships and interpreting social cues, showing social-emotional reciprocity, and adapting to changes in social environments[9]. Additionally, research shows that children with special needs are at a higher risk for negative psychological effects in the aftermath of natural disasters[7]. The pandemic affects these children and their families more than others for several reasons. They have to stay indoors for long periods, their daily routines are disrupted, and the specialized education and rehabilitation centers they need are closed. Moreover, these children struggle with online education, lack the necessary equipment, and face challenges in accessing basic health services[10].

Children with autism thrive on structure, and unexpected changes can cause them added stress. It is important to maintain a predictable routine to help them feel more secure and stable[11]. Since the changes in their daily routines during quarantine are difficult for these individuals and their families, they are at risk for developing or worsening mental health disorders, particularly anxiety disorders during the pandemic[12]. Furthermore, as these children face challenges in social communication, they require settings that can facilitate their social growth, such as school and peers[13]. The pandemic has made it harder for people with ASD to develop their social skills due to limited access to social environments, school closures, and disrupted special education. This places them at risk for negative psychosocial consequences related to the pandemic[14]. The pandemic has been a struggle for children with communication difficulties. Social isolation, disrupted therapies, and interrupted special education have all compounded the problem, making life especially challenging for them[15].

The pandemic continues to have significant ongoing impacts, including social isolation, restricted access to healthcare and education services, and decreased financial gains[16]. Although there are numerous ongoing studies regarding COVID-19 and its impact, research on the effects of this pandemic on children with ASD and their families in our country remains scarce. Limited studies have examined the effects of pandemic-induced changes in physical activity and daily routine on this population. It has been noted that various factors, including increased behavioral problems in these children, caregiving needs, and finances, increase the stress on the family. The pandemic has highlighted the added stress of parents having to take on the role of teacher for their children's education and changes in parenting roles. Furthermore, research indicates that the pandemic may have led to heightened anxiety levels in families regarding the potential impact on the physical and mental well-being of children[17-19].

The problems faced by children diagnosed with ASD during the pandemic process have been the subject of many international studies[11-15]. However, research on this topic is limited in our country[20]. Therefore, we assessed the pandemic's psychosocial impacts on children with ASD and their families using a comprehensive questionnaire. Our aim was to explore the challenges they encountered and to devise strategies for future disasters.

MATERIALS AND METHODS

This study investigates the psychosocial impact of the COVID-19 pandemic on children with ASD and their families, including the challenges encountered during this period.

The study follows a descriptive research design, and ethical approval was obtained from the Trakya University Faculty of Medicine Hospital Medical Research Ethics Committee on October 4th, 2021, with decision number 19/13. Caregivers who participated in the study received comprehensive information regarding the research and provided written authorization online for the publication of their medical data.

The study sample was comprised of children and their families diagnosed with ASD, who were followed up at the outpatient clinic of the Trakya University, Department of Child and Adolescent Psychiatry and who agreed to participate in the study. From our database, our study included 165 patients who were between 3 and 18 years old, applied to our outpatient clinic during the period of 2020-2021, and were diagnosed with ASD. We contacted the families of these patients over the phone and informed them about our study. We sent a link for our online questionnaire to the 85 families who volunteered to participate in the study and requested them to fill it out. Questionnaires were filled out via phone calls by families without online accessibility.

During the interviews, participants who consented to take part in the study were administered prepared questionnaires to assess their COVID-19 pandemic adaptation process and investigate its psychosocial impacts. Both patients and their families were included in the study. In the questionnaire form designed for parental response in our study, the questions developed as a result of the literature review and CRISIS-AFAR (The CoRonavIruS Health Impact Survey-Adapted for Autism and Related Neurodevelopmental Conditions; Child and Adolescent Responses to Stressful Situations-Autism Family Adaptation and Resilience) were included[21]. Some questionnaire questions were translated into Turkish for this purpose. CRISIS-AFAR was developed by Vibert et al.[21] and does not currently have an official Turkish translation, nor has validity and reliability been established through study. The objective of the questionnaire is to evaluate the coronavirus crisis-specific requirements and modifications in individuals with ASD and related neurodevelopmental disorders. The questionnaire includes parent notification forms for individuals aged 3-21 years, a self-report form for individuals aged 14 years and older, and an additional parent notification form for adults with autism or other neurodevelopmental disorders.

In the initial section of our four-part survey, we gathered sociodemographic data regarding the patient and their family, the pre-COVID-19 employment status of the parents, any history of psychiatric illness among family members, the patient's language proficiency, and any comorbidities aside from autism. In the second section, participants were queried on whether they had encountered any event warranting immediate communication with their psychiatrists during the pandemic, whether they obtained treatment or educational assistance during this period, and how they perceived the pandemic in comparison to pre-pandemic times. The subsequent section delved into the educational experiences of children during the pandemic. This section covers inquiries on the effects of educational services, access to distance learning, access to healthcare services, and the efficacy of such services. The last section delves into challenges faced during the pandemic, obstacles encountered, and advantageous outcomes resulting from the pandemic.

Respondents completed our online questionnaire, which is a parent notification survey consisting of closed-ended and Likert-type items with 2 or more pre-coded responses (Figure 1).

Statistical Analysis

The study's research data were analyzed using the Statistical Package for the Social Sciences 23.0 program. Categorical data were expressed as frequency (percentage), and age was expressed as mean±standard deviation. For data evaluation, descriptive statistical methods including number, percentage, arithmetic mean, and standard deviation were utilized.

RESULTS

Of the 165 families with children having ASD, who were included in the study, 85 completed our questionnaire. The participation rate was 51.5%. The mean age of the participants was 10.3±4.1 years. 20 patients were female and 65 were male. As shown in the table, 41.2% (n=35) of the patients could not speak at all, 38.8% (n=33) could speak on a word/sentence level, and 20% (n=17) could speak fluently (Table 1).

Mothers and fathers were asked about their educational level and employment status; the majority of mothers had completed primary school (43.5%, n=37%) and had not worked since pre-COVID period (83.5%, n=71). The majority of fathers had a high school education (37.6%, n=32) and were employed (88.2%, n=75). The majority of families lived in the

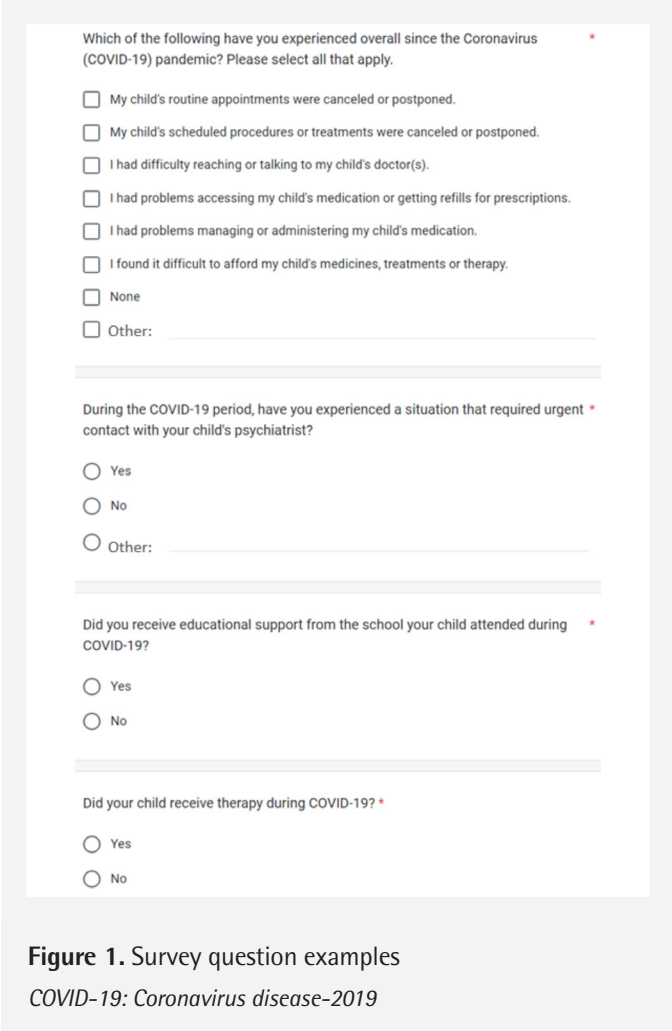

Figure 1. Survey question examples

COVID-19: Coronavirus disease-2019

Table 1. Sociodemographic characteristics of children diagnosed with ASD and their families

Cases diagnosed with ASD (n=85)	Frequency	(%)
Age, mean-SD	10.3-4.1	
Sex		
Boy	65	76.5
Girl	20	23.5
Language skills		
No conversation	35	41.2
Word-level speech	16	18.8
Sentence-level speech	17	20
Fluent speech	17	20
Mother's education level		
Primary	37	43.5
High school	27	31.8
License	17	20
Master	4	4.7
Maternal employment status		
Those who have not worked since pre-COVID-19	71	83.5
Employees	13	15.3
Those who have not worked since COVID-19	1	1.2
Father's education level		
Primary	29	34.1
High school	32	37.6
Undergraduate degree	20	23.5
Graduate degree	4	4.7
Father's employment status		
Those who have not worked since pre-COVID-19	7	8.2
Employees	75	88.2
Those who have not worked since COVID-19	3	3.5
Placement		
Province	28	32.9
County	48	56.5
Town	2	2.4
Village	7	8.2
Income level		
Low	40	47.1
Middle	43	50.6
High	2	2.4

ASD: Autism spectrum disorder, SD: Standard deviation, COVID-19: Coronavirus disease-2019

district (56.5%, n=48) and had a moderate income (50.6%, n=43). Sociodemographic data are presented in Table 1.

10.6% (n=9) of families reported experiencing an emergency during the pandemic. The most common emergency experienced by the 9 reporting families was a temper tantrum (66.6%, n=6). While 8.2% (n=7) of the parents rated the parenting process during the pandemic as easier than before, 30.6% (n=26) rated it as the same, and 61.2% (n=52) rated it as more difficult (Table 2).

During the pandemic process, educational support and health services were affected to a large extent. 37.6% (n=32) of the patients could not receive educational support during the pandemic process, 43 patients (37.1%) had to continue their education at home, 63 patients (74.1%) reported that they could not receive treatment (Table 2).

When families were asked about health care problems experienced during the COVID-19 pandemic, routine appointments and treatments were canceled/delayed in 52.4% (n=54), difficulty in reaching a doctor in 31.1% (n=32),

Table 2. Pandemic events and services affected

Pandemic emergency (n=85)	Frequency	(%)
Those who report an emergency	9	10.6
Non-reporters	76	89.4
Emergencies* (among reporters, n=9)		
Epileptic seizure	1	11.1
Self-injurious behavior	2	22.2
Excessive mobility	1	11.1
Emerging movement (Korea)	1	11.1
Tantrum	6	66.6
New-onset toothache	1	11.1
Difficulty level of closure period (n=85)		
Easy	7	8.2
Same	26	30.6
Difficult	52	61.2
Difficulty in performing daily activities (n=85)		
No	15	17.6
Partly	34	40
Yes	36	42.4
Education and other services affected since the COVID-19 crisis began (among reporters, n=81)		
Not affected	7	6
Those whose schools are closed	41	35.3
Those who continue their education at home	43	37.1
Those who have lost access to education and health care	25	21.6
Educational support intake (n=85)		
Those who do not receive support	32	37.6
Recipients of support	53	62.4
Treatment (n=85)		
Non-recipients	63	74.1
Fields	22	25.9
Benefiting from the services received (among the reporters, n=69)		
Never	15	17.6
Medium	43	50.6
High	11	12.9
Missing data	16	18.8
Health service problems in the COVID-19 outbreak (n=85)		
Cancellation or postponement of routine appointments and treatments	54	52.4
Difficulty reaching a doctor	32	31.1
Difficulty accessing or managing medications	9	8.8
Difficulty affording medications or treatment	8	7.8
Daily screen time (n=85)		
Never	8	9.4
0-3 hours	49	57.6
4-6 hours	18	21.2
More than 6 hours	10	11.8
Experiencing a positive change in the pandemic (n=85)		
No	71	83.5
Yes	14	16.5

COVID-19: Coronavirus disease-2019

difficulty in accessing or managing medications in 8.8% (n=9), and difficulty in adhering to medications and treatments in 7.8% (n=8) (Table 2).

Screen time for children diagnosed with ASD was questioned and found to be higher than it should be for most patients. It was found that 33% (n=28) of the patients were exposed to more than 4 hours of screen time per day (Table 2).

When families were asked about the problems they experienced during the pandemic, 83.5% (n=71) reported behavioral problems. The most common problems reported were anger, concentration difficulties, hyperactivity, crying easily, excessive anxiety, and increased aggression (Figure 2). When families were asked if there had been a positive change in their lives, only 16.5% (n=14) reported a positive change.

DISCUSSION

Our study found that children with ASD experienced significant problems during the pandemic period, as reported by their parents. During the pandemic period, 10.6% of children with ASD experienced a medical emergency and 74.1% were unable to maintain their current treatment. In addition, 83.5% of children had at least one behavioral problem (e.g., anger, concentration difficulties), and 33% spent more than 4 hours per day in front of a screen. At the same time, 37.6% of children with ASD were not receiving any educational services.

To date, COVID-19 has infected more than 676 million people and killed more than 6.8 million people worldwide[3]. While the pandemic is a life-threatening threat, it has also brought with it factors that will adversely affect the mental health of society. In addition to the threat of disease, the social isolation and restrictions imposed by the closure under the controlled social life principles have been a source of stress for people from all walks of life. In addition to the current effects of this

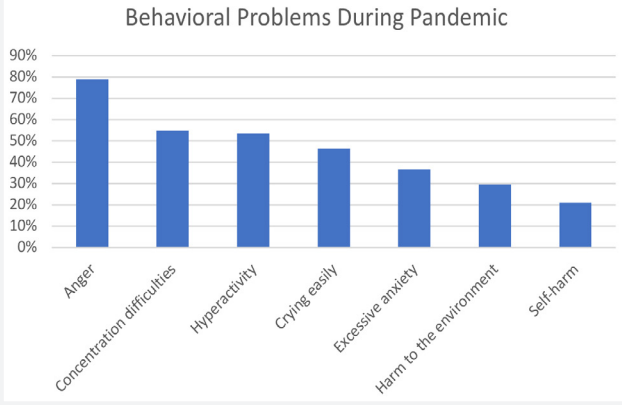

Figure 2. Behavioral problems experienced during the pandemic

epidemic, its long-term effects will only be seen in the coming years[22].

Public health emergencies, such as pandemics, negatively impact both physical and mental health. Children's limitations in understanding events make them more vulnerable than adults. Because their coping strategies are limited, they are physically and mentally unable to escape the harms of the situation. They may not be able to express their emotions like adults. In addition, school closures and separation from friends can cause stress and anxiety in children. The coverage of the crisis event in the mass media and unverified information circulating on social media can exacerbate mental distress[7,23].

The COVID-19 pandemic has caused significant challenges for all age groups. Changes in routines, social isolation, anxiety about illness, and lack of access to health services have contributed to these difficulties. However, children with special needs have faced particularly strenuous circumstances and have experienced immense stress. Many studies indicate that children with psychiatric illnesses are particularly susceptible to the pandemic's risks and the associated challenges[11,12].

According to parent surveys in previous studies, parents of individuals with ASD have described pandemic restrictions as a challenging process that requires more responsibility than before[10]. High levels of parental stress, as well as difficulty in understanding the emotions, reactions, and needs of these children, are important risk factors. In our study, 52 parents of children with ASD (61.2%) perceived the pandemic closure process as more challenging than before. This finding indicates that children with ASD are a part of a significant risk group.

Disruptions to daily routines, like school closures, can impede children with ASD and neurocognitive disabilities. This interruption may lead to problematic behaviors such as irritability, aggression, and social withdrawal, and can also cause a disruption in regular treatment sessions[6]. Healthcare and educational assistance received during the pandemic were significantly disrupted, and our study reported that 37.6% (n=32) of patients were unable to receive educational assistance, 74.1% (n=63) were unable to receive treatment, and 52.4% (n=54) had appointments and treatments canceled.

Individuals with ASD are more susceptible to routine disruptions due to deficits in executive functions. According to parental reports, managing daily activities, specifically leisure time and structured activities, posed challenges. It is important to consider the influence of the environment on behavior despite the complex genetic nature of ASD. Emotional changes resulting from the COVID-19 pandemic have been associated with heightened maladaptive behavior in individuals with ASD over a prolonged duration[11].

According to a study evaluating the effects of the pandemic on children with ASD through an online form, individuals who previously had behavioral issues experienced twice as many and more intense behavioral problems since the outbreak began[11]. In our study, 78.9% (n=56) of children with ASD had easy anger and 29.6% (n=21) had physical aggression. In addition, tantrums were reported as the most common emergency (66.6%, n=6).

Nearly 50% of the participants stated requiring assistance in healthcare, with household services being emphasized in previous studies. One in five parents mentioned that lifting restrictions or ending quarantine would be beneficial. Following the COVID-19 outbreak, persons with ASD lacking school support displayed heightened behavioral problems, underscoring the necessity of maintaining communication with educational institutions during crises[7].

In our research, 16.5% of families (n=14) reported experiencing a positive impact on their lives during the pandemic. One commonly reported aspect of these changes is the ability to spend more time with family. While social isolation has been a well-documented effect of lockdowns, the positive effects on family communication are worth exploring further.

In our study, it was observed that 33% (n=28) of the cases had more than 4 hours of daily screen use. In Guo et al.'s[24] large-sample survey study, in which they evaluated 10,933 children during the pandemic period, 44.6% (n=4,649) of the participants reported that screen exposure was over 5 hours. In a study examining the relationship between heavy screen use and mental health symptoms during the pandemic period, an increase in symptoms of depression, anxiety, behavioral problems, irritability, and hyperactivity/inattention has been reported[25]. The importance of the harmful effects of uncontrolled screen and technology use during the pandemic period is frequently emphasized, especially for risky groups such as children in developmental age and children with autism[26,27]. Children should be prevented from being exposed to panic-inducing news in the media and positive use of social media should be encouraged. In addition, children's screen time should be monitored[28].

Study Limitations

The key strength of our research is the use of telemedicine to reach families with ASD, enabling us to gather information swiftly and clarify the issues faced by ASD children during the pandemic. However, it is important to note that our study had a limited sample size (85 out of 165 patients, or 51.5%) and relied solely on parental feedback, using a descriptive approach. To better understand the experiences of children with ASD and their families during the pandemic and develop

effective solutions to address their challenges, it is necessary to conduct research that evaluates causal relationships and sheds light on this issue.

CONCLUSION

Our study reveals that the pandemic has presented significant challenges for both children with autism and their families. The education and treatment requirements, which are already difficult to meet, have been even more challenging to address[29,30]. The majority of parents reported experiencing many negative events during the pandemic and various behavioral disturbances in their children (hyperactivity, difficulty concentrating, increased anger and aggression, crying easily, and excessive anxiety). During the period of isolation, the decrease in social interaction and the increased time spent at home have led to uncontrolled growth in children's screen time. Along with negative feedback, positive responses from families suggest that the closure period has benefitted family communication and bonding, due to the increase in family time. Future studies are necessary to assess the enduring effects of the COVID-19 pandemic, which have significantly impacted this vulnerable population.

Ethics

Ethics Committee Approval: The study follows a descriptive research design, and ethical approval was obtained from the Trakya University Faculty of Medicine Hospital Medical Research Ethics Committee on October 4th, 2021, with decision number: 19/13.

Informed Consent: Caregivers who participated in the study received comprehensive information regarding the research and provided written authorization online for the publication of their medical data.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: H.C.A., E.B.K., Concept: H.C.A., B.G.Y., L.B., I.G., Design: H.C.A., B.G.Y., L.B., I.G., Data Collection or Processing: H.C.A., L.B., E.B.K., Analysis or Interpretation: H.C.A., B.G.Y., L.B., I.G., Literature Search: H.C.A., B.G.Y., L.B., E.B.K., Writing: H.C.A., B.G.Y., I.G.

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