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The Impact of the COVID-19 Pandemic on Children with Cerebral Palsy

COVID-19 Pandemisinin Serebral Palsili Çocuklar Üzerindeki Etkisi

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ABSTRACT

Aim: The purpose of this study was to examine the sustainability of the treatment of children with cerebral palsy during the pandemic, the physical and psychosocial impact of the pandemic on children, and the fear of COVID-19 among parents.

Method: The authors' questionnaire and the COVID-19 Fear Scale were completed by 350 parents who were reachable and willing to participate in the study.

Results: According to the information given, we can conclude that 46 (21.9%) of 210 children who received education could not participate in online education. In addition, 123 (63.4%) of 194 children who received individual education and 108 (78.8%) of 137 children who received physiotherapy could not continue. According to family reports, 26.3% of children had worse physical development, 21.1% had worse sleep quality, 11.7% had worse linguistic skills, and 39.1% of children had higher levels of anxiety than before the pandemic. The mean COVID-19 Fear Scale score of the parents who stated that their child's physical development was worse compared to before the pandemic (18.23±5.63) was higher than that of the parents who stated that there was no change in their child's physical development (16.91±5.26) (p=0.031). The mean COVID-19 Fear Scale score of the parents who stated that their child's anxiety was higher than before the pandemic (18.02±5.49) was higher than the parents who stated that there was no change in their child's anxiety (16.81±5.28) (p=0.04).

Conclusion: During the pandemic period, rehabilitation of children with cerebral palsy was interrupted and children were affected physically and psychosocially. Family-centered approaches and telerehabilitation opportunities should be studied for future periods.

Key Words: COVID-19, Pandemic, Cerebral palsy, Quarantine, Parent, Fear

ÖZET

Amaç: Bu çalışmada amacımız pandemi döneminde serebral palsili çocukların tedavilerinin sürdürülebilirliğini, çocukların fiziksel ve psikososyal etkilenimlerini ve ebeveynlerin COVİD- 19 korkusunu araştırmaktır.

Yöntem: Ulaşılabilen ve ankete katılmayı kabul eden 350 ebeveyne yazarlar tarafından oluşturulan anket formu ve COVİD-19 Korku Ölçeği dolduruldu.

Bulgular: Eğitim alan 210 çocuktan 46'sı (%21,9) pandemide uzaktan eğitime katılamamıştı. Bireysel eğitim alan 194 çocuktan 123'ü (%63,4) ve fizyoterapi alan 137 çocuktan 108'i (%78,8) devam edememişti. Ailelerin beyanlarına göre çocukların %26,3'ünün fiziksel durumu, %21,1'inin uyku kalitesi, %11,7'sinin dilsel becerileri daha kötüydü.Pandemi öncesine göre kaygı düzeyleri çocukların %39,1'inde daha yüksekti.Pandemi öncesine göre çocuğunun fiziksel durumunun daha kötü olduğunu ifade eden ebeveynlerin COVİD Korku Ölçeği puanı ortalaması (18,23±5,63), pandemi öncesine göre çocuğunun fiziksel durumunda değişiklik olmadığını belirten ebeveynlerden (16,91±5,26) daha yüksekti (p=0,031). Pandemi öncesine göre çocuğunun kaygı seviyesinin daha yüksek olduğunu ifade eden ebeveynlerin COVİD Korku Ölçeği puanı ortalaması (18,02±5,49), pandemi öncesine göre çocuğunun kaygı durumunda değişiklik olmadığını belirten ebeveynlerden (16,81±5,28) daha yüksekti (p=0,04)

Sonuç: Pandemi döneminde serebral palsili çocukların rehabilitasyonu kesintiye uğramış ve çocuklar fiziksel ve psikososyal açıdan etkilenmiştir. Gelecek dönemler için aile merkezli yaklaşımlar ve telerehabilitasyon olanakları üzerine çalışmalar yapılmalıdır.

Anahtar Kelimeler: COVID-19, Pandemik, Serebral palsi, Karantina, Ebeveyn, Korku

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Introduction

The COVID-19 pandemic has significantly impacted global life due to the SARS-CoV-2 virus [1]. Although every child was affected by the pandemic, children with special needs were at greater risk during this period. Due to quarantine, the closure of individual education centers, and a decline in family social support systems, it was predicted that this special population would be disproportionately affected by the COVID-19 pandemic. In the majority of countries, Cerebral Palsy (CP) is the most prevalent cause of childhood-onset and lifelong physical disability, affecting 1 in 500 newborns with an estimated prevalence of 17 million [2]. The term CP refers to a collection of lasting movement and posture impairments, which limit an individual's activities due to non-progressive damage to the brain during fetal development or infancy. Along with motor disorders, individuals with CP often experience difficulties with sensory and perception, cognitive function, communication and behavior, epilepsy, and secondary musculoskeletal disorders [3]. Due to their special needs, many children with CP receive lifelong individualized education and rehabilitation. Social isolation, economic challenges, treatment disruptions, and other factors can lead to physical, mental, behavioral, and psychosocial changes in children with CP. These factors may worsen their functional abilities and potentially lead to complications [4].

Varengue R et al. stated that 81% of children with physical disabilities were adversely affected by quarantine. They also reported that behavioral problems were more common and parental stress was higher in these children compared to children without disabilities during the pandemic period [5]. The systematic review, which aimed to analyze the results of studies examining how the COVID-19 pandemic has affected people with physical disabilities, concluded that there was insufficient early research on the impact of COVID-19 on this population [6].

The purpose of this study was to examine the sustainability of the treatment of children with CP during the pandemic period, as well as the physical and psychosocial effects of the disease on children from the parent's perspective. We aimed to compare the affect status of children according to their ambulation levels. We also aimed to compare the fear levels of parents of affected and unaffected children.

Material and Methods

The parents of children with CP younger than 18 years of age who were admitted to our hospital in the last 5 years were contacted through the phone numbers in our hospital registration system and asked whether they wanted to participate in the survey after being informed about the study. The questionnaire form created by the authors and the COVID-19 Fear Scale were filled in to the parents who could be reached and agreed to participate in the survey.

Children's age, gender, place of residence, parents' occupation, loss of job and/or income during the pandemic and whether the child has a history of COVID-19 infection were queried as demographic information.

The authors created a two-part questionnaire form based on their clinical observations of children with CP, which was subsequently utilized in their research. In the first part of the questionnaire, children's medication use, school and/or special education attendance, cognitive education, online education, physiotherapy, orthotic use, and whether they were able to continue during the pandemic period, and home exercise frequency before and after the pandemic were asked. The questions were closed-ended, yes/no, or multiple-choice in nature. Also Gross Motor Function Classification System (GMFCS) were queried.

GMFCS is a standard classification used to quantify the "severity of movement disability" in children with cerebral palsy. Children classified as Level I in the Gross Motor Function Classification System (GMFCS) can perform age-appropriate activities, but may experience some difficulty with speed, balance, and coordination. On the other hand, children classified as Level V typically have difficulty controlling their head and trunk posture in most positions, and struggle with voluntary movement [7]. Morris et al. revised the GMFCS Family Report Questionnaire for parents and caregivers in 2004 [8]. It was determined that the Turkish version was reliable, valid, and consistent [9].

In the second section of the questionnaire, changes in physical and linguistic development, sleep quality, and anxiety levels among children relative to the pre-pandemic period were examined. This section's questions were answered the same or worse. Furthermore, the study also assessed parents' fear of COVID-19 by utilizing a COVID-19 Fear Scale that comprised of 7 questions. Ahorsu et al. developed the components of this scale by extensively reviewing existing fear scales, consulting with experts, and gathering feedback from study participants. The COVID-19 Fear Scale is comprised of seven items rated on a five-point Likert scale (1 = Strongly disagree; 5 = Strongly agree), and is characterized by a single-factor structure. The internal consistency of the scale was determined to be 0.82, and its test-retest reliability was found to be 0.72. A high score on the scale suggests a greater fear of COVID-19. Additionally, the Turkish version of the scale has been shown to be both reliable and valid [10,11].

Ethics approval: The present study obtained ethical approval from the Clinical Research Ethics Committee (Protocol 2021/206, dated 02.04.2021) and the Ministry of Health, following review by the local ethics committee of Afyonkarahisar Health Sciences University

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*Statistical analysis:*The statistical analysis was conducted using SPSS Statistics 20.0 software (SPSS Inc., Chicago, IL). Descriptive statistics, such as arithmetic mean, median, standard deviation, and percentage distributions, were used to evaluate the data. The normality of the distribution was assessed based on the skewness and kurtosis values, with values less than 1 or greater than -1 considered acceptable. The Independent Groups T-Test was utilized when comparing the means of two independent groups, while the Chi-square test was used to compare the percentage distributions of categorical data between groups. A p-value of less than 0.05 was considered statistically significant.

Results

The parents of 379 of 584 children diagnosed with CP admitted to our hospital in the last 5 years were contacted by telephone between 15.04.2021 and 15.05.2021, and 350 parents who agreed to participate in the study completed the questionnaire.

The mean age of the children was 9.66±3.96 years (2-18). 52% of the children were male and 48% were female. Demographic informations, GMFCS levels, medication, assistive device/orthotic use, education and cognitive education, physiotherapy and COVID histories are given in Table 1.

Of the 173 children who used medication, 2 (1.2%) could not obtain their medication. Among 205 children using assistive devices/orthotics, 10 (4.8%) could not obtain them during the pandemic. Of the 210 children who received an education, 46 (21.9%) could not participate in online education during the pandemic. Of 194 children who received individual education, 123 (63.4%) could not continue during the pandemic. Of 137 children who received physiotherapy, 108 (78.8%) could not continue physiotherapy.

While the frequency of home exercise was 1.68±1.1 per week before the pandemic, it was 1.84±1.21 during the pandemic period (p<0.001). While the frequency of going out was 5.99±1.48 per week before the pandemic, it decreased to 2.62±2 during the pandemic (p<0.001).

According to the statements of the families, 67.1% of the children were in the same physical development as before the pandemic, while 26.3% were worse. In 69.4% of cases, their sleep quality remained unchanged, whereas, in 21.1% of cases, it deteriorated. In 84.3% of cases, their linguistic abilities were the same, and in 11.7% of cases, they were worse. In 58.6% of cases, anxiety levels remained unchanged, while in 39.1% of cases, they increased.

When the status of children according to GMFCS levels were analyzed there was no significant difference in the frequency of worsening physical development, sleep quality, linguistic development or anxiety levels (respectively p=0.078, p=0.113, p=0.130, p=0.374) between the groups (Table 2).

The mean COVID-19 Fear Scale score of the parents was 17.28±5.4. The mean COVID-19 Fear Scale score of the parents who stated that their child's physical development was worse compared to before the pandemic (18.23±5.63) was higher than that of the parents who stated that there was no change in their child's physical development compared to before the pandemic (16.91±5.26) (p=0.031). Parents who reported their child's anxiety level as higher than before the COVID-19 pandemic had a higher mean score on the COVID-19 Fear Scale (18.02 ± 5.49) compared to parents who reported no change in their child's anxiety level before the pandemic (16.81±5.28) (p=0.04) (Table 3).

Discussion

Despite its importance in controlling the pandemic and protecting at-risk groups, social isolation can have a biopsychosocial impact on the lives of children with CP. Due to strict isolation measures in some countries, Panda and Sharawat reported that children with epilepsy and neuromuscular diseases may be deprived of medication [12]. We aimed to examine the sustainability of the treatment of children with CP during the pandemic period and we detected that a small number of children (1.2%) were unable to obtain medication due to pandemic conditions. But we also detected that the rate of children who could not continue physiotherapy was 78.8%, similar to Bıyık et al [13]. Cankurtaran et al. found that in their study, 12.8% of the children with CP had dropped out of physical therapy sessions [14]. We think that this difference in the results is due to the fact that our study was conducted in the early stages of the pandemic when social restrictions were intense.

When we look at the studies carried out in the world outside our country, in surveys conducted by reaching 101 caregivers in India, 25.7% of children had never received any therapy sessions and 23.7% had received online sessions during the pandemic period [15]. In France, 76% of children were home-schooled, while 22% received ongoing medical care, 48% physiotherapy, and 27% occupational therapy. More than 60% of children received therapy from their parents [16]. We also found that the frequency of home exercise increased during the pandemic period. This situation shows the efforts of families to continue physiotherapy at home, as seen in the findings of other studies.

Bıyık et al. reported increased anxiety, pain sensation and sleep problems in at least one out of four children with CP during the pandemic [13]. In our study, 21.1% of children reported worse sleep quality and 39.1% reported

Table 1. Demographic Informations, GMFCS levels, medication, assistive device/orthotic use, education, individual education, physiotherapy and COVID history

Age (Mean±SD) (min-max)		9.66±3.96 (2-18)	
		n=350	%
Gender	Male/Female	182/168	(52%) /(48 %)
GMFCS	GMFCS 1	99	28.3 %
	GMFCS 2	70	20 %
	GMFCS 3	48	13.7 %
	GMFCS 4	10	2.9 %
	GMFCS 5	123	35.1 %
Place of residence	Town center	172	49.1 %
	Town	71	20.3 %
	Rural	107	30.6 %
Mother's Job	Housewife	316	90.3%
	Employee	9	2.6 %
	Officer	16	4.6 %
	Other	9	2.6 %
Father's Job	Employee	102	29.1 %
	Officer	72	20.6 %
	Self-employment	154	44 %
	Not working	22	6.3 %
Medication	Antispastic	62	17.71 %
	Antiepileptic	106	30.29 %
	Other	18	5.14 %
	None	176	50.29 %
Assistive device/orthotic use	Yes	208	59.4 %
	No	142	40.6 %
Education	Yes	210	60 %
	No	140	40 %
Cognitive Education	Yes	194	55.4%
	No	156	44.6 %
Physiotherapy	Yes	137	39.1 %
	No	213	60.8 %
Loss of income in the pandemic	Yes	153	43.7 %
	No	197	56.3 %
COVID positive history	Yes	18	5.1 %
	No	332	94.9%

Mean±SD:Mean ±Standart Deviation, min-max:Minimum-Maximum, n: number of patients,
GMFCS: Gross Motor Function Classification System

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Table 2. Changes in physical and linguistic development, sleep quality, and anxiety levels among children relative to the pre-pandemic period according to GMFCS groups.

	Child's Condition During the Pandemic compared to pre-pandemic		
Physical development	**The same n/(%)**	**Worse n/(%)**	**p**
GMFCS I, II, III n=217	167/77	50/23	0.078
GMFCS IV,V n=133	91/68.4	42/31.6	
Sleep quality	**The same n/(%)**	**Worse n/(%)**	**p**
GMFCS I, II, III n=217	177/81.6	40/18.4	0.113
GMFCS IV,V n=133	99/74.4	34/25.6	
Linguistic development	**The same n/(%)**	**Worse n/(%)**	**p**
GMFCS I, II, III n=217	196/90.3	21/9.7	0.130
GMFCS IV,V n=133	113/85	20/15	
Anxiety levels	**The same n/(%)**	**Worse n/(%)**	**p**
GMFCS I, II, III n=217	136/62.7	81/37.3	0.374
GMFCS IV,V n=133	77/57.9	56/42.1	

GMFCS: Gross Motor Function Classification System, n: number of patients, p: Significance level of data between groups

Table 3. Comparisons of COVID-19 Fear Scale scores according to frequency of changes in physical development, sleeping quality, linguistic development and anxiety levels during the pandemic compared to pre-pandemic

		COVID-19 Fear Scale Mean±SD	**p**
Physical development	The same n=258	16.91±5.26	
	Worse n=92	18.23±5.63	**0.031**
Sleep quality	The same n=276	17.14±5.33	
	Worse n=74	17.79±5.61	0.359
Linguistic development	The same n=309	17.11±5.39	
	Worse n=41	18.56±5.28	0.107
Anxiety levels	The same n=213	16.81±5.28	
	Worse n=137	18.02±5.49	**0.04**

Mean±SD:Mean ±Standart Deviation, n: number of patients, p: Significance level of data between groups

higher anxiety. In a study in the UK, the rate of children whose mental health was negatively affected was up to 90% [17]. In France, quarantine was reported to have negative effects on morale, behaviour, and social interactions. [16]. Sutter et al. reported that more than 40% of children experienced decreased physical activity and mobility and increased stress in their study. In our study, 26.3% of parents reported that their children's physical development was worse. In another study conducted in our country in which 110 children were evaluated, the functional independence scales of the children were significantly worse. [18]. Bıyık et al. found that in their study, more than half of the children had reduced physical activity levels [13]. All these results reveal that children with CP have been greatly affected by the pandemic.

The results of limited studies examining the effects of the pandemic on children with CP based on their mo-

bilization levels suggest that physical and psychological effects may be more prevalent in children who are unable to mobilize or who have more severe clinic. In the study by Bıyık et al. the number of body parts with increased muscle tone, the number of restricted joints, and changes in activity and participation levels were higher in children with GMFCS levels IV and V compared to children with GMFCS levels I, II and III [13]. According to the results of your study, there was no significant difference in the frequency of worsening physical development, sleep quality, linguistic development, or anxiety levels between the GMFCS groups. Bıyık et al. investigated children with objective evaluations but in our study these results were the parent's subjective assessments. For this reason, this difference in results may be due to the evaluation method.

During the pandemic, the anxiety levels of caregivers were found to be high [5,19,20,21]. Cacioppo et al. conducted a study where they found that the primary concern of parents was rehabilitation (72%), and their primary challenge was the mental burden (50%) [16]. According to Sutter et al.'s study, participants who reported a decrease in the number of therapies also reported a decrease in the child's mobility, and an increase in caregiver stress [19]. The parent's level of anxiety may affect the home-based continuation of the rehabilitation process. A statistically significant difference was found in the trait anxiety levels of caregivers who exercised their child at home compared to those who did not [20]. Because parents' anxiety and fears of COVID may affect their approach to their children and thus their situation in this period we also evaluated parents' fear of COVID. The mean COVID-19 Fear Scale score was 17.28±5.4, like the study by Cankurtaran et al [14]. The COVID fear level of parents who stated that their child's physical development and anxiety level were worse than before the pandemic was higher than the parents who stated that there was no change in their child's physical development and anxiety level before the pandemic. These results suggest that the physical and psychological effects on children may be parallel to the parents' fear of COVID. This situation of parents with high fear and anxiety may be reflected in their children and may have negatively affected the exercise and education process that should continue at home.

Limitations: In our study, the condition of the children was evaluated with questions directed to the families. The fact that children were not evaluated with objective scales is one of the limitations of our study.

Conclusion: During the pandemic period, rehabilitation of children with CP was interrupted and children were affected physically and psychosocially. Parents' fear levels and child influence may be related. Therefore, further studies on family-centered approaches and telerehabilitation opportunities are needed in the future.

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