

# The Effect of COVID-19 Pandemics on Mental Health of Caregivers of Cerebral Palsy Patients

## COVID-19 Pandemisinin Serebral Palsi Hastalarının Bakım Verenlerinin Ruh Sağlığına Etkisi

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### ABSTRACT

**Background:** The novel coronavirus disease, so-called Coronavirus disease-2019 (COVID-19), is a global public health emergency that has caused worldwide concern. The lockdown due to the COVID-19 epidemic has consequences affecting mental health on different populations in the world and in our country. This study investigated the acute and chronic phase effects of lockdown period on hopelessness, anxiety and stress of caregivers of children with cerebral palsy (CP).

**Materials and Methods:** The data of 31 caregivers of children with CP were included in this retrospective COHORT analysis. Those who had a history of treatment for depression, hypothyroidism and fibromyalgia, and caregivers who were found to have a Beck depression scale score above 16 points were excluded. Finally, the data of 22 caregivers were included. The data of each participant were analysed using Beck hopelessness scale, Beck anxiety inventory, and perceived stress scale (PSS) twice in timeline at least 10 months apart.

**Results:** There was no significant difference in the scores of the participants between the first assessment and the second assessment for the Beck anxiety inventory ( $p=0.971$ ). No significant difference in scores was observed between the first and second assessments for the Beck hopelessness scale ( $p=0.933$ ). The PSS showed a significant difference between the first assessment and the second assessment. Ten months after the lockdown process, the PSS scores were found to be significantly lower ( $p=0.001$ ).

**Conclusion:** Particular attention should be paid to groups with special needs like caregivers of patients with CP during a pandemic. Various studies have shown that pandemic and lockdown may increase perceived stress levels. According to the data of this study, the perceived stress levels of CP caregivers differed significantly in the acute and chronic periods after lockdown.

**Keywords:** Cerebral palsy, COVID-19, stress, psychological

### ÖZ

**Amaç:** Koronavirüs hastalığı-2019 (COVID-19) olarak adlandırılan yeni koronavirüs hastalığı, dünya çapında endişeye neden olan küresel bir halk sağlığı acil durumudur. COVID-19 salgını nedeniyle sokağa çıkma yasağı, dünyada ve ülkemizde farklı popülasyonlar üzerinde ruh sağlığını etkileyen sonuçlar doğurmaktadır. Bu çalışma, serebral palsili (SP) çocuklara bakım verenlerin umutsuzluk, kaygı ve stres üzerindeki karantina döneminin akut ve kronik faz etkilerini araştırmayı amaçlamıştır.

**Gereç ve Yöntemler:** Bu retrospektif COHORT analizine SP'li çocukların bakımvereni olan 31 kişinin verileri dahil edildi. Depresyon, hipotiroidi ve fibromiyalji tedavisi öyküsü olanlar ve Beck depresyon ölçeği puanı 16 puanın üzerinde bulunan bakımverenler çalışma dışı bırakıldı. Son olarak 22 bakımverenin verileri dahil edilmiştir. Her katılımcının verileri, Beck umutsuzluk ölçeği, Beck anksiyete envanteri ve algılanan stres ölçeği (ASÖ) puanları kullanılarak zaman çizelgesinde en az 10 ay arayla iki kez analiz edildi.

**Bulgular:** Katılımcıların Beck anksiyete ölçeği için ilk değerlendirme ile ikinci değerlendirme arasında puanları arasında anlamlı bir fark yoktu ( $p=0,971$ ). Beck umutsuzluk ölçeği için birinci ve ikinci değerlendirmeler arasında puanlarda anlamlı bir fark gözlenmedi ( $p=0,933$ ). ASÖ, ilk değerlendirme ile ikinci değerlendirme arasında anlamlı bir fark saptandı. Kapanma sürecinden on ay sonra ASÖ puanlarının anlamlı derecede düşük olduğu bulundu ( $p=0,001$ ).

**Sonuç:** Pandemi sırasında SP hastalarının bakımverenleri gibi özel ihtiyaçları olan gruplara özel dikkat gösterilmelidir. Çeşitli araştırmalar, pandemi ve kapanmanın algılanan stres düzeylerini artırabileceğini göstermiştir. Bu çalışmanın verilerine göre, kapanma sonrası akut ve kronik dönemde SP bakım verenlerin algılanan stres düzeyleri önemli ölçüde farklılık göstermiştir.

**Anahtar Kelimeler:** Serebral palsy, COVID-19, stres, psikolojik



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## Introduction

In December 2019, a deadly virus outbreak with severe pneumonia symptoms was detected in Wuhan, China (1). The epidemic, which was understood to be fatal with the findings of acute respiratory tract infection, was accepted as a pandemic by World Health Organization on March 11, 2020 (2). The first case that was reported in our country was on March 11, 2020. Following the first case notification, lockdown measures were implemented across the country on April 11 2020 to prevent the spread of the epidemic. The practice of lockdown due to the Coronavirus disease-2019 (COVID-19) epidemic has consequences affecting mental health on different segments in the world and in our country (3).

Cerebral palsy (CP) is the most common cause of motor disability in childhood. The condition, which is defined as the fixed damage detected in the brain that has not completed its development, continues to affect children worldwide. Today, two out of a thousand children receive this diagnosis, more frequently in developing countries (4). Although the damage that causes CP is a lesion of a fixed nature resulting from a single event, it has widespread consequences that affect the health and mobility of the individual (5,6). Children with a diagnosis of CP experience limitations in activities of daily living and have difficulties in mobility at different levels. In addition to motor developmental delay, conditions such as learning difficulties, epilepsy, speech and swallowing difficulties may accompany the symptoms. It is not a surprising result that the caregiver in this picture exerts maximum effort to protect his mental and physical health. There are many studies evaluating the mental health and quality of life of caregivers who run on this difficult track (7). It has been known for some time that functional disability in children affects the quality of life of mothers negatively, and that depression rates are higher than mothers of children with no physical or mental disabilities (8).

Previous studies have shown that pandemic and lockdown may increase mental health disorders and perceived stress levels (9,10,11). In our study; based on these findings, we investigate the effects of lockdown, which has negative psychological effects on all segments of the society, on hopelessness, anxiety and stress of caregivers of children with cerebral palsy.

## Material and Methods

This study was approved by ethical committee with approval date and number as follows: 02/11/2021-2021/15/551. The data of the caregivers of children with CP who administered to the CP outpatient clinic of Dr. Ayten

Bozkaya Spastic Children's Hospital and Rehabilitation Center in May, June and July 2020 were included. Totally, the data of 31 caregivers were included in this retrospective COHORT analysis. Among these 31 caregivers, data of those who received treatment for depression, hypothyroidism and fibromyalgia, and caregivers who were found to have a Beck depression scale score above 16 points were excluded from the study (Figure 1). Finally, 22 caregivers were included for data assessment. The first data assessment of 22 caregivers included in the study was from the files at the end of lockdown. The 2<sup>nd</sup> assessment of data of each participant who had the scores of Beck hopelessness scale (BHS), Beck anxiety inventory (BAI), and perceived stress scale (PSS) after 10 months was analysed in compared with the 1<sup>st</sup> scores.

### Evaluation scales

**BAI:** It is a self-rating scale developed by Beck et al. (12) to determine the frequency of anxiety symptoms experienced by individuals. The scale consists of 21 items. It is a Likert type scale. Each item is scored between 0-3. Its validity and reliability in Turkey were established by Ulusoy et al. (13).

**BHS:** It was developed by Beck et al. (14) in 1974. The validity and reliability of the study, which was first performed by Seber et al. (15) in 1993 in Turkey, was validated with a larger sample by Durak and Palabıyıkoglu (16). The scale consists of 20 questions. Results range from 0-20 points.

**PSS:** It was developed by Cohen et al. (17). It consists of 14 items in total. It is a 5-point Likert type scale. It is designed to measure the extent to which an individual perceives certain situations in his life as stressful. It is a widely used tool in studies of different populations in the United States, Canada, and Europe. The total score obtained

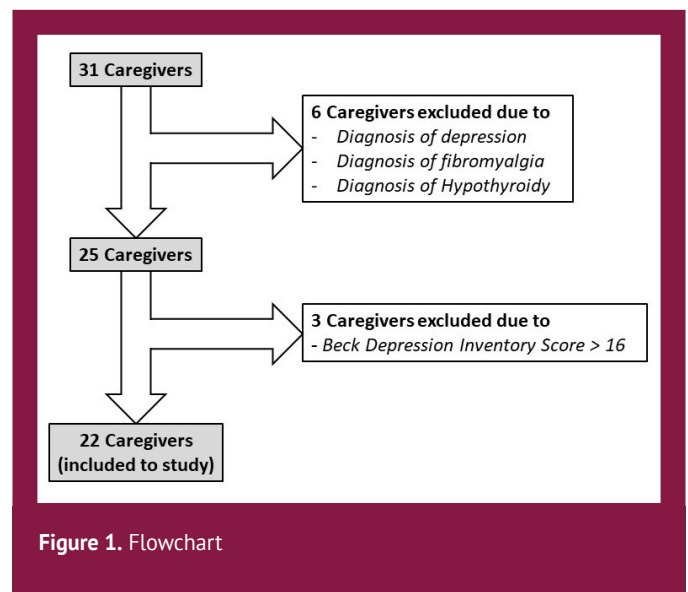


Figure 1. Flowchart

from the scale indicates the stress level of the person. A score between 11-26 indicates low stress level, a score between 27-41 indicates moderate stress level, and a score between 42-56 indicates high stress level. The validation study was conducted by Eskin et al. (18).

### Statistical Analysis

All data were statistically analysed using Version 26 of SPSS (Statistical Package for the Social Sciences) software. After processing the demographic data, following the normality tests, the comparative data were evaluated with parametric/non-parametric tests according to their distribution characteristics. The “p” value was accepted as 0.05 for statistical significance.

### Results

It was determined that all caregivers included in our study were women (mothers). The mean age of the caregivers included in the study was 38.45 (±6.07) years. Eleven (50%) of the participants had primary education, 10 (45.5%) had high school and 1 (4.5%) had university education. While 16 (72.7%) of the mothers have lived with their spouses, 6 (27.3%) of them have lived separately from their spouses. Eleven (50%) mothers said that they have their own income, while 11 (50%) mothers did not have their own income. It was determined that the monthly household income of 10 (45.5%) of the participant group was below 2500 TL, the

monthly household income of 9 (40.9%) was between 2500-5000 TL, and the monthly household income of 3 (13.6%) was 5000 TL (Table 1).

There was no significant difference in the scores of the participants between the first assessment and the second assessment for the BAI (p=0.971). The first assessment median score was 6 (minimum: 2, maximum: 23). Similarly, in the second assessment, the median score was found to be 6 (minimum: 2, maximum: 20) (Table 2).

Similarly, no significant difference in scores was observed between the first and second assessments for the BHS (p=0.933). While the median score was determined as 2 (minimum: 0, maximum: 10) for the participants in the first scoring, the median score was found to be 2 (minimum: 0, maximum: 11) in the second assessment (Table 2).

The PSS showed a significant difference between the first assessment and the second assessment. In the second data which were recorded at least 10 months after the lockdown process, the PSS scores were found to be significantly lower (p=0.001). While the mean PSS score was found to be 23.36 (±6.29) in the first evaluation, the mean PSS score was found to be 17.41 (±5.13) in the second evaluation (Table 2).

Although the PSS score at the end of the lockdown was found to be lower in primary school graduates compared to high school graduates [primary school graduate mean score: 23.18 (±6.01), high school graduate mean score: 23.3 (±7.17)] in the first evaluation, no significant difference was

**Table 1. Study group demographic data**

		n	Total	%	Total (%)
Monthly household income	<2.500 TL	10	22	45.5	100
	2.500-5.000 TL	9		40.9	
	>5.000 TL	3		13.6	
Education	Primary school	11	22	50.0	100
	High school	10		45.5	
	University	1		4.5	
Living with/without spouse	Without spouse	6	22	27.3	100
	With spouse	16		72.7	
Presence of own income	None	11	22	50.0	100
	Present	11		50.0	

**Table 2. Assessment results, values are given as median (minimum-maximum) or mean (± SD) according to distribution characteristics. The level of significance is p<0.05**

	1 <sup>st</sup> assessment	2 <sup>nd</sup> assessment	p
BAI	6 (2-23)	6 (2-20)	0.971
BHS	2 (0-10)	2 (0-11)	0.933
PSS	23.36 (±6.29)	17.41 (±5.13)	<b>0.001</b>

BAI: Beck anxiety inventory, BHS: Beck hopelessness scale, PSS: Perceived stress inventory, SD: Standard deviation

observed according to education level ( $p=0.883$ ). In the second evaluation, although the PSS score was found to be lower in high school graduates [mean score of primary school graduates: 17.73 ( $\pm 4.08$ ), mean score of high school graduates: 16.2 ( $\pm 5.75$ )], no significant difference was found according to education level ( $p=0.529$ ). One participant was not included in this analysis since she was the only participant with a university degree.

When the PSS scores of the participants were examined according to the presence or absence of their own income, it was seen that the participants without their own income in the first assessment have higher PSS scores [mean PSS score of those without their own income: 23.73 ( $\pm 5.68$ ), the mean PSS score of those who have their own income: 23 ( $\pm 7.11$ )] was observed, but no statistically significant difference was found ( $p=0.879$ ). Although the second assessment found that participants with their own income had a lower PSS score [mean PSS score of those without their own income: 18.27 ( $\pm 5.4$ ), mean PSS score of those with their own income: 16.55 ( $\pm 4.95$ )], there was no significant difference according to the presence or absence of their own income ( $p=0.642$ ).

## Discussion

In this study, the acute and chronic effects of the COVID-19 pandemic on the mental health of caregivers of children with CP and the perceived stress effect were investigated. COVID-19 pandemic conditions have created hopelessness worldwide, causing an increase in depression and anxiety (9,19,20).

There are many studies examining the mental health and quality of life of mothers of children with cerebral palsy. It is known that functional disability in children negatively affects the quality of life of mothers, and depression rates are higher than mothers of children with no physical or mental disabilities (8,21,22). Therefore, the depression parameter, which is the focus of many studies, is the exclusion criterion in our study. Our results did not include data on depression.

It is expected that the new rules created by the pandemic conditions, the change in lifestyles and the feeling of uncertainty will increase the level of anxiety. In a meta-analysis evaluating the results of 288,830 participants in 68 studies from nineteen countries, it was found that one out of every three people had symptoms of anxiety and depression related to the pandemic. It is seen that there are conflicting results among the studies for the sub-results of the meta-analysis. It has been shown that being female, younger than 35 years old, and having financial difficulties facilitates the onset of symptoms. Although there are variations in subgroup findings in studies conducted in our country, it is possible to see similar results in terms of depression and anxiety levels (11,23,24). In a study conducted in our country,

female gender, chronic and psychiatric disease history were listed as the causes of increased anxiety (11). In our study group, there was no significant difference between two anxiety assessments at different times. More detailed data for the analysis of the causes are needed.

It has been seen that one of the important reasons for the increase in hopelessness levels in the COVID-19 pandemic is the fear of contagion (19). In our study, the hopelessness parameter was evaluated with the BHS. In the scale where the maximum score was 20, it was seen that the median score was 2 (range: 0-10 and 0-11, respectively) in both assessments. This low score result might be caused by the fact that our focus group did not have direct contact with the disease or other members of the community during lockdown, and had the opportunity to be isolated at home.

Stress occurs when there is an imbalance between the expectations of the social environment and the person's perception. Perceived stress is a subjective assessment tool that defines the level of stress in one's life. It allows to evaluate the person's sense of insecurity and the burden he/she feels (9). Female gender and physical activity restrictions are defined as the most common stressors. In our study, it was observed that there was a significant difference between the first and last PSS scores. This finding is consistent with current reports. It may be attributed to the restriction of movement, which was added to the feeling of uncertainty in the first evaluation, during the period when various lockdown measures were implemented. The final evaluation which belongs to a period in when the vaccination started and returning to normal life came to the fore.

## Conclusion

When results of the subgroups were examined, it was seen that the PSS scores of high school graduate caregivers in the acute phase were higher than those of primary school graduate caregivers. In the chronic phase this outcome was reversed. Since the difference between the results was not statistically significant, it was not expressed in detail. However, this piece of outcome may gain statistical significance in further studies by using different scales and by evaluating a larger research group.

The fact of the pandemic, which will be remembered as the most important historical event of the 21<sup>st</sup> century, has created effects on the mental health of people worldwide that deserve to be examined. We see that the results of our study with mothers of children diagnosed with CP are significant. We think that it would be appropriate to support it with new studies to illuminate the areas where this study is limited.



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## Ethics

**Ethics Committee Approval:** This study was approved by ethical committee with approval date and number as follows: 02/11/2021-2021/15/551.

**Informed Consent:** Retrospective study.

**Peer-review:** Externally peer-reviewed.

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