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INVESTIGATION STRESS LEVEL, PERCEPTION OF SOCIAL SUPPORT, CAREGIVING BURDEN AND CORONAPHOBIA OF CAREGIVERS OF CHILDREN WITH CYSTIC FIBROSIS DURING THE CORONAVIRUS PANDEMIC

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ABSTRACT

Purpose: The perception of caregiving burden and social support is essential for caregivers in chronic disease management. This study aimed to examine the level of perceived stress, social support, coronaphobia and care burden of caregivers of patients with CF.

Methods: This cross-sectional study, conducted during the pandemic, included eleven mothers of children with CF and twelve mothers of healthy children. The perceived stress level (Perceived Stress Scale (PSS-10)), perceived social support (Multidimensional Perceived Support Scale (MDPSS)), coronaphobia (The Fear of COVID-19 Scale (FCV-19)), and caregiver burden (Burden Interview (BI)) were evaluated.

Results: The perceived stress level was significantly higher in the mothers of healthy children ($p = 0.016$). The level of coronaphobia was similar in both groups. PSS score among mothers who have a child with CF was related to the caregiving burden ($r = 0.710$; $p = 0.014$), MDASDS friends subscores ($r = -0.697$; $p = 0.017$), and MDASDS total scores ($r = -0.839$; $p = 0.001$). In addition, the caregiving burden of mothers in this group was correlated with MDASDS family subscores ($= -0.627$; $p= 0.039$).

Discussion: Although the burden of caregiving and coronaphobia were similar in both groups, the perceived stress level of mothers with a healthy child was higher. Perceived social support is negatively associated with perceived stress and care burden. Evaluating the perception of social support in families of individuals with CF may help to reduce the stress and care burden perceived by caregivers in the face of sudden, unexpected events.

Key Words: Menopause, sexual function, quality of life.

ÖZET

Amaç: Bakım yükü ve sosyal destek algısı, kronik hastalık yönetiminde bakımverenler için önemlidir. Bu çalışmanın amacı KF'li hastalara bakım verenlerin algıladıkları stres, sosyal destek, koronafobi ve bakım yükü düzeylerini incelemekti.

Yöntem: Pandemi sürecinde yürütülen bu kesitsel çalışmaya KF'li çocuğu olan 11 ve sağlıklı çocuğu olan 12 anne dahil edildi. Algılanan stres düzeyi (Algılanan Stres Ölçeği (PSS-10)), algılanan sosyal destek (Çok Boyutlu Algılanan Destek Ölçeği (MDASDS)), koronafobi (COVID-19 Korkusu Ölçeği (FCV-19)) ve bakım veren yükü (Bakım yükü (BI)) değerlendirildi.

Bulgular: Algılanan stres düzeyi sağlıklı çocuk annelerinde daha yüksekti ($p = 0.016$). Koronafobi düzeyi her iki grupta da benzerdi. KF'li çocuğu olan annelerin PSS'si bakım verme yükü ($r = 0.710$; $p = 0.014$), MDASDS arkadaş alt skoru ($r = -0.697$; $p = 0.017$) ve MDASDS toplam skoru ($r = -0.839$; $p = 0.001$) ile ilişkiliydi. Ayrıca, bu gruptaki annelerin bakım verme yükü MDASDS aile alt skoru ile korelasyon gösterdi ($r= -0.627$; $p= 0.039$).

Tartışma: Bakım yükü ve koronafobi her iki grupta benzer olmasına rağmen, sağlıklı çocuğu olan annelerin algılanan stres düzeyi daha yüksekti. Algılanan sosyal destek, algılanan stres ve bakım yükü ile negatif ilişkiliydi. KF'li bireylerin ailelerinde sosyal destek algısının değerlendirilmesi, ani ve beklenmedik olaylar karşısında bakım verenlerin algıladığı stres ve bakım yükünün azaltılmasına yardımcı olabilir.

Anahtar Kelimeler: anksiyete, bakım veren yükü, COVID-19, kistik fibrozis, sosyal destek

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INTRODUCTION

Cystic fibrosis (CF) is a disease with a high mortality rate caused by a mutation in the CF Transmembrane Regulator protein, characterized by chronic lung infections leading to bronchiectasis and progressive lung disease with involvement in organs such as the airways, pancreas, genital system, and digestive system (1). Mental health effects such as anxiety and depression have been demonstrated in both individuals with CF and their caregivers (2). In addition to anxiety and depression, the perception of care burden, which is defined as the degree to which caregivers feel that their emotional or physical health, social life, and financial status are affected by care, increases with disease severity and lung involvement in caregivers of individuals with CF (3). The burden of care on the parents of a child with CF decreases with the perception of social support and positively affects the care of the child (4).

Coronavirus disease (COVID-19) is a globally viral illness caused by SARS-CoV-2, resulting in more than 6 million deaths worldwide (5). Patients usually have high fever, weakness, muscle pain, sore throat, loss of appetite, nausea, vomiting, cough, and shortness of breath (6). In addition, people with chronic health problems such as obesity, hypertension, diabetes, and chronic lung disease are adversely affected by the coronavirus (7). Previous findings of virus influenza infection exacerbating CF and leading to severe pulmonary involvement raised concern about the adverse consequences of COVID-19 in the early stage of the pandemic (8). Early pandemic experiences showed that individuals with CF had a high rate of protection from the pandemic, and the incidence was low compared to other adult populations (9, 10). Osterbaur et al. showed that after quarantine, sinonasal symptoms improved, and respiratory symptoms decreased with coronavirus measures. However, coronaphobia has been shown to negatively affect anxiety, depression, general health status, and physical and psychological health in individuals with CF (11). Senkalfa et al. examined the anxiety levels of children with CF and their families during the pandemic period. They found that COVID-19 did not affect the anxiety level of children, while it increased the anxiety level of their families (12). Girdwood et al. found that individuals with CF and their caregivers had concerns about worsening outcomes in adult-centered care with the onset of the COVID-19 pandemic (13). At the same time, the caregiver burden has increased in addition to the level of anxiety in the caregivers of the elderly population and individuals with some diseases such as pediatric celiac disease, autism spectrum, and attention deficit hyperactivity during the COVID-19 pandemic (14-16).

To the best of our knowledge, although it has been reported in the literature that the level of anxiety in caregivers of individuals with CF has increased during the pandemic process, no study evaluating the care burden and social support perception of individuals with CF has been found. It is thought that the care burden and especially the perception of social support are essential in coping with CF. For this reason, this study aimed to examine the level of perceived stress, perceived social support, caregiving burden, and coronaphobia by caregivers of children with CF and healthy children during the coronavirus pandemic.

METHODS

Study Design and Subjects

This cross-sectional study was conducted using a web-based questionnaire created with Google Forms (Google, LLC) and distributed to mothers of children with CF and healthy peers in Eskisehir Osmangazi University, Turkey, from December 2021 to March 2022. The purpose of the study was explained, and consent to participate was obtained through statements at the beginning of the questionnaire. The questionnaire link was sent online to 60 caregivers. Eleven mothers of children with CF were included in the study group, and twelve mothers of healthy children were included in the control group. The inclusion criteria were determined to be a caregiver aged 18 years or older, volunteer to participate in the study, be literate enough to read and fill out the forms, and have the necessary technological equipment and internet access to fill out the forms. Individuals who did not have the required equipment and literacy level to fill out the forms were excluded from the study. The study was approved by Eskisehir Osmangazi University Non-Interventional Clinical Research Ethics Board (Decision date/Number: 26.10.2021/06).

Data Collection

The age and education levels of the participants were recorded. The time allocated to physiotherapy and rehabilitation practices and changes in their symptoms related to CF during the pandemic period for children with CF and whether the duration of physical activity for all children during the pandemic period decreased compared to the pre-pandemic period were questioned. Perceived stress level, perceived support level, caregiving burden, and fear of coronavirus among mothers were evaluated.

The perceived stress level was evaluated with the "Perceived Stress Scale-10 (PSS-10)" developed by Cohen, Kamarck and Mermelstein (17). The PSS-10 measures the extent to which the individual perceives the situations encountered in their life as stressful. This scale was adapted into Turkish by Eskin et al. (18). It consists of a total of 10 items. Participants answer each item on a 5-point Likert-type scale ranging from "Never (0)" to "Very often (4)". The total score varies between 0-40. A high score indicates an increased level of stress. The level of perceived stress was classed as low stress (0-13), moderate stress (14-26), and high perceived stress (27-40).

The level of perceived support was evaluated using the "Multidimensional Perceived Support Scale (MDPSS)" consisting of a total of 12 questions (19). The scale, adapted into Turkish by Eker et al., subjectively evaluates the adequacy of social support received from three different sources (family, friends and significant other) (20). Each item is answered using a 7-point scale *(1:Very strongly disagree-7:Very strongly agree)* . The total score is obtained by summing the scores of three subgroups. A high total score indicates that the perceived social support is high. A total score between 12 and 20 indicates low perceived social support; a score between 20 and 40 represents a moderate level of perceived social support; a score above 40 indicates high perceived social support.

The caregiver burden of mothers was evaluated with the "Burden Interview (BI)", adapted into Turkish by Inci et al. (21, 22). The scale of twenty-two statements is answered using a 5-point Likert-type scale ranging from 0 (never) to 4 (almost always). A minimum score of 0 and a maximum score of 88 can be obtained from the scale. Caregiver burden is categorized according to the scores obtained from the scale as (0–20) little or no burden, (21–40) mild or moderate burden, (41–60) moderate or severe burden, and (61–88) excessive burden. The items in the scale are generally related to the social and emotional domain, and a large scale score indicates that the distress experienced is high (23).

Coronaphobia was evaluated with the Fear of COVID-19 Scale (FCV-19) adapted into Turkish by Haktanır et al. (24, 25). The scale is unidimensional and consists of 7 items. Each item is scored on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). The total score varies between 7 and 35. A high score indicates a high level of coronaphobia. An overall scale score above 16.5 indicates anxiety associated with COVID-19 (26).

Statistical Analysis

Statistical Package for the Social Sciences (SPSS Statistics version 21.0, IBM, Armonk, NY, USA) used for statistical analysis. The data's descriptive statistics were given as median and interquartile range, while categorical variables were represented as percentages. Comparison of variables between groups was performed using the chi-squared test or Fisher's exact test for categorical variables, and Mann-Whitney U tests for continuous variables. Spearman correlation analysis was used to evaluate the correlation between the variables. $p<0.05$ was accepted as significant. According to post-power analysis, the required sample size with an effect size of 1.176 and an alfa level of 0.05 was determined to be 23 using the G Power 3.1 program. The power of the analysis with this simple is 80 %.

RESULTS

The study included eleven mothers of children with CF and twelve mothers of healthy children. Demographic characteristics of the individuals are shown in Table 1 (mothers of children with CF's response rate: 36%; response rate of mothers of healthy children: 40%). There was a significant difference between the education levels of both

Table 1: Sociodemographic characteristics of participant

	Mothers of children with CF		Mothers of healthy children		
Variables	**Median**	**IQR**	**Median**	**IQR**	**p**
Age of Mother (years)	35	33-40	35	34.5-36	0.566
Age of Children (years)	8	7-11	7	7-8	0.171
Duration of CF	10	2-12	0	0	0
	n (%)		**n (%)**		**p**
Mother diagnosed with COVID-19) (Yes/No)	3 (27.3) / 8 (72.7)		6 (50.0) / 6 (50.0)		0.400
Working status (Yes/NO)	2 (18.2) / 9 (81.88)		2 (16.7) /10 (83.3)		0.671
Education level of mothers					
Primary school	4 (34.4)		0 (0)		**<0.001***
High school	6 (54.5)		0 (0)		
University	1 (9.1)		12 (100)		

* p<0.001: Chi-squared test

groups (p <0.001). In the mothers of children with CF group, four (34.4%) mothers graduated from primary school, six (54.5%) mothers graduated from high school, and one (9.1%) mother graduated from university. In contrast, all mothers of healthy children graduated from university. 27.3 % of mothers of children with CF were diagnosed with COVID-19, while 50% of mothers of healthy children. There were no children diagnosed with COVID-19 in the study. 72.7% of the mothers of children with CF stated that they could not take their children for regular check-ups, and 36.3% of them had problems related to their children's illness during the pandemic.

The most common symptoms of children with CF were cough (63.6%), sputum (45.4%), and abdominal pain (27.2%) before the pandemic. During the pandemic process, there was an increase in cough (54.5%), sputum (27.2%), and abdominal pain (18.1%). The duration of physical activity decreased in 90% of children with CF because of social isolation. In comparison, 81.8% had no change in the time allocated to physiotherapy and rehabilitation practices compared to the pre-pandemic period. 36.36% of mothers of children with CF reported an increase in their children's CF-related symptoms. In 53.8% of healthy children, the duration of physical activity decreased compared to the pre-pandemic period.

The comparison of perceived stress level, perception of social support, caregiving burden, and fear of coronavirus between the groups is given in Table 2. The perceived stress level was significantly higher in the mothers of healthy children group than in the mothers of children with CF group (p = 0.016). Perceptions of social support, caregiving burden, and coronaphobia were similar in both groups (p = 0.05). While 54.5% of mothers of children with CF had a mild to moderate care burden, 27.3% had a moderate to severe care burden, and 18.2% had a severe care burden, 41.7% of mothers of healthy children had a mild to moderate care burden, 16.7 % had a moderate to severe care burden, and 41.7% had a severe care burden. When the perceived stress level of the mothers was classified, 63.6% of mothers of children with CF had moderate levels of stress. 8.3% of mothers of healthy children had a low-stress level, 83.3% had a moderate stress level, and 8.3% had a high-stress level. While the FCV-19 total score was above 16.5 in half of the mothers of healthy children, it was above 16.5 in 54.5% of mothers of children with CF.

Table 2. Perceived stress level, perception of social support, caregiving burden and coronaphobia

	Mothers of children with CF		**Mothers of healthy children**		
Variables	**Median**	**IQR**	**Median**	**IQR**	**p**
PSS-10 (0-40)	18.00	10.00-23.00	22.50	16.00-20.50	**0.016***
MDPSS (Family) (4-28)	18.00	25.00-28.00	28.00	22.00-28.00	0.608
MDPSS (Friends) (4-28)	24.00	17.00-28	25.50	22.00-27.50	0.928
MDPSS (Significant Other) (4-28)	24.00	12.00-28.00	25.00	15.50-28.00	0.651
MDPSS (Total) (12-84)	48.00	57.00-81.00	74.50	58.50-82.50	0.928
BI (0-88)	26.00	11.00-37.00	38.50	18.00-46.00	0.134
FCV-19 (7-35)	17.00	14.00-21.00	17.00	12.50-22.00	0.976

*p<0.05: Mann Whitney U test; BI: Burden Interview; FCV-19: Fear of COVID-19 Scale; MDPSS: Multidimensional Perceived Support Scale; PSS: Perceived Stress Scale-10

The relationships between age, perceived stress level, perception of social support, and caregiving burden in both groups are shown in Table 3. There was no relationship between coronaphobia and the age of mothers, age of children, perceived stress level, perception of social support or caregiving burden in all groups (p>0.05).

Table 3. Associations between the mother's age, perceived stress level, perception of social support, caregiving burden

	Perceived stress level				**Caregiving burden**			
	Mothers of children with CF		**Mothers of healthy children**		**Mothers of children with CF**		**Mothers of healthy children**	
	r	**p**	**r**	**p**	**r**	**p**	**r**	**p**
Mother's age (years)	-0.410	0.493	0.842	**<0.001***	-0.103	0.870	-0.263	0.434
Children's age (years)	-0.406	0.425	-0.152	0.655	-0.174	0.742	-0.666	**0.025***
Caregiving burden	0.710	**0.014***	0.278	0.382	**-**	**-**	**-**	**-**
MDPSS (Friends)	-0.697	**0.017***	0.371	0.235	-0.411	0.209	-0.108	0.738
MDPSS (Family)	-0.458	0.151	0.110	0.733	-0.627	0.039	-0.643	0.024
MDPSS (Total)	-0.839	**<0.001***	0.293	0.355	-0.451	0.164	-0.364	0.245

DISCUSSION

This is the first study to evaluate the level of perceived stress, perceived social support, caregiving burden, and coronaphobia in mothers of individuals with CF during the pandemic. The main findings of this study demonstrated that the burden of care increased for most mothers during the pandemic. Although the burden of care and level of coronaphobia were similar in both groups, the perceived stress level of mothers with a healthy child was higher. Mothers with a higher perception of social support had a lower burden of caregiving.

Parents caring for chronic disease is a multidimensional experience in which caregivers aim to provide physical, economic, or emotional support without limiting the extent of the helping action (27). In the systematic review of studies on the burden of caregiving in individuals with CF before the COVID-19 pandemic in the literature, it was reported that caregivers with CF had more significant caregiver burden, less sleep time and sleep quality, their lives were negatively affected economically, they had limitations in their working lives, and had high anxiety levels in parallel with the deterioration of their children lung function (3). In our study, mothers in both groups had mild to moderate burdened care. In our study, the care burden of mothers of children with CF parallels the studies conducted in the literature before the pandemic (28-30). No study evaluating the care burden of caregivers of individuals with CF during the pandemic period was found in the literature. Studies in different populations have reported an increased burden of care concerning anxiety levels during the COVID-19 pandemic (14-16, 31). Bucak et al. showed that caregivers of pediatric celiac disease patients had a mild to moderate care burden (14). Kezer et al. examined the caregiving burden of caregivers of older people during the pandemic and found that they had a mild to moderate level of caregiving burden (15). Yıldız et al. showed that caregivers of individuals with a psychological illness had a high care burden during the COVID-19 pandemic (31). According to our findings, the high burden of care in the study of Yıldız et al. may have been caused by negative reasons such as the high burden of care, the fact that the study was conducted in a population with a direct psychological origin, the difficulty in the supply of drugs for psychiatric diseases during the COVID-19 pandemic, a lack of mental health specialists, a lack of transportation, quarantine periods, and some of the patients stopping taking medication on their own (32). Although it is predicted that mothers of individuals with CF during the pandemic period will increase the workload associated with the disease, such as monitoring the medications used by their children and applying airway clearance techniques, only about one-third of the mothers participating in our study reported that their children's CF-related symptoms increased during the pandemic period, and, their time allocated to physiotherapy and rehabilitation practices did not change in the majority of them. The time allocated for physiotherapy and rehabilitation practices did not change, and the respiratory symptoms associated with CF were more controlled because children lived in a more protected environment within the scope of social isolation measures, which may have played a role in the increase in the burden of disease similar to the pre-pandemic period. In addition, the fact that none of the children in our study sample were diagnosed with COVID-19 may have affected the burden of the disease.

In our study, the burden of care was evaluated in mothers of healthy children as well as children with CF. Although mothers' the perceived burden of care was statistically similar between the two groups, when the burden of care of the groups was classified, the rate of perceived severe burden care was higher in mothers of healthy children.

Yazla et al. found that the burden of care of mothers with healthy children and mothers having children with hyperactivity disorder or autism during the pandemic period was similar, in line with our results (15). Mothers of healthy children having concerns about the lives of their children, financial problems, home confinement, and the inability to develop coping strategies against the risks associated with any chronic disease before the pandemic may have led them to be susceptible to the difficulties and risks associated with COVID-19 (33). The higher education level of mothers of healthy children compared to the other group may have contributed to the increase in the mentally perceived care burden (34).

COVID-19-specific stress factors and psychological experiences of the family trigger anxiety, depression and sleep problems in families of children with chronic diseases such as diabetes, cardiac disease, neurological, neuromuscular, etc. (33). In our study, most of the mothers of individuals with CF had moderate perceived stress levels in accordance with the findings of parents' chronic disease (33). The majority of mothers of healthy children had moderate stress levels. Factors such as emotional burden experienced, change in family dynamics due to COVID-19, coronaphobia, worry about not being able to protect their child, decreased level of physical activity of their children, and need for more parental support at home may have increased the perceived stress level of mothers. When the two groups were compared in terms of perceived stress level, the findings of our study showed that the stress level perceived by mothers with healthy children was higher. Similar to the results of our study, Krijger et al. reported that families of children with chronic somatic disorders experienced less stress than families in the general population (35). Mothers of children with CF may have had a lower perceived stress level due to their prior experience with a chronic disease and the insensitivity caused by the stress compared to mothers of healthy children. In contrast to our findings, some studies in the literature have reported higher anxiety levels in caregivers of individuals with CF compared to mothers of healthy children. Differences in findings may result from these studies being conducted earlier in the pandemic than ours, and the measurement tools used were different (12, 36).

Social support is an essential factor in the care of children with chronic diseases and improves the mental and physical performance of the carer (37). The findings of our study showed that the mothers in both groups had a similar high level of perception of social support. In parallel with our study findings, Tural et al. evaluated the perception of social support under coping strategies of the families of individuals with CF during the pandemic and found that they had similar social support compared to mothers of healthy children (35). Mothers may have had a similar environment in terms of social support due to social isolation and the restriction of people's interactions with each other due to the pandemic. Previous studies have shown that having a high level of social support from parents of individuals with CF positively improves the burden of care and symptoms associated with the disease (4, 37). Similarly, we found that the burden of illness decreased as the level of perceived social support increased in both groups. In addition, in our study, we showed that the perception of social support of mothers of individuals with CF was associated with perceived stress.

Limitation

This study had some limitations. One limitation of our study is that the care burden of the individuals included was not routinely evaluated objectively before the pandemic. The difference in the educational level of the caregivers was another limitation affecting the standardization between the groups. In addition, all caregivers who participated in our study were women. The fact that women have multiple social aspects that may affect their perceived care burden may limit the interpretation of the results of our study according to gender-specific differences.

CONCLUSION

During the COVID-19 pandemic, the perceived stress level and care burden increased among mothers of individuals with CF. The higher the perception of the social support of the caregiver, the lower the stress and care burden level. Therefore, evaluating the care burden and social support perception of caregivers in routine control of individuals with CF and making improvement plans may help them cope with unexpected situations that may negatively affect their lives. Although the burden of care and coronaphobia were similar in both groups, the perceived stress level of mothers with a healthy child was higher. In the face of sudden and unexpected events, it is crucial to examine not only the caregivers of chronically ill children but also the caregivers of healthy children in terms of perceived stress and care burden.

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