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Fear of COVID-19 and Care Burden in Caregivers of COVID-19 Patients

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Anahtar Kelimeler
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ABSTRACT

This study was conducted to assess the fear of COVID-19 and the caregiver burden of COVID-19 patients. This study used a descriptive design. Individuals aged 18 years and older who provided home care to COVID-19 patients. Data of study were collected using the "Introductory Questionnaire", "The Fear of COVID-19 Scale (FCV-19S)" and "The Zarit Burden Inventory (ZBI)". Number, percentage distribution, mean, standard deviation, Cronbach α, regression and general linear model multivariate analysis were used in the evaluation of the data. In this study, the mean FCV-19S score of the caregivers was 21.5±9.2, and the mean ZBI score was 37.8±24.6. Multivariate analysis found that all the independent variables accounted for 52.5% of the total variance for fear of COVID-19 (R=492589.02, F=40.78, p<0.001). Multivariate analysis found that all the independent variables accounted for 47.6% of the total variance for care burden (R=3023237.39, F=33.53, p<0.001). Having COVID-19, experiencing bereavement due to COVID-19, worry about being infected with COVID-19, fear of death while giving care, and self-assessed health status were found to be important predictors for FCV-19S and ZBI. As a result, considering that caregivers of COVID-19 patients have training and counseling, especially psychological support, can facilitate the care of COVID-19 patients at home.

COVID-19 Hastalarına Bakım Veren Kişilerde COVID-19 Korkusu ve Bakım Yükü

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ÖZ

Bu çalışma, COVID-19 hastalarının bakım verenlerinde COVID-19 korkusunu ve bakım yükünü belirlemek amacıyla yapılmıştır. Bu çalışma COVID-19 hastalarına evde bakım veren 18 yaş ve üzeri bireyler ile tanımlayıcı tipte yürütülmüştür. Çalışmanın verilerinin toplanmasında "Tanıtıcı Anket Formu", "Koronavirüs (Covid-19) Korkusu Ölçeği" ve "Bakım Verme Yükü Ölçeği" kullanılmıştır. Veriler değerlendirilirken sayı, yüzde dağılımı, ortalama, standart sapma, Cronbach α güvenirlik katsayısı, regresyon ve general linear model multivariate analizi kullanılmıştır. Bu çalışmada bakım veren bireylerin COVID-19 Korkusu Ölçeği puan ortalaması 21.5 ± 9.2 ve Bakım Verme Yükü Ölçeği puan ortalaması 37.8±24.6 olarak bulunmuştur. Çok değişkenli analiz sonucu, tüm bağımsız değişkenlerin COVID-19 korkusu için toplam varyansın %52,5'ini açıkladığını bulunmuştur (R=492589,02, F=40,78, p<0,001). Çok değişkenli analiz, tüm bağımsız değişkenlerin bakım yükü için toplam varyansın %47,6'sını açıkladığını ortaya koymuştur (R=3023237,39, F=33,53, p<0,001). COVID-19 geçirmek, COVID-19 nedeniyle kayıp yaşamak, bakım sırasında COVID-19 bulaşacağını düşünmek, bakım verirken ölüm korkusu yaşamak, algılanan sağlık durumunun COVID-19 korkusu ve bakım yükü için önemli yordayıcılar olduğu bulunmuştur. Sonuç olarak, COVID-19 hastalarına bakım verenlerin eğitim ve danışmanlık, özellikle de psikolojik destek almaları COVID-19 hastalarının evde bakımını kolaylaştırabilir.

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INTRODUCTION

COVID-19, which was first reported in the China city of Wuhan, has spread over time. The disease is transmitted through droplets and by contacting with droplets spreading as a result of coughing and sneezing of people infected with COVID-19 (1). The ways in which COVID-19 disease affects people can be different. Fever, cough, tiredness and loss of taste or smell are the most common symptoms. It is also recommended for individuals who are healthy and have mild symptoms to manage their symptoms at home (2). There is a higher risk of infection in the close contacts of people with COVID-19. Moreover, due to the quarantine measures applied to close contacts of COVID-19 patients, it is necessary to consider the mental health of these individuals. These individuals may experience stress, psychological and mental problems (3).

It has been observed that countries have accepted different practices in the fight against COVID-19. In Turkey, it gradually implemented measures that affect individual and social life by looking at the developments in the world (4). Upon reporting of the first case of COVID-19, Turkey took the necessary measures to stop the spread of the disease, including closing crowded places such as schools and shopping centers. In particular, people were asked to stay at home in order to reduce the transmission rate of the disease and to protect the elderly and those with chronic illnesses (5). Upon the recommendation of the T.R Ministry of Health, COVID-19 patients who are supposed not to need hospital treatment have been followed up at home with an appropriate treatment in Turkey. The patient should spend the follow-up period at home. It has been reported that all family members living at home should follow their health status and take necessary protective measures (6). Generally, it can be thought that individuals in the household are caregivers of these patients.

Fear causes individuals to give an acute reaction toward a possible bad situation, both physically and mentally. Fear is a normal reaction developed against the threat (7). It has been suggested that people with high levels of anxiety may not think rationally when responding to COVID-19 (8). Fear of COVID-19 may also affect an individual's level of positivity (9). Fear of COVID-19 was associated with informal caregiving in one study (10). All this can be interpreted to mean that fear of COVID-19 is an important factor in the illness and care process of carers.

Caregiving in the family takes place as a result of the needs arising from short or long-term functional problems (11). Family caregivers are accepted as important persons in the treatment process. The caregiving process can impose a burden on these people (12). Care burden is expressed as a negative response to the impact of the caregiving process on caregivers' social, professional and personal roles (13). The condition of the disease affects the care burden (14). Determining the care burden of caregivers is important in terms of interventions that can be developed to reduce the burden of care. For people caring for relatives with an infectious disease during a pandemic, both fear of transmission and caregiver burden may be important factors influencing this process.

If an individual is infected with COVID-19 disease, people who are close to him/her (family members, friends, colleagues, etc.) are psychologically negatively affected (15). In the literature, in previous studies conducted with family members caring for COVID-19 patients, it was found that caregivers experienced fear of COVID-19 (16), negative psychological experiences (17) and care burden (15,18,19). In the literature, it was observed that previous studies conducted with family caregivers providing home care to patients with COVID-19 were conducted in Iran (15-19). No previous studies on the subject of the current study were found in Turkey. On the other hand, most studies on caregivers of patients diagnosed with COVID-19 have focused on the care problems of nurses or other health professionals (20-23). For these reasons, the current study was conducted to determine the fear of COVID-19 and care burden in family caregivers of COVID-19 patients.

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Research questions

1. Does caring for COVID-19 patients affect caregivers' fear of COVID-19?
2. Does caring for COVID-19 patients affect caregivers' care burden?
3. What are the factors that influence anxiety about COVID-19 and caregiver burden in COVID-19 patients?

MATERIAL AND METHODS

Design

The current study was based on a descriptive design to determine the fear of COVID-19 and the care burden in caregivers of COVID-19 patients at home.

Setting and Time

The study was conducted through the online platform to include participants and enable them to participate in the study due to the transmission risk of COVID-19. The survey form created using Google Form was shared online via Whatsapp to be filled out between 21 December 2021 and 21 March 2022.

Population and Sample

The population of the study consisted of individuals aged 18 years and older who provided home care to COVID-19 patients living in two Family Health Centre (FHC) regions selected by lottery method in the provincal cantre.

The sample was determined as 260 individuals at power to represent the population of 0.95 at confidence interval of 95% determined with an effect size of 0.25 and a significance level of 0.05, according to the power analysis. The study was completed with 304 adults to prevent data loss. Individuals who met the inclusion criteria were included in the study using a convenience sampling method from the population according to carer contact information of the caregivers obtained from nurses and midwives.

Inclusion Criteria

- Not engaging in medicine (doctor, nurse, midwife, etc.),
- Having capability and time to answer the questionnaire.

Exclusion Criteria

- Not being willing and voluntary to participate in the study,
- Having a mental or communicative disability that may create an obstacle in answering the questions.

Measurements

Data for the study were collected using the researchers' Introductory Questionnaire, the Scale of Fear of COVID-19, and the Zarit Burden Interview.

Introductory Questionnaire

This form, prepared by the researchers, consists of a total of 14 questions, including 10 questions about the socio-demographic information of the caregivers included in the study as well as 4 questions about the perception and attitude toward the COVID-19 disease.

The Fear of COVID-19 Scale (FCV-19S)

The FCV-19S was developed in 2020 (8). Bakioğlu et al. (9), adapted the scale into Turkish. This form consists of 7 items and one dimension. The total score of the scale varies between 7 and

35 points. A higher score indicates a higher level of fear of coronavirus. The Cronbach's alpha coefficient was found to be .88. In this study, the Cronbach's alpha value of the scale was found to be .95.

The Zarit Burden Interview (ZBI)

The scale was developed in 1980 (24) and İnci and Erdem adapted it to Turkish and conducted its validity and reliability study. This scale is used to assess the stress experienced by carers of the person or older person in need of care. It consists of 22 items that measure the impact of caregiving on a person's life. The scale has rating between 0 and 4. The total score ranges from 0 to 88, with a high score indicating a high level of distress (25). In this study, the Cronbach's alpha value of the scale was found to be .97.

Data Collection

Data for the study was collected via an online questionnaire. This was due to the ongoing COVID-19 pandemic. Contact numbers of the caregivers were obtained from nurses and midwives working in two FHCs. The link to the online form was then sent to the caregivers's phone and they were asked to complete the form. It is not possible for participants to complete the questionnaire without answering a question that requires an answer. Thus, there were no incorrect and incomplete surveys.

Study Variables

Dependent variables; Fear of COVID-19, Care Burden

Independent variables; Descriptive characteristics of the caregivers, Perceptions and attitudes of the caregivers toward COVID-19.

Ethical Considerations

The necessary approval was obtained from the Health Sciences Non-Interventional Clinical Research Ethics Committee of a state university in eastern Turkey (Session Date: 30.11.2021; Decision No: 2021/2769). Participants were informed of the purpose of the study, and that participation was voluntary, that the information they provided would only be used for the study, and that they could withdraw from the study at any time. This study was conducted according to the tenets of the Declaration of Helsinki.

Statistical Analysis

The data were coded in a computer environment and SPSS 22.0 Statistical Package Programme was used for analysis. Descriptive characteristics of the caregivers were expressed as number, percentage distribution, mean, and standard deviation values. General linear model multivariate and regression analysis was used to determine the extent to which the independent variables explained the dependent variables. In the present study, the results were accepted as statistically significant with a confidence level of 95% and a significance level of $p<0.05$.

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RESULTS AND DISCUSSION

Table 1. Descriptive Characteristics of Caregivers of COVID-19 Patients (n=304)

Characteristics	n	%
Gender		
Female	220	72.4
Male	84	27.6
Marital Status		
Married	171	56.3
Bachelor	123	40.5
Divorced	10	3.2
Education Level		
İlliterate	18	5.9
Literate	10	3.2
Primary education	33	10.9
High school	58	19.1
University and over	185	60.9
Income status according to the perception of the person		
Good	59	19.4
Moderate	207	68.1
Bad	38	12.5
Self-assessed health status		
Good	135	44.4
Moderate	143	47.0
Bad	26	8.6
Status of having children		
None	152	50.0
One	38	12.5
Two	56	18.4
Three	38	12.5
Four	5	1.6
Five	11	3.7
Six	4	1.3
Chronic disease		
None	213	70.1
Heart disease	12	3.9
Hypertension	18	5.9
COPD	8	2.6
Kidney disease	6	2.0
Diabetes	30	9.9
Thyroid disease	4	1.3
Chest disease	8	2.7
Cancer	3	1.0
Venous insufficiency	1	0.3
Anemia	1	0.3
Presence of person helping to give care		
Yes	158	52.0
No	146	48.0
Relationship to patient		
Partner	66	21.7
Children	79	26.0
Mother	80	26.3
Father	27	8.9
Grandparent	29	9.5
Sibling	18	5.9
Grandchild	1	0.3
Cousin	2	0.7
Friend	2	0.7
Pull through the COVID-19		
Yes	147	48.4
No	157	51.6

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Bereavement due to COVID-19			
Yes		128	42.1
No		176	57.9
Worry about being infected with COVID-19			
Yes		258	84.9
No		46	15.1
Fear of death during care			
Yes		199	65.5
No		105	34.5
	Minimum	**Maximum**	**X±SD**
Age	18.0	82.0	35.2±12.2

%: Yüzde

It was found that the mean age of the participants was 35.2±12.2%, 72.4% were female, 56.3% were married, 60.9% had an education level of university education or higher, 68.1% perceived their income as medium, 47% perceived their health status as mediun, 50% of them had no children, 70.1% did not suffer from any chronic disease and 9.9% of those with a disease were diabetic. In addition, 52% of the participants were someone who helped for caregiving, 26.3% provided care to their mother, 51.6% did not have COVID-19 before, 57.9% did not experience loss due to COVID-19, 84.9% thought that the COVID-19 virus would be transmitted during home care and 65.5% had fear of death while providing care to their patients (Table 1).

Table 2. Distribution of Mean Scores of The Fear of COVID-19 Scale and The Zarit Burden Inventory

Scales	**Min - Max**	**X ± SD**
FCV-19S	7.0 - 35.0	21.5 ± 9.2
ZBI	0.0 – 88.0	37.8 ± 24.6

The current study, the FCV-19S mean score of the caregivers was 21.5 ± 9.2. Their ZBI mean score showed that the participants had a mild to moderate care burden (37.8±24.6) (Table 2).

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Table 3. Explanation of Predictors of FCV-19S and ZBI with General Linear Model Multivariate

Independent Variable	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	Fear of Covid-19	492589.022[b]	8	61573.628	40.785	.000***
	The burden interview	3023237,39[c]	8	377904.674	33.537	.000***
Intercept	Fear of Covid-19	495724.844	1	495724.844	328.360	.000***
	The burden interview	1784356.658	1	1784356.658	158.352	.000***
Perception the COVID-19 disease	Fear of Covid-19	2503.782	1	2503.782	1.658	.199
	The burden interview	77515.464	1	77515.464	6.879	.009*
Pull through the COVID-19	Fear of Covid-19	78540.405	1	78540.405	52.024	.000***
	The burden interview	221274.137	1	221274.137	19.637	.000***
Experiencing death due to COVID-19	Fear of Covid-19	24281.377	1	24281.377	16.084	.000***
	The burden interview	216438.286	1	216438.286	19.208	.000***
Worry about being infected with COVID-19	Fear of Covid-19	26843.298	1	26843.298	17.781	.000***
	The burden interview	51231.300	1	51231.300	4.546	.034*
The feeling of caring for a COVID-19 patient	Fear of Covid-19	509.615	1	509.615	.338	.562
	The burden interview	9616.681	1	9616.681	.853	.356
Fear of death during care	Fear of Covid-19	63243.203	1	63243.203	41.891	.000***
	The burden interview	517143.587	1	517143.587	45.894	.000***
Self-assessed health status	Fear of Covid-19	15448.512	1	15448.512	10.233	.002*
	The burden interview	207331.374	1	207331.374	18.399	.000***
Relationship to patient	Fear of Covid-19	3534.162	1	3534.162	2.341	.127
	The burden interview	659.029	1	659.029	.058	.809
Error	Fear of Covid-19	445361.656	295	1509.701		
	The burden interview	3324155.467	295	11268.324		
Total	Fear of Covid-19	6158605.000	304			
	The burden interview	23031680,00	304			
Corrected Total	Fear of Covid-19	937950.678	303			
	The burden interview	6347392.857	303			

bR Squared = ,525 (Adjusted R Squared = ,512) *p<.05
cR Squared = ,476 (Adjusted R Squared = ,462) ***p<.001

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The general linear model estimates the coefficients of a multivariate linear equation containing one or more independent variables that are the best predictors of the value of the dependent variable. The confidence interval of 95% was used for each predictor coefficient. Multivariate linear analysis was used to determine fear of COVID-19 and care burden and the findings are presented in the table. Multivariate analysis found that all the independent variables accounted for 52.5% of the total variance for fear of COVID-19 (R=492589.02, F=40.78, p<0.001). Multivariate analysis found that all the independent variables accounted for 47.6% of the total variance for care burden (R=3023237.39, F=33.53, p<0.001). In addition, it was found that having COVID-19, experiencing loss due to COVID-19, thinking that COVID-19 will be transmitted during care, having fear of death while caregiving, and perceived health status were important predictors for fear of COVID-19 and care burden (Table 3).

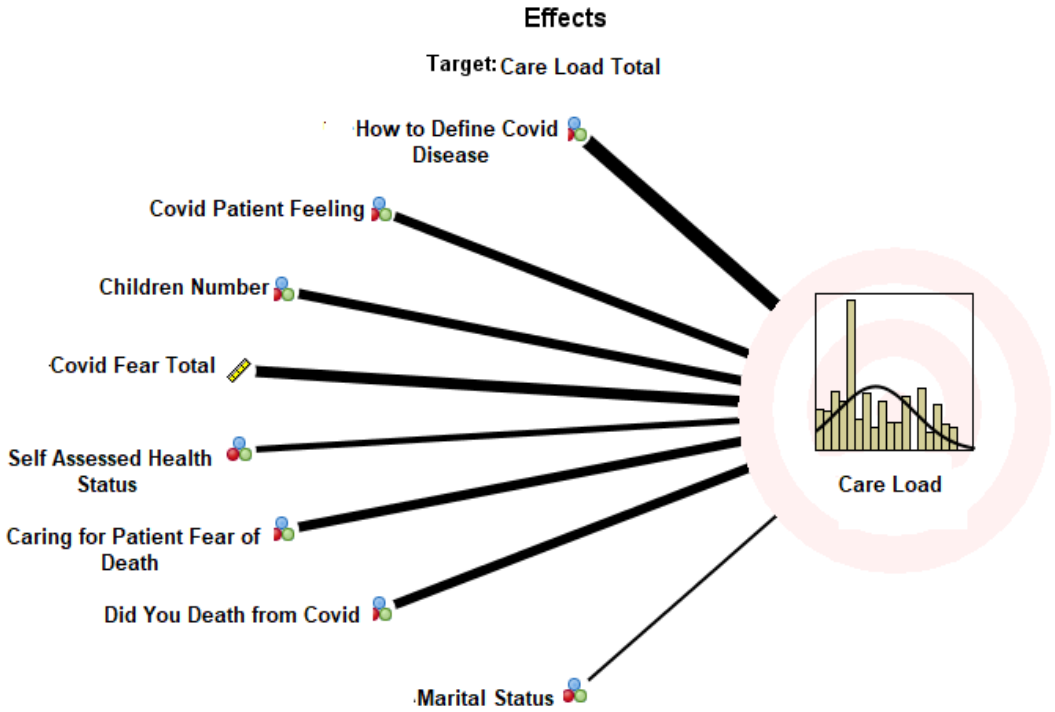

Figure 1. Effect of Independent Variables on Care Burden

Through automatic linear model it was determined that while the caregiver's self-assessment of health affected the care burden negatively, the fear of death from COVID-19, the caregiver's fear of the patient's death, the caregiver's fear of dying due to COVID-19, and status of having experienced loss due to COVID-19 had a positive effect on the care burden (Figure 1).

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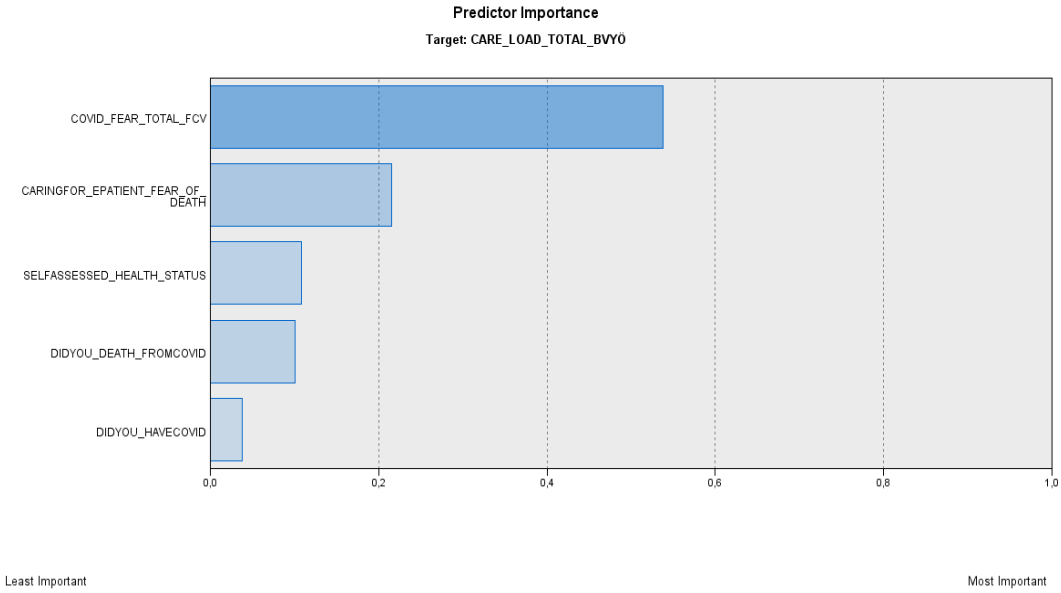

Figure 2. Effect Level of Independent Variables on Care Burden

As seen in the figure, it was determined that the most effective variable on the burden of care was the fear of death from COVID-19, and the least effective variable was the status of having COVID-19 before (Figure 2).

In this study, it was found that 52% of the participants had someone helping for caregiving and 26.3% provided care to their mothers (Table 1). In a study conducted to investigate the experiences of families providing care to COVID-19 patients, it was found that all of the participants provided care to their first-degree relatives such as mothers and fathers. In the same study, the participants stated that social support facilitated the care process (17). In a study of close contacts of COVID-19 patients, the parents of 26.67% of the participants were found to have COVID-19. In the same study, all the participants reported receiving social support from their family and friends (3). Another study found that 58% of the participants reported receiving help from other family members or friends (26). The results of the studies and the present study are similar. The results can be interpreted as the importance of support during the home care experience for COVID-19 patients as well as having experience of care in first-degree relatives, often as a result of living in the same home.

In this study, 48.4% of the caregivers stated that they had had COVID-19 before (Table 1). In a study conducted with individuals who provided care for their relatives with COVID-19 at home in Iran, it was determined that 38.86% of individuals were infected with COVID-19 (16). The findings of this study and that study are almost similar. The small difference can be interpreted as caused by the difference between the time of the studies and the duration of the COVID-19 outbreak. Since the duration of the pandemic was 2 years when this study data was collected, there may have been a higher rate of exposure to COVID-19.

In this study, 42.1% of participants experienced loss due to COVID-19 (Table 1). In the study by Mirhosseini et al. (15), 20.2% of caregivers of COVID-19 patients reported a history of death due to COVID-19 in their family members. The findings of this study and that study are not similar. It can be interpreted that the difference may be due to the socio-demographic (age, chronic disease, etc.) characteristics of the patients receiving care.

In this study, 84.9% of the caregivers stated that they thought they would be infected with the COVID-19 virus while giving home care (Table 1). In the Chen et al study, more than half of the participants reported that they were afraid of being COVID-19 (3). The Chen et al. study results show parallelism with this study.

In this study, 65.5% of the participants reported that they experienced fear of death while caring for their patients (Table 1). A study of fourth-year nursing students caring for patients with COVID-19 in Iran found high levels of death anxiety among the students (21). The sample group characteristics of this study and the given study are different. There has been no study finding that investigated fear of death in caregivers of COVID-19 patients at home.

In this study, the mean FCV-19S score of the individuals was found to be 21.5±9.2 (Table 2). In a study of caregivers in a similar sample group in Iran, the mean FCV-19S score of participants was 20.33±0.43 (16). The findings of this study and the given study are similar. The ZBI mean score of the participants was 37.8±24.6 in this study (Table 2). A study conducted with home caregivers of COVID-19 patients reported that the care burden mean score was 52.70±17.03 at a moderate level (21). Another study found very high levels of caregiver burden among family caregivers of COVID-19 patients (19). The results of this study and that study differ. This difference may be due to the fact that the given study was conducted at the beginning of the pandemic. Factors such as COVID-19 as a novel disease, its cause, and lack of information about treatment and prevention may have increased the care burden.

In this study, it was found that having COVID-19, experiencing loss due to COVID-19, thinking that they will be infected with COVID-19 during care, having fear of death during caregiving, and perceived health status were important predictors for fear of COVID-19 (Table 3). In a study of student nurses, those with COVID-19 disease were found to have significantly higher mean FCV-19S scores than the others (20). Although the sample group of this study and their study is not similar, the obtained findings are similar. A study conducted in Brazil with a different sample group found that fear was positively associated with having a relative diagnosed with or dying from COVID-19 (27). In a study, it was reported that those who were present in quarantine environments and those who were suspected of being infected with the virus had an increased risk of fear of COVID-19 (28). The fact that COVID-19 is a contagious disease may have increased the fear of individuals in settings where the risk of contact with the patient increases. Furthermore, the fact that COVID-19 is a deadly disease can cause fear of death in caregivers. As a result, it can be thought that this situation triggers the fear of COVID-19 in individuals. In a sample in Italy, it was found that participants who rated their perceived health status as poor had the highest levels of fear for themselves and their loved ones (29). This can be interpreted as presence of a correlation between seeing oneself as vulnerable to the virus and fear of contracting the disease.

Care burden is a concept that should be considered in nursing science and by nurses during the care process. In this study, it was found that the caregiver's self-assessment of health had a negative impact on the care burden of the situation (Figure 1). In their study, Ebrahimi et al. (18), determined a significant correlation between the care burden and the health status of caregivers of COVID-19 patients at home. Findings of the given study are similar with findings of the present study.

In this study, it was determined that the fear of death from COVID-19, the caregiver's fear of the patient's death, the caregiver's fear of dying due to COVID-19, and having a loss before due to COVID-19 affected the caregiver's burden positively (Figure 1). The Rahimi et al study, all of the caregivers of COVID-19 patients at home had unpleasant psychological experiences such as fear, anxiety, and sadness (17). Another study conducted in Iran found that caregiver depression and anxiety symptoms significantly predicted the care burden (15). In the present study, especially negative psychological thoughts about death significantly affected the care burden. This result can be thought to be associated with the negative experiences of the caregivers as well as the negative psychological state. As far as we know, there have been no studies investigating the death perceptions and care burden of COVID-19 patients and their caregivers. To this end, it is anticipated that the results of future studies will contribute to the relevant literature.

Study Limitations

This study has a number of limitations. First, because of COVID-19, data were collected using an online questionnaire rather than face-to-face interviews. Secondly, the data were collected according to the self-reports of the caregivers. In this case, if the correct information is not given, it may cause wrong results to be obtained.

CONCLUSION AND SUGGESTIONS

Carers of people with COVID-19 at home may experience anxiety about COVID-19 and the burden of caring for them. In both cases, the caregiving process is negatively affected. It is noteworthy that caregivers of COVID-19 patients play an important role in protecting and promoting the health of patients. Therefore, it is important to provide adequate information and support to those caring for COVID-19 patients, both at an individual and community level. Providing education and counselling to caregivers, especially psychological support, can facilitate the home care of COVID-19 patients.

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