Investigation of the Effects of the Covid-19 Pandemic on **Caregiver Burden in Disabled Nursing Homes**

Engelli Bakımevlerinde Covid-19 Salgınının Bakım Veren Yükü Üzerine Etkilerinin İncelenmesi

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Öz

Ruhsal hastalıklara bağlı engellilik nedeniyle son yıllarda bakımevlerinde yaşayan hasta sayısında artış olduğu bilinmektedir. Ruhsal hastalıklara bakım veren kişilerde bakım veren yükünün yüksek olduğuna dair veriler artmaktadır. Covid-19 pandemi sürecinde bakımevlerinde ruhsal hastalara bakım veren personellerin çalışma şartlarında değişiklikler olmuştur. Bulaş riskini azaltmak amacıyla 14 gün aralık mesai ve karantina uygulaması başlatılmıştır. Rutin çalışma düzenindeki zorlukların yanında pandemi ve pandemiye bağlı düzenlemelerin personelin ruhsal sağlığı üzerindeki etkilerini belirlemek amacıyla bu çalışmayı planladık. Personelin sosyodemografik ve klinik özellikleri belirlemek amacıyla sosyodemografik veri formunu, Covid-19 ile ilişkili anksiyete düzeylerini belirlemek amacıyla Koronavirus Anksiyete Ölçeği'ni, (KAÖ) bakım veren yükünü belirlemek amacıyla Zarit Bakım veren Yükü Ölçeği'ni (ZBYÖ), depresif belirtileri tespit etmek amacıyla Montgomery-Asberg Depresyon Ölçeği'ni (MADRS) kullandık. Katılımcıların KAÖ ortalama puani 2.72±2.91, ZBYÖ ortalama 41.6±10.6, MADRS ortalama puanı 11.55±7.70 olarak saptandı. Hemşirelerde hasta bakıcılara kıyasla daha yüksek MADRS ve ZBYÖ puanları tespit edildi. ZBYÖ puanları ile KAÖ ve MADRS puanları arasında pozitif yönde anlamlı ilişki saptandı (p<0.05). Yapılan çoklu regresyon analiziyle, MADRS puanları ve alınan ücretin yeterli bulunup bulunulmamasının ZBYÖ puanlarını yordadığı saptandı. Çalışmamızda elde ettiğimiz sonuçlar, bakımevi personelinin depresif belirti düzeylerinin pandemi ile ilişkili anksiyete düzeylerine göre daha yüksek olduğunu ve bakım veren yükünün artmasına katkıda bulunduğunu göstermiştir. Personelin depresif belirtiler açısından taranması ve gerekli ruhsal desteğin verilmesi, önemli sunulan hizmet kalitesinin artması acısından görünmektedir.

Anahtar Kelimeler: Bakım Veren Yükü, Bakımevi Personeli, Covid-19

Introduction

Special care centers play a vital role in rehabilitation of disabled individuals in our country. The number of people consulting nursing homes for disability associated with mental illnesses has grown during the previous two decades (1). Individuals, their families, and society experience negative

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Abstract

It is very well documented that the number of patients residing in nursing homes has increased in recent years due to disabilities related with mental diseases. There is mounting evidence of the enormous burden placed on caregivers who care for people suffering from mental illness. Throughout the Covid-19 pandemic, the working conditions of personnel caring for mentally ill patients in nursing homes have deteriorated. Shifts with 14-day intervals and quarantine have been implemented in order to minimize the risk of transmission. We designed this study to ascertain the impact of the pandemic and the associated regulations, as well as the issues encountered in the routine work system, on the mental health of personnel. We used sociodemographic data form to determine the personnel's sociodemographic and clinical characteristics, the Coronavirus Anxiety Scale (CAS) to determine anxiety levels associated with Covid-19, the Zarit Burden Interview (ZBI) to determine caregiver burden, and the Montgomery-Asberg Depression Rating Scale (MADRS) to determine depressive symptoms. The participants' mean CAS score was found to be 2.72±2.91, their mean ZBI score was 41.6±10.6, and their mean MADRS score was 11.55±7.70. Nurses had significantly higher MADRS and ZBI scores than caregivers. There was a positive and significant correlation between ZBI scores, and CAS and MADRS scores (p<0.05). By using multiple regression analysis, it was determined that MADRS scores and the wage received was sufficient or insufficient to predict ZBI scores. The outcomes of our study indicated that the depressive symptom levels of nursing home personnel were higher than the anxiety levels related to the pandemic, and contributed to the increase in caregiver burden. Screening personnel for depression symptoms and providing required psychological support appears to be critical for enhancing service quality.

Keywords: Caregiver Burden, Covid-19, Nursing Homes

repercussions as a consequence of these patients' care needs (2).

Caregivers of schizophrenic patients face a greater caregiver burden compared to caregivers of non-schizophrenic patients or caregivers of their own relatives with chronic medical illnesses (3). It has been reported that male, younger patients diagnosed with severe psychopathology, numerous mental hospitalizations, and a long-lasting disease cause a greater burden on caregivers (4). In a study on family members providing primary care to schizophrenic inpatients, it was established that these family members had a mild to moderate caregiver burden and scored lower on the quality of life scale (5). 47.1% of family members providing primary care were found to have a moderate caregiver burden in this study. Again, the findings of the study on quality of life were found to be lower than studies reported previously (6). According to

reports of some researchers, inpatients with schizophrenia have more complicated needs than those who receive care in an outpatient clinic (5). In a study aimed to investigate caregiver challenges, it was observed that caregiver characteristics such as age, gender, education level, religious belief, ethnic background, and socioeconomic status were determinative (7). Inadequate caregiver knowledge of caregivers regarding the illness of the people they care for causes caregivers to perceive the burden of care as greater than it actually is (8). According to studies conducted on caregivers of patients with chronic conditions; it has been determined that these people have weaker immune systems, increased risk of cardiovascular disease, and hypertension, sleep disturbances, anxiety, and depressive symptoms are more common among them (9). Although several studies have been held in which primary caregivers are family members, there is a limited number of studies on the perceived caregiver burden experienced by caregivers in nursing homes.

It has been reported that Covid-19, which is identified as a pandemic by the World Health Organization (WHO), is an acute respiratory disease with a fatality rate of around 3.2%. It is proven that health workers, particularly those on the front lines, suffer greater psychological distress throughout the pandemic process (10). A research performed during the spread of the first Covid-19 cases in Turkey revealed that health workers who participated in the study had increased levels of anxiety. According to the same study, variables such as female gender, working in the emergency room, living with a family, having children, having a chronic condition in oneself or in a family member, and having a psychiatric disorder prior to the pandemic were associated with negative mental outcomes (11). In a study examining the risk of burnout among physicians fighting the pandemic during the Covid-19 outbreak, it was noted that insomnia and isolation both increase the risk of depression. It has been that a well-organized demonstrated work environment and adequate information about the process are effective in minimizing the pandemic's negative effects on healthcare workers (12). Similarly, a study conducted in China during the Covid-19 process revealed that the incidence of insomnia, anxiety, and obsessive-compulsive disorder in healthcare workers was higher compared to the general population (13). As per a study conducted on the SARS epidemic, doctors with high levels of anxiety take precautions to manage their anxiety, which include isolating themselves (6.6%), sending their families elsewhere (3%), or continuing to use masks in their own homes (4.4%) (14). During pandemics, it is likely that anxiety levels will increase further as a consequence of the disruption of family life caused by quarantine and the decline in social support of health workers.

Although there are studies on the physical and psychological effects of Covid-19 on healthcare workers in literature, there are none on the effect of precautions such as quarantine on nursing home personnel. It is believed that this group's caregiver burden and anxiety about Covid-19 have increased after the pandemic as a result of their job in a risky group, and the 14-day continuous shifts, and 14-day quarantine practices in nursing homes in Turkey. The factors affecting the caregiver burden on nursing home workers during the pandemic will be examined in our study.

Material and Method

Our study was conducted in a total of three disabled nursing homes associated with SBU Erenkoy Mental and Nervous Diseases Training and Research Hospital; Sancaktepe Community Mental Health Mental Health Center, Sultanbeyli State Hospital, Sultanbeyli Community Mental Health Center during February 2021. All personnel at the three nursing homes were informed about the study, and those who volunteered to participate to the study were between the ages of 18 and 65, did not have mental retardation or neurocognitive disorder, and had at least a literacy education. Sociodemographic Data Form, the Zarit Burden Interview, the Coronavirus Anxiety Scale, and the Montgomery Asberg Depression Rating Scale were applied to the personnel included in the study. The data were analyzed using the SPSS v.20 program. Ethics committee approval from SBU Erenköy Mental and Nervous Diseases Training and Research Hospital was received for our study (date/number: 01.02.2021/10). Our study complies with the Declaration of Helsinki (World Medical Association Declaration of Helsinki http:// www.wma.net /en/ publications/ 10policies/ b3/ index.html). The authors declare that they have no conflict of interest.

Socio-demographic and clinical data collection form: This form was designed by the researchers in order to ascertain participants' sociodemographic and clinical features such as age, gender, marital status, education level, occupation, wage, opinion of the sufficiency of wage they receive, Covid-19 infection history, family history of Covid-19 infection, difficulties related to quarantine, job satisfaction, past psychiatric disease and family history of psychiatric disease.

Coronavirus Anxiety Scale (CAS): The CAS, which is developed by Lee is used as a brief mental health screening to identify cases of dysfunctional anxiety associated with Covid-19 (15). It was translated into Turkish by Evren et al. (16). The CAS was rated for each item on a 5-point scale from 0 (never) to 4 (almost every day) based on experience in the past two weeks. A CAS total score ≥ 9 indicates coronavirus-related dysfunctional anxiety.

Zarit Burden Interview (ZBI): ZBI was developed in 1980 and is a scale used to evaluate the difficulty experienced by caregivers of individuals with care needs (17). The Turkish validity and reliability study of the scale was carried out by Özlu et al. (18). In the Turkish validity and reliability study of the scale used for caregivers of patients with schizophrenia, 3 items were removed from original version which consisted of 22 items, resulting in a Turkish version of 19 items. It assigns a five-point Likert scale (1: never, 2: rarely, 3: sometimes, 4: often, 5: almost always). The scale's total score is calculated as the arithmetic sum of the scores for each item. The scale lacks a cut-off point and is thus suggested for use in comparative studies. The minimum score that can be obtained from the scale is 19 points and the maximum score is 95 points. A high score on the scale indicates a high level of distress. The Cronbach's alpha coefficient for the internal consistency reliability of the Turkish version was found to be 0.83.

Montgomery-Asberg Depression Rating Scale (MADRS): The scale was developed by Montgomery and Åsberg in 1979 (19). It is a tenitem scale that is scored by the interviewer. Each item is scored on a scale of 0 to 6, with 0 being the lowest and 6 the highest. In the sensitivity and specificity study of the Turkish version, cut-off points for mild, moderate, and significant depression were found to be $9\pm$, $29\pm$, and $36\pm$, respectively. It has been suggested that for defining improvement (remission) in treatment studies, the MADRS score should be less than 10. The Turkish validity and reliability of the scale was performed by Özer et al. in 2001 (20).

Statistical analyzes will be performed using SPSS version 20 software. The Kolmogorov-Smirnov and Shapiro-Wilk tests were used to determine whether or not the variables were normally distributed. Numerical variables were presented as mean±standard deviation. Categorical variables were presented with n (%) values. Pearson correlation analysis was used to determine the relationship between normally distributed numerical variables, and Spearman correlation analysis was used if at least one of the variables did not fit the normal distribution. Linear regression analysis was performed by developing a model with independent variables expected to effect ZBI scores. The total type-1 error level will be set to 5% for statistical significance.

Results

Our study consisted 40 individuals throughout the 14-day quarantine period, including 9 nurses and 31 patient caregivers. A research psychiatrist filled in sociodemographic data and scales in with face-toface interviews. The mean age of the participants was 36.7 ± 11.1 , and 9 (22.5%) were male and 31 (77.5%) were female. While 22 (55%) individuals are married, 20 (50%) are primary school graduates. The sociodemographic characteristics of the participants are summarized in Table 1.

 Table 1.
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		n (%)
Gender	Woman	31 (77.5%)
	Man	9 (22.5%)
Marital status	Single	14 (55%)
	Married	22 (35%)
	Divorced	4 (10%)
Occupation	Nurse	9 (22.5%)
	Caregiver	31 (77.5%)
Years of work	<1 Year	11 (27.5%)
	1-5 Years	14 (35%)
	6-10 Years	12 (30%)
	>10 Years	3 (7.5%)

39 (97.5%) of the participants stated that they were satisfied with their work, 22 (55%) felt exhausted, 27 (67.5%) stated that their wages were not sufficient. 33 (82.5%) of the participants stated that the number of patients being cared for remained constant during the pandemic, 23 (57.5%) stated that working conditions got tough due to quarantine, and 12 (30%) had Covid-19 infection. The variables related to the pandemic and working conditions are summarized in Table 2.

Table 2. Opinions of the participants about the working conditions

		n (%)
Change in the	Increased	5 (12.5%)
number of patients		
	Decreased	2 (5%)
	Has not	33 (82.5%)
	changed	
Satisfaction	Yes	39 (97.5%)
	No	1 (2.5%)
Exhaustion	Yes	22 (55%)
	No	18 (45%)
Wage sufficiency	Yes	13 (32.5%)
	No	27 (67.5%)
Effect of	More difficult	23 (57.5%)
quarantine		
	Easier/Same	17 (42.5%)
Covid-19	Yes	12 (30%)
infection		
	No	28 (70%)
Stigmatization	Yes	9 (22.5%)
	No/Sometimes	31 (77.5%)

The mean CAS score of participants was 2.72 ± 2.91 , ZBI mean score as 41.6 ± 10.6 , and MADRS mean score as 11.55 ± 7.7 . As a result of the

comparative analyzes for ZBI, no significant difference was found between the genders. ZBI scores were found to be significantly higher in personnel who did not find their wages sufficient (p=0.029) and those with undergraduate education (p=0.002). In the analysis made according to the occupations of the participants, it was determined that the nurses had higher MADRS (p=0.026), ZBI (p=0.002) scores and were responsible for more patients (p<0.001) compared to the caregivers.

In the correlation analysis that were performed, revealed that ZBI scores were positively correlated with CAS (r=0.342 p=0.031) and MADRS (r=0.631, p<0.001) scores. Correlations between ZBI and other scales are summarized in Table-3.

 Table 3. Relationship between scale scores

		CAS	MADRS
	r	.342	.631
ZBI	р	.031	<.001
	n	40	40

ZBI: Zarit burden interview, CAS: Coronavirus anxiety scale, MADRS: Montgomey-Asberg depression rating scale, Spearman correlation analysis was performed

The ZBI score was used as the dependent variable in the multiple linear regression analysis, whereas the MADRS and CAS scores, whether the wage was found sufficient, the history of Covid-19 infection, and occupations were used as independent variables. Our model explains 48.7% of the total variance in ZBI (R2=0.487, p<0.001). The data didn't show multicollinearity (variance inflation factors-VIFs < 2 and tolerance values > 0.5 for all independent variables). Among the independent variables, it was determined that MADRS scale scores (p=0.003) and whether the wage was deemed sufficient (p=0.009) predicted ZBI scores; while CAS scores, Covid-19 infection history and occupation did not predict ZBI scores. The results of linear regression analysis are summarized in Table 4.

Discussion

Nursing home personnel who provide service for chronic mental patients bear a greater mental burden as a result of the pandemic and pandemic related regulations. Along with the difficulties inherent in providing care to chronic mental patients, the changes made in working arrangements due to the pandemic have greatly affected everyday lives of the caregivers. By reason of the 14-day quarantine application, the staff is required to stay away from their homes during this period.

The aim of this study was to determine the caregiver burden and anxiety levels associated with depression and Covid-19 among nursing home personnel caring for chronic mental patients during the pandemic process. Additionally, we investigated clinical and sociodemographic characteristics that may affect caregiver burden.

We did not observe any statistically significant difference in caregiver burden levels between the genders. Gender is a factor that may affect the caregiver burden. While there are studies reporting that the burden of caregivers is higher in women (21), some others, like ours, found no difference between genders (22). Some studies that determined that female personnel face a higher caregiver burden noted that women are disadvantageous in comparison to males in terms of responsibilities outside of work; and women who struggle to meet their own needs carry a greater caregiver burden. Moreover, studies examining caregiver burden in the literature have primarily focused on first-degree family members. It is established that women's responsibilities other than caregiving in the family environment have an effect on caregiver burden (23). The fact that male and female caregivers cared for the same patient group and shared similar responsibilities within the institution may have led to our study's finding that perceived caregiver burden was close.

				95% CI			
	Uβ	SE	β	t	LB	UB	р
Constant	34.159	2.415		14.144	29.25	39.06	<.001
CAS	.378	.447	.104	.846	53	1.28	.404
MADRS	.626	.192	.454	3.257	.253	1.016	.003
Wage	-8.363	3.012	374	-2.777	-14.48	-2.242	.009
Covid-19 inf	2.468	3.221	.108	.766	-4.077	9.013	.449
Occupation	5.161	3.291	.206	1.568	-1.526	11.84	.126

Table 4. Multiple regression analysis with ZBI and independent variables

Uβ: Unstandardized Beta; SE: Standard Error; β: Standardized Beta Coefficient; CI: Confidence Interval, LB: Lower Bound; UB: Upper Bound

The ZBI, CAS, and MADRS scale scores did not differ between groups based on the individuals' marital status. This result is consistent with the findings of a recently published study involving 202 participants (22). While age was found to be effective on caregiver burden in that same study, we did not observe a relationship between age and caregiver burden in our study. When we assessed caregivers separately according to their occupations, we discovered that nurses had a higher caregiver burden and depressive symptoms than caregivers. Being responsible for more patients in nursing homes has been identified as a factor that increases the caregiver burden (21). Likewise, the fact that the number of patients for whom the nurses in our study were responsible was significantly higher and that they had more responsibilities due to the institution's lack of an active physician were thought to be effective in producing these results.

The mean CAS score determined in our study was quite below the cut-off point of 9. In a study conducted with 1249 physicians during the first months of the pandemic in our country, it was determined that the participants had elevated levels of anxiety and that approximately half of them reported being psychologically impacted negatively. Additionally, that study underscored the connection between a lack of knowledge about the pandemic and adverse mental outcomes (11). A recent prospective study revealed that depression, anxiety, and stress symptoms among health care workers decreased during the pandemic, indicating psychological adaptation (24). Similarly, in our study, which was conducted in a relatively late stage of the pandemic, it was thought that participants had developed positive adaptive abilities against uncertainty, therefore resulting in a decrease in anxiety levels.

We identified considerably higher levels of depression and caregiver burden compared to anxiety in relation to Covid-19. Several studies have been published on the increase in depression and anxiety symptoms amongst healthcare workers during the pandemic (25). It is known that concerns about infecting their relatives of the health workers working especially on the front lines have increased, as a result, they avoid contact with their relatives, resulting with higher exposure to social isolation and stigma (26). In our study, we determined that the mean MADRS score was above the mild depression cut-off point. The deterioration of working conditions as a result of the pandemic may have contributed to the participants' depressive symptoms, with 55% of them describing burnout.

The linear regression analysis determined the parameters affecting caregiver burden as MADRS scale scores and whether or not the wage was deemed adequate; while quarantine, age, history of Covid-19 infection, and CAS scores were found to have no significant effect on caregiver burden. We detected that depressive symptoms were a strong predictor of caregiver burden than the pandemic or pandemic-related regulations. As a result, it is important to screen the personnel for depressive symptoms and to provide the required psychological and social support.

Both ZBI and MADRS scores were associated with history of a psychiatric disease, and an increase in the number of patients receiving care was associated with ZBI scale scores. Having been diagnosed with an anxiety disorder or depression in the past is a critical determinant of psychopathology (27). Therefore, personnel who have undergone psychiatric treatment in the past are at a higher risk in terms of mental health.

Our study has some limitations. Due to the crosssectional pattern, establishing a cause-effect relationship is challenging. Additionally, it was not possible to assess the individuals' psychological health before the pandemic. Another limitation is the low participant number.

In conclusion, the results of our study are relevant in terms of demonstrating the negative psychological effects of the pandemic and the regulations made in the working conditions as a result of the pandemic, as well as highlighting the difficulties that are not related to the pandemic. Nurses taking on excessive responsibility and caring for a large number of patients, in particular, experience negative psychological consequences. Most of the participants find the amount of wages they receive insufficient. We believe that arrangements to be made in the working conditions of the caregivers will also improve the quality of health care provided. The high caregiver burden and depressive symptoms suggested the importance of providing regular psychological assistance to the personnel.

Ethics Committee Approval: Ethics committee approval from SBU Erenköy Mental and Nervous Diseases Training and Research Hospital was received for our study (date/number: 01.02.2021/10).

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