Relationships between Burden of Care and Mental Health of Family Members of Hospitalized Patients with COVID-19

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Abstract

Background: Hospitalization of coronavirus disease 2019 (COVID-19) patients can lead to a burden of care and cause health problems for the family members of the patients. This study aimed to investigate the relationship between the burden of care and the mental health of family members of hospitalized patients with COVID-19.

Methods: This cross-sectional correlation study was conducted from November 2021 to February 2022. The study population consisted of 84 family members of COVID-19 patients who were hospitalized in Shariati Hospital affiliated with the Tehran University of Medical Sciences. The subjects were selected via consecutive sampling. Data collection was done using a demographic information form, the Depression Anxiety Stress Scales-21, the Zarit Burden Interview, and the 12-item General Health Questionnaire. Data were analyzed using SPSS 16 and at a significance level of 0.05.

Results: More than half of the participants (51.22%) experienced a mild to moderate level of care burden, while 17.07% of them experienced a moderate to severe level of care burden. The mean score of mental health in the participants was 16.92±1.95. By adjusting the demographic variables and the Depression Anxiety Stress Scales-21, the level of stress of family members led to more burden of care (coefficient beta= 0.608, 95% confidence interval= 0.451-1.556, P=0.001).

Conclusion: Paying attention to the issue of stress in the family members of hospitalized patients with COVID-19 and supporting these individuals can help to provide better care to the patients and reduce health challenges.

Highlights:

What is current knowledge?
The world is dealing with COVID-19. Family caregivers of patients are exposed to psychological distress and care burden.

What is new here?
Family members of patients with COVID-19 experience stress as well as the burden of care. Measures should be taken to reduce stress and care burden in COVID-19 patients' family caregivers.

Introduction

Throughout history, humans have faced pandemics and epidemics of infectious diseases, including coronavirus disease 2019 (COVID-19). The first case of COVID-19 in Iran was detected and confirmed in February 2018. Since then, the disease quickly spread all over the country (1). In the mild form of COVID-19, patients are usually cared for at home, but in the moderate form, patients may require hospitalization. In severe and critical forms, patients may need respiratory support, intubation, and mechanical ventilation (2, 3).

The pandemic, the high number of hospital visits, and the following admissions create many challenges for medical centers and people who care for these patients. People involved in the care of COVID-19 patients can include healthcare workers, family members, or informal caregivers (4). The family members of patients with COVID-19 are at the forefront of care delivery to these patients. Multiple responsibilities, ambiguity and concern over the patient's condition, fear of the patient's death, the need to wear personal protective equipment, observing social distancing, and emotional support of the patient put the burden of care on family members (4). The burden of care is a general term that describes the psychological, physical, social, and financial burden of care that caregivers must endure (5). In addition, caregivers themselves are exposed to the coronavirus, which threatens their health (6) and further increases the burden of care.

The negative effects of the burden of care on patients' family members can manifest as anxiety, depression (7, 8), emotional and psychological distress, activity restrictions, reduced physical health, financial problems, and ambiguity towards the patient's condition (9). After the COVID-19 outbreak, studies began to investigate the burden of care of patient's family members. For example, a study conducted in Italy showed that families of hospitalized patients experience psychological distress, anxiety, and stress (10). In America, families of COVID-19 patients hospitalized in the intensive care units (ICUs) experienced stress and uncertainty (11). In Iran, a study investigated the burden of care in family members of COVID-19 patients after hospital discharge and found that family members endured a moderate to severe burden of care (12, 13). However, it is necessary to conduct more studies on this field in different societies, because the burden of care can be affected by the financial, social, psychological and physical status of caregivers during the provision of care, as well as the limited access to health and support services (14).

The spread of infectious diseases such as COVID-19 creates psychological distress such as fear, anxiety, depression, and nervousness at the individual, national, and global levels (15, 16). Although psychological distress can be seen in all members of society, families of those affected by COVID-19 can experience a higher level of psychological distress (17). Considering the importance of maintaining the physical and psychological well-being of caregivers and the need to pay attention to various aspects of COVID-19, this study was conducted to determine the relationship between the burden of care and the mental health of family members of hospitalized patients with COVID-19.

Methods

This study is a cross-sectional correlational study that was conducted in three months from November 2021 to February 2022.

The participants included 84 family members of COVID-19 patients hospitalized in Shariati hospital affiliated to Tehran University of medical sciences. Inclusion criteria were; being a family member of patient with COVID-19 who has definitive diagnosis of COVID-19 by the attending physician, being 18 years old and older, being first-degree relative of patient who remains hospitalized during the study, such as patient's father, patient's mother, patient's child, patient's sister, brother or spouse, and completing the questionnaire in full.

Also, family members who had a history of mental illnesses and medication use for mental problems (through self-deceleration), and were taking care of several patients in the family at the same time, or were taking care of other patients with diseases such as diabetes, dementia or other chronic diseases were not included in the study.

No study was found that investigated the burden of care and mental health in the family of patients with infectious diseases, but according to other studies conducted on chronic diseases (18), the sample size was estimated to be 82 participants according to 90% power, a=0.05, r= 0.347, and the following formula: N = [(Zα+Zβ)/C]2 + 3. To carry out the sampling, first, the list of patients with COVID-19 admitted to the hospital, including medical-surgical wards, emergency department and ICUs obtained from the nursing office and then, consecutive sampling was done.

After receiving approval from the Ethics Committee of Tehran University of Medical Sciences, and obtaining permission from the directorate of Shariati Hospital, the researcher began the sampling process. Data collection in this study was done by a demographic information form (which included family members and patient's clinical information), depression anxiety stress scales—21 (DASS-21), 22-Item Zarit Burden Interview (ZBI-22), and 12-items general health questionnaire (GHQ-12).

Demographic information form of patients was collected from their hospital documentation by one of authors (F.M), and information of family members was collected by giving them questionnaires (by F.M) to complete through the self-report method in a private room in the hospital. The necessary principles to prevent COVID-19 transmission were considered in this room.

The demographic and clinical information of the patients included age, gender, ward hospitalization, oxygen usage, severity of the disease according to physician diagnosis (moderate or severe), and length of hospital stay. Demographic information of family members also included age, gender, marital status, education level, occupation, number of children, number of hours caring for patients per day, relationship with patient, comorbidity and economic status by self-reporting. Considering the impact of situation on the participants' anxiety, stress and depression, these variables were measured by DASS-21 scale. This scale has 21 questions, which are answered based on 4-option Likert scale that ranges from 0 (it does not apply to me at all) to 3 (it completely applies to me). In this tool, questions 3, 5, 10, 13, 16, 17 and 21 are related to depression, questions 2, 4, 7, 9, 15, 19 and 20 are related to anxiety and questions 18, 14, 12, 11, 8, 6, 1 are related to stress (19) . The score of each subscale is multiplied by 2, and higher scores indicate more frequent symptoms. The reliability of this tool has been reported in various studies. In Iran, this tool has been psychometrically evaluated and acceptable reliability has been reported for it (20, 21).

The care burden of participants was determined by the 22-item questionnaire of Zerit et al. (1998). ZBI-22 has 22 questions related to personal, emotional, social, and economic pressures. Each item is scored on a 5-option Likert scale, ranging between 0 (never), 1 (rarely), 2 (sometimes), 3 (often), and 4 (almost always). The total score of this scale ranges from 0 to 88, so that score of 0-20 reflects no to mild burden, score of 21-40 indicates mild to moderate burden, score of 41 to 60 reflects moderate to severe burden, and score of 61-88 indicates a severe burden (22). This questionnaire has already been used in Iran with acceptable reliability (23).

The general health of the participants in this study was measured by GHQ-12, which was developed by Goldberg in the 1970s to measure mental health/mental distress. GHQ-12 has been used in different societies and cultures.(24)In GHQ-12, factors such as ability to concentrate, insomnia, sense of usefulness, ability to make decisions, sense of mental pressure, inability to overcome difficulties, enjoying daily activities, ability to face problems, feeling sad and depressed, loss of self-confidence, feeling unvalued, and sense of rational happiness were measured. Six items in this questionnaire are positive (items 2, 3, 4, 6, 10, 12) and the other 6 items are negative (questions 1, 5, 7, 8, 9, 11). Each item has four answers from 0 to 3. Negative answers range between not at all (score 0), rarely (score 1), usually (score 2), and more than usual (score 3), while positive items are scored in the opposite way. To determine the total score, which ranges from 0 to 36, scores are added together, and higher score indicates worse mental health. This tool has been translated into Farsi and its validity and reliability have been measured and reported as acceptable (25).

In order to determine the validity, the Persian questionnaires were given to 10 nursing faculty members, and after their approval, their reliability was checked. Fore reliability of DASS-21, ZBI-22 and GHQ-12, they were completed by 20 family members and their reliability was calculated by Cronbach's alpha method, which was 71%, 82% and 75% for DASS-21, ZBI-22 and GHQ-12, respectively.

The collected data were analyzed by SPSS-16 software. Qualitative and quantitative variables were summarized and reported by frequency (percentage), and mean ± standard deviation, respectively. Considering the normality of the data, correlation analysis, t-test and chi-square were used to evaluate any relationship between the variables (demographic variables and DASS-21). The relationship between each of demographic variables and DASS-21, and the independent variables was assessed by logistic regression after controlling other variables in the model. The significance level of 0.05 was considered for all tests.

Results

The results showed that the average age of patients in this study was 61.73±17.375 years, and majority of them (51.2%) were male. Majority of patients (75.6%) were hospitalized in the general wards of the hospital. Also, 62.2% of the hospitalized patients had moderate disease according to physician's diagnosis. The mean number of days of hospitalization among patients with COVID-19 was 12.18±7.695 days. The mean age of family members was 42.80±11.11 years, and most of them were female (65.9%) and married (73.2%). On average, family members were spending 10.21±5.792 hours caring for patients with COVID-19 (Table 1).

Table 1: Demographic and clinical characteristics of patients and family members

Variables		Number (%) / M ± Sd/Min-Max	
		Patients	Family Member
Age (years)		61.73±17.37/18-82	42.80±11.11/20-81
Length of hospital stay (days)		12.18±7.69/4-40	
Gender	Male	42(51.2)	28(34.1)
	Female	40(48.8)	54(65.9)
Admitted ward	General & Emergency	62(75.6)	
	ICU	20(24.4)	
Marital status	Single	-	22(26.8)
	Married	-	60(73.2)
Education Level	Below diploma	-	14(17.1)
	High school diploma	-	34(41.5)
	University degree	-	34(41.5)
Occupation	Office worker	-	21(25.6)
	Homemaker/unemployed	-	39(47.6)
	Self-employed	-	22(26.8)
Oxygen usage	O₂ with nasal mask	35(42.7)	-
	O₂ with mask	22(26.8)	-
	Non-invasive ventilation	19(23.2)	-
	Ventilator	6(7.3)	-
Severity of the disease	Moderate	51(62.2)	
	Severe	31(37.8)	
Number of children	0	-	26(31.7)
	1	-	16(19.5)
	2	-	26(31.7)
	3	-	11(13.4)
	4	-	3(3.7)
Duration of care for patient per day (hours)			10.21±5.792
Relationship with patient	Parent		42(51.2)
	Spouse		21(25.6)
	Brother/sister		9(11)
	Children		10(12.2)
Comorbidity	Yes		16(19.5)
	No		66(80.5)
Economic status	Poor		7(8.5)
	Moderate		65(79.3)
	Good		10(12.2)

Table 2 shows that, the mean score of depression, anxiety and stress in the family members of patients with COVID-19 was 16.76±7.04, 17.33±7.56, and 20.92±8.76, respectively. The mean score of care burden for family members of COVID-19 patients was 30.98±14.61, which showed moderate level of care burden in the participants. More than half of the participants (%51.22) experienced mild to moderate level of care burden and 17.07% of them experienced moderate to severe level of care burden. The mean score of mental health in the participants was 16.92±1.95.

Table 2: The mean score of depression, anxiety, stress, burden of care, and mental health of the family members

Variables	Number (%) / M±Sd
Depression	16.76±7.04
Anxiety	17.33±7.56
Stress	20.92±8.76
Burden of care	30.98±14.61
No to mild burden	22(26.83)
Mild to moderate burden	42(51.22)
Moderate to severe burden	14(17.07)
Severe burden	4(4.88)
Mental health	16.92±1.95

Except for gender, there was no significant relationship between any of the demographic variables, clinical condition of patients, and mental health of family members. It means that mental health in female was significantly lower than male. But there was a negative and significant relationship between stress (P = 0.003), anxiety (P = 0.022) and depression (P = 0.009) of the family member, and their mental health. Also, there was a positive and significant relationship between care burden and stress (P < 0.001), anxiety (P < 0.001) and depression (P < 0.001) of family members. The results also showed that, the burden of care was significantly higher in participants with low income (Table 3).

Table 3: The difference between total burden of care, mental health, and demographic and clinical characteristics of the participants

Variables		Burden of care		Mental health	
		Mean ± SD/ Pearson[†]	P value	Mean ± SD/ Pearson[†]	P value
Patient's age (years)[†]		0.037	0.741	0.078	0.489
Family member's age (years)[†]		0.095	0.403	0.169	0.137
Length of hospital stay[†] (days)		-0.033	0.772	0.064	0.572
Duration of daily care for patients (hours)[†]		0.206	0.067	0.015	0.898
Patient's gender[†]	Female	31.076±13.995	0.891	16.538±1.744	0.015
	Male	31.540±15.473		17.594±1.935	
Family member's gender[†]	Female	32.056±15.731	0.363	16.886±1.947	0.808
	Male	28.888±12.138		17±2	
Marital status[†]	Single/divorced/widow	28.772±12.297	0.407	17.136±1,698	0.555
	Married	31.827±15.420		16.844±2.050	
Admitted ward[†]	General	30.916±14.931	0.941	16.933±1.885	0.948
	ICU	31.20±13.998		16.9±2.198	
Economic status[‡]	Poor	45.142±18.951	0.025	17.428±3.047	0.508
	Moderate	29.593±13.384		16.796±1.861	
	Good	29.888±15.414		17.444±1.666	
Education level[‡]	Under diploma	36.142±14.40	0.289	16.857±2.107	0.811
	High school diploma	31.062±15.710		16.781±2.059	
	University degree	28.794±13.479		17.088±1.831	
Occupation[‡]	Office worker	29.35±14.083	0.790	16.85±1.598	0.703
	Homemaker	31±15.315		17.102±2.036	
	Self-employed	32.523±14.306		16.666±2.152	
Relationship with patient[‡]	Parents	33.024±14.887	0.534	17.243±2.009	0.234
	Sister or brother	25.875±13.010		15.875±2.356	
	Spouse	30.381±14.012		16.571±1.832	
	child	28±16.418		17.20±1.398	
Depression[†]		0.607	<0.001	-0.298	0.009
Anxiety[†]		0.456	<0.001	-0.258	0.022
Stress[†]		0.681	<0.001	-0.333	0.003

SD: standard deviation.
† Pearson correlation; ‡Independent sample t-test
‡ANOVA.

By adjusting non-dependent variables (demographic variables and depression anxiety stress scales-21), there was only a significant relationship between the stress of family members and their care burden (P=0.001). This means that with an increase of one score in the level of stress, the score of care burden of family members increased by 0.608 (95% confidence interval= 0.451-1.556) (Table 4).

Table 4: The results of multivariate logistic regression analysis regarding the relationship between mental health, care burden, and demographic characteristics of family members

Independent variables	Coefficient Beta	P-value	95% CI
Mental Health	0.092	0.355	-0.807 – 2.212
Stress	0.608	0.001	0.451-1.556
Anxiety	-0.094	0.516	-0.716-0.364
Depression	0.165	0.299	-0.309-0.985
Economic status	-0.151	0.131	-21.526-2.863
Family member's gender	-0.048	0.637	-7.939-4.902

CI: confidence interval

Discussion

Results of present study showed that the mean score of burden of care in the family members of patients with COVID-19 was 30.987 ± 14.617. Half of the participants experienced mild to moderate level of care burden. Family members with lower income reported higher level of burden of care. Also, there was a significant relationship between stress, anxiety, depression and burden of care, which is consistent with the results of other studies. The results of a study aimed at investigating the care burden of adults caring for elderly people during the COVID-19 pandemic showed that 82% of caregivers had experienced mild to moderate level of care burden (26). Results of studies conducted in Iran on the care burden of family caregivers of patients with COVID-19 discharged from hospital also showed of burden of care in caregivers (12, 27). Studies have shown that caregivers of COVID-19 patients with lower income experience more negative consequences than other caregivers (14). Studies conducted on depression and anxiety of family members of COVID-19 patients have also shown that, they experience high level of anxiety and worries about the pandemic (28), which can increase their burden of care. Also, studies conducted on the caregivers of patients with other diseases show that subjective care burden are associated with anxiety and depression (29, 30) .

In this study, the mean score of mental health in COVID-19 patients was 16.92±1.95, which is in the moderate range. The results also showed a positive and significant relationship between stress, anxiety and depression of family member and GHQ-12. Various studies have pointed to the mental health problem of society, and especially families, during the COVID-19 pandemic. Although mental distress and mental health disorders during COVID-19 pandemic have been reported in the entire society (31, 32). But, a study conducted in Japan

showed that family members of COVID-19 patient experience a higher level of mental distress in comparison with family members of patients with other diseases(17) . Other studies have also shown that family members of patients with COVID-19 experience more mental health problems (33). A study in United States conducted on the family members of COVID-19 patients found more negative outcomes such as anxiety, depression, fatigue, sleep disturbance, comparing to people who did not provide care (14). Mental distresses have also been reported in nurses (34) and physicians (35), and this issue reveals the relationship between close contact with COVID-19 patients and mental health.

The results also showed that by adjusting the independent variables, a significant relationship could be found between stress and burden of care. The effect of mental distress and stress on burden of care has been mentioned in many studies. For example, in a study conducted in 2022 with the aim of determining the relationship between burden of care and psychological distress among 163 caregivers of patients with chronic disease, the results showed a relationship between care burden and psychological distress (36). In a study conducted in Iran, a positive and significant relationship was found between the perceived stress and burden of caring in the family members of COVID-19 patients (37) . In a study in Argentina, 46% of caregivers reported depression, 68% reported care burden and 71% reported anxiety (38) . The results of a systematic review and meta-analysis regarding the subjective burden of care and anxiety of informal caregivers showed that, subjective burden of care was one of the important risk factors of caregivers' anxiety (30).

Based on the results of present study and considering that the world is still dealing with the COVID-19 pandemic, it is necessary for medical centers to consider the caregivers of COVID -19 patients as an impact group and a priority, and apply evidence-based solutions to provide support for them and reduce their psychological distress and burden of care. In future, other studies can be conducted in order to investigate various interventions in reducing the care burden and stress and increasing mental health of family members of those infected with COVID-19. This study was conducted during the crisis of COVID-19, when the infection rate was high, and this itself could affect the stress and mental health of family members. Vaccination and effective treatment can reduce the stress of family members and the burden of care; so repeating this study in the future can clarify this issue.

This study is important because of the attention paid to the family members of patients with COVID-19 during hospitalization; but study was conducted in only one hospital. It is recommended to conduct sampling from different hospitals with random sampling in future studies.

Conclusion

The results of present study showed that more than half of the family members of COVID-19 patients had experienced a moderate level of burden of care. By adjusting the variables, a significant relationship could be found between caregivers' stress and their care burden. Therefore, paying attention to the issue of stress in the family members of patients with COVID-19 in medical centers and supporting them can help to provide better care to patients and reduce the health challenges and burden of care in families of these patients, especially when new variants of coronavirus are still emerging. Implementing strategies to reduce the stress of family members of COVID-19 patients is one of the measures that can be considered in hospitals.

Ethical statement

This study is the result of a registered research project (1400-2-160-52916) approved by the research ethics committees of the schools of nursing & midwifery and rehabilitation - Tehran University of Medical Sciences (IR.TUMS.FNM.REC.1400.131) in 2021. Informed consent obtained from all participants.

Conflict of interest

The authors declare that there is no conflict of interest.

Author contributions

Leila Sayadi: designing the study, conceived and designed the analysis, wrote the paper Faranak Masoumi Fard: Collected the data, contributed data, wrote the paper.

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