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## RESEARCH ARTICLE

### Evaluation of Family Caregiver Burden among COVID-19 Patients

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#### Abstract:

#### Background:

Coronaviruses are a large group of viruses from the Coronaviridae family. Not only do the coronaviruses disrupt patients' lives, but they also affect caregivers. This study aimed to assess the burden of family caregivers of COVID-19 patients discharged from a hospital in eastern Iran.

#### Materials and Methods:

A descriptive cross-sectional study was conducted with 210 family caregivers of COVID-19 inpatients and outpatients. A total of 210 COVID-19 patients referred to 22nd-Bahman Hospital of Khaf from March 2020 to June 2020 were selected via simple randomization. Data were collected using the Zarit caregiver burden scale and a demographics form.

#### Results:

The care burden scores were 83.2% and 80.9% in the family caregivers of inpatients and outpatients, respectively, indicating the severity of care burden for COVID-19 patients. The mean scores of objective, subjective, and subjective-objective caregiver burden were significantly higher in male family caregivers and caregivers of inpatients than in female caregivers and caregivers of outpatients [ $p < 0.01$ ].

#### Conclusion:

The high objective, subjective, and subjective-objective caregiver burden in family caregivers is an alarm for mental health policy-makers. Therefore, healthcare managers need to consider plans and measures to reduce the care burden of family caregivers of COVID-19 patients.

**Keywords:** Care burden, Family caregivers, Patient, COVID-19, Health care, Policy makers.

#### Article History

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## 1. INTRODUCTION

Coronaviruses constitute many viruses from the Coronaviridae family and include the common cold virus to more serious diseases such as SARS, MERS, and COVID-19. Coronaviruses were discovered in 1965 and have continued to be studied until the mid-1980s. The virus exists naturally in mammals and birds, yet seven human-transmitted coronaviruses have been identified so far [1]. The latest species, COVID-19, became widespread in December 2019 in Wuhan, China. The first case of the virus in Iran was reported in early March 2020 and has, ever since, affected all the provi-

-nces and cities. The World Health Organization has recently declared the disease a pandemic. All countries are taking similar measures to combat the disease, depending on the political, sociocultural, and healthcare system and the economic conditions of the respective country. With many possibly unknown dimensions, the disease has shocked families, socioeconomic agencies, and large economies of the world. Hence, all nations must cooperate with their governments to overcome the damage caused by the disease in the shortest possible time and with the lower number of casualties [2].

The sudden onset of the disease can have profound effects on one's mental health. The more widespread the prevalence of the disease, the more substantial its impacts on society. The

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spread of an epidemic causes fear, and the fear may continue even after the disease has been eradicated. Improper control of a coronavirus may result in high prevalence, large-scale hospitalization, and poor quality of life of the affected individuals. A coronavirus disease and its complications impose economic burdens and reduce the psychological wellbeing of individuals. The disease can disrupt the patient's social and familial relationships. Not only it disrupts the lives of patients but it also affects the caregivers [3].

Caregivers are individuals who are most involved in a patient's care provision and his/her adaptation and disease control during the course of an illness and its treatment. Studies indicate that caregivers' quality of life is affected during the treatment course of a patient. When a person is inflicted with the COVID-19, his/her family members, spouse, friends, and colleagues are also affected. Fear of the disease and its impacts, feelings of helplessness, ambiguity about the future, anxiety, sadness, anger, grieving reactions, economic worries, psychological stress in interpersonal relationships, and fear of death are among the major psychosocial stresses during COVID-19. The process of transferring care provision from the hospital setting to home imposes a care burden to the family [4]. A patient's care has an objective dimension and a subjective dimension: Objective care can be considered in terms of the time and finance devoted to caring, including financial, familial, and social expenses. Subjective care burden denotes the caregiver perception of the care burden, which includes mental, emotional, and behavioral problems caused by the disease.

Since around 20 years ago, new indicators called the *burden of disease* indicators were introduced to address the three issues of mortality, morbidity, and quality of life [5]. A disease burden is an indicator that includes the most important causes of disability and death. Therefore, it is a highly valuable indicator of operational and interventional planning. The disease burden provides the most important and objective part of needs-assessment and evidence-based policy-making [6]. This study aimed to evaluate the care burden of family caregivers of COVID-19 patients discharged from 22nd-Bahman Hospital in the city of Khaf, eastern Iran.

## 2.. METHODOLOGY

### 2.1. Materials and Methods

This is a descriptive cross-sectional study, which was conducted from March 2020 to June 2020. Given that the number of individuals in the population (patients) during this period was known and the total number of inpatients and outpatients amounted to 465, the Cochran's formula was used to estimate the sample size as  $n = 210$ . This calculation was made with an error rate of 5%. The main formula for calculating the sample size is as follows:

A total of 210 family caregivers of COVID-19 inpatients and outpatients discharged from the 22nd-Bahman Hospital of Khaf city, Iran, were selected by simple randomization. Inclusion criteria comprised a lack of mental problems in primary caregivers, the ability to read and write, a minimum age of 18 years, and a willingness to participate in the study.

At first, the purpose of the study was explained to the caregivers of the patients. Subsequently, they completed a demographics form. The researcher completed the Zarit caregiver burden scale one week after the patient was discharged through a phone call with the caregiver.

The caregiver burden scale was developed by Zarit et al. [1998] to measure the caregiver burden. The scale includes 22 items on personal, social, emotional, and economic pressures. The tool categorizes a caregiver's experienced pressures into objective and subjective types. Objective burden refers to the negative effects of the disease on the primary caregiver and involves disruption of family relationships; restrictions on social activities, work and leisure; and physical and financial problems. Subjective burden refers to a caregiver's emotional reactions to the patient, including mental stress, feelings of loss, and regret. According to this classification, in the Zarit caregiver burden scale, three items [*i.e.*, 2, 3, 15] assess the objective burden, three items [*i.e.*, 7, 8, 14] examine the subjective caregiver burden, and item 22 examines the subjective-objective burden.

### 2.2. Scoring and Interpretation

This questionnaire is based on a five-point Likert scale, with 0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Often, and 4 = Always. To calculate the total score of the scale, the scores of all items are summed up, which can range from 0 to 88. A smaller score indicates a lower burden. The sum of the scores obtained by each caregiver denotes the caregiver's burden. Scores 0 to 20 indicate low or no caregiver burden, scores 21 to 40 indicate moderate caregiver burden, and scores 41 to 88 indicate severe caregiver burden.

Desirable content validity has been reported for the scale items in the literature. In terms of CVI, a score range from 0.7 to 1 has been reported, which suggests the appropriateness of the scale in terms of the simplicity, relevance, and clarity of the items. The intraclass correlation coefficient [ICC] has been reported as 0.958, and the internal consistency of the instrument has been confirmed by determining the Cronbach's alpha coefficient of 0.86 [7].

As this scale has not been used in the context of the COVID-19 disease, the validity of the instrument was assured by assessing its content validity through the opinions of 6 experts and specialists. For reliability purposes, a pilot study was performed with 30 people who had similar characteristics to the research population. The scale was completed by them twice within 10 days. The test-retest reliability of the tool and Cronbach's alpha coefficient were calculated, indicating a correlation coefficient of 0.92.

The data were analyzed in the SPSS-16 statistical software using the Pearson correlation coefficient and Chi-square tests. The study protocol was approved by the ethics committee of Tehran Islamic Azad University of Medical Sciences (identifier: ID IR.IAU.PS.REC.1399.069).

## 3. RESULTS

Comparison of demographic characteristics showed that the inpatient and outpatient groups did not differ significantly in terms of gender, age, marital status, educational level, and occupation [ $p < 0.05$ ] (Table 1).

**Table 1. Comparison of demographic characteristics of inpatient and outpatient groups**

Variables	Group	Inpatient	Outpatient	P-Value
		Number [percent]	Number [percent]	
Gender	Male	56[58.9]	68[59.1]	0.98
	Female	39[41.1]	47[40.9]	
Age [year]	≥40	24[25.3]	29[25.2]	0.80
	41-60	40[42.1]	53[46.1]	
	<60	31[32.6]	33[28.7]	
Marital status	Single	8[8.4]	12[10.4]	0.62
	Married	87[73.6]	103[89.6]	
Educational level	Illiterate	50[52.6]	61[53]	0.99
	Elementary	12[12.6]	15 [13]	
	High school	20[21.1]	23 [20]	
	Tertiary	13[13.7]	16[13.9]	
Occupation	Unemployed	16[16.8]	21[18.3]	0.97
	Employee	14[14.7]	17[14.8]	
	Housewife	34[35.8]	36[31.3]	
	Self-employed	30[31.6]	40[34.8]	
	Student	1[1.1]	1[0.9]	

Most of the family caregivers of inpatients were male [60%], while those of outpatients were female [73%] [ $p < 0.001$ ]. There was no significant difference between family caregivers in the two groups in terms of age, relationship with the patient, level of education, and occupation [ $p > 0.05$ ] (Table 2).

The results showed that the frequency distribution of care burden in family caregivers of inpatients and outpatients was not significantly different [ $p = 0.28$ ] (Table 3).

The results showed that the mean score of care burden in the family caregivers did not differ significantly in terms of gender, age, level of education, and occupation [ $p > 0.05$ ] (Table 4).

The results showed that the mean score of objective, subjective, and subjective-objective caregiver burden in male family caregivers was significantly higher than those of female counterparts [ $p < 0.01$ ]. However, the mean scores of the total caregiver burden were not significantly different in male and female family caregivers [ $p = 0.85$ ]. The mean score of total caregiver burden and its components did not differ significantly in the studied family caregivers regarding age, education level, and occupation [ $p > 0.05$ ] (Table 5).

The results showed that the mean scores of objective, subjective, and objective-subjective caregiver burden in family caregivers of inpatients were significantly higher than those of outpatient family caregivers [ $p < 0.001$ ] (Table 6).

**Table 2. Comparison of demographic characteristics of family caregivers of inpatients and outpatients**

Variables	Group	Inpatient	Outpatient	P-Value
		Number [percent]	Number [percent]	
Gender	Male	57[60]	31 [27]	<0.001
	Female	38[40]	84[73]	
Age [year]	≥30	19 [20]	18[15.7]	0.86
	31-40	44[46.3]	57[49.6]	
	41-50	20[21.1]	24[20.9]	
	>50	12[12.6]	16[13.9]	
Relationship with the patient	Daughter	24[25.3]	30[26.1]	0.96
	Spouse	59[62.1]	72[62.6]	
	Son	12[12.6]	13[11.3]	
Educational level	Elementary	32[33.7]	42[36.5]	0.87
	High school	24[25.3]	26[22.6]	
	Bachelor's degree and higher	39[41.1]	47[40.9]	
Occupation	Employee	29[30.5]	34[29.6]	0.96
	Housewife	46[48.4]	58[50.4]	
	Self-employed	20[21.1]	23 [20]	

**Table 3. Comparison of the frequency distribution of family caregivers' burden in inpatient and outpatient groups**

Group	Mild	Moderate	Severe	P-value
Inpatients	0[0]	16[16.8]	79[83.2]	0.28
Outpatients	3[2.6]	19[16.5]	93[80.9]	
Total	3[1.4]	35[16.7]	172[81.9]	

**Table 4. Comparison of the mean score of care burden in the family caregivers according to demographic characteristics**

Variable	Group	Caregiver's burden score	P-Value
		Mean±SD	
Gender	Male	53.03±13.09	0.85
	Female	53.39±14.13	
Age [year]	≤30	53.46±14.62	0.82
	31-40	53.72±13.85	
	41-50	53.41±12.28	
	>50	50.96±14.32	
Educational level	Elementary	52.93±14.22	0.97
	High school	53.44±15.63	
	Bachelor's degree and higher	53.40±12.04	
Occupation	Employee	53.1±13.62	0.34
	Housewife	54.37±13.99	
	Free	50.74±12.90	

**Table 5. Comparison of the mean score of total caregiver burden and its components in the studied family caregivers according to demographic characteristics**

Group Variable		Objective caregiver burden	Subjective caregiver burden	Objective-subjective caregiver burden	Total caregiver burden
		Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD
Gender	Male	8/30±1/37	9/28±1/89	3/34±0/66	53/03±13/09
	Female	7/57±1/25	8/27±1/78	3/11±0/65	53/39±14/13
p-value [independent t-test]		< 0.001	< 0.001	< 0.01	0.85
Age [year]	≤ 30	8/00±1/31	8/70±1/98	3/27±0/61	53/46±14/62
	31 – 40	7/79±1/44	8/69±1/92	3/11±0/65	53/72±13/85
	41 – 50	8/00±1/28	8/75±1/79	3/39±0/69	53/41±12/28
	> 50	7/79±1/17	8/61±1/89	3/21±0/69	50/96±14/32
p-value [ANOVA]		0.75	0.99	0.12	0.82
Education	Elementary	7/89±1/39	8/80±1/94	3/26±0/66	52/93±14/22
	High-school	8/20±1/47	8/38±1/69	3/34±0/63	53/44±15/63
	Tertiary	7/66±1/19	8/79±1/95	3/09±0/66	53/40±12/04
p-value [ANOVA]		0.08	0.40	0.08	0.97
Occupation	Employee	7/79±1/18	8/70±1/91	3/16±0/63	53/10±13/62
	Housewife	7/82±1/43	8/74±1/87	3/26±0/65	54/37±13/99
	Self-employed	8/12±1/37	8/58±1/92	3/16±0/72	50/74±12/90
p-value [ANOVA]		0.41	0.90	0.55	0.34

**Table 6. Comparison of the mean scores of objective, subjective, and objective-subjective caregiver burden in inpatients and outpatients**

Group Caregiver burden	Inpatients	Outpatients	p-value [independent t-test]
	Mean ± SD	Mean ± SD	Mean ± SD
Objective	8/82±1/20	7/09±0/86	< 0.001

(Table 6) contd.....

Group Caregiver burden	Inpatients	Outpatients	p-value [independent t-test]
	Mean ± SD	Mean ± SD	Mean ± SD
Subjective	10/42±1/15	7/27±0/95	< 0.001
Objective-subjective	3/58±0/50	2/90±0/62	< 0.001

#### 4. DISCUSSION

The current study results showed that the mean scores of objective, subjective, and subjective-objective caregiver burden were significantly higher in male than in female family caregivers. Moreover, male family caregivers endured a higher care burden in caring for inpatients, while females showed a higher burden in caring for outpatients. This issue is closely related to the Iranian socio-cultural circumstances, where the task of caring for children, the elderly, the disabled, and the sick are often infused with the housewives and girls. This care is considered as a part of housework. Given their major role in generating income and employment outside the home, men are not prepared to care for patients; besides, they fail to have sufficient time to play the caregiver role effectively [8]. Thus, men experience higher levels of objective, subjective, and objective-subjective caregiver burden when they act as family caregivers. Studies in Iran and other countries also show that women in most cases play the role of the primary caregiver at home [9 - 11]. This is probably why most of the family caregivers of outpatients in the present study were female. Family caregivers are often the parents, spouse, and other family members, who have the most contact with the patient in the treatment course and often experience emotional problems such as anxiety, depression, loneliness, frustration, anger, isolation, fear, and anxiety [12].

The study found that the mean scores of objective, subjective, and objective-subjective caregiver burden were significantly higher in family caregivers of inpatients than those of outpatients. Contributors to this can be the inpatients' older age, the presence of underlying diseases, more intense care needs of these patients, and the poor prognosis. In their study, Tenforde et al. [2020] examined the characteristics of COVID-19 inpatients and outpatients, stating that the inpatients were typically older, had an underlying disease, more care needs, and a weaker prognosis. These findings have also been observed with influenza patients [13 - 16].

According to the results of the present study, the caregiver burden was severe in family caregivers, both of inpatients [83.2%] and outpatients [80.9%], with no significant difference between the groups. Also, the mean score of care burden in the studied family caregivers did not differ significantly in terms of gender, age, educational level, and occupation.

A search through available databases did not reveal a study examining the care burden in family caregivers of COVID-19 patients, although there were studies on the care burden of caregivers in other chronic diseases. Bamari et al. [2016] studied the primary caregiver's burden of patients with type 2 diabetes, showing that the mean caregiver burden score was 38.85±11.91 [range: 6 - 77], which indicates moderate care burden [17]. Mollai et al.'s 2019 study reported a moderate care burden for most family caregivers [54%] of cancer patients [18]. Miguel et al. [2017] reported a moderate level of caregiving burden in caregivers of Portuguese patients with

head, neck, cervical and rectal cancers [19]. Hosseini et al. [2014] concluded that most women caring for the elderly with Alzheimer's disease [62%] have a high care burden [20].

In the studies mentioned above, the level of care burden in most caregivers was moderate, while it is severe in the present study, which may be due to the novelty of COVID-19, limited information about the disease, its high prevalence, and unavailability of vaccines to treat it.

When a person is affected by COVID-19, his/her family members, spouse, friends, and colleagues are also affected by the caregiving burden. Fear of the infection and its complications, feelings of helplessness, ambiguity about the future, anxiety, sadness, anger, grieving reactions, economic concerns, and psychological stress in interpersonal relationships are some of the social-psychological tensions in the COVID-19 disease. Due to the increasing spread of COVID-19 and the shortage of hospital facilities and space for the care of these patients, the early discharge of COVID-19 patients from the hospital is on the rise. Therefore, most of the care is provided at home and family members take responsibility for care, whereas they have limited training and resources at hand [21]. As a result, the process of care transference from the hospital to home imposes a burden on the family. One of the reasons for the severe care burden in family caregivers of COVID-19 patients in this study is probably their lack of knowledge about the way to care for the patient.

In this regard, Ossee et al. [2006] stated that the lack of necessary information and specialized knowledge of family caregivers about their patients' illness and their health stands as a major problem for family caregivers [22]. Fulfillment of the informational needs of caregivers in the course of the disease and after its treatment can play an important role in increasing the physical and psychological capacity of caregivers [23, 24]. Although the Internet, especially social networks, has greatly enhanced information accessibility and dissemination, this platform has the potential to spread false information or fake news. Governments must guarantee the dissemination of accurate knowledge and clarify misinformation to help people deal with the COVID-19. If not, the rumors, false information, and the subsequent stress and anxiety among the patients will disrupt the process of health care provision [25].

Moreover, caregivers may suffer from socioeconomic problems that need special attention. They need to receive special attention and psychological support to cope with social problems. Studies indicate that caregivers, in addition to socioeconomic problems, may also have physical symptoms such as muscular pains and mental disorders such as stress, anxiety, or depressed mood [18, 21], all of which exacerbate the care burden for family caregivers.

As family caregivers are the key elements of home care provision, familial care and support can be seriously hampered if they have unsolved pressures and problems [26].

Accordingly, to adapt to the course of the disease, caregivers should be familiarized with the normal course of the disease. This way, they will have better adaptation, reduced fear of recurrence and the unknown disease, and higher tolerance of disease burden.

Therefore, it is necessary to design productive and informative training programs for home care providers of COVID-19 patients. Such programs can help caregivers increase their knowledge, enhance their management skills, and work more independently in care provision. Caregivers can envisage a better picture of the disease course [27]. Therefore, educational support given to caregivers can alleviate the suffering and burden caused by care provision. In most studies, educational programs have been considered for caregivers and families of chronic patients, which has led to improved care, lower psychological burden, and increased satisfaction of the caregiver [8]. In this regard, Navidian et al. [2019] conclude that family education has been effective in reducing the psychological burden in a sample of home caregivers and that this can, in turn, improve the quality of life of both the patient and his/her caregiver[s] [6].

Thus, this study suggests that appropriate programs be considered to support caregivers and that measures be taken to reduce the care burden of primary caregivers of COVID-19 patients.

## CONCLUSION

The results showed that care burden was severe in family caregivers of COVID-19 inpatients and outpatients. The mean score of objective, subjective, and subjective-objective caregiver burden in male family caregivers is significantly higher than in female ones and the caregivers of inpatients than outpatients. The high level of care burden in the objective, subjective, and subjective-objective components is an alarm for mental health policy-makers to consider measures that can reduce the care burden of home caregivers. As a result, the consequences of care burden for family caregivers are reduced and caregivers can actively participate in caring for their family members, as part of community-based care. Also, according to local data collection, the results are not representative of the general community of patients with Covid-19 and the results of this article will not be able to generalize to all patients with Covid-19 in Iran and the world.

The results of the study showed that the burden of care in most family caregivers is severe for both inpatient (83.2%) and outpatient (80.9%) patients, which is in contrast to the care burden of most chronic diseases, which are usually moderate. This finding could be due to reasons such as the emergence of Covid-19, limited information about the disease, the high prevalence and lack of vaccines to treat it, and can be an important discovery and innovation in this study.

## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study protocol was approved by the ethics committee of Tehran Islamic Azad University of Medical Sciences, Iran (identifier: ID IR.IAU.PS.REC.1399.069).

## HUMAN AND ANIMAL RIGHTS

Not applicable.

## CONSENT FOR PUBLICATION

All patients participated on a voluntary basis and gave their informed consent.

## AVAILABILITY OF DATA AND MATERIALS

The raw data and materials used to support the findings of this study are available from the corresponding author [A.M] upon request.

## FUNDING

None.

## CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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