

Original Article

The Relationship between Caregivers' Burden of Care and Psychological Well-Being Levels of Heart Failure Patients

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Abstract

Background: The burden of care, which is difficult to live with and to determine, has been little studied in caregivers of patients with heart failure. The burden of care experienced by caregivers who are neglected by health personnel can affect psychological well-being. However, there are no studies on psychological well-being in the literature.

Objective: This research was conducted as a descriptive and correlational study to examine the relationship between caregiver burden and psychological well-being in caregivers of patients with heart failure.

Methodology: The study sample consists of individuals who care for 225 patients with heart failure. Introductory Information Form, Zarit Caregiver Burden Scale and Psychological Well-Being Scale were used to collect data. Frequency, percentage calculation, mean calculation, Kruskal-Wallis T test and Pearson correlation test were used in the analysis of the data.

Results: It was found that caregivers of individuals with heart failure had a moderate level of care burden and psychological well-being. A moderately significant ($p < 0.05$) negative correlation was found between caregiving burden and psychological well-being.

Conclusions: Caregivers of individuals with heart failure perceive a moderate burden of care and psychological well-being. There is a relationship between care burden and psychological well-being.

Keywords: Heart failure, caregiver, care burden, psychological well-being

Introduction

Heart failure (HF), which requires a long care process from the diagnosis stage on, affects caregivers as well as patients. This disease causes many problems in the physical, psychological, social, and economic areas for caregivers. These problems can create a burden for caregivers (Gok Metin & Helvaci, 2019; Suksatan et al., 2022). Caregiver burden is defined as "the degree to which caregivers perceive that caregiving has a negative impact on their emotional, social, financial, physical, and spiritual functioning" (Zarit & Zarit, 1990; Suksatan et al., 2022). It has been reported that caregivers who assume the role of caregiver and advocate for HF patients may experience a burden of care (Gok Metin & Helvaci, 2019; Suksatan et al.,

2022). One-third of caregivers of HF patients are affected by this burden (Zincir et al., 2014). In studies, it has been determined that caregivers of HF patients experience a moderate (Hu et al., 2017; Dirikan, Baysan Arabaci, & Mutlu, 2018) or low (Gok Metin & Helvaci, 2019) care burden. However, it is reported that studies on the subject are limited in the literature (Zincir et al., 2014; Jackson et al., 2018; Gok Metin & Helvaci, 2019). However, considering that the support of caregivers is important in the successful disease management of patients and that it has been shown that the support of caregivers improves the health of patients (Lum et al., 2014), it is important to be aware of this issue. The burden of care is a difficult situation to experience and determine. Because caregivers see it as a duty to take care of the patient, they

often hide their reactions and feelings (Bialek & Sadowski, 2019). However, due to the care given and the burden, caregivers may experience many psychological problems such as anxiety, depression, deterioration in family relationships and feeling out of control. (Pressler et al., 2009; Zincir et al., 2014; Gok Metin & Helvaci, 2019; Bialek & Sadowski, 2019; Suksatan 2022). In studies conducted with individuals who care for HF patients, it has been determined that caregivers experience many psychological problems such as depression and anxiety, limited social life and changing roles (Hu et al., 2017; Saritas & Isik, 2017; Bialek & Sadowski, 2019; Chung, 2020). In one study, it was determined that 74% of caregivers were sad and experienced negative emotions (Dirikan et al., 2018). These psychological problems can cause many health problems such as increasing the risk of cardiovascular disease and sensitivity to infectious agents (Pressler et al., 2009; Bialek & Sadowski, 2019). For this reason, it is reported that even just giving care can threaten the well-being of caregivers (Kol & Yilmaz Karabulutlu 2021). Deterioration of the well-being of caregivers, on the other hand, deteriorates the quality of care and causes the patient's condition to worsen (Thomson et al., 2020). Psychological status of caregivers must be known in order to adequately fulfill their roles and provide quality care (Northouse et al. 2010; Kol & Yilmaz Karabulutlu 2021). Therefore, well-being is important for caregivers to perceive the burden of care (Bahrami et al., 2014). Psychological well-being is the excess of positive feelings and thoughts about the life of the individual (Myers & Diener 1995). It expresses a successful struggle with existential situations such as advancing toward goals, being in positive relationships with others, and striving for development (Keyes, Shmotkin, & Ryff, 2002; Telef, 2013). The level of psychological well-being in the care process, where caregivers struggle with their patients, can affect the care process and burden. When the literature is examined, it is seen that previous studies show caregiver burden (Agren et al., 2010; Gusdal et al., 2016), depression (Pressler et al., 2013; Zincir et al., 2014; Gok Metin & Helvaci, 2020) and anxiety (Zincir et al., 2014; Saritas & Isik, 2017). It did not focus on positive aspects such as psychological well-being. No study

was found that examined the relationship between caregivers' status and care burden related to psychological well-being. However, it is reported that those with a high level of psychological well-being feel and think more about positive emotions and can make a successful struggle for existence more easily (Keyes, Shmotkin, and Ryff, 2002; Telef, 2013). It is stated that positive and negative psychological outcomes may create different emotional states and may be related to different causal factors (Grigorovich et al., 2017). The psychology of the caregiver is important in preventing the hospitalization of the patient. For all these reasons, it is vital to recognize and meet the needs of caregivers. Understanding the factors associated with increased burden can contribute to the development of caregiver and patient recovery interventions, clinical practice, and policy development to reduce the burden of care (Burton et al., 2012). Therefore, this study was conducted to determine the care burden and psychological well-being levels of family members who care for heart failure patients and to determine the relationship between these two factors.

Methods

This descriptive and cross-sectional study was conducted in the cardiology ward of a university hospital. The population of the study consisted of 225 individuals who cared for a patient with a diagnosis of heart failure in the cardiology service of his hospital between January 2021 and May 2021. Therefore, no sampling method was chosen. 225 individuals who care for a patient with heart failure and who met the inclusion criteria of the study were included in the study sample. Inclusion criteria for the study; cared for his patient for at least 3 months, being 18 years or older, agreeing to participate in the research care, 5 hours of care a day, literature, loss of vision and hearing, not being a primary caregiver family member open to communication and cooperation. Caregivers of patients newly diagnosed with heart failure, professional caregivers, those who did not provide regular care, and caregivers who could not understand or speak Turkish were the criteria for not being included in the study. In the study, it was explained that by informing the individuals about the study, they could be free to refuse to participate in it.

While collecting data; the individuals were informed about the subject of the study, and the questionnaire forms were filled out by the researcher through face-to-face interviews with the individuals, paying attention to privacy.

Data Collection Tools

Patients Information Form: The form, which was created by the researcher following a literature review and assessed sociodemographic (e.g., age, gender, marital status, educational status) and medical characteristics (e.g., disease duration, New York Heart Association (NYHA) stage used to determine HF stage), had six questions (Gok Metin & Helvacı, 2019; Gok Metin & Helvacı, 2020; Kol & Yılmaz Karabulutlu 2021).

Caregiver Information Form: This form, developed by the researcher based on the literature, consisted of questions to determine the sociodemographic characteristics (e.g., age, gender, marital status) and caregiving-related characteristics (e.g., caregiving time) of the family caregivers (Gok Metin & Helvacı, 2020; Kol & Yılmaz Karabulutlu 2021).

The Zarit Caregiver Burden Interview (ZCBI). This form, developed by Zarit, Reever and Bach-Peterson (1980), is a scale used to evaluate the care burden of caregivers for the person in need of care. The validity and reliability of the scale in Turkey were tested by İnci and Erdem (2008), and its reliability coefficient was found as 0.99. The scale consists of 22 items. The items of the scale are rated as a 5-point Likert-type scale ranging from 0 to 4. A minimum score of 0 and a maximum score of 88 can be obtained from the scale. In this study, the scores obtained from the scale were evaluated in four categories of burden as none/mild (0–20 points), moderate (21–40 points), severe (41–60 points) and highly severe (61–88 points) (İnci & Erdem, 2008; Tuncay & Fertelli, 2019). In this study, the Cronbach's alpha value of the scale was found as 0.85.

Psychological Well-Being Scale (PWBS): The Psychological Well-Being Scale was developed by Diener et al. (2010) to measure psychological well-being to complement existing measures of well-being. The Turkish adaptation of the scale was done by Telef (2011). It consists of 8 items. The Cronbach's alpha internal consistency coefficient of the

scale is 0.80. The items on the Psychological Well-Being Scale are answered between 1 and 7, as I strongly disagree (1) to I strongly agree (7). All items are expressed positively. A minimum of 8 and a maximum of 56 points are obtained from the scale. A high score indicates that the person has many psychological resources and strengths (Diener et al., 2010). In this study, Cronbach's alpha value of the scale was found to be 0.75.

Application of Data Collection Tools:TBF, ZCBI, and PWBS were administered to individuals who met the criteria of the study and agreed to participate in the study after being informed about the study. The scales were administered to the individuals by the researcher. Interviews were held in a separate room. It was stated to the individuals that the information obtained would only be used by the researcher, and their names would not be written on the scales. During the application, the incomprehensible points in the form and scale were explained individually, without giving any direction to the person. The administration of the scales took an average of 25 minutes for each individual.

Evaluation of Data: The data of the research were analyzed in SPSS (Version 22.0, SPSS Inc., Chicago, IL, USA). In the statistical analyses of the data related to caregivers and patients, frequencies, percentages, and mean values were used. The relationship between the variables was analyzed using Pearson correlation analysis and the Kruskal-Wallis T-test. A p value of <0.05 was considered statistically significant.

Ethical Dimension of the Study: The study was conducted according to the Declaration of Helsinki, and the University's Clinical Research Ethics Committee approved this study (2021-11/48). The aim and method of the study were explained to the participants by the researcher, and verbal and written consent was obtained.

Results

A 2.2% of the caregivers with a mean age of 53.23 ± 14.13 were female, 41.8% were primary school graduates, 81.3% were married, 82.7% had children, and 43.6% had given care to their patients for less than six months. It was determined that 38.7 of them were children of the patient, and 88% of them gave care for five hours. It was determined that 58.7% of HF patients with a mean age of

62.78±12.15 years included in the study were male, 56.8 % were primary school graduates, 78.2% were married, 34.6% had third-stage HF, and the mean age of disease was 6.85±2.28. (Table 1). When Table 2, which includes the caregiver burden and mean scores of psychological well-being of the caregivers of the individual with heart failure, is examined; the care burden of individuals (27.62 ± 12.28) and psychological well-being level (35.69 ± 13.50) were found to be moderate (Table 2). In the analysis, there is a moderately negative relationship between caregivers' burden of care and psychological well-being ($r=-.616$).(Table 2). According to the Zarit Care Burden Scale, it was found that the psychological well-being of individuals whose care burden was high and excessively burdened was lower, and the difference was significant. With the full-house test, this difference was due to low and high load and low and overload (Table 4).

Discussion

In this study, it was found that caregivers of individuals with heart failure had a moderate level of care burden and psychological well-being, and that as the burden of care increased, the level of psychological well-being decreased.

Healthcare professionals generally research patient-related issues. On the other hand, caregivers considered hidden patients to be neglected (Fertelli & Tuncay 2019; Bialek & Sadowski, 2019). However, problems such as dyspnea, insomnia, fatigue, insomnia, and repeated hospitalizations of individuals with heart failure affect the health of caregivers as well as patients. These problems cause caregivers to experience a burden of care (Gok Metin & Helvaci, 2019; Suksatan et al., 2022).

On the other hand, in this study, it was determined that caregivers experienced a moderate care burden. The reason for the difference between the aforementioned studies and the results of this study may be the HF stage of the patients included in the sample. In this study, the fact that the patients

had third-stage HF may have caused them to need more support from their caregivers in maintaining their daily lives and to have a moderate care burden. It is noteworthy that in a study in which the caregiver burden was low, the majority of the patients in the sample consisted of patients with second-stage HF (Gok Metin & Helvaci, 2019). Another reason for the difference between the results of the study is thought to be the elderly patient group that received care. Because the care of the elderly with chronic diseases in advanced age differs and can bring different roles and burdens to caregivers (Fertelli & Tuncay, 2019). On the other hand, the result of this study is similar to the results of some studies conducted with caregivers of heart failure patients (Hu et al., 2016; Hu et al., 2017).

Studies have shown that caregivers of HF patients experience negative psychological problems such as depression, anxiety, and sadness (Gok Metin & Helvaci, 2020; McHorney et al., 2021). Even caregiving alone can threaten the well-being of caregivers. It is stated that psychological well-being may be effective in reducing the caregiver's perceived burden of care (Bahrami et al., 2014; Kol & Yilmaz Karabulutlu, 2019). In this study, it was found that the psychological well-being of caregivers was moderate. No study was found on the psychological well-being of caregivers of HF patients. Therefore, the result could not be compared with similar studies. However, similar results were found in a study conducted with caregivers of individuals with chronic diseases (Kol & Yilmaz Karabulutlu, 2019). The deterioration of well-being can hinder the care process. The heavy burden perceived by the caregivers and their low psychological well-being will also make the care given inadequate. The psychological well-being of caregivers must be addressed to improve the quality of care and ensure that caregivers can continue their roles (Ryan, & Sawin, 2009; Northouse et al., 2010). For this reason, it is recommended to determine the psychological well-being of nurses and caregivers and to conduct research on this.

Table 1: Descriptive Features

	Caregivers		Patients	
	n	%	n	%
Age mean (x±sd)	53.23±14.13		62.78±12.15	
Gender				
Woman	140	62.2	132	58.7
Male	85	37.8	92	40.9
Education level				
Illiterate	63	28.0	79	35.2
primary school graduate	94	41.8	128	56.8
High school	68	30.2	18	8.0
Marital status				
Married	184	81.3	176	78.2
Single	42	18.7	49	21.8
Status of having a child				
There is	184	82.7		
None	40	17.3		
Caregiving time				
3-6 months	98	43.6		
7-12 months	43	19.1		
12 ay <	84	37.3		
The degree of proximity				
Mom dad,	52	23.1		
Spouse	64	28.4		
Child	87	38.7		
Brother	22	9.8		
Daily caregiving time (hours)				
≤8	128	88.0		
8<	97	43.1		
New York Heart Association Stage				
Stage 1			49	21.7
Stage 2			53	23.5
Stage 3			78	34.6
Stage 4			45	20
Average age of disease (x±SD)			6.85± 2.28	

Table 2. Zarit Caregiver Burden Interview and Psychological Well-Being Scale mean scores of caregivers

Scales	X±SD	n	%
Zarit Caregiver Burden Interview (min: 2, max: 68.00)	27.62 ± 12.28		
None (0-20 points)		58	25.8
Moderate care burden (21-40 points)		119	52.9
Severe care burden (41-60 points)		35	15.6
Highly severe care burden (61-88 points)		13	5.8
Psychological Well-Being Scale (min: 8, max: 56.00)	34.40 ± 14.44		

Table 3. Correlation of caregivers' Zarit Burden Interview and Psychological Well-Being Scale score

Variables	Psychological Well-Being Scale	
Zarit Caregiver Burden Interview	r	-0.616**
	p	0.000

**p<0.001, *p<0.05

Table 4. Comparison of Psychological Well-Being Scale According to Zarit Caregiver Burden Interview Levels

*p<0.05, ** Measurements that show differences as a result of the Tamhane test., 1= low load, 2= medium load,

Zarit Caregiver Burden Interview	Low load (n=58)	Medium load (n=119)	High load (n=35)	Overload (n=13)	Test (KW/p)	Difference in test** p
Variable	X±SD	X±SD	X±SD	X±SD		
Psychological Well-Being Scale	51.65±5.23	48.13±8.89	19.22±8.94	10.07±2.10	KW=178.842	1-3** p=0.00
					p=0.000*	1-4** p=0.00

3=high load, 4=overload

It is stated that psychological well-being may be effective in reducing the caregiver's perceived burden of care (Bahrami et al., 2014; Kol & Yilmaz Karabulutlu, 2019). Another finding obtained from this study is that there is a moderately negative and significant relationship between the care burden of individuals and their psychological well-being. According to this result, it can be said that as psychological well-being increases, the burden of care decreases. The results could not be compared with other studies, as there was no study in the literature about the burden of care and psychological well-being of caregivers of HF patients. However, in a study conducted with caregivers of individuals with chronic diseases, a negative relationship was found between care burden and caregiver well-being (Kol & Yilmaz Karabulut, 2021). In the literature, it is reported that those with high psychological well-being experience positive emotions more frequently, while those with low psychological well-being experience negative evaluations of their lives more frequently (Richman et al., 2005; Cevik, Ozden, & Saritas 2019). The psychological well-being of the caregiver is important for both the caregiver and the patient. In a study, it was found that the emotional well-being of caregivers and the improvements in the emotional well-being and condition of patients with HF were positively related (Rohrbaugh, 2009; Jackson et al., 2018). Considering this information and the result, it can be said that as psychological well-being increases, the burden of care may decrease. In addition, considering that psychological well-being means reaching goals, being in positive relationships with others, and successfully struggling with existential situations (Keyes, Shmotkin, and Ryff, 2002; Telef, 2013), nurses should evaluate the psychological well-being of the caregiver and include practices that increase well-being to ensure successful disease management is considered necessary.

In the study, it was found that the level of perceived psychological well-being of individuals with an advanced and excessive care burden was lower, and the difference was significant. It is known that those who care for their relatives need social and psychological support (Fertelli & Tuncay 2019). This result

is considered a finding that shows that nurses, together with all caregivers, consider individuals who experience excessive and advanced care burdens more carefully. In addition, the result is interpreted as a finding showing that patient care should be planned in a way that prevents individuals from experiencing an advanced and excessive care burden by approaching them with a primary protective approach.

Limitations: This study had some limitations. Firstly, because of the use of a small sample size from a single health center, the results cannot be generalized to other patients. Secondly, the fact that the study was performed in a clinical setting does not provide information on the assessment of care given at home.

Conclusion and Recommendations: In the study, it was found that caregivers of individuals with heart failure had a moderate level of care burden and psychological well-being. In addition, it was determined that there was a moderately significant negative relationship between care burden and psychological well-being. It was concluded that while the caregiver burden increased, their psychological well-being decreased. In addition, it has been determined that individuals who experience an advanced and excessive care burden have a lower perceived level of psychological well-being. In line with these results:

- Raising awareness of nurses on the subject by emphasizing that caregivers of patients with heart failure -should be considered as a risky group in university and in-service training.
- Raising nurses' awareness of the issue by stressing that in college and in-service training, those who care for individuals with heart failure should be treated as a risky group.
- Planning the interventions of nurses to reduce the burden of care without neglecting the caregivers,
- While evaluating the caregivers of stroke individuals holistically, nurses also evaluate psychological well-being along with the burden of care,

- Determining the practices that will increase the psychological well-being of caregivers by nurses, using these practices for caregivers in their care, and researching methods to increase these practices,
- Identifying the behaviors that will improve caregivers' psychological well-being, implementing these behaviors with caregivers under their care, and investigating ways to expand these behaviors,
- Counseling and training the caregivers of the patient with heart failure on how nurses can reduce the burden of care and increase their psychological well-being,
- To evaluate the health of the caregiver together with the patient, nurses make home visits to evaluate the caregiver's care burden and psychological well-being and monitor them at regular intervals,
- Nurses visit patients at home to assess both the patient's and the caregiver's health, as well as the caregiver's care burden and psychological well-being, which are then periodically checked on.
- It is recommended to conduct large-scale and intermittent follow-up studies with a mixed method in a larger sample on the subject.

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