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Evaluation of Caregiver Burdens of Caregivers to Individuals with Chronic Heart Failure

Kronik Kalp Yetmezliği Olan Bireylere Bakım Verenlerin Bakım Verme Yüklerinin Değerlendirilmesi

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Abstract

Aim: In this study we aimed to determine the burden of caregiving and the factors affecting the burden of caregiving among caregivers of patients with chronic heart failure (HF).

Material and Method: In this prospective study, the Zarit Care Burden Scale (ZCBS) was applied face-to-face to caregivers of 178 HF patients. On the scale scoring, 0-20 points indicate "no care burden", 21-40 points indicate "light care burden", 41-60 points indicate "moderate care burden" and 61-88 points indicate "heavy care burden".

Results: The burden of caregivers over 65 years of age with HF was higher ($p<0.01$). Caregivers with a heavy burden of care were those who had a bad economic situation, did not receive support from family members, had other caregivers, and had a high number of children ($p<0.001$). There was no significant relationship between the caregiver's age, occupation, education level, place of residence, proximity and ZCBS ($p>0.05$). Depression was the most common psychiatric problem in both HF patients and caregivers.

Conclusion: Especially family, psychological, and economic support should be provided to patients with chronic HF and their caregivers. As the living standards of patients with HF improve, the burden of caregivers decreases.

Keywords: Heart failure, caregiving,depression

Öz

Amaç: Bu çalışmada kronik kalp yetmezliği (KY) olan hastalara bakım verenlerin bakım verme yükünü ve bakım verme yükünü etkileyen faktörleri belirlemeyi amaçladık.

Gereç ve Yöntem: Bu prospektif çalışmada 178 kalp yetmezlikli hastaya bakım verenlere zarit bakım yükü skalası (BYÖ) yüzyüze uygulandı. Ölçek puanlamasında 0-20 puan "bakım yükü yok", 21-40 puan "hafif bakım yükü", 41-60 puan "orta bakım yükü" ve 61-88 puan "ağır bakım yükü" anlamına gelmektedir.

Bulgular: 65 yaşın üzerindeki kalp yetmezlikli kişilere bakım verenlerin yükü daha fazlaydı ($p<0.01$). Bakım yükü ağır olan kişiler ekonomik durumu kötü, aile bireylerinden destek almayan, başka baktığı kişi olan ve fazla çocuk sayısın sahip olan kişilerdi ($p<0,001$). Bakım verenin yaş, meslek, eğitim durumu, yaşadığı yer, yakınlık durumu ile BYÖ arasında anlamlı bir ilişki tespit edilmedi ($p>0,05$). Hem KY'li hastalarda hem bakım vericilerde ortaya çıkan en sık psikiyatrik problem depresyondu.

Sonuç: Kronik KY'li hastalara ve onlara bakım verenlere özellikle ailevi, psikolojik ve ekonomik yönden destek sağlanmalıdır. KY'li kişilerin yaşam standartları iyileştikçe bakım verenlerin yükü de azalmaktadır.

Anahtar Kelimeler: Kalp yetmezliği, bakım verme, depresyon

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INTRODUCTION

Heart failure (HF) is a complex condition in which the heart cannot pump enough blood to meet the metabolic needs of the body due to a structural or functional defect.[1] As a result of the advancement of science and technology, the population is aging, chronic patients can live longer, and the mortality rate in acute coronary events is decreasing. As a result of these developments, the prevalence and incidence of HF are increasing. The prevalence of HF exceeds 40 million worldwide, with approximately 6 million in the United States and 6.5 million in Europe. In Turkey, approximately 3-4 million people have HF.[2]

In a patient with HF, dyspnea, fatigue, edema, and activity limitation are among the primary symptoms. In these patients, deterioration in quality of life is observed due to dietary restrictions, difficulties in normal work performance, difficulties in sexual intercourse, progressive loss of self-confidence, side effects of drug treatment, and rehospitalizations.[3] The goal of HF treatment is to reduce mortality and unnecessary hospitalizations, eliminate symptoms (dyspnea, fatigue, depression, anxiety, and cognitive disorders), and provide quality of life. Since HF requires a long care process starting from the diagnosis stage, it affects the families of caregivers as well as patients physically, psychologically, socially, economically, and spiritually, and creates a heavy economic burden with intense stress. As a result of all these problems, the search for new service models such as home care for patients with chronic diseases such as HF is on the agenda.[4]

Although caregiving is not limited to a single type of assistance, it includes the coordinated execution of many tasks such as providing emotional, physical, or financial support, coordinating health care, carrying out routine health care, personal care, transportation, shopping, doing small household chores, and money management in addition to providing the patient's care needs.[5]

Care burden includes negative objective or subjective results, such as problems in many areas, including psychological, economic, social, physical, and health; deterioration in family relationships; and the feeling that the caregiver is not in control .This multidimensional and complicated caregiving process may cause the caregiver to feel burdened and experience psychosocial problems as a result of being forced at times. The transformation of caregiving into a one-way, dependent, intensive, and long-lasting obligation that puts the individual's life in distress causes the caregiver to experience problems of harmony between family relations, work, entertainment, social life roles, and care roles and to perceive care as a burden. The burden of caregivers should be determined, the factors affecting them should be revealed, and the degree to which their quality of life is affected should be determined.[4-6]

In this study, it was aimed to determine the burden of caregiving and the factors affecting the burden of caregiving among caregivers of patients with chronic HF.

MATERIAL AND METHOD

The study was carried out with the permission of Kayseri City Hospital Ethics Committee (Date: 14.05.2020, Decision No: 66). All procedures were carried out in accordance with the ethical rules and the principles of the Declaration of Helsinki.

The population of this prospective study was the primary caregivers of patients with chronic HF admitted to the cardiology outpatient clinic of a district state hospital. Among the caregivers included in the study, 178 caregivers and 178 care recipients were included in accordance with the principle of voluntary participation. The criteria for inclusion in the study were that the caregiver cared for the patient at home and in the hospital, was over 18 years of age, the caregiver had no perception, hearing, speech, and mental problems, was literate, and agreed to participate in the study. Exclusion criteria were illiteracy, being younger than 18 years of age, caring for the patient for less than 6 months, caregivers for financial gain, and those who did not accept participation in the study were excluded from the study. The demographic data form, including the descriptive characteristics of the caregivers and the care burden scale, was used to collect the data. Data collection tools were prepared by the researchers in line with the literature, with a form including descriptive characteristics of caregivers and descriptive information about the disabled person. The caregiver information form and Zarit Caregiver Burden Scale (ZCBS) were used to evaluate the stress experienced by caregivers of elderly individuals in need of care.[7] The scale, which can be completed by the caregivers themselves or by the researcher, consists of 22 statements that determine the impact of caregiving on the individual's life. With this scale, the caregiver/patient relationship, the caregiver's health status, psychological comfort, social life, and economic burden can be evaluated. The evaluation of the ZCBS, in which all items are expressed in plain language, is based on the total score. The higher the score, the higher the burden of care, and a maximum score of 88 points can be obtained from the scale. The relevant forms were applied by the researchers to the caregivers who agreed to participate in the study by face-to-face interview technique in an empty patient room, and each interview lasted approximately 15-20 minutes. The scale has a Likert-type evaluation ranging from 0 to 4 as (0) "Never", (1) "Rarely", (2) "Sometimes", (3) "Quite Often", (4) "Almost Always". A minimum score of 0 and a maximum score of 88 can be obtained from the scale. In scoring, 0-20 points indicate "no care burden", 21-40 points indicate "light care burden", 41-60 points indicate "moderate care burden" and 61-88 points indicate "heavy care burden". The validity and reliability study of the adaptation of the ZCBS to the Turkish population was conducted in 2006.[7-9]

Statistical Analysis

Mean, standard deviation, median, minimum, minimum, maximum, frequency, and ratio values were used in the descriptive statistics of the data. The Mann-Whitney U test and Kruskall-Wallis Test were used to analyze quantitative independent data. The chi-square test was used in the analysis of qualitative independent data, and the Fischer test was used when the chi-square test conditions were not met. The SPSS 26.0 program was used in the analysis.

RESULTS

The study included 178 caregivers and 178 care recipients of HF patients. The mean age of caregivers was 44.5±10.2 years, and the mean age of care recipients was 63.1±7.35 years. 59% of care recipients were female, and 77.5% of caregivers were female. 58.4% of the caregivers were the daughters of the patients receiving care, 92.1% were married, and 23.6% had an additional disease. Of the comorbidities, 57.1% had depressive disorders and 42.9% had chronic diseases (HT, DM). Depression in patients with HF occurred during the caregiving process. Psychiatric problems experienced by caregivers occurred during the caregiving process. Caregivers had no previous education in caregiving. 59% of the caregivers were housewives, 60.1% were high school graduates, and 55.1% lived in the district. The proportion of caregivers who had no other patients was 88.2% and the proportion of caregivers whose expenses were higher than their income was 46.6%. The CBM was administered to 78.1% of caregivers before the pandemic and 21.9% during the pandemic. In the care burden grading, 44.7% had a light burden, 43.6% had a moderate burden, and 5.8% had a heavy burden. 51.7% of caregivers provided both treatment and care (**Table 1**).

Table 1.

		Caregiver (n) ZCBS	p value
Gender	Male (40)	49.5 (22-86)	0.107
	Female (138)	41.5 (22-86)	
Marital Status	Married (164)	44.5 (22-86)	0.236
	Single (14)	35 (22-84)	
Job	Housewife (105)	44 (22-86)	0.051
	Civil servants (31)	40 (22-84)	
	Self-employed (30)	40 (22-54)	
	Unemployed (12)	52 (22-86)	
Education	Primer education(27)	50 (22-84)	0.351
	High School(107)	44 (22-86)	
	University (44)	40 (22-86)	
Living stage	County (98)	45 (22-86)	0.566
	Village (61)	40 (22-85)	
	Town center (19)	49 (22-54)	
Care	Treatment and care (92)	49 (22-86)	0.044
	Treatment (86)	40 (22-86)	
Other caregiver	No	0 (22-86)	<0.001
	Yes	52 (48-86)	
Economical situation	Expense Excess (83)	51 (24-86)	<0.001
	Income-Expense (72)	35.3 (22-85)	
	Equal Income more (23)	22 (22-44)	
Child	Yes	45 (22-86)	0.001
	No	23 (22-25)	
Relationship	Wife/husband	40 (22-86)	0.234
	Daughter	48 (22-85)	
	Son	50 (22-86)	
	Sister	38 (22-50)	

ManN Whitney U testi ve Kruskall Wallis Testi. p<0.05 was considered statistically significant. ZCBS: Zarit Caregiver Burden Scale

The care burden scale of caregivers was similar in terms of gender, marital status, occupation, educational status, place of residence, and degree of closeness (p:0.107, p:0.236, p:0.051, p:0.351, p:0.566, p:0.234, respectively). Participants who both helped in the treatment of the patient and provided care had higher ZCBS (p:0.044). Patients who also cared for patients other than HF patients had a higher ZCBS (p:0,000). Caregivers who had children had a significantly higher ZCBS (p<0,001). There was a significant difference between the groups in terms of economic status (p:0,000). The group with higher expenses had a higher CBS than the group with equal income and expenses (p:0,000). The group with more expenses had a higher ZCBS than the group with more income (p:0,000). The ZCBS of the group with equal income and expenses was higher than that of the group with more income (p:0,003). According to the age groups of the patients being cared for, the ZCBS of the caregivers was statistically different. Participants who provided care to patients over the age of 65 years had a higher ZCBS (p:0.000). However, according to the gender of the patient being cared for, caregivers' ZCBS scales were similar (p:0.320) (**Table 2**).

Table 2. Caregiver burden by age and gender of caregiver

		ZCBS	P
Patient Gender	Male	40 (22-86)	0.320
	Female	48 (22-84)	
Age	<65	40 (22-55)	<0.01
	>65	50 (22-86)	

p<0.05 was considered statistically significant.

There was a very weak positive correlation between the caregiver's ZCBS and the age of the caregiver (r:0.157, p:0.037), a moderate positive correlation with the age of the care recipient (r:0.459, p:0.000), and a weak positive correlation with the duration of caregiving (r:0.367, p:0.000) (**Table 3**).

DISCUSSION

In our study, we found that caregivers experienced the most psychological and economic problems, and that patients with heart failure also had problems in terms of psychological and familial support. Taking care of an individual with a chronic disease such as HF, meeting his/her needs, and helping him/her causes physical, psychological, social, and economic difficulties for his/her family and relatives, and the role of the caregiver may worsen as the course of the disease worsens.[10] In recent years, many new treatment technologies, such as implantable defibrillators (ICD), biventricular pacemakers, and left ventricular assist devices, have been developed.[11] As a result of these developments, the life expectancy of patients is prolonged, and the parameters of care (such as treatment, follow-up, nutrition, and cleaning) are increased.[4] Given the central role of caregivers for patients with HF, it is important to understand the burden of caregiving responsibilities on these individuals in order to meet their needs and promote their continuous and effective support.

Many factors such as age, gender, cultural characteristics, socioeconomic status, educational level, health status, family dynamics, closeness to the patient, willingness to provide care, presence or absence of disease, coping skills, beliefs, and the presence of social support may affect the caregiving role of caregivers.[5,12]

In studies, the effect of age and gender on caregiving burden varies. Şahin et al. reported that there was no significant difference between age groups and caregiving burden scale scores ($p>0.05$).[13] In a study conducted by Yüksel et al. with the caregivers of Parkinson's patients, they stated that when they made an evaluation according to the age and gender of the caregiver, they found that women and older people were under more burden, although there was no statistical significance.[14] Şahin et al. determined that the burden of care decreased with increasing age.[15] In our study, there was a very weak positive correlation (r:0.157, p:0.037) between the caregiver's ZCBS and the caregiver's age. In a study conducted by Tülüce, it was found that women experienced more care burden than men.[16] The fact that women experience more care burden than men may be due to their inability to cope effectively with the caregiving function, having other responsibilities other than caregiving, and not having adequate and effective support systems. In our study, the majority of caregivers were women, but there was no significant difference in terms of ZCBS in terms of gender. Participants caring for patients over the age of 65 years had significantly higher ZCBSs, but the ZCBS scales of the caregivers did not differ according to the gender of the patient being cared for. In previous studies, it was determined that the care burden of married caregivers was higher than that of single caregivers.[17] It is thought that married caregivers experience more care burden than single caregivers because they have more responsibilities in daily life (housework, child care, etc.). In our study, there was no difference between married and single caregivers in terms of care burden. We believe that these results were obtained according to the sociocultural situation in which the studies were conducted.

The primary caregivers of chronically ill people are wives, daughters, and daughters-in-law. In our country, the care of the elderly is carried out by family members, especially women and spouses. In another study conducted with caregivers of patients with HF, it was determined that 20% of the participants were the patient's spouse.[16,17] In the literature, it is stated that caregivers for chronic diseases requiring physical or psychological long-term care are mostly women from the family who do not have a job and are often the mother, sister, or wife of the patient. Since unemployed individuals are responsible for caregiving, economic problems may arise. In our study, in line with the literature, the majority of caregivers were daughters and spouses. The unemployed caregivers had poor economic status and a moderate to heavy care burden. According to this information, which overlaps with the study findings, it was thought that caregiving is a social role assigned to women in different cultures, and this view was effective in this result.[5,18]

Education level is also one of the factors affecting care burden. Iconomou et al. reported that caregivers with lower educational levels experienced more emotional stress, had more impact on their lives, and had worse physical health than those with higher educational levels.[19] In our study, there was no difference in terms of care burden in terms of educational status and occupation. Different results were obtained between care burden and number of children according to the socio-demographic data of the caregiver. In the study of Özdemir, the burden of caregiving was found to be higher in mothers with three or more children, but it was not found to be significant.[20] In our study, the care burden of caregivers with children was significantly higher. This may be attributed to the increase in stress and fatigue experienced by the caregiver with the increase in workload. In our study, a weak positive correlation was found between the duration of caregiving and care burden scores ($p<0.001$). Yüksel et al. found that there was a significant direct correlation between the duration of caregiving and care burden ($p=0.032$) and that the burden of the caregiver increased as the duration of caregiving increased.[14] In a study that the burden perception of caregivers who provided care for 13-24 months was higher than that of those who provided care for 24 months or more.[21]

Psychological problems may also occur in caregivers of patients with HF. The most common conditions that occur or worsen are stress, anxiety, sleep problems, migraine/headache, and depression.[22] Physical problems also arise as caregivers limit their physical activities. Therefore, perceived care burden negatively affects not only the care given to the patient but also the lives of caregivers. As a result of the study conducted by Balaban, it was found that there was a significant relationship between care burden and anxiety and depression levels of caregivers, and as the care burden increased, anxiety and depression levels increased.[23] In a study conducted by Zincir et al., it was found that caregivers of patients with HF experienced high levels of care burden and anxiety, and female caregivers experienced more care burden and anxiety than male caregivers.[24] As a result of the study to determine the care stress of family caregivers, it was found that HT , weakening of the immune system, depression, and anxiety were observed in caregivers. In a study conducted by Peter et al., it was found that caregivers of patients with HF experienced high rates of depressive symptoms and care burden, and their quality of life decreased in parallel. In a study conducted by Harkness, it was found that 48% of caregivers of patients with HF experienced anxiety.[25-27] In our study, depression, sleep problems, and HT were present in patients with heavy care burdens, in accordance with the literature.

There is an important relationship between the prognosis of patients with HF and social relationships. Social support given to patients with HF has beneficial effects on the prognosis of the disease. As the quality of life of patients with HF increases, the prognosis of the disease is better and caregivers are less needed. Depression was present in 16% of the patients in our study, and caregivers of depressed HF patients were mostly non-nuclear family members. Research clearly demonstrates the importance of the support of family members, especially spouses, in disease management and self-care. There is evidence that spousal support has a positive effect on the outcomes of patients with HF and other heart diseases.[28,29]

In order to reduce caregiver burden, the first step is to identify the experienced burden. Knowing and revealing the burden contributes to improving the quality of life of both caregivers and recipients. Therefore, approaches to reducing the burden of care are important in terms of maintaining the well-being of both the patient and the caregiver. In our country, providing psychological support training to both family members and patients may be a healthier health practice. In our study, caregivers did not receive any training, etc., on this subject. Reducing the burden of caregiving causes the HF patient receiving care to receive better quality care and to have a better quality of life.[6,29]

CONCLUSION

Caregivers of patients with HF should receive more support and training from healthcare providers to develop their coping and resilience skills in a way that decreases their care burden and improves their quality of care and self-confidence. Especially economic and psychological problems arise in caregivers, so they also need economic and psychological support. In addition, the number of studies on the difficulties and needs of caregivers in our country is not sufficient. It is thought that there is a need for more comprehensive and qualitative studies on this subject.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Kayseri City Hospital Ethics Committee (Date: 14.05.2020, Decision No: 66).

Informed Consent: All patients signed the free and informed consent form.

Referee Evaluation Process: Externally peer-reviewed.

Conflict of Interest Statement: The authors have no conflicts of interest to declare.

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