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Caregiver Burden and Stress Levels among Family Members Caring for Heart Failure Patients

Kalp Yetmezliği Hastalarına Bakım Veren Aile Üyelerinin Bakım Verme Yükü ve Stres Düzeyi

ABSTRACT

Objective: This study aimed to investigate the impact of caregiving burden on the stress levels of family caregivers of patients with heart failure and the relationship between them.

Methods: This cross-sectional descriptive study took place at a Lokman Hekim University Hospital between December 2022 and June 2023, involving volunteer primary and informal caregivers of patients hospitalized in the cardiology ward for at least one day due to heart failure. Data were collected through face-to-face interviews utilizing the "Caregiver Identification Form," "Caregiver Burden Scale," and "Caregiver Stress Scale."

Results: Among the caregivers participating in the research, it was found that 28.7% were between the ages of 41-50, and 62% were women. Upon examining the correlation between caregiver stress and caregiving burden scores, a positively moderate correlation (r=0.658, P=0.000) was observed between caregiving burden and caregiver stress. The regression analysis conducted to determine the causal relationship between caregiving burden and caregiver stress yielded significant results (P=0.000). The caregiving burden explained 42.9% of the total change in caregiver stress levels. Caregiving burden was found to increase caregiver stress levels (B=0.658).

Conclusion: Based on our research findings, it is recommended to provide support for family members caring for HF patients, enhance home care services, and establish support groups to alleviate caregivers' stress levels.

Keywords: Caregiver, caregiving burden, heart failure, nursing, stress

ÖΖ

Amaç: Bu çalışma, kalp yetmezliği olan hastaların bakım veren aile üyelerinin bakım verme yükünün stres düzeylerine olan etkisinin ve aralarındaki ilişkinin araştırılması amacıyla yapıldı.

Yöntem: Bu kesitsel tanımlayıcı çalışma özel Lokman Hekim Üniversitesi Hastanesinde Aralık 2022 ile Haziran 2023 tarihleri arasında kalp yetmezliği nedeniyle kardiyoloji servisinde en az 1 gün yatan hastaların çalışmaya katılım kriterlerini sağlayan gönüllü primer ve informal bakım vericileri ile yapılmıştır. Araştırmanın verileri, "Bakım Verici Tanıtıcı Formu", "Bakım Verici Yükü Ölçeği" ve "Bakım Verenin Stres Ölçeği" kullanılarak yüz yüze görüşme ile toplandı.

Bulgular: Araştırmaya katılan bakım verenlerin; %28,7'sinin 41-50 yaş aralığında, %62'sinin kadın olduğu saptandı. Bakım veren stres, bakım verme yükü, puanları arasında korelasyon analizleri incelendiğinde; bakım verme yükü ile bakım veren stres arasında r=0,658 pozitif orta (P=0,000) düzeyde korelasyon bulundu. Bakım verme yükü ile bakım veren stres arasındaki neden sonuç ilişkisini belirlemek üzere yapılan regresyon analizi anlamlı bulundu (P=0,000). Bakım Veren Stres düzeyindeki toplam değişim %42,9 oranında bakım verme yükü tarafından açıklanmaktadır. Bakım Verme Yükü bakım veren stres düzeyini arttırmaktadır (β=0,658).

Sonuç: Araştırmamızın sonuçlarından yola çıkarak, KY hastalarına bakım veren aile üyelerinin desteklenmesi, evde bakım hizmetlerinin artırılması ve bakım verenlerin stres düzeylerine yönelik destek gruplarının oluşturulması önerilmektedir.

Anahtar Kelimeler: Bakım verici, bakım verme yükü, kalp yetmezliği, hemşirelik, stres

Introduction

Heart failure (HF) is a chronic condition characterized by the heart's inability to pump sufficient blood to meet the body's essential needs. This multifaceted

ORIGINAL ARTICLE



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Content of this journal is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License. condition can arise from various causes, manifesting through symptoms and physical indicators.^{1,2} The prevalence of heart failure is on the rise, presenting a significant economic burden on our nation.³

In Türkiye, the responsibility of caring for chronically ill individuals typically falls on family members. According to the Family Caregiver Association, non-professional caregivers are individuals who provide physical, psychosocial, and financial assistance to chronically ill or disabled individuals, offering their support without compensation.⁴

There are various definitions of caregiving found in the literature. Professional care is described as "care provided by public and private institutions and voluntary organizations".⁵ It involves services delivered by professional caregivers, such as nurses, for a fee.⁶ Non-professional care, on the other hand, encompasses assistance offered by family members, close relatives, neighbors, and friends, and is characterized as "informal or non-professional caregiving; a voluntary act of helping someone with whom one is personally close, without receiving compensation in return".^{5,8,9}

Numerous researchers have highlighted both the negative and positive impacts of caregiving.^{7,10} Negative aspects include caregiver burden and caregiver stress. "Burden in the Caregiver Role" is one of the nursing diagnoses recognized by the North American Nursing Diagnoses Association (NANDA). It defines "Caregiver Burden" as the condition experienced by individuals encountering physical, emotional, social, and/or economic challenges while caring for another person.¹¹

In the literature, stress is characterized as "physical, chemical, or emotional factors that cause physical or mental strain".¹⁰ Pearlin et al.⁹ identified two types of caregiver stress: primary and secondary stress. Primary stress stems from difficulties encountered in providing physical care to the ill individual, while secondary stress encompasses economic hardships, conflicts with family members, loss of employment, and reduced social activities.⁹

Caregivers play a crucial role in maintaining the medical treatment of HF patients and enhancing their quality of life. However, despite the invaluable support provided by caregivers, it's essential not to overlook the burden they bear. Managing heart failure involves a prolonged care process starting from the time of diagnosis, impacting both patients and their family members.^{12,13}

MAIN POINTS

- Heart failure is a chronic disease that requires a long treatment and care process.
- Caregiver burden and stress levels of family members caring for patients with heart failure should be measured.
- It is recommended to establish support groups to reduce the stress level of caregivers of patients with heart failure.
- Home care services should be developed for caregivers of patients with heart failure.

The challenges encountered by family caregivers as they assist heart failure patients through severe symptoms and recurrent hospitalizations require attention.¹⁴ Nurses play a vital role in aiding caregivers to develop coping strategies, manage stress, and address anxiety and depression. Additionally, they provide education on disease symptoms and management to caregivers. Consequently, our study was designed to assess the caregiving burden, stress levels, and mutual effects experienced by caregivers of heart failure patients. It is anticipated that this information will inform the development of care services tailored to meet caregivers' needs.

Materials and Methods

This cross-sectional, descriptive, and correlation-seeking study focused on caregivers of heart failure patients admitted to a private university hospital in Ankara. Participants included voluntary primary and informal caregivers of patients hospitalized in the cardiology ward for at least one day due to heart failure between December 2022 and June 2023.

The inclusion criteria comprised primary and informal caregivers of heart failure patients over 18 years old, without mental or communication disorders, proficient in Turkish reading and writing, participating voluntarily, and whose patients were hospitalized for at least one day during the study period.

The required number of participants was calculated using the G*Power 3.1.9.7 program, with a significance level (α) of 0.05, power (1- β) of 0.80, a medium effect size of 0.15, and 14 independent variables (12 as general characteristics). Considering the minimum sample size needed for multiple regression and correlation analysis as 180,¹⁵ with a 20% dropout rate, the final sample size was determined as 144, with 150 individuals participating in the study.

Data Collection Tools

Data collection involved the utilization of the Caregiver Identity Form, Caregiver Burden Scale, and Caregiver Stress Scale. Prior to administering these tools, the researcher provided explanations to the participants, ensuring their understanding, and obtained their voluntary consent.

Caregiver Identification Form

The Caregiver Identification Form was created by the researcher, drawing upon insights from the literature, to gather data regarding the characteristics of caregivers.^{16,17} This form comprises inquiries about the caregiver's age, gender, relationship with the patient, marital status, number of children, educational background, occupation, social security status, employment status, income level, presence of dependents, duration of caregiving, and whether the caregiver receives assistance from others.

Caregiver Burden Scale

The Caregiver Burden Scale, developed by Zarit et al. in 1980, was adapted for Turkish use and its validity and reliability were established by Inci.¹⁸ This scale comprises a total of 22 items and follows a 4-point Likert scale format. Scores on the scale range from a minimum of 0 to a maximum of 88 points, with

higher scores indicating increased caregiving burden. The Cronbach's alpha coefficient for the scale is reported as 0.95,¹⁸ while in our study, the Cronbach's Alpha value was found to be 0.84.

Caregiver Stress Scale

The Caregiver Stress Scale, developed by Robinson in 1983, aims to assess caregiver stress levels. Its reliability and validity in the Turkish context were evaluated by Uğur¹⁹ in 2006, yielding a Cronbach's alpha value of 0.75. This scale comprises 13 items, with scores ranging from a minimum of 0 to a maximum of 13. A positive response to 7 or more items on the scale indicates high perceived caregiver stress, suggesting caregiver burden.¹⁹ In our study, the Cronbach's Alpha value for the Caregiver Stress Scale was determined to be 0.83.

Data Collection

Research data were gathered between December 2022 and June 2023. Caregivers were briefed about the study and provided with the necessary forms to complete at their convenience.

Ethical Considerations

Prior to commencing the research, an application was submitted to the Lokman Hekim University Scientific Research Ethics Committee, and approval was obtained (Approval Number: 2023/1, Date: 10.01.2023). Caregivers participating in the study were provided with detailed information about the research, and their consent was obtained. The study adhered to the principles outlined in the Declaration of Helsinki. No artificial intelligence program was utilized in the data collection or article creation process.

Data Analysis

The research data were analyzed using the Statistical Package for Social Sciences version 22.0 (IBM SPSS Corp., Armonk, NY, USA).Descriptive statistics, including frequency and percentage analyses, were employed to delineate the characteristics of the participating patients. Mean and standard deviation statistics were utilized to analyze the scales. Kurtosis and skewness values were assessed to ascertain the normal distribution of research variables,^{20,21} revealing that the variables were indeed normally distributed. Consequently, parametric methods were applied to analyze the data.

Pearson correlation and linear regression analyses were conducted to explore the relationships among the dimensions determining the patients' scale levels.²² T-tests, one-way analysis of variance (ANOVA), and post hoc analyses (Tukey, LSD) were employed to investigate differences in scale scores based on the descriptive characteristics of the patients. Effect sizes were determined using Cohen's d and eta-squared (η 2) coefficients.²³

Results

Analysis of the descriptive characteristics of the caregivers revealed that 28.7% were aged between 41 and 50 years, with 62% being female, and 55.3% being the daughters or sons of the patients. Additionally, 56% of the caregivers were married, and 45.3% had no children. Furthermore, 42% of the caregivers had obtained a college degree, 97.3% had health insurance,

Table 1. Distribution of Caregivers by DescriptiveCharacteristics

Characteristics		
Descriptive Characteristics	n	%
Age		
≤30 years	35	23.3
31-40 years	42	28
41-50 years	43	28.7
51≥ years	30	20
Gender		
Male	57	38
Woman	93	62
Degree of closeness to the patient		
Daughter -son	83	55.3
Wife	24	16
Brother- sister	21	14
Other	22	14.7
Marital status		
Married	84	56
Single	66	44
Child ownership		
No children	68	45.3
1-2 children	41	27.3
3-4 children	41	27.3
Education status		
Middle school and below	27	18
High school	60	40
Jniversity	63	42
Health insurance status		
Yes	146	97.3
Νο	4	2.7
Employment status		
Full day	83	55.3
Shift	16	10.7
Not working	51	34
Income level		
ncome equal to expenditure	122	81.3
t's income is more than its expenses	20	13.3
It's income is less than its expenses	8	5.3
Presence of another dependent		
Yes	2	1.3
No	148	98.7
Maintenance time		
≥ 6 month	116	77.3
≤ 7 month	34	22.7
Presence of someone else who is assis		
Yes	113	75.3
No	37	24.7
	0,	27.7

Table 2. Differentiation of Caregiver Stress and Caregiving Burden Scores According to Descriptive Characteristics					
Descriptive Characteristics	n	Caregiver Stress M±SD=2.487±2.792	The Burden of Caregiving M±SD=7.800±7.706		
Age					
≤30 years	35	2.686 <u>+</u> 2.928	7.829±7.782		
31-40 years	42	2.286±2.644	6.405±5.365		
41-50 years	43	2.326±2.958	8.698±9.831		
51≥ years	30	2.767 <u>+</u> 2.687	8.433±7.001		
		F=0.276 P=0.843	F=0.717 P=0.543		
Gender					
Male	57	2.000±2.500	7.333 <u>+</u> 7.670		
Woman	93	2.785±2.930	8.086±7.755		
		t=-1.682 P=0.095	t=-0.579 P=0.563		
Degree of closeness to the patient					
Daughter -son	83	2.687±3.123	8.422 <u>+</u> 8.267		
Wife	24	2.542 <u>+</u> 2.085	9.042 <u>+</u> 6.471		
Brother- sister	21	1.952 <u>+</u> 2.598	4.524 <u>+</u> 5.269		
Other	22	2.182±2.343	7.227 <u>+</u> 8.234		
		F=0.484 P=0.694	F=1.718 P=0.166		
Marital status					
Married	84	2.560 <u>+</u> 2.735	8.500 <u>+</u> 8.073		
Single	66	2.394 <u>+</u> 2.882	6.909 <u>+</u> 7.174		
		t=0.360 P=0.720	t=1.258 P=0.211		
Child ownership					
No children	68	2.588 <u>+</u> 3.097	7.765±8.661		
1-2 children	41	2.683 <u>+</u> 2.640	8.610 <u>+</u> 6.848		
3-4 children	41	2.122±2.410	7.049 <u>+</u> 6.885		
		F=0.493 P=0.612	F=0.419 P=0.659		
Education status					
Middle school and below	27	2.148±2.996	7.074 <u>+</u> 8.218		
High school	60	2.700±2.953	8.167±7.623		
University	63	2.429 <u>±</u> 2.563	7.762 <u>+</u> 7.664		
		F=0.384 P=0.682	F=0.186 P=0.830		
Health insurance					
Yes	146	2.514±2.814	7.890 <u>+</u> 7.768		
No	4	1.500±1.732	4.500±4.203		
		t=0.715 P=0.476	t=0.867 P=0.387		
Employment status					
Full day	83	2.337 <u>+</u> 2.868	7.096±7.849		
Shift	16	3.813±3.167	13.500±8.959		
Not working	51	2.314±2.470	7.157 <u>+</u> 6.342		
		F=2.049 P=0.133	F=5.175 P=0.007 2>1, 2>3		

(Continued)

Descriptive Characteristics	n	Caregiver Stress M±SD=2.487±2.792	The Burden of Caregiving M±SD=7.800±7.706
Income level			
Income equal to expenditure	122	2.328±2.695	6.975 <u>+</u> 6.828
It's income is more than its expenses	20	1.900±2.150	6.400±4.925
It's income is less than its expenses	8	6.375±3.021	23.875 <u>+</u> 8.919
		F=9.337 P=0.000 3>1, 3>2	F=24.167 P=0.000 3>1, 3>2
Maintenance time			
\geq 6 month	116	2.285±2.772	6.569 <u>+</u> 6.945
≤ 7 month	34	3.177±2.790	12.000 <u>+</u> 8.749
		t=-1.648 P=0.102	t=-3.771 P= 0.000
Presence of someone else who is assisted in care			
Yes	113	2.062±2.476	6.885±7.661
No	37	3.784±3.301	10.595±7.247
		t=-3.367 P= 0.005	t=-2.590 P= 0.011

and 55.3% were employed full-time. It was noted that 81.3% of caregivers' incomes equaled their expenses, 98.7% did not have any other dependents, 77.3% had been caring for their patients for less than 6 months, and 75.3% received assistance while providing care (refer to Table 1).

The mean caregiver stress score was calculated as 2.487 ± 2.792 (Min=0; Max=11), while the mean caregiver burden score was 7.800 ± 7.706 (Min=0; Max=45). Among the participating caregivers, 132 (88.0%) experienced low caregiver stress, while 18 (12.0%) reported high caregiver stress.

According to Table 2, caregiver stress and caregiver burden scores did not differ significantly according to age, gender, closeness to patient, marital status, having children, educational status, and having health insurance (P > 0.05). Caregivers' work status was found to have no effect on caregiver stress levels, but there was a significant difference in caregiver burden scores (P > 0.05; F = 5.175; P = 0.007 < 0.05; η 2=0.066). The reason for the difference was that the caregiver burden scores of those with shift work status were higher than the caregiver burden scores of those with fulltime and non-working status (P > 0.05). Caregiver stress scores of caregivers differ significantly by income level $(F=9,337; P=0<0.05; \eta 2=0.113)$. The reason for the difference is that the caregiver burden scores of those whose income is less than expenses are higher than the caregiver burden scores of those whose income is equal to expenses and those whose income is more than expenses (P > 0.05). Caregiver burden scores differ significantly by income level (F=24.167; P=0<0.05; $\eta 2=0.247$). The reason for the difference is that the caregiver burden scores of those whose income is less than expenses are higher than the caregiver burden scores of those whose income is equal to expenses and those whose income is more than expenses (P > 0.05). Caregiver burden

scores of caregivers with 6 months or less of caregiving (x=6,569) were lower than caregiver burden scores of caregivers with 7 months or more of caregiving (x=12,000) (t=-3,771; P=0<0.05; d=0.735; η 2=0.088). Caregiver stress scores did not differ significantly by duration of caregiving (P > 0.05). Caregiver stress scores (x=2,062) of caregivers with another caregiver were lower than caregiver stress scores (x=3,784) of caregivers without another caregiver (t=-3,367; P=0.005<0.05; d=0.638; η 2=0.071). The caregiver burden scores (x=6,885) of those with other caregivers were lower than the caregiver burden scores (x=10,595) of those without other caregivers (t=-2,590; P=0,011<0,05; d=0,491; η 2=0,043).

According to Table 3, a positive moderate correlation (r=0.658, P=0.000<0.05) was identified between caregiver burden and caregiver stress scores.

In Table 4, the regression analysis conducted to explore the cause-and-effect relationship between caregiver burden and caregiver stress yielded significant results (F=113.050; P=0.000<0.05). It was observed that caregiver stress explained 42.9% of the total variance in caregiver stress levels (R2=0.429). Notably, caregiver burden was found to increase caregiver stress levels (β =0.658).

Table 3. Correlation Analys is Between Caregiver Stress andCaregiving Burden Scores

0.658**
0.000
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Argument	Non-Standardized Coefficients	Standardized Coefficients			95% Confidence Interva		
	В	SE	ß	t	р	Min	Max
Constant	0.627	0.245		2.554	0.012	0.142	1.112
The Burden of Caregiving	0.238	0.022	0.658	10.632	0.000	0.194	0.283

Table 4 The Effect of the Burden of Caregiving on Caregiver Stress

Discussion

In this study, it was observed that 28.7% of caregivers fell within the 41-50 age group, with women comprising 62% of the sample, and 55.3% being the children of the patient. These findings align with Turkish family traditions, reflecting an expected demographic distribution. Additionally, 56% of participating caregivers were married, and 45.3% did not have children, consistent with similar studies.^{17,24} Conversely, another study reported that the majority of heart failure caregivers were spouses of middle-aged and elderly patients.²⁵

Regarding educational attainment, 42% of caregivers in our study were college graduates, with 97.3% possessing health insurance, and 55.3% employed full-time, mirroring findings from other studies.²⁶ Moreover, the majority of caregivers (81.3%) reported incomes equal to their expenses, 98.7% had no other dependents, 77.3% had been caregiving for less than 6 months, and 75.3% received assistance while providing care. These results are consistent with those of Hu et al,¹⁷ where the majority of caregivers reported incomes equal to expenses, and over half had been caregiving for less than one year.

The average caregiver burden and caregiver stress levels among the participants in our study were noted to be low. This observation might be attributed to the patients being hospitalized in the cardiology ward, where intensive care was not required, and a significant proportion (77.3%) of caregivers had been providing care for their patients for less than one year. Notably, a study conducted within our country yielded similar findings, indicating that perceived caregiver burden ranged from low to moderate.²⁷

Based on the results of our study, caregiver stress and burden scores did not exhibit significant differences concerning age, gender, level of closeness to the patient, marital status, having children, educational attainment, or possessing health insurance. However, although no statistically significant difference was noted between caregiver burden and stress scores based on gender, it was observed that female caregivers tended to have higher scores compared to male caregivers. This observation might be attributed to the greater need for social support among women. Consistent with our findings, a study by Luttik et al.28 in 2007 reported higher levels of caregiver stress and burden among women, corroborating our study's results.

It was observed that caregivers working in shifts exhibited higher caregiver burden scores compared to other groups. This could be attributed to the irregular work hours of caregivers, along with additional responsibilities during their free time.

Previous research supports this notion, as working caregivers of heart failure patients were found to experience heightened caregiver burden due to conflicts between caregiving duties, employment, and their immediate family.²⁹ Similarly, another study highlighted the added burden faced by caregivers balancing employment outside the home with caregiving responsibilities.³⁰ Conversely, individuals who were not employed or retired tended to have lower caregiver burden, possibly because they had more available time and energy to dedicate to patient care.18

According to the findings of our study, caregiver stress and burden scores varied significantly based on income level, with the group reporting income less than expenses standing out as the primary reason for this disparity. This indicates that financial strain could contribute to heightened caregiver burden and stress. In light of this, strategies to mitigate caregiver burden in low-income areas could include increased financial support from the government and the provision of additional resources for heart failure patients. It's noteworthy that similar to our study, previous research has also identified a predominance of caregivers with low monthly family incomes.¹⁷

According to the findings of our study, there was a decrease in caregiver burden scores as the duration of caregiving decreased, while caregiver stress scores did not exhibit significant differences based on the duration of caregiving. Additionally, caregivers who received assistance from others demonstrated lower caregiver burden and stress scores compared to those who did not receive such support. These results align with previous studies, highlighting an inverse relationship between social support and caregiver burden.^{13,31,32} Thus, interventions aimed at reducing caregiver burden should focus on enhancing social support networks, such as bolstering home care services and establishing support groups for caregivers.

Providing long-term care and enduring severe caregiver stress can contribute to heightened rates of depression, anxiety, stress, and even mortality among caregivers.33 Consequently, many family members caring for patients with heart failure may encounter substantial health issues that impact their quality of life.³⁴ In our study, when correlational analyses between caregiver stress, burden, and stress scores were examined, a positive moderate correlation between caregiver burden and stress emerged. Moreover, the regression analysis aimed at elucidating the cause-andeffect relationship between caregiver burden and stress yielded significant results. This suggests that caregiver strain exacerbates caregiver stress.

Limitations

The findings obtained from this study are only generalizable to the specific population to which it was applied.

Conclusion

This study provides valuable insights into the current situation of family members caring for patients with HF, making a significant contribution to the existing literature. The findings indicate that women, shift workers, and individuals with lowincome status tend to experience higher levels of caregiver burden and stress, regardless of total caregiving time or lack of assistance from family members. Based on these results, it is imperative to implement measures to support family caregivers of HF patients, such as enhancing home care services and establishing support groups specifically tailored to address caregiver stress. These interventions can help alleviate the challenges faced by caregivers and improve the overall quality of care for HF patients.

Ethics Committee Approval: Approval was obtained from Lokman Hekim University Scientific Research Ethics Committee (Approval Number: 2023/1, Date: 10.01.2023).

Informed Consent: Verbal and written informed consent was obtained from the caregivers participating in the study.

Peer-review: Externally peer-reviewed.

Authors Contribution: Concept – E.T.; Design – E.T., S.A.; Data Collection and/or Processing – S.A.; Analysis and/ or Interpretation – E.T., S.A.; Literature Search – E.T.; S.A.; Writing – E.T.; Critical Review – E.T., S.A

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