ORIGINAL ARTICLE

The caregiver burden and the psychosocial adjustment of caregivers of cardiac failure patients

Kalp yetersizliği tanısı olan hastalara bakım verenlerin bakım verme yükü ve psikososyal uyumları

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ABSTRACT

Objective: This cross-sectional, descriptive study evaluated the relationship between the caregiver burden and the psychosocial adjustment of caregivers to cardiac failure patients. *Methods:* Between November 18, 2015 and March 1, 2016, a preliminary information form, the Caregiver Burden Scale, and the Psychosocial Adjustment to Illness Scale were used to assess the caregivers of 200 patients being treated in the cardiology service of a university hospital.

Results: Among the caregivers, 75% were primary or secondary school graduates, 36% were housewives, and 43% were the patients' spouse. Of the group, 71% had been caring for the patients for 5 years or less. The caregivers described cardiac failure as "difficulty with inhalation, fatigue, asthenia, insomnia, and swelling in the hands and feet." They reported feelings of sorrow, fear, despair, bewilderment, anger, and guilt when they learned about the diagnosis, and they indicated that they generally managed those feelings by themselves. A total of 94% of the caregivers remarked that after the diagnosis they experienced physical, psychological, social, occupational, or economic changes. Of the respondents,74% felt sad and adversely affected, 71.5% faced difficulties with care provision, and 84% felt anxiety about the possibility of losing the patient while under their care, the disease prognosis, surgery (pacemaker implantation), and adjustment to the treatment. The study participants' caregiver burden and psychosocial adjustment scale scores were below average. There were moderate statistically significant relationships between 3 subdimensions of the caregiver burden and psychosocial adjustment to illness scales (p<0.05).

Conclusion: The participating caregivers of cardiac failure patients described moderate difficulties due to caregiving and adjusting to the illness. It was determined that as the distress felt due to caregiving increased, psychosocial adjustment to illness deteriorated.

ÖZET

Amaç: Bu çalışma, kalp yetersizliği tanısı olan hastalara bakım verenlerin bakım verme yükü ve hastalığa psikososyal uyumları arasındaki ilişkiyi değerlendirmek amacıyla kesitsel nitelikte tanımlayıcı tipte yapıldı.

Yöntemler: Bir üniversite hastanesinin kardiyoloji kliniğinde 18 Kasım 2015–1 Mart 2016 tarihleri arasında tedavi gören 200 hastanın bakım verenleri ile gerçekleştirilen çalışmada, Tanıtıcı Bilgi Formu, Bakım Verme Yükü Ölçeği (BVYÖ) ve Hastalığa Psikososyal Uyum-Öz Bildirim Ölçeği (PAIS-SR) kullanıldı.

Bulgular: Bakım verenlerin %75'i ilk-orta öğrenim mezunu, %36'sı ev hanımı, %43'ü hastanın eşi, %71'i beş yıl ve daha kısa süredir hastasına bakım vermekte idi. Bakım verenler, kalp yetersizliğini "nefes almada güçlük, yorgunluk-halsizlik, uyuyamama ve el-ayaklarda şişlik" olarak tanımlamaktaydı. İlk tanıyı duyduklarında üzüntü, korku, çaresizlik, şaşkınlık, öfke ve suçluluk yaşadıklarını, bu duygularla sıklıkla kendi kendilerine baş ettiklerini ve %94'ü tanı sonrası yaşamlarında fiziksel, psikolojik, sosyal, mesleki ve ekonomik değişiklikler olduğunu, %74'ü tanı sonrası üzüldüğünü ve olumsuz etkilendiğini belirtti. %71.5'i bakım verme sürecinde güçlükler yaşadığını, %84'ü hastanın bakım ve tedavisi sırasında hastayı kaybetme, hastalık prognozu, ameliyat (nakil-pil), tedaviye uyum gibi nedenlerden dolayı kaygı yaşadığını belirtti. Bakım verme yükü ve hastalığa psikososyal uyum ölçek puanlarının ortalamanın altında olduğu saptandı. Bakım verme yükü ile hastalığa psikososyal uyum ölçeğinin üç alt boyutu arasında orta düzeyde istatistiksel olarak anlamlı düzeyde ilişki bulundu (p<0.05).

Sonuç: Kalp yetersizliği tanılı bireylere bakım verenler, bakım vermekten dolayı orta düzeyde sıkıntı yaşamakta ve hastalığa orta düzeyde uyum sağlamaktadır. Sağlık bakımına oryantasyon dışında, bakım vermekten dolayı hissedilen sıkıntı arttıkça, hastalığa psikososyal uyum da bozulmaktadır.

Cardiac failure is a major, life-threatening health problem that occurs more often in industrialized communities. The frequency increases with age. Congestive heart failure (CHF) may arise as the result of many cardiovascular diseases and is a primary cause of morbidity and mortality. The American Heart Association's 2013 Heart Failure Manual describes it as a complex clinical syndrome that causes both structural and functional disorders in ventricular storage and blood circulation. CHF means that the heart cannot pump enough blood to meet the metabolic and oxygenation needs of tissues, in spite of normal blood pressure. Due to left ventricle dysfunction, serious dyspnea, apnea, asthenia, fatigue, edema in the ankles, and reduced tolerance to exercise may occur.

The adjustment of patients to CHF treatment can be difficult. Patients may fail to adjust for reasons including not sufficiently having their physiological needs met, the lowest step in Maslow's hierarchy of needs; [4] reduced quality of life; and various psychosocial difficulties (economic, sexual, familial, and social). [11] It is an important disease burden, not just for patients, but also for caregivers and health systems. The cost to health systems can be great, because the caregiver burden is an important social issue in many industrialized countries and patients may need a significant amount of treatment. [11]

The concept of burden is described as psychological distress, physical health problems, economic problems, social problems, deterioration of family relationships, and subjective results, such as feeling a lack of control. ^[5] Caregivers encounter many physical, psychological, social, economic, and moral problems that affect their daily lives. Like other developing countries, in Turkey, too, caregivers are generally family members. ^[6] This gives families the responsibility to provide patients with emotional support in addition to physical care. ^[7,8]

CHF patients often cannot perform daily activities on their own and become dependent on their caregivers. A reduced quality of life over time, deterioration of clinical status, increased treatment needs, prolongation and difficulty of care provision depending on the prognosis, the difficulty and complexity of caregivers' roles, mourning periods, and the responsibility of the family members in providing emotional support as well as physical care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to caregivers experiencing anxiety and depression, so need to care of the lead to care of the lead to caregivers experiencing anxiety and depression.

glecting their physical and mental health,^[14] and frequently feeling oppressed and burned-out due to biopsychosocial problems.

Abbreviations:

CBS Caregiver Burden Scale
CHF Congestive heart failure
PAIS-SR Psychosocial Adjustment
to Illness Scale

^[9,10] Today, many patients are sent to home care by the health systems, which further increases caregiver burdens.^[9]

According to studies, caregivers and families experience emotional problems similar to those of patients. The most prevalent problem is depression. It had been documented that 23% to 47% of caregivers for CHF patients experienced depression, and this rate has increased to 45% to 53% in recent years. As the care provision period increases, depression often also increases due to the perception of caregiving as excessive and difficult. An increase in anxiety due to a perceived caregiving burden may also reduce the quality of life and lead to feelings of despair, anxiety, and helplessness. [8,10,12]

Regardless of the burden and psychosocial problems, caregivers often overextend themselves to ensure patients' self-care, perform medical treatment, help them with daily activities, manage disease symptoms and the emotions and actions of patients, to coordinate health services and to ensure patients' survival.[10,14,15,19] It is very important to remember that caregivers may be latent patients and to provide them with as much psychological support as patients. In fact, it is the legal responsibility of health professionals, exclusively nurses to empower not only patients, but caregivers, too. Pursuant to an amendment to nursing regulations enacted in 2011, it is one of the main duties and liabilities of psychiatric consultationliaison nurses to provide patients and their families with biopsychosocial support. [20] Consequently, the support of nurses, especially psychiatric consultationliaison nurses, provided to patients and their families is very important. It will contribute considerably to the wellbeing of patients and their families, and to the development of nurses if knowledge about psycho-social care is put into practice. The concepts of psychiatric consultation-liaison nursing and of psycho-cardiology should be popularized.

METHODS

This cross-sectional, descriptive study was conducted to evaluate the relationship between the caregiver bur-

den and the psychosocial adjustment of the caregivers who provide care to patients under treatment for cardiac failure. The researcher carried out the study in the cardiology department of a university hospital between November 18, 2015 and March 1, 2016 with literate caregivers between the ages of 18 and 65 who cared for 200 patients. The data were collected in face-to-face interviews after obtaining permission from ethical committee and the institutions. The caregivers who met the inclusion criteria provided written, voluntary consent to participate. The data were collected in 25 to 30 minutes in an environment without patients present and without interruptions. The researcher used 3 forms.

The Preliminary Information Form: There were 33 open-ended and close-ended questions on this form prepared by the researcher regarding sociodemographic characteristics, care status in recovery, debriefing status, caregiver emotions and coping mechanisms, difficulties experienced and the period of adaptation, training and support, receiving information about the disease, and the family's ability to cope with the disease and the influences it has had.

The Caregiver Burden Scale: The Caregiver Burden Scale (CBS) was developed by Zarit, Reever, and Bach-Peterson in 1980. Its adaptation to Turkish as well as validity and reliability studies were conducted by İnci in 2006. This scale is used to evaluate the stress of caregivers. In this study, the tool was used to assess the perceived burden of caregivers. The scale, which can be completed by the caregivers themselves or as questions asked by the researcher, consists of 22 statements about the effects on caregivers' lives of providing care. The scale is a 5-point Likert-type scale with the responses of never, rarely, sometimes, often, and always. The minimum possible score is 0, and the highest is 88. The items are generally about social and emotional issues, and the higher the score is, the more distress is indicated. The internal consistency coefficients of the Turkish adaptation of the scale were between 0.87 and 0.94, its test-retest reliability coefficient was 0.71, and its alpha coefficient was 0.95.[21] The Cronbach's alpha coefficient of the CBS for this sample was 0.87.

The Psychosocial Adjustment to Illness Scale: Derogatis and Lopez developed the Psychosocial Adjustment to Illness Scale (PAIS-SR) in 1983. The adaptation to Turkish and validity and reliability studies were

performed by Adaylar in 1995. It is a multi-dimensional scale that evaluates psychosocial adjustment to illness. The PAIS-SR measures the interaction of individuals with others and institutions in the sociocultural environment. There are 46 items on the scale. The questions are divided into 7 subscales of psychosocial adjustment to illness: health care orientation, vocational environment, domestic environment, sexual relationship, extended family relationships, social environment, and psychological distress. The scores for each item ranges from 0 to 3. The lowest possible PAIS-SR score is 0, and the highest is 138. A score of less than 35 indicates good psychosocial adjustment, a score between 35-51 indicate moderate psychosocial adjustment, and a score above 51 indicates poor psychosocial adjustment.[22] The alpha reliability values of the adaptation to Turkish were 0.87, 0.85, 0.80, 0.95, 0.89, 0.93, and 0.83 for the PAIS-SR subscales (in the order listed) for a sample of patients with acute and chronic disease, and 0.94 for the overall scale. [23] The reliability coefficients for this study's sample were: 0.58, 0.67, 0.78, 0.91, 0.66, 0.87, and 0.76, respectively.

The data were analyzed using IBM SPSS Statistics for Windows, Version 22.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics were used (mean, standard deviation) to summarize the study data. One-way analysis of variance was also used to evaluate more than 2 groups in comparisons of the quantitative data, and Student's t-test was applied to compare 2 groups. The results were evaluated at a confidence interval of 95% with a threshold for significance of p<0.05.

RESULTS

Of the caregivers surveyed, 36% (n=72) were housewives and 24% (n=48) were retired. In all, 14.5% (n=29) were civil servants, 14.5% (n=29) were employed in other professions, and 11% (n=29) were laborers. In this study group, 37.5% (n=75) had completed primary school, 37.5% (n=75) were secondary school graduates, 19% (n=38) were college graduates, and 6% (n=12) were graduates of other schools. The relationship of the caregiver to the patient was spouse for 43% (n=112) of the respondents, child for 36% (n=94), another relative for 13.5% (n=35), parent for 5.5% (n=15), and another relationship for 2% (n=5).

Table 1 shows the caregivers' descriptions of cardiac failure, their emotions upon diagnosis, and their

Table 1. Distribution of caregivers by type of cardiac failure description, their emotions upon diagnosis, and their ability to cope with their feelings

Cardiac failure description* Fatigue 93 17.6 Swelling in the abdomen, hands or feet 60 11.4 Difficulty with inhalation 130 24.6 Insomnia 59 11.1 Asthenia 102 19.3 Other 84 16.0 First emotions upon diagnosis* Fear 116 20.4 Bewilderment 67 11.8 23 5.6 Anger 46 8.0 28.1 60 28.1 Guilt 32 5.6 46 8.0 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 28.1 60 60 60 60 60 60 60 60 60	and their ability to cope with their feeling	js 	
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Emotions felt during illness Denial 67 33.5 Anger 2 1.0 Adaptation 78 39.0 Depression 22 11.0 Fear of death 14 7.0 Anxiety 11 5.5 Resignation 5 2.5 Other 1 0.5	Improving morale	30	9.6
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Anger 2 1.0 Adaptation 78 39.0 Depression 22 11.0 Fear of death 14 7.0 Anxiety 11 5.5 Resignation 5 2.5 Other 1 0.5	Emotions felt during illness		
Adaptation 78 39.0 Depression 22 11.0 Fear of death 14 7.0 Anxiety 11 5.5 Resignation 5 2.5 Other 1 0.5	Denial	67	33.5
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Fear of death 14 7.0 Anxiety 11 5.5 Resignation 5 2.5 Other 1 0.5	Adaptation	78	39.0
Anxiety 11 5.5 Resignation 5 2.5 Other 1 0.5	Depression	22	11.0
Resignation 5 2.5 Other 1 0.5	Fear of death	14	7.0
Other 1 0.5	Anxiety	11	5.5
	Resignation	5	2.5
Toal 200 100.0	Other	1	0.5
	Toal	200	100.0

^{*}The caregivers selected more than one response.

ability to cope with their feelings. The caregivers reported various cardiac failure symptoms: 24.6% as difficulty with inhalation; 19.3% as asthenia; 17.6%

as fatigue; 16% as other symptoms; 11.4% as swelling in the abdomen, hands or feet; and 11.1% as insomnia. When asked about their understanding of cardiac failure, 72% of the caregivers indicated that it is a cardiovascular disease and 9.5% responded with insufficient operation of heart and blood pumping. Another 10% described the etiological basis, 5% replied with a perception on the basis of symptoms, 2% on the basis of treatment type, and 1.5% had another understanding (Table 1).

Upon diagnosis, 28.1% (n=160) of the caregivers reported feeling sorrow, 20.4% (n=116) felt fear, 18.1% (n=103) felt despair, 11.8% (n=67) felt bewilderment, 8% (n=46) felt angry, 5.6% (n=32) felt guilty, 5.2% (n=30) felt defiant, and 2.8% (n=14) felt various emotions. The caregivers stated that they coped with their feelings as follows: 33.6% (n=105) by themselves, 30.1% (n=34) by applying treatment immediately, 11.5% (n=36) by enduring, 9.6% (n=30) by improving their morale, 7.6% (n=24) by praying, 2.6% (n=8) by talking to a friend or relative, and 15% (n=1) used other methods. In all, 39% (n=78) of the respondents reported having feelings of adaptation, 33.5% (n=67) denial, 11% (n=22) depression, 7% (n=14) fear of death, 5.5% (n=11) anxiety, 2.5% (n=5) resignation, 1% (n=2) anger, and 0.5% (n=1)other feelings (Table 1).

Of the caregivers in this study, 94% said they had experienced physical, psychological, social, professional, or economic changes after the cardiac failure diagnosis, while 6% did not. Of those who responded positively, 46.5% got support exclusively from their spouses and children during treatment. In the group, 71.5% experienced anxiety for these reasons: difficulties during care provision (25.8%), economic difficulties (27.3%), difficulties obtaining information from health professionals (7.7%), hospital conditions (13.2%), and transportation (8.4%). The survey revealed that 84% felt anxiety for reasons such as fear of patient death during the care and treatment (26.2%), disease prognosis (39.8%), pacemaker implantation (3.5%), and adjustment to treatment (18.5%) (Table 2).

Table 3 illustrates the finding that 46.5% of the caregivers received social support for the treatment of the illness from local institutions or associations: 42% from their children, 35.3% from their spouse, 22.6% from other relatives, and 0.1% from other institutions, and 53.5% had no external support.

Table 2. Findings about changes in caregivers' lives after cardiac failure diagnosis

n % Changes 188 94.0 Experienced changes 188 94.0 Did not experience changes 22 6.0 Total 200 100 Physical changes* Fatigue/asthenia 98 49.0 Pain 23 11.5 Insomnia 43 21.5 Anorexia 15 7.5 Limitation of movement 10 5.0
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Did not experience changes 22 6.0 Total 200 100 Physical changes*
Total 200 100 Physical changes* Fatigue/asthenia 98 49.0 Pain 23 11.5 Insomnia 43 21.5 Anorexia 15 7.5
Physical changes* Fatigue/asthenia 98 49.0 Pain 23 11.5 Insomnia 43 21.5 Anorexia 15 7.5
Fatigue/asthenia 98 49.0 Pain 23 11.5 Insomnia 43 21.5 Anorexia 15 7.5
Pain 23 11.5 Insomnia 43 21.5 Anorexia 15 7.5
Insomnia 43 21.5 Anorexia 15 7.5
Anorexia 15 7.5
Limitation of movement 10 5.0
Swollen feet/edema 3 1.5
Other 8 4.0
Psychological changes*
Crying 2 0.7
Sorrow 95 35.7
Fear/panic/worry 46 17.3
Despair 16 6.0
Anger/temper 14 5.2
Bewilderment 6 2.2
Anxiety 38 14.3
Stress 40 15.0
Other 9 3.6
Social changes*
Limited social life 108 86.4
Changed roles 7 5.6
Health-promoting lifestyle 7 5.6
Other 3 2.4
Professional changes*
Quitting work 18 19.0
Change in work order 27 28.7
Reduced productivity 9 9.5
Changed domestic work responsibilities 36 38.3
Other 4 4.5
Economic changes*
Reduced income 5 5.5
Increased expenses 84 92.3
Workforce loss 2 2.2

The research also indicated that 28.5% (n=57) of the caregivers reported having no difficulties providing care and treatment to the patient, while 71.5% (n=143)

*The caregivers selected more than one response.

Table 3. Caregivers' support for treatment of the illness and difficulties and anxieties they experienced providing care and treatment

Experiencing difficulties Having difficulties Not having difficulties Not receiving information from healthcare personnel Economic challenges Care provision Hospital conditions Transportation to the hospital Changed domestic roles Insufficient care provided by the healthcare personnel Anxiety status Experiencing anxiety Not experienced* Fear of patient death Concern if the patient will recover Post-surgery issues Recovery issues Pacemaker implantation P143 71.5 72.5 72.5 72.5 72.5 72.5 72.5 72.5 72	providing care and treatment		
Receiving		n	%
Not receiving	Social support		
Place/person providing social support* Spouse	Receiving	93	46.5
Spouse 55 35.3 Children 65 42.0 Relatives 35 22.6 Institutions 1 0.1 Total 200 100.0 Experiencing difficulties 143 71.5 Not having difficulties 57 28.5 Difficulties experienced* 7 28.5 Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 168 84.0 Not experiencing anxiety 168 84.0 <	Not receiving	107	53.5
Children 65 42.0 Relatives 35 22.6 Institutions 1 0.1 Total 200 100.0 Experiencing difficulties 143 71.5 Not having difficulties 57 28.5 Difficulties experienced* 8 28.5 Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 168 84.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover	Place/person providing social support*		
Relatives 35 22.6 Institutions 1 0.1 Total 200 100.0 Experiencing difficulties Having difficulties 143 71.5 Not having difficulties 57 28.5 Difficulties experienced* Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Spouse	55	35.3
Institutions	Children	65	42.0
Total 200 100.0 Experiencing difficulties Having difficulties 57 28.5 Not having difficulties 57 28.5 Difficulties experienced* Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Recovery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Relatives	35	22.6
Experiencing difficulties Having difficulties Not having difficulties Not receiving information from healthcare personnel Economic challenges Care provision Hospital conditions Transportation to the hospital Changed domestic roles Insufficient care provided by the healthcare personnel Caregiver's needs not met Other Anxiety status Experiencing anxiety Not experienced* Fear of patient death Post-surgery issues Recovery issues Pacemaker implantation 9 5.4 Other 11 6.6	Institutions	1	0.1
Having difficulties 57 28.5 Not having difficulties 57 28.5 Difficulties experienced* Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Total	200	100.0
Not having difficulties 57 28.5 Difficulties experienced* Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Recovery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Experiencing difficulties		
Difficulties experienced* Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Having difficulties	143	71.5
Not receiving information from healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Not having difficulties	57	28.5
healthcare personnel 11 7.7 Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Difficulties experienced*		
Economic challenges 39 27.3 Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Not receiving information from		
Care provision 37 25.8 Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	healthcare personnel	11	7.7
Hospital conditions 19 13.2 Transportation to the hospital 12 8.4 Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Economic challenges	39	27.3
Transportation to the hospital Changed domestic roles Insufficient care provided by the healthcare personnel Caregiver's needs not met Other Anxiety status Experiencing anxiety Not experiencing anxiety Anxieties experienced* Fear of patient death Concern if the patient will recover Post-surgery issues Recovery issues Pacemaker implantation Other 12 8.4 42.8 44 2.8 45 66 3.6 84.0 46 47 48 49 40 40 40 40 40 40 40 40 40	Care provision	37	25.8
Changed domestic roles 2 1.4 Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Hospital conditions	19	13.2
Insufficient care provided by the healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Transportation to the hospital	12	8.4
healthcare personnel 4 2.8 Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Changed domestic roles	2	1.4
Caregiver's needs not met 8 5.6 Other 11 7.8 Anxiety status 168 84.0 Experiencing anxiety 36 16.0 Anxieties experienced* 7 39.8 Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Insufficient care provided by the		
Other 11 7.8 Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	healthcare personnel	4	2.8
Anxiety status Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Caregiver's needs not met	8	5.6
Experiencing anxiety 168 84.0 Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Other	11	7.8
Not experiencing anxiety 36 16.0 Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Anxiety status		
Anxieties experienced* Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Experiencing anxiety	168	84.0
Fear of patient death 44 26.2 Concern if the patient will recover 67 39.8 Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Not experiencing anxiety	36	16.0
Concern if the patient will recover6739.8Post-surgery issues63.5Recovery issues3118.5Pacemaker implantation95.4Other116.6	Anxieties experienced*		
Post-surgery issues 6 3.5 Recovery issues 31 18.5 Pacemaker implantation 9 5.4 Other 11 6.6	Fear of patient death	44	26.2
Recovery issues3118.5Pacemaker implantation95.4Other116.6	Concern if the patient will recover	67	39.8
Pacemaker implantation 9 5.4 Other 11 6.6	Post-surgery issues	6	3.5
Other 11 6.6	Recovery issues	31	18.5
	Pacemaker implantation	9	5.4
Total 200 100 0	Other	11	6.6
200 100.0	Total	200	100.0
*The caregivers selected more than one response.	*The caregivers selected more than one response.		

described economic challenges (27.3%), difficulty with care provision (25.8%), difficulty with hospital conditions (13.2%), difficulty with transportation to the hospital (8.4%), not being informed by healthcare

Table 4. The distribution of caregivers' subscale and total mean scores on the burden and psychosocial adjustment
to illness scales

Mean Sub and Total Scale Scores	Mean	Standard deviation	Minimum	Maximum
Caregiving Burden Scale	32.75	0.94	8	65
PAIS-SR				
PAIS-SR-1: Health Care Orientation	6.45	0.22	0	18
PAIS-SR-2: Vocational Environment	7.22	0.25	0	17
PAIS-SR-3: Domestic Environment	5.84	0.30	0	22
PAIS-SR-4: Sexual Relationship	6.58	0.37	0	18
PAIS-SR-5: Extended Family Relationships	3.15	0.19	0	13
PAIS-SR-6: Social Environment	9.98	0.33	0	18
PAIS-SR-7: Psychological Distress	6.78	0.23	0	16

PAIS-SR: Psychosocial Adjustment to Illness Scale.

Table 5. Correlation analysis results of caregivers' mean scores on the caregiver burden and psychosocial adjustment to illness scales

-								
Spearman's	CBS	PAIS-SR 1	PAIS-SR 2	PAIS-SR 3	PAIS-SR 4	PAIS-SR 5	PAIS-SR 6	PAIS-SR 7
Correlation		Health Care	Vocational	Domestic	Sexual	Extended Family	Social	Psychological
		Orientation	Environment	Environment	Relationship	Relationships	Environment	Distress
CBS								
r	1.000	.068	.484**	.416**	.210**	.182**	.365**	.493**
Р		.338	.000	000	.003	.010	.000	.000
N	200	200	200	200	200	200	200	200

CBS: Caregiver Burden Scale; PAIS-SR: Psychosocial Adjustment to Illness Scale.

personnel (7.7%), the needs of the caregiver not being met(5.6%), insufficient care by the healthcare personnel (2.8%), and changed domestic roles (1.4%). The majority of respondents, 84.0% (n=168), expressed feeling anxiety about the care and treatment of the patient, and 16.0% (n=32) of the caregivers did not. The sources of anxiety worry about whether the patient would recover (39.8%), patient death (26.2%), recovery concerns (18.5%), pacemaker implantation (5.4%) and post-surgery issues (3.5%) (Table 3).

Almost all of the caregivers (99.0%) stated that they had not had any training or attended a psychosocial support program about cardiac failure, and 59.5% said that they did not get sufficient information from healthcare personnel. They expressed a desire for information about the recovery process (49.0%), treatment in the hospital and at home (14.5%), the side effects of drugs (3.0%), managing findings (5.0%), and surgery (7.5%). The caregivers' subscale and total scores on the perceived burden and psychosocial adjustment scales were below average (p<.05) (Table 4).

There was a moderately statistically significant relationship between the caregivers' subscale and total mean scores on the CBS and the PAIS-SR (excluding the subscale of health care orientation) (Table 5).

DISCUSSION

Most of the caregivers were women, the spouse of the patient, had completed primary or secondary school, and were housewives or retired. This, along with the findings in the literature, allows us to think that the responsibility for care provision is largely left to women who do not work outside the home or to those who are retired. Altun et al.^[24] found that 78% of caregivers were women, and 34% looked after their spouses. Another study of cardiac failure patient caregivers indicated that 20% of the participants were the patients' spouse. [25] Karaaslan^[6] found that 77.3% of the family members providing care to patients with cancer were female, and 35.3% of the primary caregivers were the patient's spouse. Since many men are unfamiliar with

providing patient care due to the traditional Turkish family structure, the responsibility has historically been assigned to women, [24] which leads to these results.

More than half of the caregivers stated that their CHF patient had been receiving treatment for less than 5 years, and nearly half said that the duration of the last hospitalized treatment was less than 7 days. Other studies have reported that most CHF patients had been receiving treatment for less than 3 years, [25] and their hospitalizations also lasted less than 7 days. [26] Akın et al. [27] reported that most of the patients in their study were hospitalized more than once. A holistic evaluation of studies revealing similar findings to those of the current study would suggest that successive hospitalizations and prolongation of the period of care provision period may lead caregivers to feel burned-out and to perceive an increased caregiving burden, which makes it clear that it is not only necessary to support the patient, but also the caregivers.

Most of the caregivers in this study described the condition of cardiac failure as "difficulty with inhalation," and the disease as "cardiac failure/cardiovascular disease." Many said that they had been unable to obtain enough information from healthcare personnel. They obtained the most information about the disease from physicians and nurses; however, they did not see the information provided as satisfactory and needed more information about the recovery period. Kızıl et al.[28] remarked in their thesis that the participants wanted more information about the factors that cause the disease and its clinical course. Due to the limited number of studies about caregivers in the literature, these findings were compared with the results of studies conducted with patients, which indicated that patients obtain most information about their disease from physicians and nurses.[29] This study's caregivers were not well-informed about the disease, unable to identify it exactly, and most describe it by symptoms. The general impression is that they did not have sufficient knowledge about the disease. Most of the caregivers said that their knowledge about cardiac failure was insufficient, even though they said Turkish resources about this subject are sufficient. Inadequate knowledge, obscurity and uncertainty can increase anxiety, negatively affect mental health, and hamper adjustment to the disease.[30] Çınar et al.[31] studied patients with implantable cardiac defibrillators and found that their knowledge levels increased, their anxiety and depression levels fell, and their quality of life improved on many subscales after a planned training and follow-up program administered by nurses. The healthcare personnel who serve patients have an important role in this. Nurses should take on more responsibility in training that will support patients and caregivers. This is the legal duty of nurses, especially psychiatric consultation-liaison nurses in psycho-cardiology units, according to current law.^[20]

Many of the caregivers surveyed said that they felt sadness, worried whether their patient would recover completely, and largely coped with their feelings on their own. They did not receive support for the treatment of the illness from social institutions, or associations, and they had not participated in any training or psychosocial support program about the disease. The diagnosis caused many changes in the lives of the caregivers surveyed (fatigue/asthenia, sadness, limited social life, changed domestic and labor responsibilities, and increased expenses). Their family relationships were also negatively affected, and psychological difficulties were reported. Koyuncu^[32] emphasized that caregivers can experience physical, psychological, and social problems with profound effects. Similar studies in the literature have reported that caregivers may suffer from depression. [33,34] These findings demonstrate that caregivers often experience biopsychosocial adjustment problems and difficulties in several areas. Cardiac failure is a serious health problem that is irremediable, progressive, has a high rate of hospitalization and care and treatment costs, and it can affect the entire family.[1-3] The serious results greatly affect caregivers, and they often adjust much of their life to help the patient. This can have the effect of a limitation of activities and increased symptoms, reduced independence of the patient in daily activities, and greater dependence on the caregiver, all of which then increase the caregiver burden. These findings are noteworthy in terms of demonstrating that caregivers may need professional help and psychosocial support when they are negatively affected by the burden involved related to the disease, and that biopsychosocial support should be provided. Proper psychosocial services require comprehensive training, and a supportive and secure environment. A multidisciplinary team approach can provide support to caregivers of cardiac failure patients and help them to cope with the situation and adjust to the illness. Davis et al.^[35] have demonstrated that social support for parents who have a child with disease, knowledge about the disease, seeing other sick children, and discussions with other parents of children with the disease made the parents feel better, reduced psychological distress and eased the adjustment process. This study also indicated that 41% of caregivers found that their struggle with the illness of a patient was reduced by cooperation and solidarity among family members.

The subscale and total scale mean scores on the CBS and PAIS-SR in this study demonstrated that the caregivers reported a moderate level of stress due to providing care to their relative with cardiac failure and also indicated a moderate level of psychosocial adjustment to the illness. That is, the caregivers' psychological adjustment in the social environment, vocational environment, psychological distress, sexual relationship, and psychosocial adjustment to illness subdimensions was recorded at a moderate level, and the caregivers were affected by the illness. Tülüce^[25] found that the mean CBS score of caregivers was at a similarly moderate level with a score of 29.84±12.86. Türkmen et al. [36] reported that the health care orientation, vocational environment, social environment, and psychological distress dimensions of the patients with myocardial infarction were most affected. Hallaç[37] indicated that among patients with genital cancer, the health care orientation, domestic environment, and vocational environment subdimensions were most affected. In another study, Talaz[38] found that among diabetic foot patients, that the sexual relationship, social environment, vocational environment, and health care orientation subdimensions were most affected. Akın et al.[27] studied cardiac failure patients and found that the vocational environment, social environment, and psychological distress subdimensions were most affected. These findings demonstrate that there are as many differences as similarities among studies. Thus, psychosocial adjustment also differs in patients with chronic disease, and it is vital to provide support to both the individuals with chronic diseases and their caregivers during the psychosocial adjustment process.

There was a statistically significant relationship between the CBS mean scores of the caregivers and their subdimension mean scores on the PAIS-SR scale (vocational environment, domestic environment, sexual relationship, extended family relationships, social environment, and psychological distress) (p<0.05). This suggests that, as the distress of caregivers regarding care provision increases, their family, vocational, and social relationships change. Their sexual relationships and extended family relationships often deteriorate, and their psychological distress increases. Accordingly, their psychological adjustment to the illness deteriorates. This set of findings about the general situation clearly indicates the need to provide psychosocial support not only to cardiac failure patients, but also to their caregivers.

The caregivers of the cardiac failure patients in this study reported experiencing difficulties due to caregiving and adjusting to the illness. As distress felt due to caregiving increases, psychosocial adjustment (domestic, social, vocational, sexual, and psychosocial adjustment) to illness deteriorates. This result indicates that it is important and necessary for nurses who work in cardiology clinics to attempt to reduce the distress of not only patients, but also caregivers, in order to support adjustment to the caregiving role. In addition to medical attention, cardiac failure patients and their caregivers should be provided with psycho training, and information about cardiac failure and treatment in order to cope with difficulties, and nurses who work in cardiology clinics should have psychiatric consultation-liaison nurses provide cardiac failure patients and their families with comprehensive and continuing training programs regarding rehabilitation and psycho-cardiology.

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Keywords: Cardiac failure; caregivers; caregiver burden; patients; psychosocial adjustment.

Anahtar sözcükler: Kalp yetersizliği; bakım veren; bakım verme yükü; hasta; psikososyal uyum.