

# Caregiver Burden and Quality of Life of Caregivers of Patients with Ventricular Assist Device: A Descriptive Study

## Ventrikül Destek Cihazı Olan Hastalara Bakım Verenlerin Bakım Veren Yükü ve Yaşam Kalitesi: Tanımlayıcı Araştırma

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**ABSTRACT Objective:** The aim of this study was to determine the caregiver burden and quality of life of family members who care for patients with ventricular assisted devices. **Material and Methods:** This cross-sectional and descriptive study was conducted in the cardiovascular surgery clinic of a university hospital with 90 caregivers caring for patients who implanted ventricular assist device at least 3 months ago. A questionnaire prepared by the researchers was used to collect data. The questionnaire comprised 2 sections. The first section included questions on sociodemographic and clinical characteristics of patients and caregivers, whereas the second section included the Family Caregiver Quality of Life Scale in Heart Failure (FAMQOL) and Zarit Caregiver Burden Scale (ZCBS). Research data were collected by face-to-face interview method. Descriptive statistics, independent samples t-test and one-way analysis of variance, and Pearson's correlation were used for data analysis. **Results:** The mean FAMQOL Scale score of caregivers was 47.24±14.57 and the mean ZCBS score was 58.87±19.55. Statistically significant negative correlation was determined between the mean FAMQOL Scale and ZCBS scores. **Conclusion:** Caregiver burden and quality of life of caregivers of patients with ventricular assist was moderate. Increase in caregiver burden decreases the caregiver's quality of life.

**Keywords:** Caregiver burden; heart-assist devices; quality of life

**ÖZET Amaç:** Bu çalışmanın amacı, ventrikül destek cihazı olan hastalara bakım veren aile üyelerinin bakıcı yükünün ve yaşam kalitesinin belirlenmesidir. **Gereç ve Yöntemler:** Kesitsel ve tanımlayıcı olan bu çalışma, bir üniversite hastanesinin kalp ve damar cerrahisi kliniğinde en az 3 ay önce ventriküler destek cihazı edilmiş olan hastalara bakım veren 90 bakım veren ile yürütüldü. Verilerin toplanmasında araştırmacılar tarafından hazırlanan soru kağıdı kullanıldı. Soru kağıdı 2 bölümden oluşmaktadır. Birinci bölümde hastanın ve bakım verenin sosyodemografik ve klinik özellikleri yer alırken ikinci bölümde Kalp Yetersizliğinde Aile Bakım Verici Yaşam Kalitesi Ölçeği ve Zarit Bakıcı Yük Ölçeği yer almaktadır. Araştırma verileri yüz yüze görüşme yöntemi ile toplandı. Verilerin analizinde tanımlayıcı istatistikler, bağımsız örneklem t-testi, tek yönlü varyans analizi ve Pearson korelasyonu kullanıldı. **Bulgular:** Kalp Yetersizliğinde Aile Bakım Verici Yaşam Kalitesi Ölçeği puan ortalaması 47,24±14,57 ve Zarit Bakıcı Yük Ölçeği puan ortalaması 58,87±19,55'tir. Kalp Yetersizliğinde Aile Bakım Verici Yaşam Kalitesi Ölçeği ile Zarit Bakıcı Yük Ölçeği puan ortalamaları arasında istatistiksel olarak anlamlı negatif yönlü ilişki belirlenmiştir. **Sonuç:** Ventrikül destek cihazı olan hastalara bakım verenlerin bakım yükü ve yaşam kalitesi orta düzeydedir. Bakım yükünün artması, bakım verenini yaşam kalitesini düşürür.

**Anahtar Kelimeler:** Bakım yükü; kalp destek cihazları; yaşam kalitesi

Ventricular assist devices are the most important life-saving treatment methods in end-stage heart failure.<sup>1,2</sup> According to the Society of Thoracic Surgeons INTERMACS Database Annual Report (2006-2017), there are 25,145 patients with mechanical support devices in all over the world.<sup>3</sup> In Türkiye, according to the Cardiology-Cardiovascular Consensus Report

(2016), approximately 550 mechanical assist devices have been implanted.<sup>4</sup>

Patients who received a ventricular assist device should have to cope with many complications that may develop due to major surgery. Furthermore, these patients have lifelong advanced care requirements such as regular follow-up, medication compli-

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ance and management, diet programs, self-care, dressing changes, and equipment management.<sup>5,6</sup> Caregivers play a very important role in the quality and maintenance of care of patients with ventricular assist devices.<sup>7</sup> The lack of caregivers for patients who will be fitted with a ventricular assist device jeopardize patient treatment and care; therefore, it is considered as a contraindication.<sup>8</sup> Caregivers of patients with ventricular assist devices face a complex process that requires advanced knowledge and skills.<sup>9</sup> Caregivers need to make sacrifices in many areas for the quality and continuity of care.<sup>10,11</sup> Therefore, psychological, and physical problems are frequently observed in caregivers.<sup>12,13</sup>

Caregivers of patients with ventricular assist devices go through a difficult and complex process to provide care, which is a lifelong endeavor that often places the needs of the patients ahead of the caregivers, leading to the ignorance of their needs and decrease in their quality of life.<sup>1,7,14</sup> The close communication and cooperation of cardiac surgery nurses not only with the patient but also with their caregivers is of great importance in terms of compliance of both the patient and the caregiver with the treatment and program.<sup>15</sup> When the literature was examined, only 2 studies were found in which both the burden of care and the quality of life were measured in the caregivers of ventricular assist device patients.<sup>7,16</sup> It is seen in the literature that studies on caregiver burden are generally conducted on caregivers of patients with heart failure and studies on quality of life are performed on patients with ventricular assist devices.<sup>17,18</sup> Considering that the burden of care and quality of life are affected by physical, mental, social, emotional, economic, and cultural factors, it becomes necessary to conduct the study on different sample as well.<sup>19,20</sup> At the same time, there is not much information about the factors affecting caregiver burden and quality of life, as it may vary. In this study, it was aimed to examine the relationship between caregiver burden and quality of life of caregivers of patients with ventricular assist devices and, the factors affecting care burden and quality of life. It is thought that the findings of this study will contribute to the structuring of the education to be given to the caregivers, the creation of

strategies for care, and thus the long-term success of the treatment of these patients.

## MATERIAL AND METHODS

### RESEARCH TYPE

The study was cross-sectional and descriptive.

### SAMPLES

The study was conducted between December 2018 and December 2019 in 90 individuals caring for patients who received a ventricular assist device at least 3 months ago in a university hospital's cardiovascular surgery clinic and who were admitted to the heart-lung transplant unit outpatient clinic for follow-up. Each patient's primary caregiver was included in the study. Care was taken to include caregivers of patients who had a ventricular assist device implantation at least 3 months ago in this study. Because the first 3 months after the implantation is the critical period and it is the most difficult period for the caregiver. This could have changed the research findings.<sup>21</sup>

### DATA COLLECTION

A questionnaire prepared by the researchers was used to collect data. The first part of the questionnaire comprised the sociodemographic and clinical characteristics of patients and caregivers. The second part included the Family Caregiver Quality of Life Scale in Heart Failure (FAMQOL) and the third part included Zarit Caregiver Burden Scale (ZCBS). This collect data an average of 30 min was required to fill the questionnaire.

**FAMQOL:** FAMQOL, developed by Nauser et al., is used to evaluate the quality of life of caregivers of patients with heart failure.<sup>22</sup> The Turkish version of the scale was developed by Dülgeroğlu and Gürkan. The Cronbach's alpha internal consistency coefficient of the scale was 0.82, which in the present study was 0.90. FAMQOL is a five-point Likert-type scale that comprises the following three subdimensions: spiritual, psychological, and social well-being. There are 4 (items 13, 14, 15, and 16), 6 (items 1, 2, 3, 4, 5, and 6), and 6 (items 7, 8, 9, 10, 11, and 12) items in the spiritual, psychological, and social well-being subdimensions, respectively. Items 1-7 are scored in re-

verse. The lowest and highest scores that can be obtained are 16 and 80, respectively. Higher scores indicate higher quality of life.<sup>23</sup>

**ZCBS:** ZCBS, developed by Zarit et al., is used to assess the distress experienced by caregivers.<sup>24</sup> The Turkish version of the scale was developed by Ozlu et al. The Cronbach's alpha internal consistency coefficient of the scale was 0.83, which in the present study was 0.92. ZCBS is a five-point Likert-type scale comprising 19 items. The lowest and highest scores that can be obtained are 19 and 95, respectively. The items in the scale are related to the social and emotional domains, and higher scores indicate higher caregiver burden.<sup>25</sup>

## DATA ANALYSIS

Research data were analyzed using the SPSS for Windows 25.0 (Version 25.0. Armonk, NY: IBM Corp.) program. Mean and standard deviation, median, minimum, maximum, frequency, and percentage values were used in the analysis of descriptive data. The normality assumption of the quantitative data was separately checked in the groups using Shapiro-Wilk's W test. Mean was used for variables with normal distribution, whereas median was used for without normal distribution. Independent samples t-test and one-way analysis of variance were used for variables with normal distribution. Pearson's correlation test was used to measure the degree of association between two variables. p values of <0.05 were significant in all analyses.

## ETHICAL CONSIDERATIONS

Prior to the collection of research data, ethical approval was obtained from Clinical Research Ethics Committee of Ege University (date of decision: December 25, 2018; research decision number: 18-12.1/30) and written permission was obtained from the hospital management and relatives of patients. The research was conducted in accordance with the Declaration of Helsinki. Permission was obtained from the authors by e-mail for the scales to be used in the study.

## RESULTS

Sociodemographic, Clinical, and Caregiving Characteristics of Caregivers

The mean age of caregivers was  $46.32 \pm 11.29$  (minimum, 18; maximum, 65) years; 78.9% caregivers were women, 87.8% were married, and 50.00% were primary/secondary school graduates. Further, 86.7% caregivers had social security, 66.7% caregivers were housewife, 57.8% had less income than their expenses, and 48.9% received economic aid from the state. In addition, 81.1% caregivers had children and 45.6% lived in the district. Moreover, 63.3% patients received care from their spouse. The duration of care was at least 3 months and at most 240 months, with a mean duration of  $45.50 \pm 43.54$  months. The duration of care was at least 1 hour per day and at most 24 hours, with a mean of  $11.59 \pm 8.52$  hours. Furthermore, 48.9% caregivers had health problems after they started to provide care; 73.0% did not have any previous experience of providing care to a patient; 88.9% received training for providing care to their patients; and 51.1% received support from other people in patient care. Additionally, 56.7% stated that their family and work lives were negatively affected after they started to provide care for their patients; 42.2% stated that they experienced a change in family relations; 66.7% stated that they had physical problems due to caregiving; 60.0% stated that they had psychological problems due to caregiving; and 75.6% stated that they had financial problems due to caregiving; 68.9% stated that they experienced social problems arising from providing care such as not being able to follow current events, decrease in relations with neighbors, decrease in relations with people around them, decrease in cultural activities, and decrease in social activities at night (Table 1).

## SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF PATIENTS

The mean age of patients was  $53.01 \pm 12.30$  (minimum, 14; maximum, 71) years. Further, 78.9% were male, 88.9% were married, and 60.0% were primary/secondary school graduates. Mean duration after ventricular assist device implantation was  $34.77 \pm 30.44$  (minimum, 3; maximum, 111) months. Moreover, 91.1% had social security; and 93.3% had their separate rooms in the home (Table 2).

**TABLE 1:** Sociodemographic, clinical, caregiving characteristics of caregivers.

| Sociodemographic, clinical, and caregiving characteristics   | Number |             |
|--|--------|-------------|
|  | n      | Percent (%) |
| Gender   |        |             |
| Female   | 71     | 78.9        |
| Male   | 19     | 21.1        |
| Marital status   |        |             |
| Married  | 79     | 87.8        |
| Single   | 11     | 12.2        |
| Education status   |        |             |
| Illiterate   | 8      | 8.9         |
| Primary school/secondary school  | 45     | 50.0        |
| High school  | 25     | 27.8        |
| University   | 12     | 13.3        |
| Social security  |        |             |
| Yes  | 78     | 86.7        |
| No   | 12     | 13.3        |
| Occupation   |        |             |
| Housewife  | 60     | 66.7        |
| Worker/civil servant/self-employment   | 14     | 15.6        |
| Unemployed   | 3      | 3.3         |
| Retired  | 10     | 11.1        |
| Student  | 3      | 3.3         |
| Income and expense status  |        |             |
| Income less than expenses  | 52     | 57.8        |
| Income equal to/greater than expenses  | 38     | 42.2        |
| Status of receiving economic aid from the state<br>(Social Security Institution-disabled care pension) |        |             |
| Yes  | 44     | 48.9        |
| No   | 46     | 51.1        |
| Having a child   |        |             |
| Yes  | 73     | 81.1        |
| No   | 17     | 18.9        |
| Caregiver's relation to the patient  |        |             |
| Daughter   | 8      | 8.9         |
| Son/daughter-in-law  | 12     | 13.3        |
| Spouse   | 57     | 63.3        |
| Brother/sister   | 6      | 6.7         |
| Other<br>(mother, mother-in-law, niece, cousin, caregiver)   | 7      | 7.8         |
| Having a health problem after starting to provide care   |        |             |
| Yes  | 44     | 48.9        |
| No   | 46     | 51.1        |
| Previous care experience   |        |             |
| Yes  | 17     | 18.9        |
| No   | 73     | 81.1        |
| Caregiving training  |        |             |
| Yes  | 80     | 88.9        |
| No   | 10     | 11.1        |
| Institution providing the training (n=80)  |        |             |
| The institution where the patient is treated   | 76     | 95.0        |
| Outside the institution where the patient is being treated   | 4      | 5.0         |
| Negative effect on family and business life  |        |             |
| Yes  | 51     | 56.7        |
| No   | 39     | 43.3        |

**TABLE 1:** Sociodemographic, clinical, caregiving characteristics of caregivers (*continue*).

| Sociodemographic, clinical, and caregiving characteristics  | Number |             |
|---|--------|-------------|
|   | n      | Percent (%) |
| Changes in family relationships   |        |             |
| Yes   | 38     | 42.2        |
| No  | 52     | 57.8        |
| Physical problems arising from giving care<br>(back pain, low back pain, fatigue, change in appetite, change in the form of excretion)  |        |             |
| Yes   | 60     | 66.7        |
| No  | 30     | 33.3        |
| Psychological problems arising from giving care   |        |             |
| Yes   | 54     | 60.0        |
| No  | 36     | 40.0        |
| Financial problems arising from giving care   |        |             |
| Yes   | 68     | 75.6        |
| No  | 22     | 24.4        |
| Having social problems arising from giving care<br>(inability to follow current events, decrease in relations with neighbors, decrease in relations with people around them, decrease in cultural activities, decrease in social activities at night) |        |             |
| Yes   | 62     | 68.9        |
| No  | 28     | 31.1        |
| Total   | 90     | 100.0       |

## CAREGIVER BURDEN

The mean ZCBS score of caregivers of patients who had a ventricular assist device was  $58.87 \pm 19.55$ . The mean ZCBS score of women was significantly higher than men ( $t=3.469$ ,  $p=0.001$ ). Caregivers who were married ( $t=2.357$ ,  $p=0.021$ ), whose income was less than their expenses ( $t=3.676$ ,  $p=0.000$ ), who received financial aid from the state ( $t=2.000$ ,  $p=0.049$ ), and who had children ( $t=2.569$ ,  $p=0.012$ ) had higher mean ZCBS scores. Mean ZCBS score was significantly higher for illiterate than educational level of high school ( $F=3.278$ ,  $p=0.025$ ), for housewife than worker/civil servant/ self-employment ( $F=3.925$ ,  $p=0.006$ ), for a caregiver spouse than daughter -in-law ( $t=3.540$ ,  $p=0.010$ ). Caregivers who had health problems after starting to provide care ( $t=5.078$ ,  $p=0.000$ ) and had higher ZCBS scores. Similarly, who were negatively affected in terms of family and business life ( $t=3.014$ ,  $p=0.003$ ), who experienced changes in family relationships ( $t=-5.453$ ,  $p=0.000$ ), who had physical problems ( $t=-5.866$ ,  $p=0.000$ ), psychological problems ( $t=-4.161$ ,  $p=0.000$ ), financial problems ( $t=-3.926$ ,  $p=0.000$ ), and social problems

**TABLE 2:** Sociodemographic and clinical characteristics of patients.

| Sociodemographic and clinical characteristics | Number |             |
|---|--------|-------------|
|   | n      | Percent (%) |
| Gender  |        |             |
| Female  | 19     | 21.1        |
| Male  | 71     | 78.9        |
| Marital status                                |        |             |
| Married                                       | 80     | 88.9        |
| Single  | 10     | 11.1        |
| Educational level                             |        |             |
| Illiterate                                    | 3      | 3.3         |
| Primary school/secondary school               | 54     | 60.0        |
| High school                                   | 25     | 27.8        |
| University                                    | 8      | 8.9         |
| Social security                               |        |             |
| Yes   | 82     | 91.1        |
| No  | 8      | 8.9         |
| Personal room                                 |        |             |
| Yes   | 84     | 93.3        |
| No  | 6      | 6.7         |
| Total   | 90     | 100.0       |

( $t=-5.146$ ,  $p=0.000$ ) due to caregiving had higher ZCBS scores (Table 3). In addition, a positive correlation was observed between the daily duration of providing care (hours) and the mean ZCBS score ( $r=0.227$ ,  $p=0.003$ ), between age and the mean ZCBS score ( $r=0.269$ ,  $p=0.010$ ), between duration after ventricular assist device implantation and the mean ZCBS score ( $r=0.273$ ,  $p=0.009$ ).

### QUALITY OF LIFE OF CAREGIVERS

The mean FAMQOL score of caregivers of patients who had a ventricular assist device was  $47.24\pm 14.57$ . The mean scores of the spiritual, psychological, and social well-being subdimensions were  $14.80\pm 5.21$ ,  $16.26\pm 7.30$ , and  $16.17\pm 6.31$ , respectively. Further, whose income was less than their expenses ( $t=-2.857$ ,  $p=0.005$ ) had lower FAMQOL scores. Similarly, caregivers who had health problems after starting to provide care ( $t=-4.495$ ,  $p=0.000$ ), whose family and business lives was negatively affected ( $t=-2.484$ ,  $p=0.015$ ), and who experienced changes in family relationships ( $t=3.724$ ,  $p=0.000$ ) had lower FAMQOL scores. Moreover, those with a physical ( $t=5.516$ ,  $p=0.000$ ), psychological ( $t=4.844$ ,  $p=0.000$ ), finan-

cial ( $t=3.761$ ,  $p=0.000$ ), and social ( $t=-5.146$ ,  $p=0.000$ ) problems due to caregiving had lower FAMQOL scores (Table 3). In addition, a negative correlation was observed between duration after ventricular assist device implantation and the mean FAMQOL score ( $r=-0.250$ ,  $p=0.018$ ).

### RELATIONSHIP BETWEEN CAREGIVER BURDEN AND QUALITY OF LIFE

A significant negative correlation ( $r=-0.735$ ,  $p=0.000$ ) was observed between the ZCBS and FAMQOL mean scores as well as between the mean ZCBS and psychological well-being subdimension ( $r=-0.790$ ,  $p=0.000$ ) and social well-being subdimension ( $r=-0.707$ ,  $p=0.000$ ) scores, whereas no significant correlation was observed between the mean ZCBS scores of and spiritual well-being subdimension scores ( $r=-0.093$ ,  $p=0.384$ ) ( $r$ : Pearson's correlation coefficient: significant at  $p<0.05$ ).

## DISCUSSION

The number of patients who are receiving ventricular assist device is increasing every day; accordingly, the number of caregivers tending these patients is also increasing. Considering that the caregivers support their patients in many areas by continuing lifelong care and keeping in mind the increasing number of caregivers, it is importance to assess caregiver burden as well as their quality of life. In the present study, the burden and quality of life of caregivers of patients with ventricular assist device were examined. The majority of participants were female, married, and housewives.

### CAREGIVER BURDEN OF CAREGIVERS

In the present study, the burden of caregivers of patients with ventricular assist device was moderate ( $58.87\pm 19.55$ ). In a study conducted by Kato et al. on caregivers of patients with ventricular assist devices, the caregiver burden was mild to moderate.<sup>7</sup> In other study, the caregiver burden of caregivers of patients who had mechanical support device was moderate.<sup>16</sup>

In the present study, the caregiver burden of caregivers was similar the levels reported in literature. Moderate of caregiver burden is explained by the fact that ventricular assist device applications are

**TABLE 3:** Distribution of ZCBS and FAMQOL mean scores according to caregivers' sociodemographic, clinical, caregiving characteristics.

| Sociodemographic, clinical and caregiving characteristics   |  | ZCBS             | FAMQOL           | Spiritual well-being | Psychological well-being | Social well-being |
|---|--|------------------|------------------|----------------------|--------------------------|-------------------|
|   |  | $\bar{X} \pm SD$ | $\bar{X} \pm SD$ | $\bar{X} \pm SD$     | $\bar{X} \pm SD$         | $\bar{X} \pm SD$  |
| <b>Gender</b>   |  |                  |                  |                      |                          |                   |
| Female (n=71)   |  | 62.36±18.11      | 45.74±13.39      | 14.97±5.34           | 15.46±6.93               | 15.30±5.65        |
| Male (n=19)   |  | 45.84±19.53      | 52.84±17.63      | 14.15±4.79           | 19.26±8.03               | 19.42±7.64        |
| Test (t-p)  |  | 3.469-0.001      | -1.913-0.059     | 0.602-0.549          | -2.049-0.043             | -2.602-0.011      |
| <b>Marital status</b>   |  |                  |                  |                      |                          |                   |
| Married (n=79)  |  | 60.64±19.26      | 46.40±14.27      | 15.07±5.10           | 15.60±7.03               | 15.72±6.19        |
| Single (n=11)   |  | 46.18±17.48      | 53.27±15.95      | 12.81±5.84           | 21.0±7.79                | 19.45±6.45        |
| Test (t-p)  |  | 2.357-0.021      | -1.474-0.144     | 1.351-0.180          | -2.352-0.021             | -1.863-0.066      |
| <b>Education status</b>   |  |                  |                  |                      |                          |                   |
| Illiterate (n=8)  |  | 71.0±19.42       | 40.12±10.90      | 15.87±2.85           | 11.25±5.92               | 13.0±4.98         |
| Primary/secondary school (n=45)   |  | 62.35±19.52      | 46.91±13.50      | 15.64±5.06           | 15.51±7.05               | 15.75±5.66        |
| High school (n=25)  |  | 51.36±17.74      | 49.68±16.29      | 13.20±6.05           | 18.88±7.32               | 17.60±7.25        |
| University (n=12)   |  | 54.5±17.35       | 48.50±15.51      | 16.0±4.46            | 17.5±6.99                | 15.0±6.65         |
| Test (F-p)  |  | 3.278-0.025      | 0.890-0.450      | 1.350-0.264          | 2.668-0.053              | 1.231-0.304       |
| <b>Occupation</b>   |  |                  |                  |                      |                          |                   |
| Housewife (n=60)  |  | 64.06±18.00      | 45.60±13.07      | 15.46±5.34           | 15.03±6.73               | 15.10±5.54        |
| Worker/civil servant/self-employment (n=14)   |  | 46.57±17.75      | 53.21±14.51      | 14.14±4.72           | 20.28±7.15               | 18.78±6.53        |
| Unemployed (n=3)  |  | 52.00±20.22      | 43.66±22.18      | 11.0±6.24            | 17.33±9.86               | 15.33±7.57        |
| Retired (n=10)  |  | 52.60±21.44      | 48.70±20.95      | 13.80±5.02           | 17.10±8.47               | 17.80±8.84        |
| Student (n=3)   |  | 40.33±16.28      | 51.00±13.74      | 11.66±3.51           | 18.33±10.50              | 21.0±7.0          |
| Test (t-p)  |  | 3.925-0.006      | 0.894-0.471      | 1.064-0.380          | 1.642-0.171              | 1.704-0.157       |
| <b>Income and expense status</b>  |  |                  |                  |                      |                          |                   |
| Income less than expenses (n=52)  |  | 64.94±18.61      | 43.63±14.15      | 14.69±5.67           | 14.67±6.90               | 14.26±5.64        |
| Income equal to/greater than expenses (n=38)  |  | 50.57±17.86      | 52.18±13.83      | 14.94±4.59           | 18.44±7.35               | 18.78±6.30        |
| Test (t-p)  |  | 3.676-0.000      | -2.857-0.005     | -0.228-0.820         | -2.466-0.016             | -3.571-0.001      |
| <b>Status of receiving economic aid from the state (Social Security Institution, disabled care pension)</b> |  |                  |                  |                      |                          |                   |
| Yes (n=44)  |  | 63.02±19.18      | 45.63±14.65      | 14.43±5.65           | 15.38±7.28               | 14.81±6.20        |
| No (n=46)   |  | 54.91±9.27       | 49.73±14.20      | 15.15±4.79           | 17.10±7.30               | 17.47±6.19        |
| Test (t-p)  |  | 2.000-0.049      | -1.677-0.097     | -0.653-0.516         | -1.120-0.266             | -1.120-0.266      |
| <b>Having a child</b>   |  |                  |                  |                      |                          |                   |
| Yes (n=73)  |  | 61.35±19.52      | 46.19±14.29      | 15.19±5.18           | 15.46±7.00               | 15.53±6.25        |
| No (n=17)   |  | 48.23±16.19      | 51.76±14.35      | 13.11±5.17           | 19.70±7.77               | 18.94±5.97        |
| Test (t-p)  |  | 2.569-0.012      | -1.428-0.157     | 1.487-0.141          | -2.202-0.030             | -2.040-0.044      |

**TABLE 3:** Distribution of ZCBS and FAMQOL mean scores according to caregivers' sociodemographic, clinical, caregiving characteristics (continue).

| Sociodemographic, clinical and caregiving characteristics  |  | ZCBS            | FAMQOL          | Spiritual well-being | Psychological well-being | Social well-being |
|--|--|-----------------|-----------------|----------------------|--------------------------|-------------------|
|  |  | $\bar{X}\pm SD$ | $\bar{X}\pm SD$ | $\bar{X}\pm SD$      | $\bar{X}\pm SD$          | $\bar{X}\pm SD$   |
| Caregiver's relation to the patient  |  |                 |                 |                      |                          |                   |
| Daughter (n=8)   |  | 46.0±15.53      | 54.00±15.50     | 14.0±6.04            | 20.75±7.06               | 19.25±5.99        |
| Son/daughter-in-law (n=12)   |  | 48.16±13.48     | 48.16±12.51     | 13.08±4.81           | 17.91±6.55               | 17.16±6.22        |
| Spouse (n=57)  |  | 63.98±18.25     | 44.40±13.53     | 14.78±5.47           | 14.82±6.89               | 14.78±5.65        |
| Brother/sister (n=6)   |  | 48.33±29.30     | 56.33±20.61     | 16.66±4.67           | 19.16±8.54               | 20.50±9.64        |
| Other (mother, mother-in-law, nephew, cousin, caregiver) (n=7)   |  | 59.42±20.47     | 53.90±15.45     | 17.14±2.03           | 16.26±7.30               | 18.57±6.60        |
| Test (F-p)   |  | 3.540-0.010     | 1.947-0.110     | 0.913-0.460          | 1.819-0.133              | 2.323-0.063       |
| Having a health problem after starting to provide care   |  |                 |                 |                      |                          |                   |
| Yes (n=44)   |  | 68.3±17.11      | 40.84±13.68     | 13.70±5.84           | 13.43±6.80               | 13.70±5.28        |
| No (n=46)  |  | 49.8±17.45      | 53.36±12.75     | 15.84±4.34           | 18.97±6.77               | 18.54±6.35        |
| Test (t-p)   |  | 5.078-0.000     | -4.495-0.000    | -1.980-0.051         | -3.874-0.000             | -3.934-0.000      |
| Negative effects on family and business lives  |  |                 |                 |                      |                          |                   |
| Yes (n=51)   |  | 64.07±17.51     | 44.00±13.36     | 14.49±5.44           | 14.43±6.46               | 15.07±5.18        |
| No (n=39)  |  | 52.07±20.19     | 51.48±15.15     | 15.20±4.93           | 18.66±7.70               | 17.61±7.36        |
| Test (t-p)   |  | 3.014-0.003     | -2.484-0.015    | -0.642-0.522         | -2.766-0.007             | -1.918-0.058      |
| Changes in family relationships  |  |                 |                 |                      |                          |                   |
| Yes (n=52)   |  | 67.23±16.57     | 42.67±13.67     | 14.30±5.34           | 13.65±6.47               | 14.71±5.40        |
| No (n=38)  |  | 47.44±17.56     | 53.50±13.54     | 15.47±5.02           | 19.84±6.91               | 18.18±6.95        |
| Test (t-p)   |  | -5.453-0.000    | 3.724-0.000     | 1.048-0.298          | 4.352-0.000              | 2.665-0.009       |
| Physical problems due to caregiving (back pain, low back pain, fatigue, change in appetite, change in excretion)   |  |                 |                 |                      |                          |                   |
| Yes (n=60)   |  | 66.16±17.45     | 42.05±12.45     | 14.60±5.63           | 13.48±5.64               | 13.96±4.95        |
| No (n=30)  |  | 44.30±14.94     | 57.63±12.98     | 15.20±4.31           | 21.83±7.12               | 20.60±6.48        |
| Test (t-p)   |  | -5.866-0.000    | 5.516-0.000     | 0.512-0.610          | 6.049-0.000              | 5.390-0.000       |
| Psychological problems due to caregiving   |  |                 |                 |                      |                          |                   |
| Yes (n=54)   |  | 65.31±18.20     | 41.81±13.34     | 14.09±5.50           | 13.33±6.28               | 14.38±5.57        |
| No (n=36)  |  | 49.22±17.61     | 55.38±12.52     | 15.86±4.61           | 20.66±6.52               | 18.86±6.47        |
| Test (t-p)   |  | -4.161-0.000    | 4.844-0.000     | 1.589-0.116          | 5.339-0.000              | 3.495-0.001       |
| Financial problems due to caregiving   |  |                 |                 |                      |                          |                   |
| Yes (n=68)   |  | 63.14±18.72     | 44.17±13.83     | 14.19±5.60           | 15.07±7.15               | 14.91±5.49        |
| No (n=22)  |  | 44.0±14.53      | 56.72±12.85     | 16.68±3.21           | 19.95±6.62               | 20.09±7.15        |
| Test (t-p)   |  | -3.926-0.000    | 3.761-0.000     | 1.978-0.051          | 2.830-0.006              | 3.558-0.001       |
| Having social problems arising from giving care (inability to follow current events, decrease in relations with neighbors, decrease in relations with people around them, decrease in cultural activities, decrease in social activities at night) |  |                 |                 |                      |                          |                   |
| Yes (n=62)   |  | 65.16±17.91     | 43.35±12.88     | 14.74±5.58           | 14.40±6.69               | 14.20±5.08        |
| No (n=28)  |  | 44.96±15.60     | 44.96±15.60     | 14.92±4.37           | 20.39±6.99               | 20.53±6.65        |
| Test (t-p)   |  | -5.146-0.000    | -5.146-0.000    | 0.156-0.876          | 3.875-0.000              | 4.949-0.000       |

Correlated factors are indicated in bold; t, t-test; F, Analysis of variance; ZCBS: Zarit Caregiver Burden Scale; FAMQOL: Family Caregiver Quality of Life Scale in Heart Failure; SD: Standard deviation.

critical operations, they require complex care and lifelong treatment, and these patients have a higher level of dependence. In addition, high caregiver burden may lead to a situation wherein the needs of patients are not adequately met; therefore, there is a need to reduce the burden of caregivers of patients with ventricular assist devices.

In the present study, female gender; married, having children; low economic status; and having physical, psychological, and social problems due to caregiving were factors that increased caregiver burden. This can be explained by the low physical endurance of women, the need to divide attention from the patient to children who require care, and the need for financial resources to provide care. Thus, providing psychological, social, and financial support to caregivers is highly important in reducing caregiving burden.

#### QUALITY OF LIFE OF CAREGIVERS

In the present study, the quality of life of caregivers of patients with ventricular assist device was moderate ( $47.24 \pm 14.57$ ). The psychological and social well-being subdimension scores were higher, whereas the spiritual well-being subdimension scores were lower. Not similar results were obtained in other studies, stating that the spiritual and psychological well-being of caregivers were higher than their social well-being.<sup>22,23</sup> This can be explained by the fact that the critical conditions of the patients can affect the inner peace of the caregivers. The studies on caregivers of patients with ventricular assist devices reported that the quality of life was low and moderate.<sup>7,26</sup> In the study conducted by Kirkpatrick et al. on the caregivers of patients with left ventricular assist devices for the purpose of destination treatment, it was emphasized that the quality of life of the caregivers was low, especially their lives were affected more psychologically and socially.<sup>27,28</sup> In another study on patients with ventricular assist devices and their caregivers; it is stated that the quality of life of caregivers deteriorates significantly after ventricular assist device implantation.<sup>29</sup>

Thus, the quality of life of caregivers varies. In the present study, the quality of life of caregivers was higher than expected. This can be explained by the

improvement in physical functions of patients with ventricular assist device after surgery and consequently the patients undertaking their own treatment and care.<sup>30</sup>

In the present study, when the economic status of the caregiver was poor and the caregivers had physical, psychological, and social problems due to caregiving, their quality of life decreased. This can be explained by various factors in physical, biosocial, psychological, technical, economic, social, political, and cultural areas that affect the quality of life.<sup>31</sup> Caregiving may affect the caregivers's quality of life as well as the patients's.<sup>32</sup> In addition, the quality of life of caregivers and patients can be affected by similar factors, and in line with the findings of this study, it is thought that providing psychological, social, and financial support to caregivers will increase the quality of life of both the caregiver and patient.

#### CAREGIVER BURDEN AND QUALITY OF LIFE

In the present study, caregiver burden increased, whereas their quality of life decreased. This relationship was found to be consistent with the literature.<sup>7,33,34</sup>

Patients who have ventricular assist device need lifelong care and support because of the dramatic change in their lives.<sup>35</sup> Therefore, the burden and quality of life of caregivers who undertake the difficult, complex, stressful, and lifelong care of these patients should not be ignored. Determining the burden and quality of life of caregivers will contribute toward identifying the existing care needs. As these needs are addressed, the burden of caregivers will decrease, and the quality of life of caregivers and patients will increase. In addition, decreasing caregiver burden and increasing quality of life will lead to an increase in the quality of care, which will in turn reduce morbidity and mortality rates.

#### LIMITATIONS

Limitation of the study is that the findings cannot be generalized as the research was conducted at a single center.

#### CONCLUSION

With the increasing number of patients with ventricular assist devices, many relatives of patients are in-



volved in the long, difficult, and stressful treatment and care process of these patients. Therefore, the life of caregivers undertaking the lifelong treatment and care of these patients is negatively affected. In the present study, caregiver burden, quality of life, and related factors were examined in caregivers of patients with ventricular assist device. Thus, caregiver burden and quality of life was moderate, and increased caregiver burden decreased the quality of life. Further, caregiver burden and quality of life were affected by certain sociodemographic, clinical, and caregiving characteristics. In this direction, it is recommended that cardiovascular surgery nurses who care for patients with ventricular assist devices should provide guidance to those who give home care to these patients to anticipate the difficulties they will encounter in the care of patients and to cope with them.

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### Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

### Authorship Contributions

**Idea/Concept:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker, Serpil Bulut; **Design:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker, Serpil Bulut; **Control/Supervision:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker, Serpil Bulut; **Data Collection and/or Processing:** Nihal Çeliktürk Doruker, Serpil Bulut; **Analysis and/or Interpretation:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker; **Literature Review:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker; **Writing the Article:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker; **Critical Review:** Fatma Demir Korkmaz, Yelda Candan Dönmez, Nihal Çeliktürk Doruker.

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