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Original Article Klinik Çalışma



## The Correlation Between Quality of Life, Depression, Anxiety, Stress, and Spiritual Well-Being in Patients with Heart Failure and Family Caregivers

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#### Abstract

**Objective:** This study aimed to examine the correlation between quality of life, depression, anxiety, stress, and spiritual well-being in patients with heart failure and their family caregivers.

**Methods:** This descriptive, correlational study was carried out in a coronary outpatient clinic, located in Ankara between March-October 2018. Sixty patients with heart failure, and 60 family caregivers who providing care for these individuals, a total of 120 participants were included in the study. The Kansas City Cardiomyopathy Questionnaire, the Depression Anxiety Stress Scale, the World Health Organization Quality of Life Short Form, and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale were utilized for data collection. The data were analyzed using descriptive and correlational statistics. The Pearson correlation test was used to determine the association between the Kansas City Cardiomyopathy Questionnaire, the Depression Anxiety Stress Scale, the World Health Organization Quality of Life Short Form, and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale scores. **Results:** As quality of life scores increased in patients with heart failure, depression, anxiety, stress scores increased (p<0.05). On the other hand, as quality of life scores increased in patients with heart failure, spiritual well-being scores increased (p<0.05). With regard to family caregivers, as quality of life scores decreased, depression, anxiety, stress scores increased, and spiritual well-being scores decreased (p<0.05). Moreover, as quality of life and spiritual well-being scores of patients with heart failure decreased, depression, anxiety, stress scores of family caregivers increased (p<0.05).

**Conclusion:** This study revealed that as quality of life and spiritual well-being scores decreased, depression, anxiety, stress scores of both patients with heart failure and family caregivers increased. Further education and counseling programs targeting patients with heart failure and their family caregivers are recommended to assess both patients' and family caregivers' psychological health and spiritual well-being.

Keywords: Caregiver; depression; heart failure; quality of life; spirituality.

## Kalp Yetersizliği Hastaları ve Bakım Veren Aile Üyelerinde Yaşam Kalitesi, Depresyon, Anksiyete, Stres ve Spiritüel İyilik Hali Arasındaki İlişki

#### Özet

Amaç: Bu araştırmanın amacı, kalp yetersizliği hastaları ve bu hastalara bakım veren aile üyelerinde yaşam kalitesi, depresyon, anksiyete, stres ve spiritüel iyilik hali durumları arasındaki ilişkiyi belirlemekti.

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Yöntemler: Bu tanımlayıcı, korelasyonel araştırma, Ankara'da bir koroner bakım ünitesinde Mart-Ekim 2018 tarihleri arasında yürütüldü. Çalışmaya, 60 kalp yetersizliği olan hasta ve bu hastalara bakım veren 60 aile üyesi olmak üzere toplam 120 kişi dahil edildi. Araştırma verilerinin toplanmasında Kansas City Kardiyomiyopati Anketi, Depresyon, Anksiyete, Stres Ölçeği, Dünya Sağlık Örgütü Yaşam Kalitesi Ölçeği-Kısa Formu ve Spiritüel İyilik Hali Ölçeği kullanıldı. Araştırma verileri tanımlayıcı ve korelasyonel istatistikler ile analiz edildi. Kansas City Kardiyomiyopati Anketi, Depresyon, Anksiyete, Stres Ölçeği, Dünya Sağlık Örgütü Yaşam Kalitesi Ölçeği-Kısa Formu ve Spiritüel İyilik Hali Ölçeği puanları arasındaki ilişkinin belirlenmesinde Pearson korelasyon testi kullanıldı.

**Bulgular:** Hastaların yaşam kalite puanları azaldıkça depresyon, anksiyete, stres puanlarının arttığı bulundu (p<0.05). Öte yandan, hastaların yaşam kalitesi puanları arttıkça, spiritüel iyilik halinin de yükseldiği belirlendi (p<0.05). Bakım verenler ele alındığında, benzer şekilde yaşam kalitesi puanları azaldıkça depresyon, anksiyete, stres puanlarının arttığı ve spiritüel iyilik halinin azaldığı bulundu (p<0.05). Ayrıca, hastaların yaşam kalitesi ve spiritüel iyilik hali puanları azaldıkça bakım verenlerin de depresyon, anksiyete, stres puanların azaldıkça bakım verenlerin de depresyon, anksiyete, stres puanları azaldıkça bakım verenlerin de depresyon, anksiyete, stres puanlarının arttığı tespit edildi (p<0.05).

Sonuç: Bu çalışma, hem kalp yetersizliği hastalarında hem de bakım verenlerde yaşam kalitesi azaldıkça depresyon, anksiyete, stres durumunun arttığını ve spiritüel iyilik halinin azaldığını ortaya çıkardı. İleride kalp yetersizliği hastaları ve bu hastalara bakım veren aile üyeleri için düzenlenen eğitim ve danışmanlık programlarının hem hastaların hem de bakım veren aile üyelerinin psikososyal durumlarını ve spiritüel iyilik hallerini değerlendirmesi önerildi.

Anahtar sözcükler: Bakım veren; depresyon; kalp yetersizliği; spiritüalite; yaşam kalitesi.

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eart failure (HF) being a progressive, common, and Chronic disease, is a substantial reason of morbidity and mortality in the worldwide.<sup>[1-3]</sup> Patients with HF have symptoms such as difficulty in breathing, excessive tiredness, leg swelling, limitation of physical capacity, sleep disturbance, anxiety and depression. Patients with HF suffer from physical limitation, social isolation and decreased quality of life (QoL) due to unpredictable course of the illness, repeated hospitalizations, and increased depression and anxiety levels.<sup>[4-6]</sup> With the progress in the disease, patients with HF have difficulties in daily living activities such as walking, clothing, and eating, and therefore they become dependent on family members.<sup>[5, 7, 8]</sup> Consequently, patients with HF who do not effectively cope with poor physical, psychological and social functioning limitations may experience depression. Moreover, environmental factors including family and social surroundings increase both physical and emotional burden of the disease in patients with HF. The changes in physical health, psychological condition, level of dependency and social relationships may be influential on spiritual wellbeing (SWB).<sup>[9-11]</sup> On the other hand, quantity and quality of social relationships may affect subjective well-being that directly associated with spiritual status. Generally, as the disease severity increases, patients may rely on family caregivers to provide security and a sense of belongingness.<sup>[12]</sup>

Significantly more, HF imposes major problems not only patients but also family caregivers starting from the diagnosis due to requiring the support of caregivers. Family caregivers play a unique role in disease management through providing both physical and emotional support for patients with HF.<sup>[12, 13]</sup> In this process, family caregivers of patients with HF cope with numerous symptoms, behaviors, loss of physical capacity, diet, and the self-care programs of patients and face a major problems.<sup>[7, 13, 14]</sup> In time, they experience important physical, psychological, social, financial problems and even caregiver burden. In addition, a combination of these factors has a strong potential impact on caregivers' psychological status including depression, anxiety, stress, QoL and SWB.<sup>[7, 15-17]</sup> However, family caregivers' QoL and psychological condition are often neglected. In fact, this status is considered as a serious gap in health care system.<sup>[18]</sup>

Considering the previous studies, mostly of them have been performed in the caregivers of patients with Alzheimer, stroke, cancer, or psychiatric disorder,<sup>[13, 19-22]</sup> while the caregivers of patients with HF has taken less attention in spite of high prevalence of HF, and high care demands.<sup>[7, 23, 24]</sup> On the other hand, spiritual needs of patients with HF and family caregivers are recently recognizing in Turkish health care system, and the information is lack of SWB in patients with HF and family caregivers. Although studies reporting problems among patients with HF and family caregivers have been published,<sup>[24,</sup> <sup>25</sup> no previous research have investigated the correlation between QoL, depression, anxiety, stress, and SWB of patients with HF and their family caregivers. Therefore, considering the significance and lack of studies on the psychological health and SWB of patients with HF and family caregivers in Turkey, the present study aimed to investigate the correlation between QoL, depression, anxiety,

stress, and SWB in patients with HF and family caregivers, concurrently. Toward this aim, the following research questions were developed as follows:

- How are QoL, depression, anxiety, stress, and SWB scores in patients with HF and their family caregivers?
- Do QoL, depression, anxiety, stress, and SWB scores differ according to socio-demographic characteristics of patients with HF and their family caregivers?
- Is there a correlation between QoL, depression, anxiety, stress, and SWB scores in patients with HF and their family caregivers?

#### **Material and Methods**

#### **Study Design**

A descriptive-correlational design was utilized in the current study.

#### **Study Sample and Setting**

The present study was conducted in a coronary clinic of a university hospital located in Ankara, Turkey, between March and October 2018. Patients were included if they (a) were older than 18 years old, (b) were diagnosed with HF, (c) had no psychiatric diagnosis and communication problems, (d) accepted to participate to this study. The exclusion criteria; patients had (a) no family caregiver, (b) a history of psychiatric illness (e.g., psychotic illness, bipolar illness, and schizophrenia) as the responses of these patients may cause misinterpretation of scale scores focusing on psychosocial status and SWB, (c) communication problems, and (d) refused to participate to the study. Additionally, family caregivers were included if they (a) were older than 18 years old, (b) had no cognitive or communication problems, (c) had provided care to a patient with HF during at least six months, and (d) volunteered to participate to this study. Sixty patients with HF and 60 family caregivers who providing care for these individuals, a total of 120 participants were included in the current study (Fig. 1). Due to lack of any study that focusing on correlation between QoL, depression, anxiety, stress, and SWB scores of patients HF and their caregivers, the authors could not utilize a priori power analysis.<sup>[26]</sup> After completing data collection, the power of the study was calculated using the G Power 3.0 program. In this context, the power of this study was defined as 95% based on completed data set (60 HF patientsfamily caregiver dyads): with 0.80 correlation between the WHOQOL-BREF and the DASS scores, minimum effect size (0.3), and alpha value 0.05.

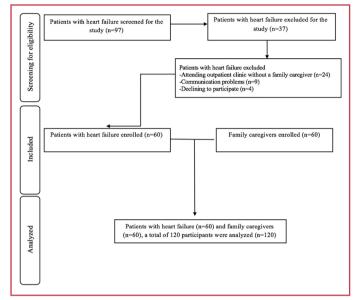


Figure 1. Flow diagram of the study sample.

#### **Outcome Measures**

The Patient Information Form: The form was created by researchers based on previous studies and included 11 guestions: age, gender, marital condition, educational status, income level, time of HF diagnosis, value of ejection fraction (EF), use of supportive device, HF stage based on the New York Heart Association (NYHA) classification, drug regimens, and comorbid diseases.<sup>[5-7, 12]</sup> The responses were obtained through face-to-face interview with HF patients. The gender was coded as female and male. Educational status was coded as "primary school", "high school" and "university". Marital condition was coded as "single (never married or divorced) and "married". In addition, income level was defined based on the average income level in Turkey, and coded "lower", "moderate", and "higher". The clinical data including time of HF diagnosis, NYHA class, EF value, drug regimens, and comorbid diseases such as hypertension, diabetes mellitus, and hyperlipidemia were obtained from medical records. As for the use of supportive device, all medical records of patients were checked, and coded as "yes-presence of any device" and "no-not presence of any device".

**Family Caregiver Information Form:** The form was created by researchers based on previous studies and involved 10 questions: age, gender, marital condition, educational status, place of residence, income level, employment, degree of relationship to patient, duration of caregiving, and daily caregiving time.<sup>[11, 14, 24, 27]</sup> Same codes were also utilized for socio-demographic characteristics of family caregivers such as gender, employment status and income level. With regard to living place, it was coded as "rural"

or "urban". Relationship with care recipient was coded as "spouse", "son/daughter" and "other: mother or father". Duration of caregiving, and daily caregiving time were recorded based on family caregiver's statements, and then coded according to distribution.

Kansas City Cardiomyopathy Questionnaire (KCCQ): This scale was formed by Green et al. (2000) and reported a Cronbach's alpha value of 0.88 for symptoms, 0.90 for physical limitation, 0.78 for QoL, 0.86 for social limitation and 0.62 for self-efficacy. The instrument consists of 23 items and measures physical function (1 item), symptoms (2-9 items), social function (10 item), self-efficacy (11-12 items), and QoL (13-15 items) of patients with HF. Each of the items is answered on a five-or seven-point Likert scale. Scale scores are standardized to vary from 0 to 100, with lower scores demonstrating higher symptoms, worse health status, and lower disease-specific QOL.<sup>[28]</sup> Duruöz et al. performed Turkish validity and reliability of the KCCQ. In this study, the Cronbach's alpha value was found to be 0.94 for patients with HF. Total scores of KCCQ, varying from 0 to 50 points indicate poor QOL, 50 to 75 points indicate moderate QoL, and 75 to 100 points indicate good QOL.

The Depression Anxiety Stress Scale (DASS): The scale was designed by Lovibond et al. (1995) and Cronbach's alpha value of depression, anxiety and stress domains was reported 0.91, 0.84, and 0.90, respectively. The scale comprises of 42-items and evaluates the psychological conditions including depression, anxiety and stress. Each item of the scale is rated from 0 (strongly disagree) to 3 (totally agree). Lower scores indicate lower depression, anxiety, or stress.<sup>[29]</sup> The Turkish validity and reliability of the DASS was carried out by Bilgel and Bayram (2009), who reported a Cronbach's alpha value of 0.92 for depression, 0.88 for anxiety, and 0.86 for stress.<sup>[30]</sup> The Cronbach's alpha value was found to be 0.89 for patients with HF and 0.91 for family caregivers in this study. The scores obtained from depression domain of DASS, between 0-9 points are considered as healthy, 10-13 points are poor, 14-20 points are moderate, 20-27 points are advanced, and 28 and above are very advanced depression. In terms of anxiety domain, 0-7 points are considered as healthy, 8-9 points are poor, 10-14 points are moderate, 15-19 points are advanced, and 20 and above points are very advanced anxiety. In terms of stress domain, 0-14 points are considered as healthy, 15-18 points are poor, 19-25 points are moderate, 26-33 points are advanced, and 34 and above are very advanced stress.

The Functional Assessment of Chronic Illness Therapy– Spiritual Well-Being Scale (FACIT–Sp): This scale was designed by Peterman et al. (2002), and reported a Cronbach's alpha value of 0.86. The instrument consists of 12 items and three domains including peace (items 1, 4, 6, and 7), meaning (items 2, 3, 5, and 8) and faith (items 9–12). Each item on the scale is rated from 0 (not at all) to 4 (very much). The fourth and eighth items of the scale are scored reverse (from 0= very much to 4=not at all). The range of total score changes from 0 to 48, with lower scores show lower SWB. <sup>[31]</sup> The validity and reliability for Turkish version was studied by Aktürk et al.<sup>[32]</sup> (2017), who reported a Cronbach's alpha value of 0.87. The Cronbach's alpha value was found to be 0.77 for patients with HF and 0.86 for family caregivers in the present study. FACIT-Sp has no cut-off points. However, in previous studies, the total scores obtained from FACIT-Sp, varying between 0-24 points indicate lower SWB and 25-48 points show higher SWB.

The World Health Organization Quality of Life Short Form (WHOQOL-BREF): This scale consists of 27 items and a Cronbach's alpha value of psychological condition, physical condition, environment, and social relationships domains was reported 0.81, 0.82, 0.80, and 0.68, respectively. Each item is scored from 1 (never) to 5 (always). The third, fourth, 26th and 27th items of the scale are scored reverse (from 1= always to 5=never). The total score is ranged from 27 to 135, with lower scores demonstrating lower QoL. The validity and reliability for Turkish version was studied by Eser et al (1999), and had a Cronbach's alpha of 0.66 for psychological condition, 0.83 for physical condition, 0.73 for environment, and 0.53 for social relationships domains.<sup>[33]</sup> In this study, the Cronbach's alpha value was calculated to be 0.92 for family caregivers. The cut-off point for the scale is 60 points. Between 0-60 points indicate poor QoL, and 60 and above points indicate good QoL.

#### **Data Collection Procedure**

The aim of this study was explained to the eligible patients with HF and their family caregivers. The co-author interviewed patients with HF face-to-face, and completed the patient information form, KCCQ, DASS, and FACIT–Sp. After patients' data collection was completed, the co-author achieved the data of family caregivers one-on-one in a separate room using the caregiver information form, WHOQOL-BREF, DASS, and FACIT-Sp. Each data collection interview took approximately 30 min.

#### **Ethical Considerations**

The Ethics Committee of X University reviewed and approved the current study (Decision Number: GO 17/338). Patients with HF and their family caregivers were separately clarified the study's purpose and obtained a verbal and explicit consent from all the participants. Patients with HF and their family caregivers were explained that they could

leave from the study at any time and would not be given any incentive for the participating in the study.

#### Data Analysis

The data analyses were performed with SPSS IBM 25.0 software. The assumption of normality was assessed using the Shapiro–Wilk test. Frequency and percentage were utilized for categorical data, while mean and standard deviation were used for numerical data. The differences between socio-demographic characteristics of patients with HF and their family caregivers' and scale scores were tested using Kruskal-Wallis test, Mann-Whitney U test, and Bonferroni test. The Pearson's correlation test was used to determine the correlation between the KCCQ, the WHOQOL-BREF, the DASS, and the FACIT–Sp scale scores. Value of p<0.05 was considered statistically significant.

#### Results

#### **Socio-demographic Characteristics of Participants**

The mean age of patients with HF was  $65.5\pm12.4$  years, 58.3% of them were males. The great majority of patients (80%) had primary school degree. Almost three-fourth of the patients were married (75.0%) and had a moderateincome level (70.0%). The mean time of HF diagnosis was  $5.9\pm4.8$  years and the mean EF value was  $31.0\pm10.3\%$ . According to NYHA functional classification, 40% of the patients had stage II HF. More than half of patients with HF were using pace-maker (58.3%). All patients had at least one comorbid disease including hypertension (80.0%), diabetes mellitus (50.0%), hyperlipidemia (48.3%), coronary artery disease (26.7%), arrhythmia (26.7%), and chronic obstructive pulmonary disease (20.0%) (Table 1).

Considering socio-demographic characteristics of family caregivers, the mean age was 52.0±13.5 years. Similar to patients with HF, family caregivers were substantially male (75.0%) and all were married. Most of the family caregivers (80.0%) had primary school degree, and were unemployed (81.7%). When examining the relationship between patients with HF and family caregivers, we determined that mostly of family caregivers were the spouses of patients with HF (53.3%), followed by their children (38.3%). Most of the family caregivers (75.0%) provided care for patients with HF 5 years and below. Forty percent of the family caregivers had provided care more than 8 hours per day (Table 1).

## Quality of Life, Depression, Anxiety, Stress, and Spiritual Well-Being Scores of Patients with HF

The mean of total KCCQ scores were 38.7±14.3 which indi-

| Table 1. Socio-demographic characteristics of participants (n=120) |                            |                             |  |  |  |  |  |
|--|----------------------------|-----------------------------|--|--|--|--|--|
| Characteristic   | Patients with HF<br>(n=60) | Family Caregivers<br>(n=60) |  |  |  |  |  |
| Age (year), mean (SD)  | 65.5 (12.4)                | 52.0 (13.5)                 |  |  |  |  |  |
| Gender   | % (n)                      | % (n)                       |  |  |  |  |  |
| Male   | 58.3 (35)                  | 75.0 (45)                   |  |  |  |  |  |
| Female   | 41.7 (25)                  | 25.0 (15)                   |  |  |  |  |  |
| Educational status   | . ,                        | . ,                         |  |  |  |  |  |
| Primary school   | 80.0 (48)                  | 80.0 (48)                   |  |  |  |  |  |
| High school  | 15.0 (9)                   | 11.7 (7)                    |  |  |  |  |  |
| University   | 5.0 (3)                    | 8.3 (5)                     |  |  |  |  |  |
| Marital status   |                            |                             |  |  |  |  |  |
| Married  | 75.0 (45)                  | 100.0 (60)                  |  |  |  |  |  |
| Widowed  | 25.0 (15)                  | 0.0 (0)                     |  |  |  |  |  |
| Income level   | 23.0 (13)                  | 0.0 (0)                     |  |  |  |  |  |
| Low  | 25.0 (15)                  | 13.3 (8)                    |  |  |  |  |  |
| Moderate   | 70.0 (42)                  | 85.0 (51)                   |  |  |  |  |  |
| High   | 5.0 (3)                    | 1.7 (1)                     |  |  |  |  |  |
| Diagnose time of HF,   | 5.9 (4.8)                  | 1.7 (1)                     |  |  |  |  |  |
| mean (SD <sup>a</sup> )  | 5.5 (1.6)                  |                             |  |  |  |  |  |
| EF value %, mean (SD <sup>a</sup> )                                | 31.0 (10.3)                |                             |  |  |  |  |  |
| NYHA class   | 51.0 (10.5)                |                             |  |  |  |  |  |
|  | 21.7 (13)                  |                             |  |  |  |  |  |
|  | 40.0 (24)                  |                             |  |  |  |  |  |
|  | 26.7 (16)                  |                             |  |  |  |  |  |
| IV   | 11.6 (7)                   |                             |  |  |  |  |  |
| Pacemaker usage  | 11.0(7)                    |                             |  |  |  |  |  |
| Yes  | E0 2 (2E)                  |                             |  |  |  |  |  |
| No   | 58.3 (35)<br>41.7 (25)     |                             |  |  |  |  |  |
| Comorbidities  | 41.7 (23)                  | -                           |  |  |  |  |  |
|  | 80.0 (48)                  |                             |  |  |  |  |  |
| Hypertension<br>Diabetes mellitus                                  |                            |                             |  |  |  |  |  |
|  | 50.0 (30)                  |                             |  |  |  |  |  |
| Hyperlipidemia   | 48.3 (29)                  |                             |  |  |  |  |  |
| Coronary artery disease<br>Arrhythmia                              |                            |                             |  |  |  |  |  |
|  | 26.7 (16)                  |                             |  |  |  |  |  |
| COPD   | 20.0 (12)                  |                             |  |  |  |  |  |
| Employment   |                            | 01.7(40)                    |  |  |  |  |  |
| Employed   | -                          | 81.7 (49)                   |  |  |  |  |  |
| Unemployed   |                            | 18.3 (11)                   |  |  |  |  |  |
| Relationship   |                            | F2 2 (22)                   |  |  |  |  |  |
| Spouse   | -                          | 53.3 (32)                   |  |  |  |  |  |
| Son/Daughter   |                            | 38.3 (23)                   |  |  |  |  |  |
| Other  |                            | 8.4 (5)                     |  |  |  |  |  |
| Duration of caregiving   |                            |                             |  |  |  |  |  |
| ≤5 years   | -                          | 75.0 (45)                   |  |  |  |  |  |
| >5 years   |                            | 25.0 (15)                   |  |  |  |  |  |
| Daily caregiving time  |                            | 22.2 (20)                   |  |  |  |  |  |
| ≤5 hours   | -                          | 33.3 (20)                   |  |  |  |  |  |
| 5-8 hours  |                            | 26.7 (16)                   |  |  |  |  |  |
| >8 hours   |                            | 40.0 (24)                   |  |  |  |  |  |

Table 1. Socio-demographic characteristics of participants (n=120)

n: The number of participants; SD: Standard deviation; HF: Heart failure; EF: Ejection fraction; NYHA: New York heart association; COPD: Chronic obstructive pulmonary disease.

cates poor QOL, as for KCCQ's domains scores were found as  $37.4\pm17.4$  points for physical limitation,  $36.5\pm16.6$  for symptoms,  $32.0\pm14.9$  for self-efficacy, and  $38.5\pm17.9$  for QoL. The mean of total DASS scores were found to be 17.6±11.2 which shows healthy status, the subscales sores of DASS were 3.9±3.8 points for depression, 6.3±3.8 for anxiety, and 6.8±5.0 for stress domains. The mean of total spiritual well-being scores was 36.2±5.0, which demonstrates good spiritual status, and the domain scores of FACIT-Sp were found to be 11.7±2.3, 13.4±2.0, and 10.9±2.6 points for faith, meaning and peace, respectively (Table 2). No significant difference was found between gender of patients with HF and the KCCQ (X2=0.998, p>0.05), DASS (X<sup>2</sup>=-0.886, p>0.05), and the FACIT-Sp scale scores ( $X^2$ =-0.707, p>0.05). Besides, there was no statistically difference between HF stage of patients with HF and the KCCQ (X<sup>2</sup>=2.819, p>0.05), DASS ( $X^2$ =3.338, p>0.05), and the FACIT-Sp scale scores (X<sup>2</sup>=1.454, p>0.05). However, age of patients with HF was negatively associated with the KCCQ scores (r=-0.373, p<0.05) (Table 3). In considering the relationship between the KCCQ, and the DASS scales scores of patients with HF, the results revealed a moderately negative correlation between these two scales (r=-0.611, p<0.05). When considering Pearson correlation test results, a moderately positive correlation was explored between the QOL and SWB in the study (r=0.354, p<0.05). In addition, there was a negative correlation between the DASS and the FACIT-Sp scales (r=-0.514, p<0.05) (Fig. 2).

#### Quality of Life, Depression, Anxiety, Stress, and Spiritual Well-Being Scores of Family Caregivers

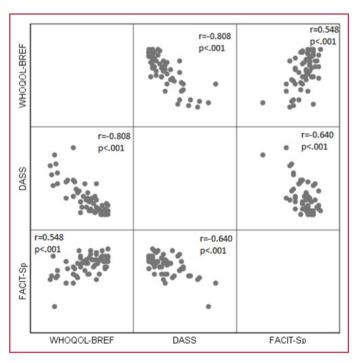
Considering the scales scores of family caregivers, the mean of total WHOQOL-BREF scores was 118.2±11.4, which demonstrates good QOL and the mean scores of WHOQOL-BREF domains were 30.5±3.6 points for physical health, 26.5±2.8 for psychological, 13.8±1.3 for social relationships and 34.5±3.4 for environment, respectively. The mean of total DASS scores was 9.1±8.6, which indicates healthy status, the remaining scores for domains were 2.2±2.2 points for depression, 2.3±2.7 for anxiety, and 4.6±4.4 for stress. The mean of total FACIT-Sp scores was found to be 39.0±5.6, which shows good spiritual status, scores of FACIT-Sp domains were 12.3±2.3, 14.2±2.1, and 12.4±2.7 points for faith, meaning and peace, respectively. The WHOQOL-BREF (X<sup>2</sup>=2.110; 2.094, p<0.05) and DASS scores (X<sup>2</sup>=-3.527; -2.921, p<0.05) were significantly differed in terms of family caregivers' gender, and work status. There was a significant difference between daily caregiving time, and the WHO-QOL-BREF (X<sup>2</sup>=6.966, p<0.05) and DASS scores (X<sup>2</sup>=7.665, p<0.05). In addition, there was no statistically difference between family caregivers' relationship with patients with HF and duration of caregiving, and the aforementioned three scale scores (p>0.05) (Table 3). When examining the correlation between the WHOQOL-BREF, and the DASS scores for the family caregivers, there was a strong negative

| Scales               | Patients with HF |             | Family Caregivers |              |  |
|----------------------|------------------|-------------|-------------------|--------------|--|
|                      | Min-Max          | Mean (SD)   | Min-Max           | Mean (SD)    |  |
| KCCQ                 | 27.2-54.5        | 38.7 (14.3) | -                 | -            |  |
| Physical limitation  | 22.4-54.3        | 37.4 (17.4) | -                 | -            |  |
| Symptoms             | 26.3-47.5        | 36.5 (16.6) | -                 | -            |  |
| Self-efficacy        | 25.7-41.2        | 32.0 (14.9) | -                 | -            |  |
| Quality of life      | 24.1-48.7        | 38.5 (17.9) | -                 | -            |  |
| DASS                 | 9.0-37.0         | 17.6 (11.2) | 7.0-25.0          | 9.1 (8.6)    |  |
| Depression           | 1.0-9.0          | 3.9 (3.8)   | 1.0-9.0           | 2.2 (2.2)    |  |
| Anxiety              | 3.0-12.0         | 6.3 (3.8)   | 2.0-5.0           | 2.3 (2.7)    |  |
| Stress               | 3.0-14.0         | 6.8 (5.0)   | 3.0-11.0          | 4.6 (4.4)    |  |
| FACIT-Sp             | 29.0-48.0        | 36.2 (5.0)  | 35.0-48.0         | 39.0 (5.6)   |  |
| Faith                | 8.0-16.0         | 11.7 (2.3)  | 10.0-16.0         | 12.3 (2.3)   |  |
| Meaning              | 11.0-16.0        | 13.4 (2.0)  | 10.0-16.0         | 14.2 (2.1)   |  |
| Peace                | 9.0-16.0         | 10.9 (2.6)  | 8.0-16.0          | 12.4 (2.7)   |  |
| WHOQOL-BREF          | -                | -           | 87.0-135.0        | 118.2 (11.4) |  |
| Physical             | -                | -           | 28.0-35.0         | 30.5 (3.6)   |  |
| Psychological        | -                | -           | 22.0-29.0         | 26.5 (2.8)   |  |
| Social relationships | -                | -           | 8.0-15.0          | 13.8 (1.3)   |  |
| Environment          | -                | -           | 28.0-40.0         | 34.5 (3.4)   |  |

SD: Standard deviation; HF: Heart failure; KCCQ: Kansas City Cardiomyopathy Questionnaire, DASS: The Depression Anxiety Stress Scale, FACIT-Sp: The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale, WHOQOL-BREF: The World Health Organization Quality of Life Short Form.

|                        | Patients with HF  |             |                |        |                |           |  |
|------------------------|-------------------|-------------|----------------|--------|----------------|-----------|--|
|                        | KCC               | Q           | DASS           |        | FACIT-Sp       |           |  |
| Patient's variables    | Test statistic    | р           | Test statistic | р      | Test statistic | р         |  |
| Age                    | -0.373*           | 0.003       | 0.083*         | 0.526  | -0.136*        | 0.300     |  |
| Gender                 | 0.998**           | 0.318       | -0.886**       | 0.376  | -0.707**       | 0.479     |  |
| HF stage               | 2.819***          | 0.420       | 3.338***       | 0.342  | 1.454***       | 0.693     |  |
| Diagnosis time         | -0.244*           | 0.060       | 0.035*         | 0.789  | 0.011*         | 0.936     |  |
|                        | Family Caregivers |             |                |        |                |           |  |
| Caregiver's variables  | WHOQOL-BREF       |             | DASS           |        | FACIT- Sp      |           |  |
| Age                    | -0.182*           | 0.163       | 0.092*         | 0.485  | -0.063*        | 0.632     |  |
| Gender                 | 2.110**           | 0.035       | -3.527**       | <0.001 | 0.548**        | 0.584     |  |
| Relationship           | 1.470***          | 0.479       | 2.179***       | 0.336  | 0.603***       | 0.740     |  |
| Work status            | 2,094c**          | 0.036       | -2,921**       | 0.003  | 1.044**        | 0.296     |  |
| Daily caregiving time  | 6.966***          | 0.031       | 7.665***       | 0.022  | 1.328***       | 0.515     |  |
| Duration of caregiving | -1.290**          | 0.197       | 0.873**        | 0.383  | 0.274**        | 0.784     |  |
| Patient's scales       | WHOQO             | WHOQOL-BREF |                | DASS   |                | FACIT- Sp |  |
| KCCQ                   | 0.434*            | 0.001       | -0.390*        | 0.002  | 0.064*         | 0.625     |  |
| DASS                   | -0.506*           | < 0.001     | 0.509*         | <0.001 | -0.321*        | 0.012     |  |
| FACIT-Sp               | 0.575*            | 0.001       | -0.513*        | <0.001 | 0.576*         | <.001     |  |

KCCQ: Kansas City Cardiomyopathy Questionnaire, DASS: The Depression Anxiety Stress Scale, FACIT-Sp: The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale, WHOQOL-BREF: The World Health Organization Quality of Life Short Form; \*: Pearson's Correlation Test; \*\*: Mann-Whitney U Test Value; \*\*\*: Kruskal-Wallis Test Value.



**Figure 3.** Correlation between the WHOQOL-BREF, DASS, and FACIT-Sp scores of family caregivers.

WHOQOL-BREF: The World Health Organization Quality of Life Short Form; DASS: The Depression Anxiety Stress Scale; FACIT-Sp: The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale; r: Pearson's Correlation Test. correlation between the two scales (r=-0.808, p<0.05). The results showed that there was a moderately positive correlation between the WHOQOL-BREF and FACIT-Sp scales (r=0.548, p<0.05). Furthermore, there was a negative correlation between the DASS and the FACIT-Sp scales of family caregivers (r=-0.640, p<0.05) (Fig. 2).

# Correlation Between the Scale Scores of Patients with HF and Family Caregivers

The present study found that the WHOQOL-BREF total score of family caregivers was moderately correlated with the KCCQ and the FACIT-Sp total scores of patients with HF, respectively (r=0.434, r=0.575, p<0.05). In addition, there was a moderately negative correlation between the WHO-QOL-BREF total scores of family caregivers and the DASS total scores of patients with HF (r=-0.506, p<0.05) (Table 3).

Considering the DASS total scores of family caregivers, these scores were negatively correlated with the KCCQ and the FACIT-Sp total scores of patients with HF, respectively (r=-0.390, r=-0.513, p<0.05). Otherwise, there was a moderately positive correlation between the DASS total scores of family caregivers and patients with HF (r=0.509, p<0.05). Taking into consideration SWB, the FACIT-Sp total score of

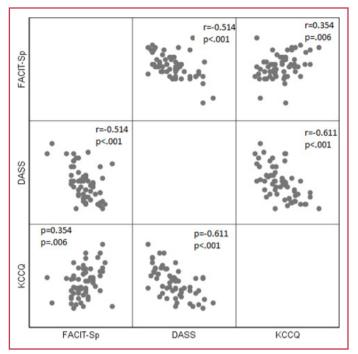


Figure 2. Correlation between the KCCQ, DASS, and FACIT-Sp scores of patients with HF.

KCCQ: Kansas City Cardiomyopathy Questionnaire; DASS: The Depression Anxiety Stress Scale; FACIT-Sp: The Functional Assessment of Chronic Illness Therapy–Spiritual Well-being Scale; r: Pearson's Correlation Test.

family caregivers was negatively correlated with the DASS total scores of patients with HF (r=-0.321, p<0.05). In addition, there was a moderately positive correlation between the FACIT-Sp total scores of family caregivers and patients with HF (r=0.576, p<0.05). However, no correlation was found between the FACIT-Sp scores of family caregivers and the KCCQ scores of patients with HF (r=0.064, p>0.05) (Table 3).

#### Discussion

To our knowledge, studies have not examined the correlation between the QoL, psychosocial health including depression, anxiety, stress and SWB in patients with HF and family caregivers, concurrently. Thus, this is the preliminary study examining the correlation between QoL, psychological health and SWB in patients with HF and their family caregivers in Turkey. Study results revealed that patients with HF had poor QOL, were healthy in terms of depression, anxiety, stress, and had good SWB. With regard to family caregivers, we found that family caregivers of patients with HF had good QOL, were healthy in terms of depression, anxiety, stress, and had good SWB. Another striking finding of this study was that as QOL scores increased, the scores of depressions, anxiety, stress decreased, and SWB scores increased both patients with HF, and their family caregivers.

Previous studies reported that patients with HF had multidimensional problems throughout the disease process. The nature of the disease, unpredictable trajectory and unexpected death may cause heavy symptom burden, which may heighten their distress.<sup>[23]</sup> Limitations in physical activities, increased symptom burden including shortness of breath, fatigue, edema and sleep disturbance make patients with HF dependent on someone's assistance and accompanying social life changes can deteriorate healthrelated QoL.<sup>[10, 34]</sup> Therefore, depression may be an essential predictor of health status in patients with HF. Depression is thought to worsen the perception and lead to over-reporting of HF symptoms. Depression is also associated with poor compliance to healthy behavior's and engagement of additional risks factors like smoking, alcohol consumption, sedentary life, unhealthy diet and substance abuse, which may lead to worsening of the severity of depression.<sup>[6, 35, 36]</sup> Mostly of the studies identified the high prevalence of depression in HF population.<sup>[36-38]</sup> Likely, we evaluated health-related QoL, depression, anxiety and stress scores of patients with HF in our study, and found a negative correlation between the KCCQ, and the DASS. In other words, higher QoL scores was correlated with lower depression, anxiety and stress scores. Our study sample had higher scores in the symptom and physical limitation domains of the KCCQ, thus, this may explain better QoL among patients with HF and lower depression, anxiety and stress level, as well.

The health-related QoL and depression, anxiety, stress symptoms of patients with HF may also influential on family caregivers. Although several treatment options have been utilizing for patients with HF, these strategies could not manage HF symptoms sufficiently. Thus, previous studies reported that the patient's serious symptoms lead to depression and anxiety among family caregivers.<sup>[13, 22, 39]</sup> Providing longterm care and experiencing severe stress associated with caregiving potentially impose caregivers to physical disorders, psychological morbidity such as depression, anxiety, stress, and even mortality.<sup>[22]</sup> So, mostly of family caregivers providing care for patients with HF may face major health problems that directly deteriorate health-related QoL.<sup>[39]</sup> Confirming this outcome, we revealed that a strong significantly negative correlation between the WHOQOL-BREF, and the DASS among family caregivers. This results may be explained by the fact that the severe depression, anxiety, and stress in family caregivers arise from their changing responsibilities toward family and unfamiliar duties at home, struggling with the heavy symptom burden, and repeated hospitalizations of patients with HF, important decisions related

patients' conditions or advance directives, and concerns for the future.<sup>[6, 13, 15]</sup>

As physical symptoms increase, patients with HF experience a decrease in psychosocial health and SWB, and this distress may also be influential on family caregivers' SWB. Although some studies reported that SWB was correlated with less depression in patients with cancer, this correlation has not been investigated in patients with HF.<sup>[23, 36,</sup> <sup>40]</sup> Spirituality is important for ascertaining health-related behaviors, attitudes and beliefs in patients with HF.<sup>[36, 41,</sup> <sup>42]</sup> Bekelman et al. stated that the mean FACIT-Sp scores of patients with HF were 37.0 and a better SWB was strongly associated with lower depression in their cross-sectional study.<sup>[36]</sup> Similar to this finding, the mean FACIT-Sp scores were 36.2 in our study, and we confirmed that there was a moderately negative correlation between the DASS and the FACIT-Sp scales in patients with HF. Besides, we found that the scores of DASS and FACIT-Sp scales of family caregivers had a moderately significant negative correlation. Since spirituality is associated with symptoms of depression both patients with HF and family caregivers, further interventions focusing on spirituality should be integrated to promote QoL, psychological health of patients with HF and family caregivers, as well.

#### Limitations

This study has several limitations. Patients with HF and their caregivers were included from a single-center, which limits generalizability of the study findings. Secondly, we included all stages of HF patients. So, this could be a limitation how associations may be affected among the used scales based on HF stage. Finally, as cross-sectional correlational design was utilized in the current study, the prospective causal effects could not be interpreted. Considering these limitations, the results of the present study may lead to further studies using a longitudinal design, larger sample size and categorizing patients based on HF stage examining potential factors that may be influential on QoL, depression, anxiety, stress and SWB in patients with HF and family caregivers.

### Conclusions

The study results ensure an important contribution to the literature through examining how QoL, depression, anxiety, stress state and SWB correlated in Turkish patients with HF and family caregivers. The study showed that higher QoL is associated with lower depression, anxiety and stress and higher SWB in patients with HF and family caregivers. Further qualitative studies are warranted to investigate cul-

tural, and individual experiences from the perspective of Turkish patients with HF and family caregivers in terms of psychological health and spirituality.

Further research should focus on individualized education and counselling programs to promote patients with HF and family caregivers in Turkey. Such initiatives could improve QoL, psychological health, and SWB. Designing interventional programs are also suggested for stress management, better coping strategies and consequently, promotion of health-related QoL and SWB of patients with HF and family caregivers. Results of this study also showed that family caregivers who are female, unemployed, and providing care longer than eight hours per day had lower QoL scores and higher depression, anxiety, and stress scores; therefore, further research should be carried out to reveal experiences of such family caregivers within Turkish culture.

**Ethics Committee Approval:** The present study was reviewed and approved by the Non-Interventional Clinical Trials Ethics Committee of Hacettepe University, Turkey (Decision Number: GO 17/338).

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