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Research Article / Araştırma Makalesi

Comparison of Perceived Burden of Patients with Hearth Failure and Their Caregivers

Kalp Yetersizliği Olan Hastaların ve Bakım Verenlerinin Algıladıkları Yükün Karşılaştırılması

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Abstract: This study was conducted to compare the perceived burden of patients with heart failure and their caregivers. The descriptive and correlational study was conducted in the cardiology service and outpatient clinic of a university hospital. Sociodemographic characteristics form was used as data collection tools, Burden Interview was used to measure caregiver's perception of burden, and Self-Perceived Burden Scale was used to measure patients' perception of burden. The relationship between patient and caregiver burden perception was examined using Pearson correlation analysis. According to the results of the research, it was found that the burden perception of the patients was high, and the caregivers' burden of care was slightly lower than moderate. It was determined that there was a moderately significant positive correlation between the patients' self-perception of burden scale and the caregivers' mean scores of the caregiver burden scale (r=0.489 p=0.000). As the burden score perceived by the patients increases, the burden score perceived by the caregivers increases. As the burden score perceived by the patients increases, the burden score perceived by the caregivers increases. It is recommended to plan interventions to reduce the burden of patients and caregivers, and to conduct research showing the effectiveness of these interventions.

Keywords: Caregiver burden, Heart failure, Nursing, Self-perceived burden.

Öz: Bu araştırma kalp yetersizliği olan hastaların ve bakım verenlerinin algıladıkları yükün karşılaştırılması amacıyla yapılmıştır. Tanımlayıcı ve korelasyonel nitelikte olan çalışma bir üniversite hastanesinin kardiyoloji servis ve polikliniğinde yürütülmüştür. Veri toplama araçları olarak sosyodemografik özellikler formu, bakım verenlerin yük algısını ölçmek için Bakım Verme Yükü Ölçeği ve hastaların yük algısını ölçmek için Kendini Yük Olarak Algılama Ölçeği kullanılmıştır. Hasta ve bakım veren yük algısı arasındaki ilişki pearson korelasyon analizi kullanılarak incelenmiştir. Araştırma sonuçlarına göre hastaların yük algısının yüksek olduğu, bakım verenlerin bakım verme yükünün orta düzeyden biraz düşük olduğu bulunmuştur. Hastaların kendini yük olarak algılama ölçeği ile bakım verenlerin bakım verme yükü ölçeği puan ortalamaları arasında pozitif yönde orta düzeyde anlamlı bir ilişki olduğu saptanmıştır (r=0,489 p=0,000). Hastaların algıladığı yük puanı arttıkça bakım verenlerin algıladığı yük puanı artmaktadır. Bu durum hastaların algıladığı yük arttıkça bakım veren yük algısının arttığını göstermektedir. Hasta ve bakımverenlerin yükünü azaltmaya yönelik girişimlerin planlanması, bu girişimlerin etkinliğini gösteren araştırmalar yapılması önerilmektedir.

Anahtar Kelimeler: Bakım veren yükü, Hasta yük algısı, Hemşire, Kalp yetersizliği.

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Introduction

Heart failure is a disease that causes poor quality of life due to conditions such as inability to meet basic requirements, changing body image, lack of self-care behaviors and daily life activities, chronic fatigue, impaired sexual function, future-related concerns (Durante et al., 2019; Wilikins et al., 2017; Savarese et al., 2017; Nieminen et al., 2015; Bidwell et al., 2015; Hwang et al., 2014). As the stages of the disease progress, patients become in need of someone else's help to meet their needs, and the majority of patients' care is provided by family members. Especially the caregiver who has

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an advanced stage patient; may quit his job or reduce his working time to meet the needs of his patient, may not be able to devote time to his children/other family members or social activities, and may not even be able to carry out his own self-care activities (Özer, 2010; Williams et al., 2008; Greco et al., 2017; Vellona et al., 2019). All these reasons affect the lives of caregivers physically, psychologically, socially, economically and spiritually and create a heavy burden with intense stress (Molloy, 2005).

According to the results of the study examining the burden of caregivers of heart failure patients, it was found that the quality of life of the caregivers was low, and the emotional and physical burden caused the caregivers to experience more anxiety and depression, deteriorate their health, go to the doctor more, and use more psychotropic drugs (Özer, 2010; Williams et al., 2008; Greco et al., 2017; Vellona et al., 2019). Mclfatrick et al. (2018) conducted a study to evaluate the support needs of caregivers in heart failure, and it was found that caregivers did not receive professional support, needed support during the diagnosis, and had problems due to physical limitations and psychosocial influence. For this reason, it has emerged that interventions should be increased in order to provide social support to caregivers and the necessity of minimizing the negative impact experienced by the caregiver after the discharge of the patient (Hwang et al. 2010; Mclfatrick et al., 2018).

While working on the emotions and burdens experienced by caregivers, the caregivers' feeling of burden to their caregivers is ignored. These feelings are expressed as perceived burden and cause the caregiver to experience feelings of guilt, anxiety, and depression (Arechabala et al., 2012). The patient's perception of feeling burdened is defined as guilt, responsibility, anxiety caused by the need to depend on others due to one's illness (McPherson, 2007). This situation can be evaluated in cognitive, emotional and interpersonal dimensions. The perception of being a burden to a loved one can negatively affect the person and increase the risk of suicide. The high prevalence of depression in chronic patients is a factor for increasing these risks (Kowal et al., 2012).

The burden perceived by the patients; It has been studied in individuals with chronic diseases such as pain, chronic kidney failure, ALS, and stroke, but studies on patients with heart failure and their caregivers are quite limited. In the studies, it was found that the patients were uncomfortable with the care-receiving situation, they experienced anxiety and depression, the needs, feelings and experiences of the patients were ignored, these feelings experienced by the patients could lead to communication problems between the caregiver and the patient in the future, and this situation negatively affected the quality of care (Kowal et al. 2012; Arechabala et al. 2012).

In health problems such as heart failure, where the need for care increases, nurses have a very important role in improving patient and caregiver outcomes. It is important for nurses to determine the perceived burden of both the patient and the caregiver and to compare the burden in terms of holistic care. Based on this determination, this study was conducted to compare the burden perceived by patients with heart failure and the burden perceived by their caregivers.

Materials and Methods

Design and Sample

The study was conducted as a descriptive, correlational study to examine the perception of burden between heart failure patients and their caregivers. The research sample consists of 95 patients and 95 caregivers who applied to the cardiology service and polyclinic of Dokuz Eylül University between February 2015 and July 2015. Caregiver sampling criteria in the study; Being primarily responsible for care, being older than 18 years of age, not having communication difficulties, and voluntarily accepting to participate in the study, the patient sampling criteria were as follows: having been diagnosed with heart failure

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at least six months ago, not having communication difficulties, and voluntarily accepting to participate in the study. The sample exclusion criteria are for the patient; any psychiatric illness diagnosis, for the caregiver; It was determined as having a diagnosis of any psychiatric disease and providing care for a certain fee by the caregiver.

Instruments

Sociodemographic and Medical Data Collection Form

Caregiver socio-demographic characteristics form; It consists of a total of 11 questions, including "age, gender, marital status, educational status, occupation, social security, economic status, closeness with the patient, living with the patient, duration of care and having a chronic disease". Patient socio-demographic characteristics form; It consists of a total of eight questions: "age, gender, marital status, educational status, social security, time of diagnosis, left ventricular ejection fraction (LVEF) value, and chronic disease other than heart failure".

Burden Interview

Zarit Burden Interview Scale was developed by Zarit et al. in 1980 and adapted into Turkish by İnci in 2008. The caregiving burden scale consists of 22 statements that determine the effect of caregiving on the individual's life. The scale has Likert-type ratings ranging from 0 to 4 as "never", "rarely", "sometimes", "often", or "almost always". A minimum of 0 and a maximum of 88 points can be obtained from the scale. The items in the scale are generally related to the social and emotional domain, and a high score indicates that the distress experienced is high (İnci and Erdem, 2008; Zarit, 1980). In the studies conducted, the internal consistency coefficient of the scale was found to be between 0.87 and 0.94, and the test-retest reliability was found to be 0.71. In this study, the internal consistency coefficient of the scale was found to be 0.89.

Self-Perceived Burden Scale

The Self-Perceived Burden Scale was developed by Cousineau et al. in 2003. A 5-point Likert-type (1-never, 5-always) scale consisting of 10 items is scored between 10-50. It is stated that as the score increases, the load increases. In the validity and reliability study of the original scale, the cronbach alpha value was found to be .85 (Cousineau et al., 2003). The Turkish validity and reliability of the scale was done by Demir Barutcu and Mert (2017). In the validity and reliability study, the internal consistency coefficient of the scale was found to be 0.88 (Demir Barutcu and Mert, 2017). In this study, the internal consistency coefficient of the scale was found to be 0.87.

Data Analysis

For data analysis, the SPSS 22.0 software (SPSS, Inc., Chicago, IL, USA) was used. A test of hypothesis with p value of <0.05 was considered significant. In the analysis of the data, number, percentage, mean, standard deviation, t test were used as descriptive statistics. The Pearson correlation test was used to evaluate the relationship between the scale. The statistic 'r' value of 0.00 to 0.24 was considered a weak relationship; 0.25 to 0.49 was a moderate relationship; 0.50 to 0.74 was a strong relationship; and 0.75 to 1.00 was a very strong relationship (Aksakoğlu, 2006).

Ethical Considerations

Prior to using the scale, permission was obtained from the author who developed the scale via electronic mail. Verbal and written informed consent was obtained from the participants in the study. Written permission from Dokuz Eylül University Ethical Committee (1769-GOA 2014/34-18 and the Dokuz Eylül University Hospital (99577370-11338) was also obtained. The objective of the research was explained to the

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participants and written permission was received from those agreeing to participate in the research.

Table 1. Socio-demographic and disease-related characteristics of the patients and caregivers.

	Patients (n=95) $\overline{X}$ ± SD		**Caregivers (n=95) $\overline{X}$ ± SD**	
Age	71.12± 10.81 **(min:47-max:90)**		57.35±12.87 **(min:23-max:85)**	
Disease duration/caregiving period (years)	7.8±6.9 **(1-26)**		6.5±5.7 **(1-20)**	
Left ventricular ejection fraction (LVEF) (%)	37.61 ± 9.72		*	
	n	**%**	**n**	**%**
Gender				
Female	44	46.3	67	70.5
Male	51	53.7	28	29.5
Marital status				
Married	76	80.0	83	87.4
Single	19	20.0	12	12.6
Educational level				
Not literate	15	15.8	13	13.7
Primary /Secondary	55	57.9	35	36.8
High School/University	25	26.3	47	49.5
Working status				
Yes	**		35	36.8
No			60	63.2
Social insurance				
Have	95	100	91	95.8
Have not	0	0	4	4.2
Income status				
Income more than expenditure	**		19	20.0
Income less than expenditure			32	33.7
Income is equal to expenditure			44	46.3
Chronic disease				
Have	78	82.1	44	46.3
Have not	17	17.9	51	53.7
His/her relationship to patient				
Spouse	**		56	58.9
Adult child			31	32.6
Others (relatives, friend, etc.)			8	8.4
Living together				
Yes	**		76	80.0
No			19	20.0
Total	**95**	**100.0**	**95**	**100.0**

Abbreviation: SD, standard deviation.
* Was not asked to the caregiver
** Was not asked to the patient

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Results

The mean age of the caregivers was 57.35±12.87 years, and the mean caregiving period was 6.5±5.7 years. 70.5% of caregivers are women, 87.4% are married, 49.5% are high school graduates and above, 36.8% of caregivers are working. 95.8% of caregivers have social security and 46.3% of them have income status equal to expenditure. It was determined that 46.3% of the caregivers had another chronic disease and 58.9% of the caregivers were spouses, 32.6% were adult children, and 8.4% were other relatives and friends. 80% of caregivers live in the same house with the patient (Table 1).

The mean age of the patients was 71.12 ± 10.81 years. The mean duration of heart failure of the patients was 7.8±6.9 years. The mean left ventricular ejection fraction (LVEF) value of the patients was 37.61±9.72. 53.7% of the patients are male, 80% are married, 57.9% are primary school graduates and all of them have social security. 82.1% of the patients have another chronic disease (Table 1).

The mean score of the patients on the self-perceived burden scale was found to be 28.41 ± 9.72, and the score of the caregivers from the scale of burden interview was found to be 32.56 ± 18.43 (Table 2). It was determined that there was a moderately significant positive correlation between the patients' self-perceived burden scale and the caregivers' mean scores of the burden interview scale (r=.489 p=.000) (Table 3).

Table 2. Scores of self perceived burden and burden interview scale (n=95)

Scales	**Min**	**Max**	$\bar{X}$ **± SD**
Self-Perceived Burden Scale	11.00	47.00	28.41 ± 9.72
Burden Interview Scale	4.00	81.00	32.56 ± 18.43

Table 3. Relationship between self perceived burden and burden interview scale **scores** based on their socio-demographic and disease-related characteristics

	Self Perceived Burden Scale		**Burden Interview Scale**	
Patients Age	r = 0.312	**p=0.002***	r=0.275	p=**0.007***
Disease duration (years)	r= 0.241	**p=0.019***	r= 0.046	p=0.660
Caregivers age	r= -0.022	p=0.829	r= 0.090	p=0.386
Caregiving period (years)	r= 0.277	**p=0.007***	r = 0.040	p=0.699
		r=0.489	**p=.000***	

***p<0.05**

Discussion

In the study, it was found that the caregiver burden of caregivers was slightly lower than moderate, according to the score obtained from the sum of the scale.

In studies with heart failure patients and their caregivers, our sample group; Hu and colleagues (2016) a multidisciplinary supportive program for caregivers of patients with heart failure, caregiver burden, and depression in a study to test the effects on quality of life, supportive multidisciplinary program for caregivers of heart failure patients have been found to have positive effects. It has been determined that caregivers have a high burden and need support. In the study conducted by Agren et al. (2015) to evaluate the effects of psycho-educational intervention on caregiver burden in caregivers of patients with heart failure, it was found that education did not reveal significant effects in reducing the burden of caregivers. Man et al. (2018) examined the effects

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of home palliative heart failure program on quality of life, symptom burden, functional status, patient satisfaction and caregiver burden among patients with heart failure. It has been found to be effective in reducing caregiver burden. Mclfatrick et al. (2018) conducted a study to determine the psychosocial factors associated with caregiver burden in heart failure and to evaluate the support needs of caregivers, and it was determined that more than half (53%) of caregivers had distress levels related to depression (Zarit Burden score >24). As a result of the qualitative analysis, it was determined that caregivers wanted emotional support from someone who understood them, needed information about the disease process, wanted information about how and where to get support, and what to expect at the end of life. Strömberg and Luttik (2015) stated that the lives of caregivers are severely affected by heart failure, heart failure patients and their caregivers do not have enough information about prognosis and end-of-life care, and they cannot communicate adequately with the healthcare team. Durante et al. (2019) in their study to determine the caregiver and patient determinants of the caregiver burden in heart failure, and to evaluate the caregiver's contribution to heart failure, determined that the determinants of caregiver burden are old age, female gender, fewer care hours and poor social support. Hu et al. (2016) investigated caregiver burden among family caregivers of patients with heart failure and found that caregiver burden was associated with monthly family income, relationship with the patient, caregivers' self-efficacy, and social support. In parallel with the results of the studies investigating the burden of caregivers with heart failure in the literature, the burden perceived by the caregivers was found to be moderate in our study. In Turkish society, it is thought that giving care to the person in need of care in the family is perceived as a duty and responsibility, and in parallel with this, caregivers are not aware of the burden they experience during the caregiving process and have difficulty in expressing the difficulties they experience. This situation was evaluated as caregivers' low awareness of the burden in the caregiving process or they submitted to this situation within the scope of learned helplessness.

In the study, it was determined that the burden perception of the patients was higher than the moderate level according to the score obtained from the total scale, that is, the patients perceived themselves as a burden to their caregivers. In the study conducted by Jıng and Wang (2017) to investigate the burden perceived by patients with chronic heart failure and related factors, it was determined that the score of the patients on the self-perception scale was (24.84±6.74) and it was mild-moderate. Factors such as age, gender, and self-efficacy were associated with perceived burden in patients with chronic heart failure. In the study conducted by Aldred (2005), heart failure patients and their caregivers stated that the disease affects their whole life, the patients feel unhappy because it creates a burden on their caregivers, that social isolation affects both the patient and the caregiver negatively, and that they need professional support even though they need it in this period. stated that they did not receive it. It has been determined that the number of studies evaluating the self-perception of burden in heart failure patients is limited in the literature. In the literature, there are studies in which patients in different sample groups consider themselves as a burden. Accordingly, Xu et al (2021) patients with gastrointestinal tumors, Ritche et al (2017) cancer patients, Ahmed et al (2022) and Ribe et al (2018), schizophrenia patients, Grace et al (2018) patients with hemolytic anemia, Fishbain et al. (2016) conducted studies on patients with chronic pain to perceive themselves as a burden. According to the results of the study, it was found that the patients felt dependent on their caregivers, felt uncomfortable with this situation, and experienced psychological anxiety, depression, and guilt, and these feelings negatively affected the caregivers' physical, mental and emotional health. In addition, it has been stated that care for the chronic patient will cause the caregiver to be restricted and stressed after a certain period of time, as a result of which the perceptions of the patients receiving care may change and their end-

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of-life decisions may be affected. The degree of burden of individuals with chronic diseases and their relationships with their caregivers may cause anxiety, depression and treatment non-compliance. All these affect the patients' decision on life expectancy, and with the increase in burden perception, euthanasia requests may increase. In this whole process, it has been found that individuals experience feelings of loss of control and independence, guilt, indebtedness, worry about the caregiver, the thought of negatively affecting the health of the caregiver due to physical strain while giving care, anger, disappointment and helplessness. It has been found that there is a positive relationship between the performance ability of the patients and the perception of being a burden, and the perception of burden increases when the need for care increases. At the same time, it has been stated that the feelings and burden perceptions experienced by the care recipients vary according to geographical areas and culture. In addition, it was stated that the patients who received care for a long time perceived themselves as a greater burden and the perception of the care recipients to create a burden on their caregivers gradually increased. (Oeki et al., 2012). End-stage renal disease patients stated that they needed caregivers to maintain their daily living activities, they thought that caregivers were restricted due to their diseases, they lost their independence, and they were grateful for them. Patients stated that providing care is stressful and difficult. It has been stated that the feelings of care recipients are not given enough importance. It was found that the burden perception of the patients was multidimensional, related to the degree of chronic disease and affecting their relationship with the caregiver, and experienced negative emotions such as the feeling of limiting the caregiver, disappointment, guilt, anxiety, and depression. For this reason, it was stated that such patients had attempted suicide or had euthanasia requests (Arechabala et al., 2012). In the study of Özer et al. (2006), the caregivers of the patients; It has been found that they see themselves as a burden to their caregivers because they are tired, worried about their health, causing economic distress and disrupting their daily plans.

According to the results of the study, it was determined that there was a moderately significant positive correlation between the patients' self-perception of burden scale and the caregivers' mean scores of the caregiving burden scale (r=.489 p=.000). As the burden score perceived by the patients increases, the perceived burden score of the caregiver increases. This shows that as the burden perceived by the patients increases, the perception of caregiver burden increases.

Conclusion

Nursing care has a very important place in reducing the negative effects of chronic disease on the individual, family and society. Nursing care to be applied in this context should be planned to include the individual and the family. The nurse should lead the way in helping the patient's personal control, informing the patient and caregivers, ensure the participation of the individual in his own care, implement training programs that will increase the quality of life, including the patient and his family, and follow the individuals regularly. While evaluating the individuals who care for patients with chronic and loss of function holistically, considering the care burden in terms of both the caregiver and patients, determining the factors affecting the care burden, determining the needs, health conditions and support resources of the individual and the caregiver, the individuals and the individuals in the institution and home environment. It is recommended for caregivers to plan interventions to reduce the burden of care, to conduct extensive research and follow-ups showing the effectiveness of these interventions, and to evaluate the self-perceived burden separately from physical, emotional and financial aspects in future studies.

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