

## THE QUALITY OF LIFE AND HOME CARE NEEDS OF PATIENTS TREATED FOR HEART FAILURE

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### **Contribution**

AC, BA conceived the idea, planned the study and drafted the manuscript. AC, collected data. AC, BA did statistical analysis. AC, BA drafted the manuscript and critically reviewed manuscript. Both the authors contributed significantly to the submitted manuscript.

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### **ABSTRACT**

**Objectives:** To identify the quality of life and need for home care of patients treated for heart failure and the socio demographic and disease-related features that affect them.

**Methodology:** This cross sectional study included patients treated at the Cardiology-Coronary Intensive Care Unit of Ondokuz Mayıs University, Turkey. Data was collected from patients who were willing to participate in the study from December 2010 to June 2012. The data collection tools were the Katz Daily Living Activities Scale and the MacNew Heart Disease Health-related Quality of Life Questionnaire. The data collected was analyzed using the SPSS 16.0, and the descriptive statistics were analyzed using the t-test, Spearman's correlation analysis, the Mann-Whitney U test and the Chi-square test.

**Results:** About 180 patients were included. It was found that in participating patients, when their level of need for home care increased their quality of life decreased. Research reveals that the activities with which patients with heart failure need the most home care assistance are cleaning, cooking, eating, bathing, and using the toilet.

**Conclusion:** It was found that the more patients with heart failure need home care, the more their quality of life falls.

**Key Words:** Heart Failure, Home Care Needs, Quality Of Life, Nursing

## INTRODUCTION

Heart failure is a leading public health problem since its prevalence is increasing.<sup>1</sup> In European countries, nearly one million people are diagnosed with primary heart failure per year.<sup>2</sup> In the US, 5.1 million people are suffering from heart failure.<sup>3</sup> According to data from the HAPPY (Heart failure prevalence and predictors in Turkey) study, the absolute value of the adult prevalence of heart failure in Turkey is 2.9%, and the estimated value is 6.9%. While the prevalence rate of heart failure is about 2-3%, after 70 years old this rate is 10%, and after 80 years old it was 15-20%.<sup>1</sup>

In addition to being a chronic, progressive, and common disease, heart failure also dramatically increases the cost of care due to its poor prognosis.<sup>4</sup> Today, suitable treatment strategies include lifestyle changes (salt restriction, exercise, quitting alcohol, etc.) and pharmacological treatment for the treatment of heart failure.<sup>5</sup> The American Heart Association has identified heart failure as one of the most expensive illnesses, costing over \$31 billion annually.<sup>6</sup> This is a heavy load for national economies due to repeated hospitalizations and losses to the labor force.<sup>7</sup> There are many studies being conducted to fight heart failure more effectively, which is associated with high mortality rates, repeated hospitalizations and impaired quality of life.<sup>5,8</sup>

Heart failure is a chronic syndrome in which the heart cannot pump enough blood to meet the body's metabolic needs due to impairment of heart functions and an increase in neurohormonal activity.<sup>9</sup> Since the disease requires long term care once diagnosed, it affects patients and their families physically, psychologically and socially, and it creates an economic burden for patients and their families as well. Patients often need help in daily activities such as shopping, house cleaning, showering, and dressing.<sup>10</sup>

The leading factor that increases morbidity and repeated hospitalization is the ineffective disease management by patients and their families.<sup>9</sup> Patients and their families need to have specific knowledge and skills to be able to manage heart failure. Nurses have an important role in the multidisciplinary team (cardiologist, nurse, dietitian, social service specialist, gerontologist, psychologist, etc.). They provide consultancy to patients and their families, ensure compliance with medical treatment and coordinate patient training and care.<sup>11</sup> Home care effectively and continuously provides chronic heart failure patients and their families with the knowledge and skills they need to cope with the disease and prevent complications.<sup>12</sup> Care in the home showed a decreased risk for all-cause mortality and hospitalizations combined so patients suffering from heart failure need home care from a nurse.<sup>13</sup> Health training planned, organized, and conducted by public health nurses will be important in the fight against heart failure, which is a leading public health problem in Turkey.

Therefore, this study aims to identify the quality of life and need for home care of patients treated for heart failure and the socio demographic and disease related features that affect them.

## METHODOLOGY

This cross sectional study was conducted from December 1<sup>st</sup>, 2010 to June 15<sup>th</sup>, 2012 in Ondokuz Mayıs University Hospital's Cardiology-Coronary Intensive Care Unit, Turkey. All the required permissions were obtained. The number of the participants in research was determined using power analysis.

The study sample included heart failure patients who met the following criteria: inpatients in the cardiology and coronary intensive care unit of Ondokuz Mayıs University Hospital during the data collection period, diagnosed with heart failure at least 6 months ago, being 18 years or older, having a stabilized clinical condition, not being on the first or last day of hospitalization (these patients were not included since on the first day symptoms and anxiety levels can be high, and on the last day the discharge process begins) and being willing to participate in the research.

The need for home care and quality of life were the dependent variables of the research. Independent variables included age, sex, marital status, number of children, educational level, employment status, having health coverage, income, residence, length of the disease, restricted activities, specific home care help needs, home care personnel and level of knowledge about home care.

The data collection tools were the patient information sheet with socio demographic and disease related information, the MacNew Heart Disease Health-related Quality of Life Questionnaire (MacNew), and Katz Daily Living Activities Scale to measure the need for home care.

**The Patient Information Sheet:** The patient information sheet contained informative data about the patient and the disease collected from the person, information about the disease and home care. It was based on a review of the relevant literature.

**The MacNew Heart Disease Health-related Quality of Life Questionnaire (MacNew):** MacNew is a valid scale for myocardial infarction, angina pectoris, and heart failure patients and can be used easily. The questionnaire is used to compare the symptoms and changing status of cardiovascular patients. It is the first international questionnaire for measuring quality of life and it is also specific to the disease. The validity study (in Turkish) of the MacNew questionnaire was conducted by Daskapan et al., and its reliability coefficient is 0.80. In this study, the reliability coefficient of the entire scale was 0.89. It took less than 10 minutes for the participants to fill out the scale. The MacNew Heart Disease Health-related Quality of Life

Questionnaire consisted of 27 items on a 7-point Likert-type scale. The total score on the MacNew scale was the mean of all of the items in the scale. Low scores indicated a low quality of life, while high scores indicate a higher quality of life.

**The Katz Daily Living Activities Scale:** The Katz Daily Living Activities Scale was developed by Katz et al. in 1963 to evaluate basic daily living activities. Used both in Turkey and other countries, its validity and reliability are very good. Daily living activities were evaluated by this scale to find out if the patients are dependent or not. This scale consisted of 6 items: bathing, dressing, toilet use, moving, continence, and eating. Independent daily living activity scores 3 points each. A partially aided activity scores 2 points, and entirely assisted daily living activities score 1 point. On the daily living activities scale, 0-6 points meant dependent, 7-12 points meant partially dependent, and 13-18 points meant independent. The reliability coefficient of the scale in this research was 0.77.

**Data Evaluation:** The Katz Daily Living Activities scale was used to evaluate the patients' home care needs. According to this scale, dependent persons needed home care, partially dependent persons need partial home care, and independent persons did not need home care. SPSS 16, a statistics program, was used for data analysis. Descriptive statistics (percentages, means), t-test for normally distributed data (t), Spearman's correlation analysis, and multi variable ANOVA test were also used for data analysis. Data which did not distribute normally on the normality test was tested using the Mann-Whitney U test and the chi-square test.

The study was approved by the Medical Research Local Ethics Committee and Hospital. The patients were informed about the study, and they gave their written and oral consent to participate.

## RESULTS

During the period when the study was being conducted, 228 patients were admitted to Cardiology-Coronary Intensive Care Unit. The mean age of the participants was 65.97 years, and 62.8% were older than 65 years old. Of the patients, 51.7% were male, and 82.8% were married. Of them, 6.1% had no children, 15% had 1 or 2 children, 41.1% had 3 or 4 children and 37.8% had 5 or more children. It was found that 35.6% of the patients were illiterate, and 36.1% finished primary school. About 60% were diagnosed with the disease at least two years ago. Patients who had previously been hospitalized with heart failure constituted 66.7% of the sample. Of the patients 80.6% said that heart failure affected their life negatively. While 63.3% of the patients said that they could perform daily care activities, 81.7% said that they have a caregiver for daily care activities.

The activities of the patients restricted by heart failure were: going up hills or stairs (26.2%), running (17.3%), performing tasks requiring strength and energy (14.8%) and doing housework (13.9%).

Of the patients, 63.3% stated that they perform daily personal care activities. The activities that require help were cleaning (27.2%), cooking and eating (20.6%), bathing and using the toilet (20.6%) and shopping (15.0%). Of the patients, 81.7% said that they have a caregiver at home. Of the caregivers, 54.4% were spouses and 38.8% were children. Of the caregivers, 83.7% had no training in home care, and 51.7% of them needed training.

The mean scores of the heart failure patients on MacNew Quality of Life scale and its sub-scales were found to be  $3.90 \pm 0.95$  for emotional,  $3.40 \pm 1.14$  for physical,  $3.80 \pm 1.25$  for social, and the total score was  $3.71 \pm 0.94$ . The minimum total score was 1.74, and the maximum total score was 6.62.

While the mean score of the heart failure patients for Katz Daily Living Activities Scale in the dependent, partially dependent group was calculated to be  $16.13 \pm 2.98$ , the mean score of the independent group was calculated to be  $25.05 \pm 2.69$ . The minimum score was 10 for dependent-partially dependent group, and the maximum score was 20. The minimum score for independent group was 21, and the maximum score was 30.

The levels of the need for home care were significantly lower for patients who had 1 or 2 children, of whom 88.9% are independent. The relationship between educational status and the level of need for home care was found to be statistically significant ( $p < 0.05$ ). The patients living in cities and towns were significantly more independent than patients living in villages ( $p < .001$ ) (Table 1).

The emotional, physical, social, and total mean scores of the patients who perform daily personal care activities were found to be higher than those of the patients who do not perform daily personal care activities. The relation between the two was found to be statistically significant ( $p < .001$ ) (Table 2).

When the mean scores on the Katz Daily Living Activities Scale and MacNew Quality of Life Scale were compared, the mean score on the Katz DLA Scale for the independent group was found to be higher than the emotional, physical, social, and total mean score of MacNew Quality of Life Scale. A statistically significant negative correlation was found between the level of heart failure patients' quality of life in all sub-scores and level of need for home care ( $p < .001$ ) (Table 3).

When the score on the Katz Daily Living Activities Scale rises (dependency for home care increases), the score on the MacNew Quality of Life increases as well.

**Table 1. Distribution of the Findings Showing the effects of Patient's Descriptive Features on their ability to perform daily living activities (n=108)**

Descriptive features		Daily living activities		$\chi^2$ <sup>a</sup>	p-value
		Dependent-partially dependent n (%)	Independent n (%)		
Age (years)	Under 65	20 (29.9)	47 (70.1)	2.85	.091
	65 or more	48 (42.5)	65 (57.5)		
Sex	Female	39 (44.8)	48 (55.2)	3.56	.059
	Male	29 (31.2)	64 (68.8)		
Marital status	Married	52 (34.9)	97 (65.1)	3.05	.081
	Unmarried	16 (51.6)	15 (48.4)		
Number of children	None	4 (36.4)	7 (63.6)	10.73	.013
	1 or 2	3 (11.1)	24 (88.9)		
	3 or 4	29 (39.2)	45 (60.8)		
	5 or more	32 (47.1)	36 (52.9)		
Educational status	Illiterate	35 (57.4)	29 (45.3)	17.86	.001
	Literate	10 (41.7)	14 (58.3)		
	Primary school	20 (30.8)	45 (69.2)		
	Middle school	2 (18.2)	9 (81.8)		
	High school or university degree	1 (6.3)	16 (93.8)		
Employment Status	Working	3 (18.8)	13 (81.2)	2.70	.100
	Not working	65 (39.6)	99 (60.4)		
Health Coverage	Yes	60 (37.3)	101 (62.7)	0.17	.681
	No	8 (42.1)	11 (57.9)		
Income Status	Income lower than expenses	26 (32.8)	42 (61.2)	0.34	.844
	Income equal to expenses	37 (36.6)	64 (63.4)		
	Income higher than expenses	5 (45.5)	6 (54.5)		
Residence	City	12 (24.5)	37 (75.5)	17.24	.000
	Town	16 (26.7)	44 (73.3)		
	Village	40 (56.3)	31 (43.7)		

Note. <sup>a</sup>Chi-square test.

**Table 2: Distribution Of The Mean Scores For Macnew Quality Of Life Scale Based On The Patient's Home Care Features Macnew Quality Of Life Scale (n=108)**

Home care opportunities	Emotional				Physical			Social			Global		
	n	M±SD	U <sup>a</sup>	p-value	M±SD	U <sup>a</sup>	p-value	M±SD	U <sup>a</sup>	p-value	M±SD	U <sup>a</sup>	p-value
<b>Ability to perform daily personal care activities</b>													
Yes	124	4.01±0.93	2685.50	0.014	3.65±1.13	1994.50	0.00	4.03±1.23	2160.00	0.00	3.87±0.95	2328.50	0.00
No	56	3.66±0.96			2.85±0.94			3.27±1.11			3.35±0.83		
<b>Having a caregiver at home</b>													
Yes	147	3.94±0.92	2220.50	0.448	3.43±1.12	2252.00	0.70	3.81±1.25	2336.50	0.742	3.74±0.93	2201.00	0.407
No	33	3.70±1.03			3.28±1.25			3.81±1.49			3.54±0.98		
<b>Knowledge of the caregiver about home care</b>													
Knowledgeable	24	4.05±0.95	1291.50	0.333	3.53±1.06	1381.00	0.61	4.04±1.11	1167.00	0.105	3.95±0.88	1274.00	0.290
Not knowledgeable	23	3.88±0.94			3.36±1.15			3.72±1.25			3.65±0.95		

**Table 3. Findings About The Relation Between The Daily Living Activities Scale And The Macnew Quality Of Life Scale (n=108)**

Katz daily living activities scale	MacNew emotional			MacNew physical			MacNew social			MacNew total		
	M±SD	t <sup>a</sup>	p-value	M±SD	t <sup>a</sup>	p-value	M±SD	t <sup>a</sup>	p-value	M±SD	t <sup>a</sup>	p-value
Dependent - partially dependent	3.57±0.96	-4.08	.000	2.93±1.05	-4.84	.000	3.31±1.20	-4.50	.000	3.33±0.88	-4.53	.000
Independent	4.10±0.89			3.69±1.09			4.09±1.86			3.94±0.91		
Total		r <sup>b</sup>	p-value		r <sup>b</sup>	p-value		r <sup>b</sup>	p-value		r <sup>b</sup>	p-value
		0.407	.000		0.490	.000		0.445	.000		0.452	.000

Note. <sup>a</sup>Independent t test; <sup>b</sup>Significance of correlation

## DISCUSSION

This study identified the patients' activities restricted by heart failure. The first was found to be going up hills or stairs (26.2%), the second was running (17.3%), and the third one was performing tasks that require strength and energy (14.8%). According to a previous study, the activity most often restricted was going up hills or stairs (46.3%) followed by running (19.1%), doing housework and strength and energy demanding activities.<sup>19</sup> Similar to results in the relevant literature, heart failure was also found to interrupt life with symptoms such as dyspnea, fatigue, and impaired heart function.<sup>13</sup> Of the patients, 63.3% were able to perform daily personal care activities. Some patients needed help to perform housework such as cleaning, cooking and eating.

According to a study conducted in Netherlands, most heart failure patients (53.9%) have difficulty bathing and dressing.<sup>20</sup> In another study conducted with heart failure patients, 75% were dependent in one or more instrumental activities of daily living, usually shopping.<sup>21</sup> Other similar studies have indicated the levels of need for home care, emphasizing that the levels of need for professional home care service are high.

Patients with heart failure have difficulty performing daily living activities. The dependency level of patients with heart failure should be determined, and then the requisite nurse care should be planned. Nursing care for heart failure should be planned to involve patients and their families as well. Patients should be encouraged to participate in their own care.<sup>22-24</sup>

This study found that age has no effect on the level of dependency in daily living activities. Similarly, Demir did not find a significant difference between the age and the daily living activities.<sup>25</sup> The effect of the age may have been eliminated by reasons such as the patients being treated in a faculty hospital and having an advanced level of heart failure. However, there are also other studies claiming that the level of dependency in daily living activities increase with age.<sup>17</sup> Considering that the level of heart failure and comorbidity rises with age, these factors probably increase dependency in daily living activities. The difference between the studies might also be based on the sociocultural differences in the regions where studies were conducted.

This study found that men are more independent than women in performing daily living activities, but it was not statistically significant. According to another study, the level of independence in daily living activities is lower among women.<sup>17</sup> In Demir's study, a statistically significant difference was not found between the genders. In the study conducted by Subasi and Oztek, of the patients receiving home care, 62.5% were females, and 37.5% were males.<sup>26</sup> In the US, 67.0% of the people who receive care from a home care facility are women, and more than 80% of heart failure patients receive home care.<sup>27</sup> Delivering and raising children, taking more responsibility for housework may be reasons for women's higher level of home care needs.

This study found that the number of children affects heart failure patients' level of dependency in daily living activities. Patients who have 1 or 2 children had the highest level of independence in daily living activities. In the US, it was found that living conditions of those who are living alone and need care are worse than those of others.<sup>27</sup> Since heart failure is a chronic disease and requires long term care, patients with heart failure need regular care and social support. If they are not hospitalized in health facilities, they have to cope with health problems on their own and the people with whom they reside. Thus having children is an important factor in supporting the costs of home care and the need for home care.

The patients' educational level increases, the need for home care decreases. Like our study according to other studies, the level of independence in daily living activities is lower with high educational level.<sup>16,22,25</sup> This study found that patients' place of residence affects their need for home care. The need for home care of patients living in villages was found to be higher than that of patients living in towns and cities. Since the hospital where the study was conducted is a regional hospital, it serves the patients from the surrounding cities, towns, and villages. The participating patients were living in a variety of places. The socio-demographic features of the places where the patients live may affect the way health service is provided and its accessibility. Health insurance restrictions and access to health service in rural

regions may have caused the level of need for home care to increase. In Demir's study, a statistical significance was not found between the patients' place of residence and their level of need for home care.<sup>25</sup> This difference may be due to the fact that the two studies were conducted in different populations and cultures.

While the lowest mean sub-score of the participating patients was their physical score and the highest was their emotional score, the general quality of life is above the moderate level. Studies analyzing the quality of life among heart failure patients found that their physical quality of life is lower than their mental quality of life.<sup>19,28</sup> Study results suggest that the levels of physical disability of heart failure patients are quite high. According to the literature, social support is important in cases of chronic disease.<sup>29</sup> In this study, the emotional and social scores were found to be high, showing that positive support is an important factor in dealing with the disease.

The mean score of the patients in daily living activities was found to be  $21.68 \pm 5.16$ . In Demir's study the patients' mean score in daily living activities was reported as  $15.41 \pm 3.13$ . In the study conducted by Karaca and Mert with heart failure patients, the mean score in daily activities was found to be  $15.61 \pm 3.13$ .<sup>11</sup> According to a study experiencing difficulties in daily living activities, 24.1% were moderate and 12.9% were severe.<sup>30</sup> The patients participating in this study were the most independent in performing daily living activities. It is obvious that chronic heart failure patients have different dependency levels, and they need preventive, treater and therapeutic care at home. Since the treatment and rehabilitation of the heart failure takes long time, training for the new situation is an important way to help patients handle the illness and facilitate the adjustment to living with it. As the health professionals who are closest to patients, nurses have the most important role in providing continuous training and advisory services to patients and their families.

According to the studies, the quality of life levels of heart failure patients who are able to perform daily personal care activities are higher than the patients who cannot, and physical competency in daily living has been found to be the most important factor of quality of life. The physical competency of heart failure patients is closely connected to their clinical status. Most patients with heart failure suffer from dyspnea and fatigue, which restrict their ability to perform daily living activities, and symptom load negatively affects their quality of life. Worsening symptoms also increase the likelihood of repeated hospitalization.<sup>31</sup> Activities such as bathing, using the toilet, and dressing are among our basic needs, so anything that hinders them will decrease the quality of life. Any activity performed independently will increase the quality of life emotionally, physically, and socially.

The relationship between the quality of life and daily living activities of the participating patients was analyzed, and it was found that the level of need for home care of heart failure patients with a high quality of life was low. Like our study, Demir found a negatively significant relationship between the quality of life and daily living activities of heart failure patients.<sup>25</sup> A study claimed that when the independency level of heart failure patients in daily living activities decreases, they have difficulty in performing personal care activities and need home care.<sup>11</sup> An experimental study found that home care service given by nurses increases heart failure patients' quality of life.<sup>4</sup> The relationship between the quality of life and dependency level in daily living activities shows that home care services are important to increasing patients' quality of life. The home care service provided to heart failure patients is considered to enhance their physical, psychosocial, and functional health status and contribute to maintaining and increasing their quality of life. Since heart failure is a chronic disease with high incidence and prevalence rates and a major health problem in our society, improving home care service can help to handle this problem.

## CONCLUSIONS

According to this study, 31.7% of the patients were unable to perform daily personal care activities, and the percentage of patients with a caregiver at home was 81.7%. Based on the Katz Daily Living Activities Scale, 37.8% of the patients were dependent for their home care needs. The quality of life of the independent groups in daily living activities was found to be significantly high in all sub-dimensions. The more the home care needs of heart failure patients increase, the more their quality of life is reduced.

Training for patients, their families, and caregivers to improve prognosis and reduce the frequency of hospitalization should begin during hospitalization and after discharge. For disease to be manageable at home, nurses in particular should continuously offer training and consultancy on manageable factors (use of medicine, diet, exercise, smoking, alcohol, stress, etc). Moreover, using valid and reliable scales, nurses should regularly analyze the dependency levels of patients in daily living activities and develop care schedules based on the results.

## IMPLICATIONS FOR PRACTICE

The content of the nursing interventions to be provided at home can be determined by the identification of the home-care needs of patients who have cardiac insufficiency.

The connection between patients' quality of life and their home-care needs indicates that the quality of life of patients with cardiac insufficiency can be increased by home-care service.

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