

Self-Care Agency and Associated Factors in Heart Transplant Patients

Kalp Nakli Olan Hastalarda Öz Bakım Gücü ve Etkileyen Faktörler

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ABSTRACT Objective: Heart transplant patients must maintain their self-care at the highest level and take responsibility for their own treatment and care. The study determined the self-care agency of heart transplant patients and associated factors. **Material and Methods:** This is a descriptive and cross-sectional study. The study universe consisted of 117 patients over the age of 18 who underwent heart transplant surgery at a university hospital. The study sample included 50 patients. The research data were collected using the Self-Care Agency Scale. **Results:** Only 38% of the patients defined themselves as independent in their daily activities. Of them, 94% received support from one of their family members in their daily life activities. Their mean self-care agency score was 97.10±11.31. Age, marital status, education level, and people helping them to perform daily life activities did not affect the heart transplant patients' self-care agency. However, economic status did affect their self-care agency. **Conclusion:** The heart transplant patients had low self-care agency scores, which shows that patients' self-care responsibility and health protection behaviors were inadequate.

Keywords: Activities of daily living; heart transplantation; self-care

ÖZET Amaç: Kalp nakli hastaları öz bakımlarını en üst düzeyde tutmalı ve kendi bakımları ve tedavileri için sorumluluk almalıdır. Araştırma kalp nakli olmuş hastaların öz bakım güçleri ve bunu etkileyen faktörleri saptamak için yapılmıştır. **Gereç ve Yöntemler:** Çalışma tanımlayıcı ve kesitlidir. Çalışmanın evrenini bir üniversite hastanesinde kalp nakli olmuş 18 yaşından büyük 117 hasta oluşturmuştur. Örneklem grubuna 50 kişi alınmıştır. Veriler demografik özellikleri belirlemeye yönelik bir anket formu ve "Öz-Bakım Gücü Ölçeği" kullanılarak elde edilmiştir. **Bulgular:** Hastaların sadece% 38'i günlük aktivitelerinde kendilerini bağımsız olarak tanımladı. Onların %94'ü günlük yaşam aktivitelerinde aile üyelerinden destek aldığını ifade etti. Kalp nakli olan hastaların öz bakım gücü puan ortalamaları 97,10±11,31 olarak belirlenmiştir. Yaş, cinsiyet, medeni durum, eğitim durumu, günlük yaşam aktivitelerini yerine getirmede yardım eden kişilerin varlığının, öz bakım gücünü etkilemediği fakat maddi durumun ise öz bakım gücünü etkilediği saptanmıştır. **Sonuç:** Kalp nakli olan hastaların öz bakım puanları düşük bulunmuştur. Bu da hastaların öz bakım sorumluluğunun ve sağlık koruma davranışlarının yetersiz olduğunu göstermektedir.

Anahtar Kelimeler: Günlük yaşam aktiviteleri; kalp nakli; özbakım

A heart transplant is used to treat heart failure patients whose medical treatment has failed and who have a life expectancy of less than two years.¹ In Europe, 1,776 heart transplants and 2,884 heart transplants in North America were done in 2017.² Data on heart transplants before 2011 have not been published by the Ministry of Health in Turkey. The Ministry of Health reported 659 patients have undergone heart transplant surgery between 2011 and 2019.³ Today, the number of heart transplants is increasing slightly.

Heart transplant patients encounter many new situations, like all organ transplant patients. For heart transplant patients, close cooperation with a healthcare team and a closely monitored and controlled life are needed after the surgical operation. Organ transplant patients should have knowledge about possible complications, organ rejection signs and symptoms, the importance of immunosuppressive drug treatment, and adverse drug reactions. Organ transplant patients need to change their lifestyles and concern themselves with many issues such as preventing infections, details about taking medications, dietary restrictions, and permitted and restricted activities.^{4,5} Complications or functional weakness can cause psychological problems, impaired physical well-being, and inability to perform daily life activities in organ transplant patients. Patients may have difficulties to maintain self-care, especially when suffering from the disease.

Heart transplant patients must maintain their self-care agency at the highest level and take responsibility for their own treatment and care. Therefore, it is very important to determine their levels of self-care agency. There are many studies focused on self-care in the literature. However, only a limited number of studies address the self-care of organ transplant patients, most of which are about kidney and lung transplant patients.⁶⁻¹² There are no studies about the self-care agency of heart transplant patients. This study was conducted to determine the self-care agency of heart transplant patients and associated factors.

MATERIAL AND METHODS

This descriptive and cross-sectional study was conducted in the heart transplant unit of the cardiovascular surgery department of a university hospital in the Aegean Region of Turkey. The university hospital is where the first heart transplant was done. In this unit, 238 patients had heart transplant surgery as of February 2016, of them, 100 patients died of various causes and 21 had heart transplant surgery during childhood. The study universe consisted of 117 heart transplant patients over the age of 18. Of these patients, 46 were not available because they did not attend the regular

outpatient clinical checkup and 21 refused to participate in the study. The research sample comprised 50 patients. Patients who had undergone heart transplant surgery at least three months prior and were able to communicate verbally were included in the study. Patients who had undergone heart transplant surgery before the age of 18 were excluded from the study. We collected data of the study between June 2015 and January 2016.

This research used a personal information form and the Self-Care Agency Scale. The researchers prepared the personal information form. This form consisted of 12 questions about the socio-demographic characteristics of the patients. The original version of the Exercise Self-Care Agency Scale was developed by Kearney and Fleischer in 1979. The test-retest total mean score and split-half-test reliability coefficient of the original scale were 0.77 and 0.80, respectively.¹³ The Turkish version of the self-care agency scale was developed by Nahcivan, and its internal consistency reliability coefficient was 0.89. It is a 5-point (0-4) Likert-type scale.¹⁴ The scale is one dimension. The scale evaluates whether people perform self-care actions. The lowest possible score is zero and the highest is 140. It has no cut-off point. A high total score indicates high self-care agency.¹⁴ The data were collected with face-to-face interviews by the researcher.

Data Analysis: The data were evaluated using SPSS (SPSS Inc., Chicago, IL, USA) 15.0 software. The Mann-Whitney U test was performed to determine the differences between the self-care agency scores of the participants by gender, marital status, time since the heart transplant operation, and the presence of a ventricular assist device before the heart transplant operation. The Kruskal-Wallis test was used to determine the differences between the self-care agency scores of the participants by age, education level, dependency status, economic status, and people helping them to perform daily living activities. The threshold for statistical significance was $p < 0.05$.

Ethics: Institutional permission from the university hospital where the study was conducted and approval from the ethics committee of the uni-

versity were obtained (approval no: 2015/16-11). This research was conducted in accordance with the principles of the Declaration of Helsinki. Informed written and verbal consents were obtained from the participants who voluntarily agreed to participate in the study.

RESULTS

The mean age of the heart transplant patients was 44.76 ± 13.43 years (min:19, max: 64). Of the patients, 80% were male, and 66% were married. Of them, 94% were unemployed, 62% had incomes equal to their expenses, and 54% had used a ventricular assist device before the heart transplant. Of the patients, 82% were more than one year's length of time after the transplant. The mean length of time since the heart transplant operation was 42.28 ± 40.44 months (min:4, max:186). Only 38% of the patients defined themselves as independent in their activities, and 94% of the patients received help with their daily living activities from a family member after heart transplant. These patients were Class III or IV according to New York Heart Association (NYHA) classification criteria before heart transplantation. The patients' self-care agency score was 97.10 ± 11.31 .

There was no statistically significant difference between the self-care scores by patients' gen-

der, marital status, length of time since the heart transplant operation, and presence of a ventricular assist device before the heart transplant operation. (p: 0.784, p: 0.247, p: 0.258, and p: 0.133, respectively, $p > 0.05$) (Table 1).

There was no statistically significant difference between the self-care scores by patients' age, education level, dependency perception, and people helping them with daily life activities (p: 0.552, p: 0.601, p: 0.303, and p: 0.855, respectively, $p > 0.05$) (Table 2). However, economic status did make a statistically significant difference self-care agency scores. Further analysis found this difference was due to the self-care agency score of the patients who had incomes equal to their expenses (p: 0.014, $p < 0.05$) (Table 2).

DISCUSSION

The characteristics of our patients are different to other patients. The number of the patients who are unemployed and receive help for their daily living activities from a family member after heart transplant is high in Turkey. About 40% of heart transplant patients were working according to data of International society for heart and lung transplantation.¹⁵ About 40% of heart transplant patients had good functional status according to data of International society for heart and lung transplanta-

TABLE 1: The patients' self-care agency scores by gender, marital status, transplant time and presence of a ventricular assist device.

Variables	Self-care agency scores		
	$\bar{X} \pm SD$	U	p
Gender			
Female (n: 10)	95.90 \pm 9.18	188.500	0.784
Male (n: 40)	97.40 \pm 11.87		
Marital status			
Married (n: 33)	95.66 \pm 10.26	224.00	0.247
Single (n: 17)	99.88 \pm 12.99		
Presence of a ventricular assist device before the transplant			
Yes (n: 27)	99.48 \pm 12.83	252.000	0.258
No (n: 23)	94.30 \pm 8.68		
Length of time since the transplant			
Less than 1 year (n: 9)	101.00 \pm 9.24	125.00	0.133
More than 1 year (n: 41)	96.24 \pm 11.64		

U: Mann-Whitney U, $p < 0.05$.

TABLE 2: The patients' self-care agency scores by age, education level, economic status, dependency and help with daily life activities.

Variables	Self-care agency scores		
Age group	$\bar{X} \pm SD$	KW	p
20-35 years (n: 12)	98.25±8.82		
36-50 years (n: 18)	98.00±13.06	1.187	0.552
51-65 years (n: 20)	95.60±11.32		
Education level			
Primary school (n: 28)	97.75 ±13.05	1.019	0.601
High school (n: 17)	94.88± 9.55		
College/university (n: 5)	101.00±3.16		
Financial Status			
Low income (n: 15)	100.26±10.46	8.577	0.014*
Middle income (n: 31)	93.64±9.02		
Over income (n: 4)	112.00±17.18		
Dependency perception			
Dependent (n: 7)	93.42±10.32	2.385	0.303
Semi-dependent (n: 24)	96.45±10.45		
Independent (n: 19)	99.26±12.74		
People helping with care			
Spouse and children (n: 28)	96.50±11.02	0.314	0.855
Mother and siblings (n: 19)	98.47±12.49		
Nobody (n: 3)	94.00± 7.21		

KW: Kruskal-Wallis, *p<0.05.

tion.¹⁵ Heart transplant is the cause of disability in Turkey. Therefore, the majority of our patients may not work, and receive help for their daily living activities from a family member after heart transplant.

Self-care is the activity that individuals perform to protect their personal lives, health, and well-being. Self-care contains all health decisions people make for themselves and their families to get and stay physically and mentally fit. Self-care includes routine health maintenance activities like eating, sleeping and personal hygiene. Self-care activities can also be health promotion or disease prevention practices such as exercising, dieting, self-examination practices, and immunization.¹⁶

Self-care is important to the maintenance of medical stability and to maintain life in patients with heart transplantation. The self-care agency score of the heart transplant patients was 97.10±11.31. One Turkish study of organ transplant patients' self-care was found.⁶ Different self-care

scales have been used in foreign studies of organ transplant patients' self-care. There are studies that evaluate the self-care of patients who had open heart surgery due to heart failure. Therefore, the discussion of self-care agency score refers to kidney transplant, and heart failure studies because this study's patient sample is similar to theirs. The self-care agency score of kidney transplant patients was 108.9±20.11.⁶ The self-care agency score of patients who underwent coronary artery bypass surgery was 108.5±17.00.¹⁷ The self-care agency score of chronic heart failure patients was 94.00±22.77.¹⁸ The self-care agency score of the heart transplant patients was similar to the score of the heart failure patients, but lower than the scores of the kidney transplant and coronary bypass patients. Our patients were class III or IV according to NYHA classification criteria before heart transplantation. Patients had fatigue, dyspnea, and limited physical activity before heart transplantation.¹⁹ Two studies report that patients had muscle weakness and lack

of strength and energy after heart transplantation.^{20,21} The low self-care agency scores of the patients may be due to severe impairment in the pre-transplant waiting period and accordingly, loss of physical strength due to inotropic drugs, ventricular support devices, and mechanical ventilation. Low self-care scores show that heart transplant patients' self-care responsibility and their health protection and development behaviors were inadequate.

This study found no significant difference between the self-care agency scores of the heart transplant patients by gender. Studies of kidney transplant, lung transplant, and heart failure patients also found that gender does not affect self-care.^{6,11,22} This study's finding of no effect of gender on self-care suggests that self-care is an individual skill that is not gender-related.

This study found no significant difference between the self-care agency scores of the heart transplant patients by age. Studies of kidney transplant⁶ and lung transplant patients also found that age does not affect self-care.¹¹ However, other studies of kidney transplant and heart failure patients found that age affects self-care.^{7,22} According to the results of the present study, the heart transplant patients have no difference in their self-care agency by age. This may be because they did not want to repeat the experiences they had before the transplant, so they made efforts to protect their health and be healthy, maintain their self-care to improve their health, and receive support where necessary.

The marital status of heart transplant patients did not affect their self-care agency score. Studies have reported that marital status does not affect self-care of kidney transplant, chronic heart failure patients and those waiting for heart transplant.^{6,18,23} Another study has determined that marital status affects the self-care of kidney transplant patients, and reported that the self-care agency of married patients was higher than that of single patients.⁷ Other studies of heart failure and heart transplant patients found that single patients had higher self-care than married patients.^{22,24} This study's finding

of no difference by marital status between the patients' self-care agency levels suggests that the married patients received support for their self-care from their spouses and children, and the single patients received support from their parents and siblings. The majority of patients reported receiving help with their daily living activities from family members.

The education level of the heart transplant patients did not affect their self-care agency scores. Studies of kidney transplant, lung transplant, and chronic heart failure patients also found that education level does not affect self-care.^{6,11,18} Patients who have undergone heart transplant surgery for various reasons are required to do what is necessary to maintain their health and comply with the rules. The support systems (spouses, children, family, friends, etc.) of heart transplant patients may have given reminders to them. Therefore, the self-care of patients may not be affected by the level of education.

This study found a difference between the self-care agency scores of the heart transplant patients by economic status due to the lower self-care agency scores of the patients with incomes equal to their expenses. Studies of lung transplant patients found that economic status does not affect self-care.¹¹ Another study of heart failure patients found that economic status positively affected self-care agency.²² Patients with heart transplantation experience changes due to surgical interventions, regular checkups, continuous drug use, long hospitalizations, unemployment due to their disease, and moving to a city with a transplant center. These changes cause financial burdens because patients need sufficient income to maintain their health and care. The difference between the self-care agency scores of the patients with low and moderate incomes may be because the opportunities for the patients with low incomes (social relief and aid from the Ministry of Health, governorships, etc.) are more than the opportunities for patients with moderate incomes. In addition, the financial aid received by low income patients may be an incentive for them to continue their care.

The dependency status perceptions of heart transplant patients had no effect on their self-care agency scores. There are no studies of the relationship between dependency status and self-care. Although heart transplant patients identify themselves as dependent or independent, they may feel that they have to maintain their self-care to continue their post-transplant life in a healthy way and may maintain their self-care with the help of their relatives when they cannot do their self-care. One study stated that patients had difficulties to maintain the required care and lost their autonomy after heart transplantation.²⁵ This may be why there was no difference between self-care agency scores by dependency status.

This study found no significant difference between the self-care agency scores of the heart transplant patients due to the people who support them in performing daily living activities. No studies assess the relationship between the self-care of organ transplant patients and the people who support them to perform daily living activities. Studies found that heart failure patients with high social support had a high score of self-care agency.^{26,27} Almost all of the heart transplant patients in the present study reported receiving support from their families. In Turkish culture, helping needy people is a socially condoned behavior, which may be why receiving support and assistance did not affect the patients' self-care agency.

The self-care agency scores of the patients were not affected by the length of time since the heart transplant. A study of kidney transplant patients determined that length of time since the transplant did not affect self-care.⁷ No other studies were found in the literature. The length of time since the transplantation may have no effect on self-care because of the use of immunosuppressive drugs, the side effects of drugs, and regular health checkups for organ rejection after transplantation.

The self-care agency scores of the heart transplant patients were not affected by the use of a ventricular assist device before heart transplantation. There are no studies assessing the relationship between the presence of ventricular assist devices be-

fore heart transplantation and self-care. Heart transplant patients experience serious heart failure symptoms in all cases, regardless of whether or not they have ventricular assist devices prior to the transplant. With or without ventricular assist devices, patients experience a similar process, come to regular check-ups, carry out regular treatments, and communicate constantly with the healthcare team. Thus, the presence of a ventricular assist device in patients before the transplant operation did not affect their self-care agency after the operation.

CONCLUSION

Low self-care scores of heart transplant patients show that patients' self-care responsibility and their health protection and development behaviors were inadequate. Many factors did not affect self-care. Therefore qualitative research regarding how organ transplant patients, especially those with heart transplantation, maintain their self-care and the factors that affect their self-care agency should be conducted. Heart transplant patients need to assess longitudinal self-care behaviors.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

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

Authorship Contributions

Idea/Concept: Aylin Durmaz Edeer, Nihal Çeliktürk; **Design:** Aylin Durmaz Edeer, Nihal Çeliktürk; **Control/Supervision:** Aylin Durmaz Edeer, Nihal Çeliktürk; **Data Collection and/or Processing:** Nihal Çeliktürk; **Analysis and/or Interpretation:** Aylin Durmaz Edeer, Nihal Çeliktürk; **Literature Review:** Nihal Çeliktürk; **Writing the Article:** Nihal Çeliktürk; **Critical Review:** Aylin Durmaz Edeer, Nihal Çeliktürk; **References and Fundings:** Nihal Çeliktürk.

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