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Knowledge and Attitudes of Patients with Advanced Heart Failure Toward Heart Transplantation

İleri Evre Kalp Yetersizliği Hastalarının Kalp Nakline Yönelik Bilgi ve Tutumları

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Abstract

Introduction: The increased prevalence of heart failure (HF) has also led to an increased prevalence of advanced HF. Heart transplantation (HTx) is still considered the "gold standard therapy" in the treatment of advanced HF. We sought to determine the attitudes and knowledge of patients with advanced HF toward HTx.

Materials and Methods: This is a cross-sectional study conducted in an outpatient advanced HF and transplant clinic in a tertiary care center from February 2021 to January 2022 and 110 patients were included.

Results: The mean age was 49.5±10.50 years and 82.7% of the patients were male. The majority of the patients (77.2%) stated that they thought HTx was religiously appropriate. However, only 50.6% of patients stated that if they were healthy, they would have donated their organs. 49.2%, received education about HTx. Only 27.3% of the patients found the education they received sufficient. The patients who received education about HTx had significantly better knowledge regarding the pre-transplant evaluation process and adverse conditions that may develop after HTx. There were no significant differences in terms of patients' knowledge and attitudes toward the HTx according to quality of life. Only the Minnesota Living with Heart Failure Questionnaire score of the patients who were afraid of surgery was found to be significantly higher.

Conclusions: Patients did not have sufficient knowledge about HTx, but they had a positive attitude toward it. A multidisciplinary team should address the concerns of the patients, and assist the patients in adapting to the HTx process by providing the necessary education.

Keywords: Advanced heart failure; heart transplantation; knowledge; attitude; quality of life.

Özet

Amaç: Artan kalp yetersizliği (KY) prevalansı aynı zamanda ileri evre KY prevalansının da artmasına neden olmaktadır. İleri evre KY tedavisinde kalp nakli halen "altın standart tedavi" olarak kabul edilmektedir. Bu çalışmada, ileri evre KY hastalarının kalp nakline karşı tutum ve bilgilerini belirlemek amaçlanmıştır.

Gereç ve Yöntem: Çalışma, kesitsel nitelikte olup Şubat 2021 ile Ocak 2022 tarihleri arasında üçüncü basamak sağlık merkezindeki ileri evre KY ve nakil polikliniğinde takip edilen 110 hasta ile gerçekleştirildi.

Bulgular: Hastaların %82,7'si erkek ve ortalama yaşı 49,5±10,50 yıl bulundu. Hastaların çoğunluğu (%77,2) naklin dini açıdan uygun olduğunu düşündüklerini belirtti. Ancak hastaların sadece %50,6'sı sağlıklı olsalar organlarını bağışlayacaklarını bildirdi. %49,2'si nakil ile ilgili eğitim almıştı. Hastaların sadece %27,3'ü aldıkları eğitimi yeterli bulduğunu bildirdi. Nakil konusunda eğitim alan hastalar, nakil öncesi değerlendirme süreci ve nakil sonrası gelişebilecek olumsuz durumlar hakkında anlamlı düzeyde daha iyi bilgiye sahipti. Yaşam kalitesine göre hastaların nakile yönelik bilgi ve tutumları açısından anlamlı farklılık saptanmadı. Yalnız ameliyattan korkan hastaların Minnesota Kalp Yetersizliği ile Yaşam Anketi puanı anlamlı olarak yüksek bulundu (p<0,001).

Sonuç: Hastalar nakil hakkında yeterli bilgiye sahip değillerdi, ancak buna karşı olumlu bir tutumları vardı. Multidisipliner bir ekip hastaların endişelerini ele almalı ve gerekli eğitimi vererek hastaların nakil sürecine uyum sağlamasına yardımcı olmalıdır.

Anahtar Kelimeler: İleri evre kalp yetersizliği; kalp nakli; bilgi; tutum; yaşam kalitesi.

Introduction

Heart failure (HF) is a progressive disease and one of the leading causes of cardiovascular morbidity and mortality (1). HF affects 6.2 million adults, with an incidence approaching 2.1% after the age of 65 years in the United States of America (USA) (2). HF prevalence was found to be 2.9% in Turkey in the Heart Failure Prevalence and Predictors in Turkey (HAPPY) study (3). The prevalence of HF increases with age, and despite the advances in evidence-based practices in the treatment of HF they still progress to an advanced stage of the disease. The increased prevalence of HF has also led to an increased prevalence of advanced HF (1,2-4). Advanced HF can simply be defined as persistent severe symptoms despite maximal evidence-based medical, surgical, and

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device therapy (4-5). Advanced HF accounts for 1-10% of HF prevalence (6-8). The one-year survival rate was reported as 25% in the EURObservational Research Program Heart Failure Pilot Survey study (9). The primary indications for heart transplantation (HTx) for adult patients have been advanced HF, which accounts for more than 90% of cases, and other indications for less than 10% of cases (10). Although there are optimal treatment approaches to ensure a better quality of life and survival in advanced HF patients, HTx is still considered the "gold standard therapy" in the treatment of advanced HF (1,4-5). While HTx provides a better quality of life and an improvement in morbidity and mortality in patients with advanced HF, the transplantation evaluation process is a difficult period for patients and can take a long time (11). In addition, the inadequacy of organ donation prevents it from being an easily accessible treatment method for patients in Turkey as well as all over the world. Studies with patients on the waiting list for HTx revealed that patients were hopeful about the future, but on the other hand, patients managed the waiting time before HTx differently and therefore needed different forms of support (11-12). Healthcare professionals have a critical role in providing support to patients through the transplant process in the form of education and information (11). In a study by Delbario et al. on organ transplant recipients, it was found that knowing the thoughts and experiences of the patients enabled the organ transplant team, and especially the coordinator nurse, to have a more comprehensive understanding of the patients' perspectives on the preparation and waiting list processes (13). Not having enough information about the problems that might arise during and after the transplantation process prior to HTx and not knowing how to deal with these problems causes them to suffer future anxiety (12). Being aware of the knowledge and attitudes of HTx recipients about transplantation increases trust and communication with the healthcare team. Also, it will enable patients to support positive feelings about the process and to relieve their anxieties. The knowledge and attitudes of both health professionals and society about organ transplantation have been investigated in many studies. However, little information exists in the literature regarding the knowledge and attitudes of advanced HF patients toward the HTx. In this study, we aimed to evaluate the attitudes and knowledge of patients with advanced HF toward HTx.

Material and Method

This is a cross-sectional and descriptive study carried out in an outpatient advanced HF and transplant clinic in a single center from February 2021 to January 2022. One hundred and ten patients were included.

Study population: During the recruitment phase, adults who were referred to the outpatient advanced HF and transplant clinic for additional evaluation of HTx and device therapy were invited to take part in the trial. This study included patients over the age of 18, who were literate, had no history of organ transplantation, met the updated HFA-ESC criteria for the definition of advanced heart failure (4), and consented to participate. Patients who were illiterate, had expected survival of fewer than 2 years due to other diseases, severe comorbidities (severe lung disease, end-stage renal or liver disease) excluding isolated HTx, and declined to participate were excluded from the study. The final study population consisted of 110 patients.

Data collection: Data were collected by using a structured data collection form and Minnesota Living with Heart Failure Questionnaire. The researchers obtained information about patients' demographic and clinical characteristics from them during face-to-face interviews at the outpatient clinic's index visit, as well as from the electronic medical record system using the data collection form.

Data collection form: The researchers created the data collection form after conducting a literature review. This form included 35 questions about socio-demographic characteristics (age, gender, marital status, education level, etc.), HF status (duration of disease) and the presence of comorbidities, as well as concerns about HTx.

Minnesota Living with Heart Failure Questionnaire (MLHFQ): One of the most widely used health-related quality of life questionnaires for HF patients is the Minnesota Living with Heart Failure Questionnaire (MLHFQ). It was created by Rector et al. (1987) (14) and adapted to Turkish by Aşık Özdemir and Pınar (2009) (15). It consists of 21 items, each of which is graded on a 6-point Likert Scale (0 to 5). It provides a total score (range 0–105), as well as scores for two dimensions, physical (8 items, range 0–40) and emotional (5 items, range 0–25).

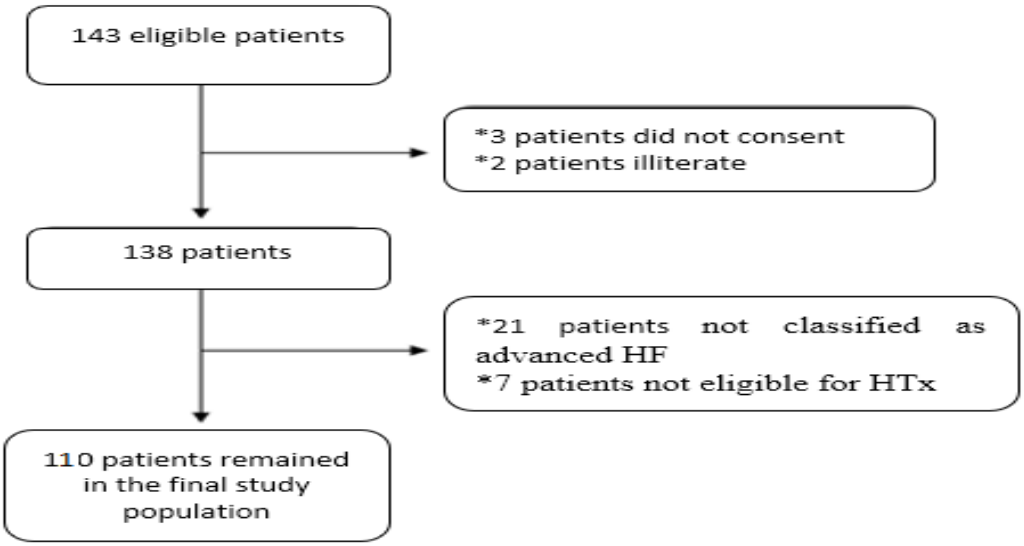

Figure 1. Flowchart of the study sample selection

The other eight items are only considered for the calculation of the total score. The other eight items are only used to calculate the total score. Higher scores indicate a greater reduction in health-related quality of life. In the Turkish validity and reliability study of the questionnaire, the Cronbach alpha internal consistency coefficient was found to be 0.85 for the total of MLHFQ, 0.89 for the physical sub-dimension, and 0.76 for the emotional sub-dimension. In this study, the internal consistency coefficient was found to be 0.79, 0.91, and 0.86 for the total MLHFQ, physical and emotional sub-dimensions, respectively.

Ethical consent: The study complies with the ethical standards specified in the Helsinki Declaration. The university Institutional Review Board (IRB date and number: 27.01.2021/2021.06) granted approval for the ethics committee. Patients who met the study criteria provided informed consent.

Statistical analysis: Continuous variables are expressed as means ± SD, and categorical variables as percentages. Patients' knowledge and attitudes toward HTx were compared the t-test or one-way analysis of variance (ANOVA) for continuous variables. Chi-square test was performed to determine relationships between categorical variables. Statistically significant level was considered 0.05 for all statistical tests. The Statistical Package for the Social Sciences (SPSS) version 20.0 for Windows was used for statistical analysis (SPSS Inc, Chicago, Illinois, USA).

Results

One hundred and forty-three consecutive patients who were referred to the outpatient advanced HF clinic were screened initially. Twenty-one patients were not classified as advanced HF according to the definition criteria of ESC-HFA, 7 patients were not candidates for HTx due to severe lung disease, end-stage renal or liver disease, 2 patients were illiterate, and 3 patients declined to participate in the study. After the exclusion of these patients, the final study population consisted of 110 patients (Fig 1). The mean age was 49.5±10.50 (24-66) years and 91 (82.7%) of the patients were male. The mean duration of heart failure was 54.9±51.2 (1-300) months. The majority of the patients were married (81.8%), literate/primary school graduates (61.8%), and retired/unemployed (78.2%). While 65.5% (n = 72) of the patients had comorbidities, coronary artery disease (27.3%) and diabetes (24.5%) were the leading ones (Table 1). The majority of the patients (77.2%) stated that they thought HTx was religiously appropriate. However, only 50.6% (n = 41) of patients stated that if they were healthy, they would have donated their organs (Table 2). Of the patients in the study, 41.8% (n=46) reported that they believed in selling organs for money. Approximately half of the patients, 49.2% (53), received education about HTx. Of the patients who received an education, the majority of them, 34.5% (38), stated that they received education from a physician or nurse, and only

Table 1: Demographic and clinical characteristics of patients

Variables	% (n)
Age (year) Mean±SD (Min.-max.)	49.49±10.50 (24-66)
Gender	
Male	82.7 (91)
Female	17.3 (19)
Education level	
< High school	61.8 (68)
≥ High school	38.2 (42)
Marital status	
Married	81.8 (90)
Single	18.2 (20)
Home status	
Living with a family member	94.5 (104)
Living alone	5.5 (6)
Working status	
Not working	78.2 (86)
Working	21.8 (24)
Presence of caregiver	
Yes	78.2 (86)
No	21.8 (24)
Duration of HF (year)	
≤ 5 years	66.4 (73)
6-10 years	25.5 (28)
≥ 11 years	8.2 (9)
Presence of comorbidities	
Yes	65.5 (72)
No	34.5 (38)
Comorbidities	
CAD	27.3 (30)
DM	24.5 (27)
HT	22.7 (25)
COPD	11.8 (13)
Smoking	
Yes	85.5 (94)
No	14.5 (16)
Alcohol	
Yes	97.3 (107)
No	2.7 (3)
Presence of HF in the family	
Yes	62.7 (69)
No	37.3 (41)
Have you received education about HTx	
Yes	48.2 (53)
Sufficient	27.3 (30)
Insufficient	20.9 (23)
No	51.8 (57)
Sources of Education	
Doctor /Nurse	34.5 (38)
TV	10.9 (12)
Social media	8.2 (9)
Newspaper	1.8 (2)
Other	3.6 (4)

CAD: Coronary Artery Disease, **COPD:** Chronic Obstructive Pulmonary Disease, **DM:** Diabetes Mellitus, **HF:** Heart Failure, **HT:** Hypertension, **HTx:** Heart Transplantation, **SD:** Standard Deviation.

27.3% (30) of the patients found the education they received sufficient (Table 1). The patients who received education about HTx had significantly better knowledge regarding the pre-transplant evaluation process and adverse conditions that may develop after HTx (Table 2). The mean total, the physical sub-dimension, and the emotional sub-dimension scores of MLHFQ were 58.02±28.95 (4–105), 24.89±11.37 (2–40), and 12.53±8.64 (0–25) respectively. There were no significant differences in terms of patients' knowledge and attitudes toward the HTx according to quality of life. Only the MLHFQ score of the patients who were afraid of surgery was found to be significantly higher ($p<0.001$) (Table 2).

Diccussion

Patients' good knowledge and positive attitude play key roles in the process of decision making and coping with diseases and treatments. In this study, we aimed to understand the attitudes and knowledge of patients with advanced HF toward HTx. We also aimed to reveal whether advanced HF patients have knowledge about HTx, their perspective on the HTx process, and the factors affecting it. HTx is not only a simple surgery aimed at prolonging life expectancy and good quality of life, but also requires many procedures and lifestyle changes. Preparation for transplant and post-surgical care are complex and affect the lives of both the patient and their families. After HTx, different problems such as drug side effects, transplant rejection, infection, and financial limitations may ocur (12). For this reason, patients should have knowledge about the transplantation evaluation process, changes in lifestyle after HTx, daily activities, work, social and family life, etc. (16). In their study, Monemian et al. (2015) emphasized that patients face post-transplantation problems because they do not receive enough information about HTx (12). In the study by Sadala and Stolf, HTx recipients (n = 26) reported that they were satisfied with their new life after HTx; on the contrary, they stated that they encountered pharmaceutical side effects and different problems (17). In a study conducted with advanced HF patients, it was stated that the most important needs of the patients were education and knowledge (18). In our study, we found that 51.8% of the patients did not receive education about Htx, and the majority of those who did receive education did not find it sufficient. The patients who received education about HTx had

Table 2: Comparison of patients' knowledge and attitudes toward the HTx according to having education about the HTx and quality of life

Variables	% (n)	Education about HTx		p	MLHFQ Mean±SD	p
	(N=110)	Yes= 53	No=57			
HTx is a lifesaving procedure?						
Yes	99.1 (109)	100.0 (109)	0.0 (0)	0.48	70.00±00.00	0.68
No	0.9 (1)	0.0 (0)	100.0 (1)		57.91±29.06	
Knows the benefits of HTx?	79.1 (87)	52.9 (46)	47.1 (41)	0.06	55.86±29.42	0.12
Yes	20.9 (23)	30.4 (7)	69.6 (16)		66.17±26.06	
No						
Is a HTx religiously appropriate?	72.7 (80)	55.0 (44)	45.0 (36)		58.61±28.92	
Yes	3.6 (4)	25.0 (1)	75.0 (3)	0.06	55.00±30.67	0.93
No	23.7 (26)	30.8 (8)	69.2 (18)		56.65±29.87	
No idea						
Does a donor's race, gender, or beliefs matter?	12.7 (14)	42.9 (6)	57.1 (8)	0.67	51.14±34.66	0.34
Yes	87.3 (96)	49.0 (47)	51.0 (49)		59.02±28.09	
No						
If you were healthy, would you donate your organs?	73.6 (81)	50.6 (41)	49.4 (40)		59.52±28.49	
Yes	6.4 (7)	28.6 (2)	71.4 (5)	0.51	50.43±31.53	0.62
No	20.0 (22)	45.5 (10)	54.5 (12)		54.91±30.57	
No idea						
Does anyone have a donor card in the family?	20.9 (23)	43.5 (10)	56.5 (13)	0.61	53.09±28.25	0.36
Yes	79.1 (87)	49.4 (43)	50.6 (44)		59.32±29.15	
No						
Do you believe in organ sales?	41.8 (46)	45.7 (21)	54.3 (25)	0.65	58.91±29.81	0.78
Yes	58.2 (64)	50.0 (32)	50.0 (32)		57.37±28.53	
No						
Do you afraid of surgery?	50.9 (56)	48.2 (27)	51.8 (29)	0.99	63.59±27.93	**0.03***
Yes	49.1 (54)	48.1 (26)	51.9 (28)		52.24±29.10	
No						
Knowledge about the HTx preparation process?	27.3 (30)	73.3 (22)	26.7 (8)	**0.001***	56.97±28.04	0.81
Yes	72.7 (80)	38.8 (31)	61.2 (49)		58.41±28.44	
No						
Is the HTx preparation process exhausting?	33.6 (37)	56.8 (21)	43.2 (16)		61.49±29.93	
Yes	18.2 (20)	50.0 (10)	50.0 (10)	0.35	49.75±27.42	0.33
No	48.2 (53)	41.5 (22)	58.5 (31)		58.72±28.74	
No idea						
Knowledge about adverse conditions that may develop after HTx?	22.7 (25)	72.0 (18)	28.0 (7)	**0.007***	56.68±30.98	0.79
Yes	77.3 (85)	41.2 (35)	58.8 (50)		58.41±28.50	
No						
Fear of organ rejection after HTx?						
Yes	73.6 (81)	44.4 (36)	55.6 (45)	0.19	60.38±28.34	0.15
No	26.4 (29)	58.6 (17)	41.4 (12)		51.41±30.08	
Are you concerned about the medications to be used after HTx?	21.8 (24)	41.7 (10)	58.3 (14)		56.29±28.71	
Yes	44.5 (49)	55.1 (27)	44.9 (22)	0.42	56.39±27.77	0.70
No	33.6 (37)	43.2 (16)	56.8 (21)		61.30±31.07	
No idea						
Can a HTx change a person's temperament?	11.8 (13)	53.8 (7)	46.2 (6)		61.00±25.91	
Yes	43.6 (48)	45.8 (22)	54.2 (26)	0.86	58.14±30.48	0.91
No	44.5 (49)	51.0 (25)	49.0 (24)		57.10±28.66	
No idea						
Does it scare you to carry someone else's heart?	18.2 (20)	25.0 (5)	75.5 (15)		55.75±29.77	
Yes	62.7 (69)	53.6 (37)	46.4 (32)	0.07	58.81±29.03	0.91
No	19.1 (21)	52.4 (11)	47.6 (10)		57.57±29.17	
No idea						

*** HTx:** Heart Transplantation, **MLHFQ:** Minnesota Living with Heart Failure Questionnaire, **SD:** Standard Deviation.

significantly better knowledge regarding the pre-transplant evaluation process and adverse conditions that may develop after HTx ($p<0.001$). Providing the necessary education and support before HTx is very important. Nurses on the transplantation team should be actively involved in patient education (12). Fear of surgery is a major problem for many people. HTx is a very stressful surgery for the patients, and prolonging the time for listing can be a considerable factor in causes of mortality and morbidity. For this reason, necessary explanations should be made to eliminate fear and anxiety, and support should be provided to reduce anxiety and fear of the unknown (19). Melo et al. discovered in their study that when patients learn about the necessity of HTx, they experience fear and anxiety, which they overcome through spirituality and information (19). In our study, 50.9% of the patients reported being afraid of heart surgery. In addition, the MLHFQ score of the patients who were afraid of surgery was found to be significantly higher ($p<0.001$). This decreased quality of life is most likely due to the delayed listing of the patient for HTx because of the patient's fear of surgery and the progression of the disease. The quality of life of individuals with advanced HF is severely impacted by frequent and protracted hospitalizations, disease-related complications, and medications used for treatment. (16). In a study, patients waiting on the heart and lung transplant lists had worse perceived health status and quality of life compared with other categories of transplant patients (20). When the quality of life of the patients involved in our study was assessed, the physical sub-dimension score was moderate, but the emotional sub-dimension score was low. The total MLHFQ score was found to be moderate (58.02 ± 28.95). The demand for HTx in these patients grows even greater, yet the health issues they are dealing with have an impact on the transplantation process. Cultural and religious factors are considered among the important factors affecting organ transplantation (21). 99.1% (n=109) of the patients in our study thought organ transplantation would save lives, and 79.1% (n=87) knew the benefits of organ transplantation. Furthermore, the vast majority (77.2%) believed that organ transplantation is religiously appropriate. However, 73.6% of the patients stated that if they had been healthy, they would have donated their organs. Studies in the literature indicate that religious beliefs have an important place among the reasons for individuals' rejection of organ donation and that society does not know that organ donation and transplantation are compatible with the religion of Islam (22-23). A study by Gürler showed that individuals have a positive attitude toward organ transplantation but cannot transfer this to behavior and that this problem is universal (22). Of the patients in the study, 41.8% (n=46) reported that they believed in selling organs for money. Organ transplantations have long been regulated by laws and strict regulations in Turkey. We think that the patients' thoughts of selling organs for money are due to the fact that the transplantation process takes a long time due to the donated organ shortage and the conversations they had with other patients.

Study limitations: This study only included patients with advanced HF who were being considered for HTx. As a result, it cannot be generalized to other patient groups. Furthermore, this evaluation was performed only during the patient's index outpatient visit, and no further evaluation was performed after that. Therefore, changes over time were not evaluated.

Conclusion

In this study, it was determined that the patients did not have sufficient knowledge about HTx, but they had a positive attitude toward it. A multidisciplinary team (physician, nurse, psychologist, etc.) should question the thoughts and concerns of the patients, and assist the patients in adapting to the HTx process by providing the necessary information and education.

Ethical consent: Istanbul Kultur University Institutional Review Board (IRB date and number: 27.01.2021/2021.06).

Conflict of interest: The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

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