# RESEARCH ARTICLE / ARAȘTIRMA MAKALESİ

## Attitudes of Patients' Relatives towards Organ Donation

# Hasta Yakınlarının Organ Bağışına Yönelik Tutumları

# Seher ÜNVER<sup>1</sup>, Zeynep Kızılcık ÖZKAN<sup>1</sup>, Tevfik ECDER<sup>2</sup>, Bahar ÇETİN<sup>3</sup>

<sup>1</sup>Trakya University, Faculty of Health Sciences, Department of Surgical Nursing, Edirne, Turkey

<sup>2</sup>Istanbul Bilim University Faculty of Medicine, Division of Nephrology, Istanbul, Turkey

<sup>3</sup>Registered Hemodialysis Nurse (Head Nurse) (BSN), D. MED Dialysis Center, Hemodialysis Unit, Kırklareli, Turkey

#### ORCID

Seher ÜNVER https://orcid.org/0000-0003-1320-1437 Zeynep Kızılcık ÖZKAN https://orcid.org/0000-0003-1892-241X Tevfik ECDER https://orcid.org/0000-0003-3394-5775 Bahar ÇETİN https://orcid.org/0000-0002-5076-4581

Geliş Tarihi / Received:4.02.2019 Kabul Tarihi / Accepted: 24.02.2019

Corrresponding Author: Seher ÜNVER,

Trakya University, Faculty of Health Sciences, Department of Surgical Nursing, Edirne, Turkey

Tel: +90 505 500 72 17

Email: seher.unver@hotmail.com

#### Abstract

Object: This study aimed to evaluate the attitudes of patients' at surgery ward and hemodialysis patients' relatives towards organ donation.

Methods: This descriptive study's data collection was conducted between August  $15^{th}$ , 2016 - September  $06^{th}$ , 2017. A total of 197 relatives were divided into 2 groups: those who have patients on hemodialysis treatment (n = 101, group A) and those who do not have (n = 96, group B). To collect data "Organ Donation Attitude Scale" and "Data Collection Form" and for data analysis descriptive statistics, the Kruskal-Wallis H, Mann-Whitney U and Spearman

correlation tests were used. For the not normally distributed data, non-parametric tests were used. p < 0.05 was considered as significant.

Results: The mean total attitude score of both groups were above positive attitude level for organ donation. Group A relatives had a more positive attitude about organ donation and their score of "humanity and moral belief" subscale was significantly higher than group B relatives (p < 0.05).

Conclusion: Relatives of hemodialysis patients have a positive organ donation attitude with more humanity and moral conviction. Nurses and other health care professions who work at transplantation units and hemodialysis centers should be aware of this result to keep the relatives' attitudes alive.

Key words: attitude, nurse, patient relatives, organ donation, surgery

# Öz

Amaç: Bu çalışmanın amacı, cerrahi serviste yatan hasta yakınlarının ve hemodiyaliz hasta yakınlarının organ bağışına yönelik tutumlarını belirlemektir.

Materyal ve Metod: Tanımlayıcı nitelikte olan bu çalışmanın verileri, 15 Ağustos 2016 - 06 Eylül 2017 tarihleri arasında toplandı. Toplamda 197 hasta yakını, hemodiyaliz hasta yakını olanlar (n = 101, grup A) ve olmayanlar (n = 96, grup B) olarak 2 gruba ayrıldı. Veri toplamada "Organ Bağışı Tutum Ölçeği" ve "Veri Toplama Formu", analizinde tanımlayıcı istatistik, Kruskal-Wallis H, Mann-Whitney U ve Spearman korelasyon testleri kullanıldı. Normal dağılmayan veriler için parametrik olmayan testler kullanıldı. p < 0.05 değerinin elde edilmesi anlamlı olarak kabul edildi.

Bulgular: Grupların organ bağışına yönelik toplam tutum puanı ortalamaları pozitif tutum düzeyinin üzerindeydi. Grup A hasta yakınlarının organ bağışına ilişkin daha pozitif tutum sergiledikleri ve "Yardımseverlik ve Ahlaki Değerler" alt boyutu puan ortalamalarının grup B hasta yakınlarına göre anlamlı derecede yüksek olduğu belirlendi (p < 0.05).

Sonuç: Hemodiyaliz hasta yakınları, organ bağışına yönelik pozitif tutumla birlikte daha fazla yardımseverlik ve ahlaki değere sahiptir. Transplantasyon ünitelerinde ve hemodiyaliz merkezlerinde çalışan hemşire ve diğer sağlık bakımı çalışanları hasta yakınlarının organ bağışına yönelik tutumlarını canlı tutmak adına bireylerin pozitif tutumlarının farkında olmalıdır.

Anahtar Kelimeler: tutum, hemşire, hasta yakınları, organ bağışı, cerrahi

## Introduction

End-stage kidney failure is a major problem around the world, and kidney transplantation is the most important treatment method to increase the survival and life quality of these patients.<sup>1,2</sup> According to the records of The Turkish Ministry of Health in 2015, 935 patients per million population had kidney failure and only 17.4% of them were transplanted meanwhile 77.3% of them were having hemodialysis treatment.<sup>3</sup>

As kidney transplantation is a second chance for patients with kidney failure, it also brings the need of organ donation.<sup>4</sup> Despite living donation is growing around the world, it is still inadequate and lower than the number of patients awaiting kidney donation.<sup>5</sup> In Turkey, 21,952 patients with kidney failure are in the list waiting for kidney transplantation by 2018.<sup>6</sup> According to the reports by the end of 2017, 3342 patients had kidney transplantation at the total and only 693 of them were from cadavers.<sup>7</sup> Although the cadaveric organ donation rate is 80 % among European countries, it is between 20.1 and 30.9 % in Turkey.<sup>3,8,9</sup> Among living kidney donors, 44.6 % of them were first degree relatives, 21.2 % of them were partners and 17.1 % of them were second degree relatives of the patients. Besides, the rate of relative donors was 82 % in 2010 and it was reported as 67 % by the end of 2015.<sup>3</sup> As a result of insufficient donation, there is still an increased demand for kidney transplantation.

Although providing the organ is necessary for organ transplantation, there are many factors that may affect organ donation such as age, education, socioeconomic status and cultural factors.<sup>10,11</sup> Attitude towards organ donation has also a direct impact on donation willingness.<sup>12</sup> Due to the increased rate of kidney failure in population or relatives of patients with kidney failure constitute an important group that may influence donations.<sup>13-15</sup> According to a study results, people who had family members with kidney failure were more favor of donation than those who had not.<sup>16</sup> Many factors may influence relatives' opinions about the organ donation and it may also be a barrier to successful organ donation. Knowing the attitude of people who have members with organ failure in their families is important and this information may provide an overview about improving the donation rate. On the other hand, evaluating their attitudes towards organ donation is necessary to follow the changes in attitude over passing time and to keep this subject up to date. However, in the literature, there are limited studies that examine the attitudes in organ donation of individuals that have a relative undergoing hemodialysis treatment and which points the importance of this subject.

Therefore, in this study, it is aimed to evaluate the attitudes of patients' at surgery ward and hemodialysis patients' relatives towards organ donation.

# Methods

Study design and participants: This descriptive study was conducted in 4 dialysis centers and at one university hospital in Eastern Thrace of Turkey. A total of 197 relatives were divided into 2 groups: those who have patients on hemodialysis treatment for at least one year (n = 101, group A) and who do not have (n = 96, group B). The inclusion criteria were: age over 18 years, able to communicate, volunteered to participate in the study.

According to the Sayın's (2016) study,<sup>17</sup> based on the highest standard deviation value ( $3.57 \pm 2.03$  for "A way of being grateful for God" item) with 80 % power and 99 % confidence level of power analysis, the sample number was calculated as 96 for each group.

Data collection: Data of this study were collected between August 15, 2016 and September 06, 2017 with using the 'Data Collection Form' and the 'Organ Donation Attitude Scale'. Relatives of group A were interviewed by the nurse researcher in the waiting lounges of the hemodialysis treatment of their patient at the hemodialysis unit and with relatives of group B members among the treatment period of their patients at the general surgery ward. Each interview lasted approximately 20 minutes.

Data collection form was developed according the studies in the literature<sup>15,18</sup> by the researchers. It consisted five questions for the participants about their age, gender, education, working and economic status.

Parisi and Katz<sup>19</sup> were developed the Organ Donation Attitude Scale (ODAS) and the Turkish validity and reliability was conducted by Sayın in 2015. This six-point Likert-type scale was reported as adequate to be used with the Cronbach's alpha value of 0.857 and ranged between "agree strongly" and "disagree strongly". Positive and negative dimensions of organ donation are measured with 40 items collected for three factors, Positive dimension focused on humanity and moral conviction. Negative dimensions focused on medical neglect fear and bodily mutilation fear. Through the scale, negative dimensions are calculated reversely and total score changes between 40 - 240. Negative attitudes are indicated by scores under 141, and positive attitudes by scores 142 and above. The higher total score showed more positive attitudes. In this study, Cronbach's alpha for total scale was found to be 0.908.

Data analysis: The IBM SPSS 21.0 ver. software package (IBM, Armonk, NY, USA) was used to analyze the data through the descriptive statistics, Kruskal-Wallis H, Mann-Whitney U and Spearman correlation tests. Non-parametric tests were used to analyze the not normally distributed data, and p < 0.05 was considered as significant.

Ethical consideration: This study was approved by the Medical Faculty Ethics Committee (2016 / 166 - decision number 14 / 05), and institutional approval to conduct the study was obtained from the clinical directors of the dialysis centers and university hospital directory. The permission was obtained via mail to use the scale and the principles of the Declaration of Helsinki were followed in this study. The study aim was explained to the participants and informed verbal and written consent of them were taken before starting the data collection.

#### Results

Most of the relatives were female 61.4 % (n = 121), 71.1 % (n = 140) had primary-elementary degree, 49.2 % (n = 97) had outcome equal to income economic status and the mean age was  $46.28 \pm 1.20$  years (Table 1).

The total attitude score of participants who had university degree was significantly higher than those who had primary-high school degree (p = 0.011; p < 0.05). Participants who had equal to income economic status had significantly higher mean attitude score than who had lower income economic status (p = 0.000; p < 0.05). Significant difference was not found between the mean total attitude scale score of participants and the gender, and working status. There was no correlation found as statistically significant between the total attitude scale score and age (p = 0.184; p > 0.05) (Table 1).

The mean total attitude scale score of both groups were above positive attitude level for organ donation and found to be  $186.16 \pm 31.26$  for group A and  $177.79 \pm 36.73$  for group B which was statistically not significant (p = 0.144; p > 0.05). According to the sub-dimension scores, the mean score of "humanity and moral conviction" in group A was statistically significantly higher than group B (p = 0.030; p < 0.05) (Table 2).

Tables

Variables	n	Total Score	P value
	(%)	$\mathbf{X} \pm \mathbf{SS}$	Test
Age (years) $(X \pm SS)$	$46.28 \pm 1.20$	$182.08 \pm 34.21$	p = 0.184
11ge (jeurs) (11 = 55)			$r_s = -0.095$
Gender			
Female	121 (61.4)	$183.84\pm34.12$	p = 0.379
Male	76 (38.6)	$179.28\pm34.39$	U = - 0.879
Education status			
Primary-high school	140 (71.1)	$178.12\pm34.66$	p = 0.011
University	57 (28.9)	$191.82\pm31.27$	U = - 2.536
Working status			
Working	63 (32.0)	$184.79\pm33.69$	p = 0.478
Not working	134 (68.0)	$180.81\pm34.50$	U = -0.709
Economic status			$p_{L-E} = 0.000$
Lower than income	64 (32.5)	$169.185 \pm 36.19$	$p_{L-H} = 0.696$
Equal to income	97 (49.2)	$191.63\pm30.46$	$p_{E-H} = 0.109$
Higher than income	36 (18.3)	$178.08\pm33.29$	KW = 15.864

Table 1. Organ donation attitude scores of participants according to some characteristics

U: Mann-Whitney U test, KW: Kruskal-Wallis H test; r<sub>s</sub>: Spearman correlation test

Table 2. Sub-dimension scores of the scale of according to groups

	Humanity and Moral	Fears of Medical	Fears of Bodily	Total
Groups	Conviction	Neglect	Mutilation	Scale
	$X \pm SD$	$X \pm SD$	$X \pm SD$	$X \pm SD$
Group A	$104.03 \pm 18.78$	$41.17\pm13.08$	$40.95\pm13.72$	$186.16 \pm 31.26$
Group B	$99.12\pm21.05$	$38.55 \pm 14.42$	$40.11\pm14.54$	$177.79\pm36.73$
р	0.030	0.218	0.653	0.144
U	- 2.166	- 1.233	- 0.449	- 1.463
α	0.925	0.863	0.868	0.908

#### U: Mann-Whitney U test, α: Chronbach's alpha value

# Discussion

In this study, participants in group A with relatives receiving hemodialysis treatment had a higher attitude score towards organ donation than group B members who did not have a relative receiving hemodialysis treatments. Although this difference was not found to be statistically significant, it was similar in keeping with previous studies.<sup>15,20</sup> In El-Shoubaki and Bener's study,<sup>21</sup> majority of the participants from Qatari population preferred organ donating for their close relatives. In Rios et al.'s study from Spain,<sup>16</sup> respondents that had previous organ donation experience through family had a more favorable opinion towards organ donation than who had not had any experience. Similarly in Turkey, another study<sup>15</sup> assessed relatives of hemodialysis patients' organ donation attitudes, and found the rate of wishing to donate among participants with relatives receiving dialysis treatment meaningfully higher than those who do not have. This result showed that relatives of hemodialysis patients have positive attitudes towards organ donation.

In this study, participants that had higher education degree and higher income had higher organ donation attitude scores than those who had not. In Qiao et al's study,<sup>22</sup> higher education level was found encouraging hemodialysis patients for kidney transplantation. In Spain, Rios et al.<sup>23</sup> found an association between education level and attitude towards organ donation. In South-West Nigeria, Oluyombo et al.<sup>24</sup> found that having higher education and earning higher income were promoting knowledge of organ donation positively. A study<sup>20</sup> conducted with relatives of dialysis patients at intensive care and dialysis units in Turkey also reported mean organ donation attitude score was going up with increased education level. The lower level of education may be accepted as barrier in front of organ donation. Educational programmes to improve the attitude of public about organ donation may be pivotal. Also the attitude of the health care workers in the relevant departments such as transplantation nurses is important to be taken into account.<sup>25,26</sup> Nurses who work at these departments should be aware of this result and play their educative role to develop positive organ donation attitudes in patients and their relatives.

According to the sub-dimension factors of the scale, the mean score of 'humanity and moral conviction' in group A was statistically significantly higher than group B. A study conducted in Turkey<sup>27</sup> reported that 78% of individuals in households considered organ donation as a

gift of life to the others. In another study from Turkey,<sup>15</sup> participants who had a relative receiving dialysis treatment were willing to donate their kidney was found significantly higher than the rate of the participants who had no relative receiving dialysis treatment. We think that this result may differ according to the countries and cultural characteristics. In a study from Mexico,<sup>28</sup> 82.8% of the population very willing to donate in life and death and "saving a life" was reported as the main reason followed by moral and empathy. A study of Rios et al.<sup>23</sup> reported that 89% of the Latin America citizens living in Spain were in favor of living organ donation. This may reflect Turkish people desire mostly to donate their relatives. Future studies may aim to search the current belief and knowledge status of population and with a proper coordination of health professionals, the media, and religious officials, it may be possible to increase organ donation.

#### Limitations

Data of this study is provided with self reports of relatives and this may subject to bias. Further this study is limited with the hemodialysis centers in Eastern Thrace of Turkey. Therefore generalization of this study is unknown.

#### Conclusions

In line with the study results, having a relative that receives hemodialysis treatment has a positive effect on the attitude towards organ donation. Relatives who have patients receiving hemodialysis treatment had also more humanity and moral conviction with positive attitude than the relatives those who do not have. Nurses and other health care professions who work at transplantation units and hemodialysis centers should be aware of this result to keep the relatives' attitudes alive. As these relatives are an important group for living organ donation, their positive attitudes may have a positive impact on organ donation among community.

## The source of financial grants and other funding: None

Acknowledgment: The authors thank to the participants who took place in this study and saved their time.

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