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ARAŞTIRMA / RESEARCH

Attitudes and related factors toward organ donation among relatives of chronic kidney disease patients and healthy individuals

Kronik böbrek hastaları ve sağlıklı bireylerin organ bağışına yönelik tutumları ve ilişkili faktörler

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Abstract

Purpose: The current study firstly aimed at investigating organ donation and related factors. Another aim of the study is to compare the knowledge and attitude levels of organ donation between the risky population with organ failure and healthy participants.
Materials and Methods: This cross-sectional survey was conducted in the tertiary university hospital between March-October 2019. A total of 88 healthy participants (group 1) and 56 participants with chronic kidney disease ((CKD) (group 2)) were included in the study. Organ donation attitudes of participants were measured with Organ Donation Attitudes Scales Turkish Version questionnaire.
Result: A total of 144 participants (56 were CKD patients and 88 healthy participants) were included in the study. The scores of all participants from the sub-dimensions of the scale were humanity and moral conviction / beliefs (HMC): 90.70±20.36, fears of medical neglect (FMN): 27.38±11.52 and fears of bodily mutilation (FBM): 32.03±10.67, respectively. Group 2 participants' humanity and moral conviction/beliefs (HMC) dimension scores were higher than group 1. Group 2 participants' fears of medical neglect (FMN) score was higher than group 1. Factors affecting organ donation attitudes were gender and education level.
Conclusion: Organ donation positive attitude scores were higher in women and those with higher education levels. Our results may suggest developing empathy and education programs on organ transplantation, as a means for increasing the number of potential organ donors.
Keywords:. Organ donation, attitude, tissue and organ procurement, organ transplantation, empathy

Öz

Amaç: Bu çalışma öncelikle bireylerin organ bağışına yönelik tutumları ve ilgili faktörleri araştırmayı amaçlamıştır. Çalışmanın bir diğer amacı, organ yetmezliği olan riskli grup ile sağlıklı katılımcılar arasındaki organ bağışı bilgi ve tutum düzeylerini karşılaştırmaktır
Gereç ve Yöntem: Bu kesitsel çalışma bir üniversite hastanesinde Mart-Ekim 2019 tarihleri arasında yürütüldü. Çalışmaya 88 sağlıklı (grup 1) ve 56 kronik böbrek hastalığı (KBH) olan (grup 2) bireyler dahil edildi. Katılımcıların organ bağışına yönelik tutumları Organ Bağışı Tutum Ölçeğinin Türkçe versiyonu ile elde edildi.
Bulgular: Çalışmaya toplam 144 katılımcı (56 KBH birey, 88 sağlıklı birey) dahil edildi. Ölçeğin alt boyutlarından tüm katılımcıların puanları sırasıyla humanity and moral conviction / beliefs (HMC): 90.70 ± 20.36, fears of medical neglect (FMN): 27.38 ± 11.52 ve fears of bodily mutilation (FBM): 32.03 ± 10.67 idi. Grup 2'de ki katılımcıların insanlık ve ahlaki inanç / inançlar (HMC) boyut puanları ve tıbbi ihmal korkusu (FMN) skorları grup 1'den yüksekti. Organ bağışı tutumlarını etkileyen faktörler cinsiyet ve eğitim düzeyidir.
Sonuç: Elde ettiğimiz veriler katılımcıların organ bağışı konusundaki istekliliklerinin ve farkındalıklarının düşük olduğunu göstermiştir. Organ bağışı pozitif tutum puanları kadınlarda ve eğitim düzeyi yüksek olanlarda daha yüksek saptandı. Elde ettiğimiz verilere dayanarak potansiyel organ bağışçılarının sayısını artırmak için organ nakli konusunda empati ve bilgi düzeyini arttıracak eğitim programlarının geliştirilmesini önerilebilir.

Anahtar kelimeler: Organ bağışı, tutum, doku ve organ kabülü, organ nakli, empati

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INTRODUCTION

Organ donation (OD) means the donation of biological tissue or an organ of the human body, from a living or a dead person to a living recipient in need of a transplantation. Organ transplantation is a routine, valid and advanced treatment method applied in many organ failures today. Organ transplantation is the only treatment option for patients with end-stage liver and heart diseases. It is also considered as the best possible treatment for patients with renal failure in terms of cost-effectiveness and improved quality of life [1].

In 2017, the Global Observatory on Donation & Transplantation recorded approximately 139,024 solid organ transplantation cases which, however, catered to only 7.2% of the total worldwide requirement [2]. In 2018, Turkey organ transplant foundation reported that 28 777 people were in need of organ transplantation and reported that only 7405 transplants performed in Turkey [3]. The minority of organ supply from cadaver is one of the biggest problems in organ transplantation in our country and in the world. Patients waiting for organ transplantation die while waiting for the appropriate organ, and the most important reason for this is the inadequate organ donation [4].

There are many factors that influence the acceptance or denial of donation. Organ donation is influenced by multiple socioeconomic factors, religious aspects, racial disparities, age, gender, and education level. In addition, other factors such as numerous ethical conditions, in addition to other factors such as filial love, self-love, paternal mandates, and guilt can affect organ donation [5-7]. It was reported that education is the most important factor among all these factors. The unknown is often rejected and for this reason, it is imperative that we educate the community about organ donation in a way that is inclusive of people with all political, religious, and socioeconomic backgrounds [8].

The current researches have continued their efforts to better understand the decision-making processes involved in donating one's organs upon death. These research on organ donation has focused on individuals' attitudes and their willingness to become organ donors. In these studies have been reported that people with chronic illnesses or organ failure in the family or themselves have higher levels of knowledge and attitude [9-11].

Literature data reported that knowledge and attitude about organ donation had a positive effect on organ donation and that organ donation knowledge and attitude levels were higher in the population with an organ transplant risk. In this context, the current study firstly aimed at invastigate organ donation and related factors. Another aim of the study is to compare the knowledge and attitude levels of organ donation between the risky population with organ failure and healthy participants.

MATERIALS AND METHODS

This cross-sectional survey was conducted in the tertiary university hospital between March-October 2019. Ethical approval was obtained from the Ethics Committee of Non-Interventional Research of Firat University (10.01.2019/01.15). Those who met the inclusion criteria were included in the study and written consent form was obtained from all participants.

A total of 88 healthy participants (group 1) and 56 participants with chronic kidney disease (CKD) (group 2) were included in the study. 70 patients who applied to the nephrology clinic between the dates of the study and met the study criteria were invited to the study. 56 volunteers were included in the study (response rate: %80). Patients in the chronic kidney disease group; consisted of CKD patients those not requiring dialysis and followed up by a nephrologist for chronic kidney disease. The healthy participants (normotensive, non-diabetic, without chronic disease that will cause organ failure any kidney disease) from the general population were also included.

The study inclusion criteria were as follows: (i) being over 18 years old (ii) patient group; having chronic renal failure diagnosed by the nephrologist (iii) healthy group; no organ failure or no chronic disease-causing organ failure. On the other hand, the exclusion criteria were: (i) having psychiatric and neurological diseases that affect cognitive functions, (ii) hearing and vision problems that prevent filling out the questionnaire.

Measures

Research data were collected by using a structured questionnaire developed as a result of review of literature (demographics form) and Organ Donation Attitudes Scales Turkish Version questionnaire [4-9].The organ donation attitude scale (ODAS), which

was first developed by Parisi and Katz in 1986, was expanded and adapted by Kent and Owens in 1995. The scale's original version adapted by Kent and Owens in 1995 contains 46 items (23 positive, 23 negative). Validity and reliability study of the original scale was done by Yazici and the scale was translated into Turkish [12]. The Turkish form of the ODAS scale consists of 40 items related to organ donation attitude. The scale is a Likert format with 6 options, ranging from fully agree to each item option and disagree at all.

The Organ Donation Attitude Scale Turkish version, which consists of a total of 40 items, contains 20 positive items and 20 negative items. The ODAS consists of three dimensions. The first dimension consists of 20 positive items and shows the " humanity and moral conviction / beliefs (HMC)" of people about organ donation. The second dimension indicates the "fears of medical neglect (FMN)"consisting of 10 negative expressions and the third dimension indicates the "fears of bodily mutilation (FBM)" consisting of the 10 negative expressions. The score of each item of the scale is collected and the score is calculated. The first dimension which is consists of positive attitudes score is between 20-120 points. The second and third dimensions which are consists of negative attitudes scores are between 10-60 points. High positive and low negative scores are associated with strong volunteering attitudes towards organ donation. Yazici reported that ODAS Turkish version Cronbach's α level is 0,759 and it is both a reliable and valid instrument that can be useful in measuring positive and negative attitudes of Turkish people about organ donation [12].

Intervention and data collection

Study data were obtained with a demographic questionnaire and organ donation attitude questionnaire. A total of 45 questions (demograpfic form: 15 question, ODAS: 40 question) were asked to the participants. Data were collected using a face-to-face questionnaire.

The questionnaire was applied to patients with chronic renal failure in patient rooms at the nephrology clinic. The questionnaire form was applied to the participants who applied to the outpatient clinics and included in the study, in a separate room which is organized for an interview with the patient. Approximately 20 minutes were interviewed with each participants.

Statistical analysis

Statistical analysis of the data was performed by IBM SPSS 22 statistics package program. Shapiro-Wilk test was used to determine whether the data showed normal distribution. Descriptive statistics of the data were expressed as mean ± standard deviation for variables with normal distribution in continuous data and frequency for categorical variables as percentage (n (%)).

In comparison of two independent groups Student-t test and more than two independent groups, One-Way ANOVA and LSD test for post-Hoc test were used for normal distributed continuous data. Pearson chi-square test was used to analyze categorical data. Significance level was $\alpha = 0.05$. Statistically significant significance values are indicated in bold in the tables.

RESULTS

A total of 144 participants were included in the study. Among them, 56 were CKD patients and 88 healthy controls from the general population. Their ages were 59.63±14.86 and 31.92±9.70 years *(p < .001)* respectively. The education level of the participants in group 1 was higher than group 2 *(p<0.001).* In terms of occupation, health workers were the majority in participants in group 1, and housewives were the majority in group 2 *(p<0.001).* Participants in group 2 thought that their organ donation knowledge levels were insufficient *(p<0.001).* Group 2 participants were more unwilling about transplantation from someone else *(p=0.002),* the opposite gender *(p<0.001),* animal *(p=0.001)* and artificial organ *(p=0.004).* (Table 1).

The scores of all participants from the sub-dimensions of the scale were HMC: 90.70±20.36, FMN: 27.38±11.52 and FBM: 32.03±10.67, respectively. Group 2 (CKD) humanity and moral conviction/beliefs (HMC) dimension score was higher than group 1 (p=0.032). Fears of bodily mutilation (FBM) dimension indicates negative expressions about organ donation. Group 2 FNM score was higher than group 1 *(p=0.001).* (Table 2).

Table 1. Sociodemographic characteristics and opinions regarding the donation of organs and tissues of the study population

Variable	Group 1 (healthy) n=88	Group 2 (CKD) n=56	p value
Age	31.92±9.70	59.63±14.86	F:6.30 P<0.001
Gender			
Female	45 (51.1)	31 (55.4)	X^2=0.25
Male	43 (48.9)	25 (44.6)	p=0.621
Occupation			
Housewife	10 (11.4)	29 (51.8)	
Minimum wage worker	13 (14.8)	3 (5.4)	X^2=51.94
civil servant	14 (15.9)	4 (7.1)	P<0.001
private business owner	13 (14.8)	18 (32.1)	
Health staff	38 (43.2)	2 (3.6)	
Education			
illiterate	0 (0.0)	24 (42.9)	
primary school	5 (5.7)	13 (23.2)	X^2=63.30
Middle school	7 (8.0)	5 (8.9)	P<0.001
High school	36 (40.9)	10 (17.9)	
University	40 (45.5)	4 (7.1)	
Willing to donate organ?			
Yes	28 (31.8)	24 (42.9)	X^2=1.81
No	21 (23.9)	11 (19.6)	P=0.404
Undecided	39 (44.3)	21 (37.5)	
Have you donated your organs?			
Yes	1 (1.1)	1 (1.8)	X^2=0.11
No	87 (98.9)	55 (98.2)	P=0.745
Do you have sufficient information about OD?			
Yes	23 (26.1)	7 (12.5)	X^2=16.23
No	31 (35.2)	39 (69.6)	P<0.001
Undecided	34 (38.6)	10 (17.9)	
OD information source			
Family doctor	14 (15.9)	27 (48.2)	
Organ transplant centers	66 (75.0)	18 (32.1)	X^2=41.96
Family members and friends	0 (0.0)	8 (14.3)	P<0.001
media and internet	8 (9.1)	3 (5.4)	
Would you receive an OD from someone else?			
Yes	52 (59.1)	34 (60.7)	X^2=12.95
No	5 (5.7)	13 (23.2)	P=0.002
Undecided	31 (35.2)	9 (16.1)	
Would you receive an organ donation of the opposite gender?			
Yes	49 (55.7)	27 (48.2)	X^2=24.02
No	6 (6.8)	21 (37.5)	P<0.001
Undecided	33 (37.5)	8 (14.3)	
Would you receive an organ donation from the animal?			
Yes	37 (42.0)	23 (41.1)	X^2=14.49
No	17 (19.3)	25 (44.6)	P=0.001
Undecided	34 (38.6)	8 (14.3)	
Would you receive an artificial organ like a machine?			
Yes	58 (65.9)	39 (69.6)	X^2=11.05
No	5 (5.7)	11 (19.6)	P=0.004
Undecided	25 (28.4)	6 (10.8)	
Would you receive blood from someone else?			
Yes	69 (78.4)	55 (98.2)	X^2: 11.24
No	1 (1.1)	1 (1.8)	P=0.004
Undecided	18 (20.5)	0 (0.0)	
Total	88 (100.0)	56 (100.0)	

OD: Organ donation

Table 2. Mean scores of the organ donation attitudes scale (ODAS) of the participants

ODAS dimensions	Group 1 (healthy)	Group 2 (CKD)	All population	P value
HMC (positive)	87.12±23.29	96.32±16.30	90.70±20.36	t=2.20 p=0.032
FMN (negative)	26.55±12.04	28.69±13.42	27.38±11.52	t=2.84 p=0.372
FBM (negative)	29.21±10.11	36.44±12.18	32.03±10.67	t=3.86 p=0.001

HMC: humanity and moral conviction/beliefs; FMN: fears of medical neglect; FBM: fears of bodily mutilation

The female participants' ODAS positive score was higher than the male (p<0.001). Both negative dimensions scores of the participants with high education level were lower than participants with low education level (p=0.018 and p<0.001). Participants who considered the organ donation knowledge level insufficient had a higher negative attitude score (p=0.007 and p=0.001). Participants with higher positive scores had higher rates of accepting transplantation from someone else, the opposite sex, animal and artificial organ. Participants who unwilling transplantation from someone else, opposite sex, animal and artificial organ, received higher negative scores than the scale. (Table 3).

Table 3. Relationship between sociodemographic characteristics and opinions regarding the organ donation with ODAS scores

Variable	HMC (positive)		FMN (negative)		FBM (negative)	
Gender						
Female (n=76)	95.91±18.02	<0.001	26.07±11.21	0.149	30.83±10.48	0.159
Male (n=68)	84.87±21.36		28.85±11.77		33.35±10.80	
Education						
İlliterate (n=24)	77.33±30.71*		31.38±11.59*		40.84±9.03*	
primary school (n=18)	94.92±14.65	0.042	26.80±8.09	0.018	31.68±9.19*	<0.001
Middle school (n=12)	98.24±10.71*		31.04±15.23		35.58±12.02	
High school (n=46)	88.55±22.11		28.89±11.16		31.91±9.64*	
University (n=44)	90.74±19.64		22.85±10.86*		26.49±9.44*	
Willing to donate organ?						
Yes (52)	105.15±13.05*		30.36±10.21*		*23.11±7.43*	
No (32)	80.28±22.68*	<0.001	20.86±9.46*	0.001	36.61±9.60	<0.001
Undecided (60)	92.02±16.13*		28.27±12.37		32.80±10.25	
Have you donated your organs?						
Yes (2)	96.56±13.35		18.50±3.53		16.01±1.41	
No (142)	90.61±20.46		27.50±11.55		32.25±10.57	
Do you have sufficient information about OD?						
Yes (30)	93.56±21.20		21.61±10.11*		26.79±12.44*	
No (70)	91.35±21.54	0.448	29.41±11.80*	0.007	35.04±9.82*	0.001
Undecided (44)	87.70±17.76		28.08±10.91*		30.79±9.16	
Would you receive an OD from someone else?						
Yes (86)	98.29±16.22*a		25.93±12.08		30.05±11.08*	
No (18)	77.88±27.27*a	<0.001	29.15±9.56	0.186	37.86±12.57*	0.009
Undecided (40)	80.13±17.47*		29.68±10.84		33.65±7.84	
Would you receive an OD of the opposite gender?						
Yes (76)	98.93±16.99*a		25.18±12.17		28.79±10.68*a	
No (27)	80.52±24.76*	<0.001	28.96±9.45	0.050	37.75±10.98*a	<0.001
Undecided (41)	82.14±16.38*a		30.40±10.90		34.24±8.22*	
Would you receive an OD from the animal?						
Yes (60)	97.95±17.15*a		24.19±11.17*		28.23±10.52*	
No (42)	87.22±23.16*a	0.001	29.96±12.32*	0.018	36.61±11.22*	<0.001
Undecided (42)	83.60±18.66*		29.35±10.30*		32.86±8.28	
Would you receive an artificial organ like a machine?						
Yes (97)	94.50±18.77*		25.91±11.51		30.43±11.04*	
No (16)	90.60±24.18	0.001	30.67±12.35	0.088	35.05±12.43	0.035
Undecided (31)	78.84±19.09*		30.28±10.55		35.45±7.06*	

ODAS: Organ donation attitudes scale; OD: Organ donation; HMC: humanity and moral conviction/beliefs; FMN: fears of medical neglect; FBM: fears of bodily mutilation

DISCUSSION

The current study asked to participants "Willing to donate organ?". 31.8% of healthy participants and 42.9% of the participants in the CKD were found to be willing for organ donation. In our study, total of 36.1% of the 144 participants were willing for organ donation. In similar studies in the literature, organ donation willingness rates were reported as 51.2% in Morocco, 51% in Saudi Arabia, 53.9% in Tunisia and 53.5% in China, respectively [13-16]. A study conducted in Turkey, organ donation willingness rate was reported as 21.2% by Gungormus and Dayapoglu [17]. Our findings suggest that organ donation willingness in our country is insufficient.

In our study, the attitudes of the participants about organ donation were measured with ODAS. ODAS can evaluate both the positive attitudes of the participants about organ donation and the negative attitudes that may prevent organ donation. In our study, the mean HMC score (positive attitudes) of the scale was 90.70±20.36 in all patients. HMC scores of participants in two different studies conducted in Turkey were reported to be 98.0 and 95.5 points, respectively [12, 18]. Organ donation positive attitude scores of our participants were lower than similar studies conducted in Turkey.

FMN and FBN scores, which negatively affected the organ donation willingness, were 27.38±11.52 and 32.03±10.67 points, respectively. In two different studies conducted in Turkey, FMN and FBN scores were reported 25.5±11.4 and 25.5±11.4 by Ucgun et al., 27.2 ±12.1 and 31.6±10.9 by Sayin et al., respectively [12, 18]. Organ donation negative attitude scores of our participants were higher than the literature data. This situation showed that the participants' willingness for organ donation was insufficient.

It is important to identify the factors affecting positive and negative attitude scores to increase the willingness of organ donation. The scale positive attitude score was higher among females, participants with higher education levels, and participants willing to donate organs. Many of the studies in the literature reported that women had higher organ donation willingness than men, similar to the data we obtained [5, 19-22]. All these data showed that women are more sensitive about organ donation.

Another important data we obtained in our study was the effect of education level on organ donation willingness. As the education level increased, the organ donation positive attitude score increased, while the negative attitude score which is the barrier of organ donation willingness decreased. The level of education both increased the organ donation willingness and reduced the fear of organ donation. Literature studies reported that as the education level increased, the organ donation willingness increased [5, 19, 22-25]. In the literature, the relationship between education level and organ donation has been supported by our data. As a result, it was thought that it is necessary to increase the level of education in order to increase organ donation rates.

In two different studies, were reported that women had more organ donation willingness [5,20]. Similar to the data of the literature, organ donation positive attitude score was higher in women in our study. In two different studies conducted in Turkey, reported that women's positive attitudes towards organ donation have been reported to be more than men [17 ,26]. In these studies, the reason for this difference has been associated with higher education level of women. There are also findings contrary to the data we obtained in the literature. Organ transplantation data were examined in two different studies and it was reported that transplants from male cadavers were more than female cadavers[27,28].

In current study, the organ donation positive attitude scores of the participants who accepted a transplant from another person, animal, opposite sex and artificial organ were higher. We think this is an expected finding. Ucgun et al. reached the same result with the data we obtained in their study [18]. Participants who had a negative opinion about opposite sex, artificial or animal organ transplantation had higher FMN and FBM scores. Low positive attitude scores and high negative attitude scores in these participants may be related to the level of knowledge of the participants. In further studies, we believe that the relationship between participants' knowledge levels and attitude scores should be investigated.

In the literature reported that that the biggest obstacle to organ donation is the fear of medical neglect and bodily mutilation of the participants [22, 29]. Consistent with the literature, in our study, it was found that those who had higher FMN and FBM scores were less likely to have organ donation. It has been

determined that the most important reason for the fear of medical neglect and bodily mutilation is the low level of education of the participants and insufficient knowledge about organ transplantation. In order to increase organ donation rates, we need to reduce individuals' negative attitudes and fears of organ donation.

In this study, we compared the organ donation attitudes of 2 different populations. Participants with chronic kidney disease (CKD) had higher organ donation positive attitude scores than healthy participants. Riviera et al. reported that the willingness of organ donation increased if there was a relative hospitalized [5]. Wilczek-Rużyczka et al. reported that as the level of empathy increased, the willingness of organ donation increased (20). Ucgun et al reported that positive attitude score (HMC) higher and negative attitude scores (FMN and FBM) lower in participant in relatives of patients waiting for organ transplants [18]. As a result of the data we obtained, we believe that empathy is effective on organ donation positive attitude. An unexpected finding in our study was that participants in the CKD group declared that their level of knowledge about organ donation was insufficient. The reason for the fears of bodily mutilation scores of the participants in the CKD group to be higher than the healthy participants may be the insufficient level of knowledge. The finding we obtained once again suggested that informing about organ donation is important.

The first limitation is the current study is cross-sectional and does not reflect the general population. Another limitation is that the small size of the study population and groups. The state of knowledge about organ donation is the participants' own statements. The state of knowledge about organ donation is the participants' own statements. therefore, standardization may not be obtained in terms of the level of knowledge of the participants. Despite all our limitations, the organ donation attitudes of the participants were obtained with the organ donation attitude scale. In this way, we contributed to the literature on the positive and negative attitude levels of the participants and their affecting factors.

As a result, it was determined that the participants' willingness and awareness of organ donation was low. Only 1.4% of the participants donated their organs and this rate was very low. Organ donation positive attitude scores were higher in women and those with higher education level. The organ donation positive attitudes of the CKD group were higher. In this context, we believe that empathy is related to organ donation. The most important factor that reduces organ donation and willingness is fears of medical neglect and bodily mutilation. The fear level of those with low education level and those with insufficient knowledge of organ donation was higher. Our results may suggest developing empathy and education programs on organ transplantation, as a means for increasing the number of potential organ donors.

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