Development of a Reliable and Valid Organ Tissue Donation and Transplantation Knowledge Scale

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ABSTRACT

Introduction. Knowledge has an important role in an individual's willingness to donate organs upon death. Knowledge enables clarification of false beliefs, which can increase willingness to consent to organ donation. The purpose of the study was to describe and examine the validity and reliability of the Organ-Tissue Donation and Transplantation Knowledge Scale (ODTKS).

Methods. We performed a comprehensive literature review and chose 23 items for the scale according to specialists' recommendations. A total of 6 items were excluded from the scale. Finally, the scale consisted of 17 items and 2 subdimensions.

Results. The study group consisted of 540 (267 [49.4%] male and 273 [50.6%] female) nonmedical staff members; 23.5% were primary school graduates, 47.6% were high school graduates, and 28.9% had university degrees or higher. The difficulty index and discrimination index of the overall scale were 22.41% to 54.07% and 0.23 to 0.46, respectively. Cronbach α coefficient was 0.88 overall. Retest reliability scores were significant ($r = 0.87$, $P < .001$).

Conclusions. The total score of the ODTKS was significantly higher among university graduates compared with primary school graduates and among people willing to donate. The ODTKS therefore has adequate reliability and validity for evaluating Turkish adults' knowledge about organ tissue donation and transplantation.

ORGAN tissue transplantation is a treatment option that may bring hope for patients by providing disease-free living, increased quality of life, and increased recovery rates. Also, organ transplantation is a lifesaving treatment that can be used for a variety of conditions, including acute organ failure or chronic organ failure [1,2]. Organ transplantations are performed in over 100 countries, and approximately 117,700 were performed in 2013 [3]. One criterion of success of organ transplantation is determined by the number of deceased donors per million population (pmp). According to the International Registry in Organ Donation and Transplantation 2013 data, this ratio was 25.9 ppm in the United States and 35.1, 35.0, and 34.0 ppm in the 3 most successful European countries (Spain, Croatia, Malta), respectively [4]. The Turkish donation rate was 5 pmp, and over 27,000 patients were on a waiting list in the Turkey at the end of 2014 [4,5]. Shortage of organ donation in Turkey is an important public health problem that needs to be resolved quickly because of both medical and economic losses [6,7]. The most important reason for the difference between donation supply and demand is insensitivity of individuals [8].

The primary problem of transplantation is the lack of sufficient organ donors. To solve this problem, the general public should give attention to the issue [9,10].

These data can be used in determining reasons why people decide whether to donate to eliminate barriers and increase organ donation rates. Therefore, causes of whether or not people donate organs should be examined [11]. Numerous factors influence the decisions of people toward organ donation, including knowledge, attitudes, and religion [12,13]. Knowledge regarding organ and tissue donation

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plays an important role in the decision to donate [14,15]. Studies have clarified that people who want to donate their organs usually understand the transplantation process and general information about organ donation [16,17]. These studies have also shown that Turkish people have many misconceptions and lack specific knowledge of organ and tissue donation and transplantation. Specific knowledge of the organ tissue donation and transplantation process, such as brain death, medical-legal issues, and religious beliefs, provides guidance to people who have misconceptions and who lack information about organ donation [8,18–20].

In Turkey, nearly half of the society has a positive attitude about organ donation. However, many people do not know how to participate and lack general knowledge about organ donation [21,22]. This situation shows that if knowledge regarding organ donation increases in society, donation rates will increase. Previous studies that used surveys and measurement tools were not able to clarify the knowledge present in Turkish society regarding organ donation.

The present study was conducted to develop a scale for measuring the knowledge of organ tissue donation and transplantation and to assess its validity and reliability.

MATERIALS AND METHODS

Establish the Face and Content Validity of the Organ-Tissue Donation and Transplantation Knowledge Scale

Initially, we examined recent literature and educational materials from the Turkey Ministry of Health about organ tissue donation and transplantation. We performed a comprehensive literature review and discovered items that measured knowledge levels regarding organ tissue donation and transplantation. We chose 23 items for the scale according to specialists' recommendations.

The items were assessed in 2 domains: "donor characteristics" (numbers 1 to 5, 15) and "legal, ethics, medical process related to organ tissue donation and transplantation" (numbers 6 to 14, 16 to 23). Items consisted of complete sentences of correct or incorrect statements. We asked nonmedical staff to answer "right," "wrong," or "do not know" for each item. Eleven of the items were incorrect statements (numbers 2, 6, 8 to 11, 15, 18, 20, 22, 23).

The Organ-Tissue Donation and Transplantation Knowledge Scale (ODTKS) benefited from several other scales, questionnaires, guidelines, and studies: items 1, 8 to 14, 16 to 18, 20, 22 were created from the educational materials of the Turkey Ministry of Health [5]; items 2, 5, 15 were derived from the questionnaire Knowledge of and Attitudes Toward Organ Donation: A Survey of Medical Students in Puerto Rico [23]; items 3, 4, 6, 19, 21 were obtained from a questionnaire in the Development of the Organ Donation and Transplantation Knowledge Survey for Use in Asian American Adolescents [24]; item 7 was obtained from a questionnaire asking whether medical students have the knowledge needed to maximize organ donation rates [25]; and item 23 was derived from the International Registry in Organ Donation and Transplantation 2013 report [4]. Items 2 to 6, 15, 19, 21, 23 were translated into Turkish and back-translated into English.

Ten experts including 3 epidemiology specialists, 1 nephrologist, 1 general surgeon, 1 ethicist, 3 public health research assistants, and 1 Turkish language specialist were asked to review the items in the scale to determine the construct validity. They were asked to assess the items in 3 groups: "essential," "useful but inadequate," or "unnecessary." According to the specialists, item 23, "The number of deceased donor in Turkey is higher than in many European countries," was unnecessary and was excluded from the scale. A Turkish language specialist evaluated the completed scale, and necessary changes were made.

Study Group and Procedure

The Ethics Committee of Eskisehir Osmangazi University and Eskisehir Osmangazi University Medical Practice and Research Hospital Management reviewed and approved the study. Verbal consent was obtained from the participants.

The study was performed in Eskisehir, which is a province located in central Turkey with a population of 790,000. There are 2 universities in the city and 2 medical schools.

The study was carried out in Eskisehir Osmangazi University Medical Practice and Research Hospital between December 2014 and March 2015. There were 742 nonmedical staff working in the 900-bed hospital, which provided service to a 110,000 m^2 area.

The minimum sample size was calculated as 460 staff based on the statement "sample size should be 10 to 20 times the number of items in the study questionnaire" [26]. However, we assumed that individuals may be lost during the test-retest period. Therefore, the sample size was increased by about 20%, and questionnaires were completed by 540 (72.7%) individuals.

In accordance with the purpose of the study, a 2-part questionnaire was prepared. The first part focused on the sociodemographic characteristics, including age, sex, education level, marital status, monthly income of family, family status, personal/family status of physician-diagnosed diseases, family members performed transplant, willingness to donate, and having a donation card. We determined the socioeconomic status of the participants according to their own expressions (i.e., poor, moderate, or good). The second part consisted of the ODTKS.

The questionnaire was completed by the researchers in a face-to-face conversation. Questionnaire administration required between 20 and 25 minutes to complete. Retests were performed 2 weeks after the first application. Nonmedical staff who were not in the hospital, who answered less than 90% of the questionnaire, or who did not complete the retest were excluded from the study.

Analysis

Discrimination and Difficulty Indices. Difficulty and discrimination indices were calculated for each item. The difficulty index confirms that an appropriate range of results is assessed for the population under study. Knowledge questions should not be too easy or too difficult, and an appropriate range falls between 20% and 80% correct responses. This index is calculated using the formula $P = (H + L/N) \cdot 100$, where P is the item difficulty index, H is the number of nonmedical staff answering the item correctly in the high-achieving group, L is the number of nonmedical staff answering the item correctly in the low-achieving group, and N is the total number of nonmedical staff in these 2 groups. Other reliability tests include measures of robustness, such that tests can differentiate based on a range of ability (eg, high or low knowledge). This factor was measured quantitatively using an item discrimination index, which measures the ability of the item to discriminate between participants who do well on the test and participants who do not. The discrimination index was calculated using the formula $d = (H - L/N) \cdot 2$. The suggested criterion for inclusion is that items should correlate with the total score beyond a value of 0.20 [27]. The upper limit was 80% for the

study difficulty index. Items that were too easy or too hard or that exhibited low selectivity were excluded. Item 14, "People who want to donate organs must apply to provincial directorate of health, hospitals, family health centers and transplantation centers with two witness"; item 15, "Having a cardiovascular condition or diabetes mellitus is a contraindication to becoming an organ donor"; and item 16, "Islam religion supports organ and tissue donation as an act of compassion and generosity" were excluded from the questionnaire based on the difficulty and discrimination indices.

Factor Analysis. Exploratory factor analysis was calculated using a principal factor method with varimax rotation to evaluate the scale's construct validity. Factor analysis adequacy was assessed by applying the Kaiser-Meyer-Olkin (KMO) test to the scale. The KMO result was >0.50, and factor analysis was performed. Item 8, "Rich patients on the transplant waiting list get organs and tissues before emergency patients," and item 13, "It is illegal to sell your organs in the Turkey," were excluded from the scale due to factor loadings overlap. All the items exhibited factor loadings of >0.40 in the analysis, so there was no need to remove items [28].

According to the factor loadings obtained from the factor analysis, items pertained to a subdimension according to their maximum factor weight. Two subdimensions were identified by the factor analysis.

Internal Consistency. Cronbach α coefficient was calculated to evaluate the scale's internal consistency, and α coefficients were also calculated for item-total correlation and for item elimination.

Items greater than 0.30 of the total item correlations were considered reliable. None of the items gave values less than 0.30 [29].

Test-retest reliability. Test-retest reliability coefficient was calculated to evaluate the scale's stability over time. The level of agreement between responses at test and retest was measured by using Spearman rank correlation coefficient.

Scoring

The final scale had 17 items with 2 subdimensions. Each correct answer was worth 1 point. Incorrect statements were encoded inversely to the other items. The maximum score was 17 for the overall scale: 5 for the first subdimension ("donor characteristics") and 12 for the second subdimension ("legal, ethics, medical process related to organ donation and transplantation"). The minimum score was 0 for the overall scale and all subdimensions.

Statistical Analysis

Data were analyzed using SPSS 20.0 statistical software (SPSS Inc, Chicago, Illinois, United States). The demographic characteristics of the study group were reported using descriptive statistics (frequencies, proportions, means, and medians). Initially, the normality of the total scores was tested using the Kolmogorov-Smirnov normality test and graphs. The median scores of the groups were compared by Kruskal-Wallis (and Bonferroni ad hoc test) and Mann-Whitney *U* tests.

RESULTS

Sociodemographic Characteristics of Study Group

The study group consisted of a total of 540 nonmedical staff. Of these, 267 (49.4%) were men, and 273 (50.6%) were women. The mean age of the 540 participants was 34.0 ± 6.8 (range, 20 to 57) years.

The educational level of the participants included primary school (23.5%), high school (47.6%), and university or higher (28.9%). The socioeconomic status of the nonmedical staff consisted of 6.3% who were designated as poor. There were 7 (1.3%) people whose family members had transplants. When we asked the nonmedical staff about having a donation card, only 11 (2.0%) responded positively; however, 130 (24.1%) participants expressed a willingness to donate.

Discrimination and Difficulty Indices

Three items were excluded from the scale according to the difficulty index and/or discrimination index (80% and above and/or 0.20 and under, respectively). The difficulty index and discrimination index of the first subdimension ranged between 22.41% and 54.07% and 0.23 to 12.40, respectively; the second subdimension ranged between 32.78% and 0.55% and 0.29 to 0.46, respectively; the overall scale ranged between 22.41% and 54.07% and 0.23 to 0.46, respectively.

Factor Analysis

The construct validity of the ODTKS was assessed using factor analysis. The KMO measure of sampling adequacy was 0.936. Bartlett test of sphericity was significant ($\chi^2 = 2815.298$, df = 136, $P < .001$). A scree plot as well as the fact that the eigenvalues were greater than 1.0 determined that 2 factors should be retained, which accounted for 43.79% of the variance.

The first subdimension comprised 5 items, and the second subdimension comprised 12 items; the first subdimension factor loadings varied between 0.48 and 0.75, and the second subdimension factor loadings varied between 0.49 and 0.65.

Internal Consistency

Internal consistency was assessed by calculating Cronbach α, and the value was 0.73 for the first subdimension, 0.86 for the second subdimension, and 0.88 for all items.

The deletion of any item from the scale produced Cronbach α values that ranged between 0.66 and 0.73 for the first subdimension and between 0.84 and 0.85 for the second subdimension. The corrected item total correlation coefficient ranged between 0.38 and 0.56 for the first subdimension and 0.45 and 0.62 for the second subdimension.

Factor loading, the results of reliability analysis, and the percentage of correct answer of ODTKS are shown in Table 1.

Test-Retest Reliability

Two weeks later, the questionnaire was administered again. A high positive correlation was observed between the total scores of the 2 applications using Spearman rank correlation analysis ($r = 0.87$, $P < .001$). The correlation coefficient of the first subdimension was 0.84 and the second subdimension was 0.89. A scatter plot of the ODTKS test-retest scores is shown in Fig 1.

Table 1. Percentages of Correct Answer, the Results of Reliability Analysis, and Factor Loading of the ODTKS Items

Items	Percentage of Correct Answer	Factor Loading	Corrected Item Total Correlation	If Item Deleted Cronbach α
First subdimension: donor characteristics				
1. Organ donation is the process of giving an organ (or a part of an organ tissue) for the purpose of transplantation into another person. For a person to become an deceased organ donor, brain death must be declared.	83.7	0.75	0.54	0.67
2. There is an age limit on who can donate organs.	31.1	0.48	0.38	0.73
3. You can donate certain organs while you are alive and healthy.	81.3	0.74	0.56	0.66
4. High blood pressure and diabetes are common causes for people to require a kidney transplant.	59.3	0.66	0.50	0.69
5. Brain death is the irreversible and total cessation of all of the brain functions in the person, including the functions of the brainstem.	84.6	0.64	0.53	0.68
Second subdimension: legal, ethics, medical process related to organ donation and transplantation				
6. A person can recover from brain death.	69.8	0.49	0.49	0.85
7. Brain death means that the patient is dead, not in a coma.	49.8	0.51	0.53	0.85
9. Organ tissue is removed after every death.	66.9	0.63	0.51	0.85
10. Organ tissue removed from one person could be transplanted to everyone.	75.7	0.57	0.49	0.85
11. A matched donor is based on blood group for all tranplantation types.	48.9	0.65	0.45	0.85
12. Kidneys, liver, heart, lungs, bone marrow, ileum, and cornea are all transplantable organs or tissues in our country.	65.2	0.58	0.60	0.84
17. If I die at a hospital, my family will be asked to grant consent for donation even if I have signed a donor card.	62.0	0.61	0.59	0.84
18. The final decision belongs to the doctor if a deceased patient has not signed an organ donor card.	71.5	0.58	0.56	0.85
19. Donors can live healthy years after a transplant operation.	62.4	0.54	0.62	0.84
20. Organ tissue transplantation is performed only between relatives.	81.7	0.60	0.61	0.85
21. People can cause their own disease requiring an organ transplant by using intravenous IV drugs or drinking too much alcohol.	61.9	0.59	0.61	0.84
22. There is only one type of organ donation: deceased donor (only someone who had brain death declared can donate organ tissue).	55.2	0.58	0.52	0.85

Abbreviation: ODTKS, Organ-Tissue Donation and Transplantation Knowledge Scale.

Assessment of ODTKS

In the study, the fifth item (about brain death) had the highest correct answer percentage, and the second item (about age limit for donation) had the lowest correct answer percentage (Table 1).

The mean (standard deviation) and median (interquartile range) of the overall scale were 11.1 (4.3) and 12.0 (9.0 to 14.0), respectively. The mean (standard deviation) and median (interquartile range) of the first subdimension and the second subdimension were 3.4 (1.4), 4.0 (3.0 to 4.0), and 7.7 (3.3), 8.0 (6.0 to 10.0), respectively.

The distribution of total ODTKS scores with regard to various demographic characteristics and willingness to donate of the study group is given in Table 2.

Participants' age and gender were not significantly associated with organ tissue donation and transplantation knowledge. The total score of ODTKS was significantly higher among university graduates compared with primary school graduates and moderate/good socioeconomic status participants compared with poor participants. Organ tissue donation and transplantation knowledge scores were significantly higher among people who had one or more

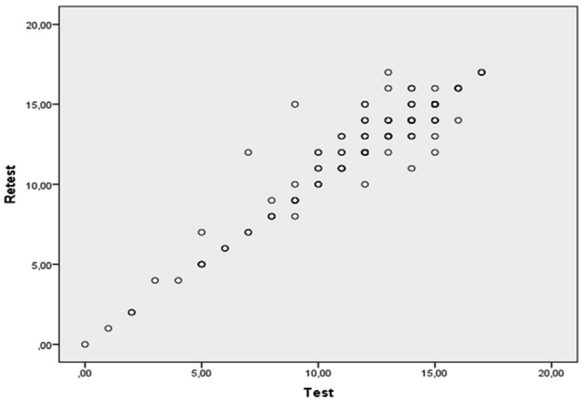

Fig 1. Scatter plot of the Organ-Tissue Donation and Transplantation Knowledge Scale test-retest scores.

family members who had transplants and among people who were willing to donate.

DISCUSSION

Although significant improvements were achieved in organ and tissue transplantation, the difference between patients who were waiting for transplants and those who receive transplants is not decreasing. These data increase the importance of performing studies on organ tissue donation. To establish knowledge level, we investigated the most important factor that affects an individual to become a donor using accurate and effective methods; we aimed to develop a knowledge scale about organ donation and transplantation and to study its validity and reliability.

Table 2. Distribution of Total ODTKS Scores With Regard to Various Demographic Characteristics and Willingness to Donate of the Study Group

Sociodemographic Characteristics	Mean (SD)	Median (Interquartile Range)	Statistical Value (z/Kw; *P*)
Sex			1.391; .164
Male	10.7 (4.7)	12.0 (9.0–14.0)	
Female	11.5 (3.8)	12.0 (10.0–14.0)	
Age group (y)			1.022; .60*
20–29	11.5 (4.0)	12.0 (10.0–14.0)	
30–39	11.0 (4.2)	12.0 (9.0–14.0)	
40 and older	10.9 (4.6)	12.0 (9.0–14.0)	
Education level			8.383; .015*
Primary school	10.1 (4.7)	11.0 (7.0–14.0)	
High school	11.2 (4.3)	12.0 (9.5–14)	
University or higher	11.8 (3.7)	12.0 (9.3–15.0)	
Socioeconomic status			7.709; .021*
Poor	10.3 (4.5)	11.0 (7.0–14.0)	
Moderate	11.4 (4.1)	12.0 (9.0–14.0)	
Good	12.0 (3.8)	13.0 (10.0–15.0)	
Family members performed transplant			2.457; .014
Yes	14.6 (1.6)	14.0 (14.0–16.0)	
No	11.1 (4.3)	12.0 (9.0–14.0)	
Willingness to donate			8.155; .017*
Yes	12.1 (3.4)	13.0 (11.0–15.0)	
No	10.5 (4.8)	12.0 (7.0–14.0)	
Not sure	11.1 (4.1)	11.0 (9.0–14.0)	

Abbreviations: ODTKS, Organ-Tissue Donation and Transplantation Knowledge Scale; SD, standard deviation.
*Kruskal-Wallis test (and Bonferroni post hoc test).

In the study, difficulty index and discrimination index of the items varied between 22.41% and 54.07% and 0.23 to 0.46, respectively. Schaeffner et al studied medical students and doctors via investigating the legal process of organ donation, waiting time for transplantation, immunosuppressive treatment following transplantation, and the differences between living and deceased donor; the difficulty indexes of the items on the scale, which contains 13 yes-or-no questions, were performed for evaluation of the knowledge of the individuals and varied between 15% and 85% [30]. In a similar study by Chung et al evaluating the knowledge level about deceased donors, only 6 of 15 information questions had a sufficient discrimination index [13]. Considering these results, all of the items in ODTKS include desirable difficulty and discrimination levels.

The construct validity of ODTKS was evaluated using factor analysis, and the factor load of each item of the scale was >0.40. For comparison, survey items used in the adolescent study of Trompeta et al regarding knowledge level about organ donation and transplantation were >0.35 [24].

For a reliable scale, Cronbach α coefficient should be above 0.70. Cronbach α coefficient was 0.88 for the overall scale and above 0.70 in both subdimensions. Cronbach α coefficient was 0.81 in another study performed with a questionnaire including 15 items that can be answered as yes or no; those questions dealt with knowledge of medical students about brain death, deceased donor need, and the medical process [13]. Also, a Likert-type scale was used in a study of Asian American adolescents regarding knowledge level about organ donation and transplantation, and Cronbach α coefficients varied between 0.74 and 0.83 in subdimensions [24].

The value of corrected item total correlation above 0.30 was considered sufficient [29]. Considering that values above 0.30 differentiate individuals using corrected item total correlation, our results using ODTKS.

Test-retest reliability refers to the correlation coefficient obtained for any variable under similar conditions and after a certain time interval. Test-retest scores less than 0.80 indicate that the participants did not answer the items the same way when retested [31]. The test-retest correlations of the subdimensions varied between 0.84 and 0.89, and overall it was 0.87. For comparison, Flower et al investigated factors that affected intention to be an organ donor of individuals aged 18 or above in India. The questionnaire contained 8 yes-or-no questions, and their test-retest correlation coefficient was >0.91 [32]. In our study, results of the ODTKS support the literature and show that the scale items did not change over time.

The ODTKS was evaluated using a population with varying sociodemographic characteristics, and no association with gender or age was found. In 3 different studies conducted in Pakistan, Taif, and Nigeria, knowledge level about organ donation and transplantation did not change depending gender or age [33–35]. In the study of Sander and Miller in northwest Ohio, there was no change in knowledge level about organ donation and transplantation depending on gender; however, younger individuals had more information with regards to this issue [36]. In another study conducted in Iran, no difference in knowledge level was found with regards to age; however, women had more information regarding this issue [37]. Differences in knowledge level about organ donation and transplantation with regards to age and gender may be a result of differences of study groups, and lack of knowledge is a holistic problem regardless of age and gender.

In this study, ODTKS suggested that the individuals who had higher education levels were more knowledgeable than the individuals who had lower education levels. In different studies of Al-Harthi and Alzahrany in Saudi Arabia and Odusanya and Ladipo in Nigeria, in accordance with our findings, knowledge level of the college graduates regarding organ donation and transplantation were higher than that of the primary school graduates [33–35].

In other studies that aimed to evaluate knowledge level of people about organ donation and transplantation, knowledge levels of the individuals were positively correlated with education levels [38,39]. Easier access to information, educational programs conducted by health care authorities, as well as printed and visual media about organ donation and transplantation are an expected and desired condition for individuals with higher educational levels.

Knowledge levels of the individuals with moderate and higher income status were higher than those of the individuals with poor income status. In an adult study conducted in Pakistan evaluating the knowledge levels and behaviors about organ donation and transplantation, knowledge level was found to be higher in individuals with higher income status as well [35]. However, in another study conducted on relatives of the patients who applied to the emergency service, there was no difference between knowledge levels with regards to the income levels [37]. Arriola et al in the United States reported that intention to become a organ donor is more frequent in individuals of higher income level. When considering that individuals with sufficient knowledge are more positive regarding this issue, it is inevitable that individuals who think more positively also have higher knowledge levels. Thereby, knowledge level will cause an increase in economic well-being [40].

In our study group, individuals with family members who had an organ transplant knew more about organ donation. In a study conducted with African Americans, individuals with family members who had an organ transplant or who were awaiting transplantation exhibited higher knowledge levels [40]. This can be explained in 2 different ways. First, having a relative that has received an organ or is a candidate may increase awareness and promote people to investigate organ donation; thereby, their knowledge level may increase as they learn about the pretransplantation and post-transplantation procedures. Second, awareness of transplantation benefits may increase via organ transplant recipients or candidates who shared their personal histories. Sharing personal stories may be integrated to the community education programs and may then be spread widely.

One of the hypotheses of this study is that the individuals who think positively about being an organ donor will score higher on the ODTKS. As support for this hypothesis, we found that individuals who were positive about being an organ donor had higher median scores in the overall scale than the individuals who thought negatively about being an organ donor. Bilgel et al conducted 2 studies regarding the comparison of the change of a community's opinion about organ donation over time, and they suggested that attitudes of the individuals toward being an organ donor was associated with their knowledge status; thus, individuals with higher knowledge levels were more willing to participate in organ donation [41,42]. It is important for individuals to have reliable information about topics such as the transplantation process, brain death, and post-transplantation process when deciding to be a organ donor. Also, multiple studies that investigated the reasons for unwillingness to donate reported that lack of knowledge about the donation and transplantation process decreases the number of deceased donors [33,36,43]. The willingness to be an organ donor is affected by multiple factors, and a common point of these factors is the lack of knowledge or wrong information provided to individuals. This indicates that the amount of available educational trainings is not currently sufficient, and informing the community about specific topics about organ donation and transplantation such as brain death and legal and medical processes may increase the amount of donors.

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