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Original Article

Knowledge, Attitudes, and Behaviors of Patients Diagnosed with End-Stage Kidney Disease Registered on the Kidney Transplant Waiting List Regarding Organ Transplantation and Donation

¹Fatma Necla Özşeker , ²Şefika Türkan Kudsioğlu ¹Medicana International Ankara Hospital, Organ Transplantation Unit, Ankara, Turkey²Dr. Siyami Ersek Thoracic and Cardiovascular Surgery Health Education and Research Hospital, Istanbul, Turkey**Corresponding author:** Fatma Necla Özşeker, Medicana International Ankara Hospital, Organ Transplantation Unit, Ankara, Turkey

E-mail: ncozseker@hotmail.com

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ABSTRACT

Background: The aim of this study is to determine the knowledge, attitudes, and behaviors of patients diagnosed with end-stage renal disease who are registered on the kidney transplant waiting list regarding organ donation and transplantation. Additionally, it will be examined whether these results vary according to sociodemographic characteristics.

Materials and Methods: The research was conducted with patients registered on the kidney transplant waiting list at Medicana International Ankara Hospital between April 15 and June 15, 2022. An attempt was made to reach the entire population, and the research was conducted with 120 participants (28.5%). A survey was used as the data collection method in this descriptive study, consisting of 30 questions that included sociodemographic characteristics as well as statements regarding organ donation and transplantation.

Results: It was found that 52.5% of the participants were female, 31.7% were in the 35-49 age range, 70.8% did not smoke, 37.5% had primary school education, and 70.8% were married. All patients were undergoing dialysis treatment, and 36.7% had been on the kidney transplant waiting list for less than 3 years. It was found that 53.3% of the participants had previously received education on organ transplantation or donation, 75% did not have an organ donation card, and 46.7% were not willing to donate organs. 74.2% of the patients found the studies conducted nationwide on organ donation to be inadequate, and 45% did not trust the organ distribution system.

Conclusion: The knowledge, attitudes, and behaviors of the participants regarding organ donation and transplantation are not at the desired level. There are statistically significant differences in the knowledge, attitudes, and behaviors of patients according to their age and education level. It is considered that the study results will assist decision-makers in identifying the situation related to patients, raising awareness among all stakeholders, and determining a roadmap for solution proposals.

Keywords: Organ donation, transplantation, ESRD, attitudes, behaviors

INTRODUCTION

Kidney transplantation is one of the most successful advancements in modern medicine (1). It improves patient survival and quality of life, while also reducing the socio-economic burden of organ failure in society (2).

Although hemodialysis is the most commonly chosen treatment method for end-stage renal disease (ESRD) patients (3,4), kidney transplantation is the desired approach (5,6). Compared to hemodialysis, kidney transplantation offers significant advantages in terms of patient survival, quality of life, and cost-effectiveness (7-9).

In the United States, despite performing 40,000 transplants in 2021, 17 people on the waiting list lose their lives each day due to the inability to undergo organ transplantation. As of August 2022, approximately 106,000 patients, with around 91,000 of them waiting for kidney transplantation, are awaiting organ and tissue transplants (10). In the European Union, within the Eurotransplant program involving eight countries, around 14,000 patients are on the waiting list, with 10,000 of them awaiting kidney transplantation as of August 2022 (11). In Turkey, despite 3,375 kidney transplantations being performed in 2021, approximately 28,000 patients, including 24,000 kidney patients, are currently on the organ waiting list (12). Worldwide,

while approximately 100,000 solid organ transplants are performed each year, over 1 million people are waiting for organ transplants (13,14). Despite the increasing number of transplantations over the years due to advancements in technology, skilled personnel, and capacity, the number of patients on the waiting lists continues to rise, resulting in many patients losing their lives before receiving a transplant (15).

Although many patients continue to wait for kidney transplantation, there are significant limitations in organ procurement (9). The fundamental challenge in organ transplantation is the imbalance between organ demand and organ supply (16). Analyzing and effectively managing this situation is crucial (9). Organ and tissue transplant coordinators play an active role in brain death determination, family consultations, organ retrieval preparation, and the monitoring and preparation of transplant recipients in the transplant process. Therefore, presenting the coordinators' experiences, the problems they encounter in the field, and their recommendations will provide significant contributions to a more comprehensive analysis of organ procurement issues.

The aim of this study is to determine the knowledge, attitudes, and behaviors of patients diagnosed with ESRD who are registered on the kidney transplant waiting list regarding organ donation and transplantation. Additionally, the study will examine the impact of sociodemographic characteristics on donation perception.

MATERIALS AND METHODS

Study Design and Participants

This is a descriptive study. The research population consists of patients registered on the kidney transplant waiting list of the Turkish Ministry of Health (Transplantation, Dialysis, and Monitoring Systems/ TDIS) through Medicana International Ankara Hospital. The aim was to reach all registered patients without calculating the sample size. Upon investigation, it was determined that there were 421 registered patients, and efforts were made to reach out to these patients. However, due to reasons such as refusal to participate, inability to establish communication, and incomplete or erroneous completion of the survey form, the study was conducted with 120 patients. The participation rate in the study is 28.5%.

Data collection

Data collection in the study was conducted using a questionnaire as the data collection tool (Suppl). The questionnaire was created by the researcher based on the literature information (references 75-77) and included 30 multiple-choice questions regarding participants' socio-demographic characteristics such as age, gender, education level, marital status, smoking status, as well as their knowledge, attitudes, and behaviors towards organ donation and transplantation. Some of the statements in the questionnaire included: "Have you

received any education on organ transplantation or organ donation?", "Have you registered as an organ donor to be used after your death?", "Do you find the efforts on organ donation adequate?", "In your opinion, what is the most effective method to increase organ donation rates?" The questionnaire form is presented in Table 1. The individual responses were did not shared with third persons or institute.

Implementation of The Study

After obtaining approval from the Hamidiye Health Sciences Institute of Health Sciences University and ethical permission from the Academic and Ethical Board of Medicana International Ankara Hospital, the study was conducted between April 15 and June 15, 2022, at Medicana International Ankara Hospital.

Participants were approached by the researcher when they visited the hospital for appointments, or attempts were made to reach them via email. The individual responses were did not shared with third persons or institute.

Inclusion criteria for participation in the study

- Being diagnosed with ESRD
- Being registered on the Ministry of Health kidney transplant waiting list and on the waiting list through Medicana International Ankara Hospital
- Volunteering to participate in the study
- Having the cognitive ability to understand and answer the questions
- Having communication skills

Exclusion criteria for the study

- Not being registered on the kidney transplant waiting list through Özel Medicana International Ankara Hospital
- Waiting for organ transplants other than kidney transplantation
- Not volunteering to participate in the study
- Not having the cognitive ability to understand and answer the questions
- Not having communication skills

This study was conducted at Medicana International Ankara Hospital Organ Transplantation Unit which has started performing kidney and liver transplants in October 2009, followed by bone marrow transplants in February 2012 (Table 1). In our hospital, 2 transplant nephrologists, 2 transplant surgeons, two coordinators, 1 transplant service, 3 transplant polyclinics provide support for recipients and donors in transplantation for more than 10 years.

Ethical approval

The ethical appropriateness of the research has been evaluated by the " Medicana International Ankara

Table 1. Kidney transplant performance of Medicana International Ankara Hospital (2017-2022)

Transplantation type	2017	2018	2019	2020	2021	2022	Total
Living	66	56	97	92	125	89	528
Deceased	5	7	10	7	-	1	30
Total	71	63	107	99	125	90	558

Hospital Academic and Ethical Committee,” and it has been determined to be appropriate in the decision dated 30/03/2022, with IRB number 2022/08. The research was conducted in accordance with the ethical principles of the Helsinki Declaration.

STATISTICAL ANALYSIS

The data collected in the study were analyzed using the Statistical Package for the Social Sciences (SPSS) version 22.0. Descriptive statistics were performed using frequency analysis, and the results were presented in numbers and percentages. The Chi-square test was used to determine the relationship between categorical variables. Regression analysis was used to demonstrate the impact of variables on organ donation willingness. A significance level of $p < 0.05$ was considered statistically significant.

RESULTS

The study involved 120 participants, with a slightly higher proportion of females (52.5%) compared to males (47.5%). The mean age was approximately 54.24 ± 14.25 . The majority of participants were between 35-64 years old (31.67%), with smaller percentages in the younger and older age groups. The majority of participants (70.8%) did not smoke, while 23.3% were smokers and 5.8% occasionally smoked. In terms of educational background, primary school education was the most common (37.5%), followed by high school education and university graduates (both 20%). A significant portion of participants (70.8%) were married, while single and divorced individuals accounted for smaller percentages. The leading cause of ESRD was attributed to hypertension (38.3%), followed by diabetes (19.2%) and other conditions such as polycystic kidney disease and kidney stones (Table 2).

Given dialysis choices, the majority of hemodialysis (HD) patients preferred center hemodialysis (90%), while smaller proportions opted for peritoneal dialysis (5.8%) or home hemodialysis (4.2%). The duration of renal replacement therapy varied, with some patients on the waiting list for less than 3 years (33.3%) and others on HD for over 10 years (23.3%).

Participants’ registration on the National Waiting List showed that a significant portion had been registered for less than 3 years (36.7%), with varying durations of 3-5

years, 6-10 years, and over 10 years. The primary sources of guidance to join the waiting list were the dialysis center (53.4%) and nephrologists (24.2%), while family members and personal decisions played smaller roles.

A minority of participants (18.3%) had undergone a kidney transplant before, while the majority (81.7%) had not. Some participants (19.2%) reported being called for a transplant, suggesting a potential opportunity for transplantation. However, the majority (80.8%) had not received a call from the registered transplant center.

In terms of familial presence on the transplant waiting list, a small percentage (7.5%) mentioned having another family member waiting for an organ transplant, while the majority (91.7%) did not have any family members in the same situation.

Regarding knowledge about organ donation and transplantation, slightly over half of the participants (53.3%) reported receiving education on the topic, while a smaller percentage (44.2%) had not. Some participants (2.5%) were uncertain about whether they had received education on organ transplantation or donation. Additionally, the majority (67.5%) reported being knowledgeable about the concept of brain death, while a significant proportion (32.5%) stated being unfamiliar with it.

A significant proportion of participants in the study had knowledge about organ transplantation and donation, including awareness of brain death. However, their personal familiarity with individuals who have received organ transplants, either through deceased or living donation, was limited. Only a small percentage knew someone who had undergone a transplant (19.2% for deceased donation and 20.8% for living donation). This suggests that participants’ awareness and education on transplantation might not be matched by personal experiences.

A minority of participants (12.5%) reported having family members who have donated organs and obtained a donation card, while the majority (84.2%) stated that no one in their families had done so. A few participants expressed uncertainty in this regard.

The majority of participants (80.8%) reported not being called for a kidney transplant by the registered transplant center. Additionally, a small percentage (7.5%) mentioned having another family member waiting for an organ transplant. More than half of the participants (53.3%) reported receiving education on the topic. Concerning awareness of brain death, a significant majority (67.5%) indicated being knowledgeable about it.

Regarding familiarity with organ transplant recipients, a minority of participants (19.2%) reported knowing someone who had received a transplant through a deceased organ donation, while a similar percentage (20.8%) knew someone who had received a transplant from a living donor.

A majority of the participants (74.2%) believed that the efforts regarding organ donation were insufficient, while 33.3% expressed trust in the organ distribution system and 45.0% did not trust it. Opinions on the right to change the decision after organ donation were divided, with 56.7% believing they had the right to change their decision and 20.8% believing they did not. Concerning the requirement of being completely healthy to become an organ donor, 57.5% believed it was necessary, while 25.8% did not.

When asked about the most effective method to increase organ donation rates, the majority (69.2%) selected

Table 3. The socio-demographic characteristics of the participants in our study are presented

Sex male/female, n	57/63	Marital status Married	85
		Status	35
Age, year		The primary cause of ESRD, n	
• 18-34	13	HT	46
• 35-49	38	DM	23
• 50-64	36	PCKD	9
• >64	33	Urological problems	13
		GN	7
		Unknown	6
		Other	16
Literacy		Smoking, yes/no, n	35/85
University	24		
High-school	24		
Primary school	61		
No Literacy	11		

ESRD, end-stage renal disease, DM; diabetes mellitus, HT; hypertension, PCKD; polycystic kidney disease, GN; glomerulonephritis

“All” as the most effective method. A notable proportion (23.3%) stated that their views and opinions regarding organ donation changed as a result of the survey.

The analysis found no significant association between gender and receiving education about organ donation and transplantation ($p > 0.05$). There was no significant association between gender and awareness of brain death ($p > 0.05$).

A small percentage (21.7%) reported having a donation card, indicating their willingness to participate. Additionally, a considerable proportion (45.8%) expressed their willingness to engage in organ donation. Gender does not have a significant influence on awareness of brain death, possession of an organ donation card, willingness to donate organs, perception of the adequacy of organ transplant efforts, or trust in the Ministry of Health Organ Distribution System ($p > 0.05$).

Age is associated with possession of an organ donation card and willingness to donate organs, with the highest percentages observed in the 35-49 age group ($p < 0.05$). However, age is not significantly associated with the perception of organ transplant efforts being adequate or trust in the Ministry of Health Organ Distribution System.

Education level is significantly associated with the possession of an organ donation card, with higher education levels being more likely to possess a card ($p < 0.05$). There is no significant association between education level and receiving education about organ donation and transplantation, knowledge about the concept of brain death, willingness to donate organs or trust in the Ministry of Health Organ Distribution System.

DISCUSSION

This study aimed to determine the knowledge, attitudes, and behaviors of patients diagnosed with chronic kidney failure who are registered on the kidney transplant waiting list regarding organ donation and transplantation.

In Turkey, the prevalence of ESRD in adults is 15.7%, and it is more common in the elderly population (17). In our study, when examining the causes of ESRD in patients, hypertension and diabetes were found to be prominent. A study conducted in the United States indicated that diabetes and hypertension were the main causes, while studies conducted in Turkey mentioned chronic glomerulonephritis, diabetes, and hypertension as the main causes (18-20). The findings of our research are consistent with the literature.

Hemodialysis is the most common type of treatment in Turkey (21,22). In this cohort, all participants were receiving hemodialysis treatment. The low number of patients in peritoneal dialysis may be attributed to the complications associated with peritoneal dialysis and its suitability, particularly for younger patients who are also more suitable for transplantation (22). The number of hemodialysis patients increased from approximately 56,000 in 2014 to over 70,000 in 2022. As a result, the number of hemodialysis centers also increased, from 849 in 2014 to 918 in 2022, in response to the growing number of patients (22,23). It is important to note that the high number of ESRD patients in Turkey constitutes approximately 5% of the health budget spent on dialysis.

In our study, more than half of the participants were informed about organ transplantation and donation, and 75% of the patients referred to transplant centers for registration on the waiting list by dialysis centers and nephrologists. Another study found that approximately 70% of patients were informed, and 75% were directed

by their dialysis physician and nephrologist (9). Patients awaiting organ transplantation often experience fear, anger, hopelessness, uncertainty, fatigue, and anxiety. Many of these emotions result from inadequate information (24,25). Therefore, it is anticipated that providing patients with information about the organ transplantation system, its operation, kidney transplantation surgery, and complications by relevant healthcare professionals would contribute to their quality of life and psychological well-being.

In this cohort, 46.7% of the participants were willing to donate organs, but only 21.7% had an organ donation card. In a study conducted with kidney and liver transplant waiting patients in Spain, 91% of the patients expressed their willingness to donate their organs after brain death, 6% were undecided, and 3% were unwilling to donate (26). Examining studies conducted with other groups is also important to clarify the community's stance on the subject. In a study conducted with teachers in Bosnia and Herzegovina, none of the participants had an organ donation card, but the majority were willing to donate organs from both living and deceased donors (27). In previous studies, Uzuntarla found that 52.8% of healthcare workers in Turkey were willing to donate their organs, but only 16.7% had an organ donation card (9). In a study conducted in Germany by Radunz et al., 74% of the participants were willing, but only 55% had an organ donation card (28). Hobeika et al. conducted a study with surgeons and medical school students in the United States, where 64% were willing, and 49% had an organ donation card (29). In a study conducted by Lima et al. in Brazil, 78% of physicians were willing, and in a study conducted in Poland, 73% of nurses were willing (30). Vlaisavljević et al. conducted a study with nurses in Serbia, where 32.0% were willing, and 0.3% had an organ donation card (31). As seen from the results of these studies, organ donation rates are high in Spain and European countries, while they are low in developing or underdeveloped countries. Furthermore, it can be stated that healthcare professionals have a more positive attitude towards organ donation and transplantation due to their knowledge and experience compared to patients and other members of society.

We determined that 45% of the participants did not trust the organ distribution system of the Ministry of Health, and 21.7% were undecided. 74.2% of the participants considered organ transplantation efforts in the country to be inadequate. Another study conducted with ESRD patients in Turkey found that 64.4% of the participants believed that they could not receive a kidney transplant from a deceased donor due to the inadequacy of donation and transplantation efforts in the country (9). In a study conducted by Balwani et al. in India with ESRD patients, approximately 32% of the participants expressed concerns about the misuse, abuse, or unfair distribution of donated organs, indicating a lack of trust in the system (32). Therefore, it becomes necessary to assure people that no priority is given to wealthy or influential individuals in the organ distribution system. It is important to build trust in society by demonstrating the transparency of the process, where factors such as wealth, social status, race, and gender are never taken into account. To establish trust and address such concerns, it is necessary to provide education to the public. When examining the reasons for individuals' negative attitudes towards organ donation in research, it was found in the study by Özkan et al. that distrust in physicians, personal preferences, concerns about the disruption of bodily integrity, and religious reasons were the reasons for not donating organs (33). In Özkan's study with the relatives of ESRD patients, lack of sufficient knowledge, fear, and religious reasons stood out as prominent factors

(34). In a study conducted by Tarhan et al. with the relatives of patients, fear, unsuitable health conditions, and religious reasons were identified as the reasons why participants did not engage in organ donation (35). Studies conducted by Nadoushan et al. with physicians in Iran, Hu and Huang with healthcare personnel in China, and Hobeika et al. with surgeons and medical students in America revealed that a significant portion of the participants had concerns about the disruption of bodily integrity (29,36,37). It is observed that reluctance to donate organs due to religious reasons can be seen in all societies. However, all Abrahamic religions approve of organ donation. The Presidency of Religious Affairs of the Republic of Turkey issued a fatwa in 1980 stating that organ transplantation is permissible if there is a medical necessity, basing it on the verse (Surah Al-Ma'idah/32) in the Quran which says, "Whoever saves one life, it is as if he has saved all of humanity."

In our study, approximately 70% of the participants, who are considered to be individuals believe that all institutions such as healthcare organizations, media, religious institutions, and schools should actively contribute to increasing the organ donation rate. Similar studies have also indicated that lack of information is the biggest obstacle to organ donation and needs to be addressed. In this regard, it has been emphasized that increasing public awareness, using media, and providing education to the community are crucial (38,39). In a study by Smiths et al. with middle school students in the Netherlands, the control group was given a questionnaire on organ donation and transplantation. The experimental group, however, was provided with a 45-minute presentation where five former patients who had previously received kidney transplants through cadaver donation shared their knowledge and experiences. The study found that the experimental group, which received the educational program, had an increased willingness to fill out organ donation forms and an increased knowledge and awareness of organ donation (40). In a study by Uzuntarla with high school students in Ankara, a pre-test was conducted first, and then the students were given a 45-minute education session by an organ transplantation coordinator, followed by a post-test. The study found that the knowledge level, which was 11.5% in the pre-test, increased to 88.5% after the education session, and the voluntary organ donation rate increased from 15% to 53.1%. This study has demonstrated that the deficiency in organ donation can be significantly addressed through education (41).

Individuals aged 35-49 had significantly more positive knowledge and attitudes regarding brain death awareness, possession of an organ donation card, and willingness to donate organs compared to others. It is believed that the higher knowledge and experience, more active working life, and presumably higher health literacy levels of individuals in this age group influenced the results. While significant differences according to age were found in some previous studies, they were not found in others (16,42-44). Those with higher education levels had a more positive attitude compared to literate and primary school graduates. The findings of the study are consistent with previous research (16, 44).

Limitations of the study: The study's participants were only patients on the kidney transplant waiting list, which may not provide a comprehensive understanding of the broader population's knowledge, attitudes, and behaviors towards organ donation and transplantation. Including a more diverse sample, such as individuals from different age groups, educational backgrounds, and socioeconomic statuses, could enhance the study's validity and generalizability. The study touched upon

certain factors, such as education level and age, but did not explore other potential influencers, such as cultural and religious beliefs, social norms, or personal experiences. Investigating a broader range of factors that may impact attitudes and behaviors towards organ donation could yield a more comprehensive understanding.

CONCLUSION

The knowledge, attitudes, and behaviors of patients on the kidney transplant waiting list regarding organ donation and transplantation require improvement. The study provides valuable insights for policymakers and stakeholders to evaluate the current situation, increase awareness, and develop strategies to address the identified issues. It underscores the need for comprehensive education programs, transparent organ allocation systems, and collaborative efforts to promote organ donation and transplantation in the population.

DECLARATIONS

Ethical approval: This study was carried out in accordance with the Declaration of Helsinki. The study was approved by the Medicana International Hospital Scientific Research Ethics Committee (Date:30.03.2022, Approval number: BŞH-2022/08).

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Supp 1

Questionnaire Form

Information, Attitudes and Behaviors of Patients with Chronic Kidney Failure Diagnosed in the Kidney Waiting List on Organ Transplantation and Donation

Dear participant; This questionnaire form has been prepared to evaluate the information, attitudes and behaviors of the patients who are registered to the Ministry of Health Organ Waiting List (TDis) in the Medica International Ankara Hospital Organ Transplantation Center, who are being treated for end-stage chronic renal failure or undergoing dialysis, and to increase the awareness of organ donation. If you agree to participate in the study, the results will be published in the research article and your personal information will be kept strictly confidential. Please read all the questions carefully and choose the option that suits you best. Thank you for your support, participation and help.

I was informed about the purpose of the survey, I voluntarily agree, participate in the research;

I CONFIRM

I DO NOT CONFIRM

1. Your gender

Male female

2. Your Age Group

18-24 25-34 35-49 50-64 Age 65 and over

3. Do you smoke?

Yes No Occasionally

4. What is your Education Status?

Literate Primary school Secondary school High school University

5. What is your marital status?

Married Single Divorced

6. Which of the following is your cause of chronic kidney failure?

- Hypertension Diabetes Polycystic Kidney Disease
 Bladder Problems Kidney Stone Nephritis
 Cause Unknown Other
7. Are you on dialysis? If yes, what type of dialysis do you do?
 Yes No
 Hemodialysis Home Dialysis Peritoneal Dialysis
8. If you are on dialysis, how many years have you been receiving dialysis treatment?
 I do not enter 1-3 years 3-5 years 5-10 years More than 10 years
9. For how many years have you been registered on the Ministry of Health National Organ waiting list?
 1-3 years 3-5 years 5-10 years More than 10 years
10. Who directed you to enroll in the Ministry of Health National Organ Waiting List?
 My family Dialysis Center My Nephrology Doctor My Friends
 Myself
11. Have you ever had a kidney transplant?
 Yes No
12. Have you been called for a kidney transplant by the transplant center you registered before?
 Yes No
13. Are there any patients in your family who are waiting for an organ besides you?
 Yes No Not sure
14. Have you ever received training on organ transplantation or organ donation?
 Yes No Not sure
15. Have you heard of the concept of brain death before? What do you think is brain death?
 Yes
- No
16. Do you know anyone who has had a transplant with organ donation as a result of death?
 Yes No Not sure
17. Do you have a relative or acquaintance who has a suitable donor and has had a transplant?
 Yes No Not sure
18. Is there anyone in your family who has donated organs and received a donation card?
 Yes No Not sure
19. Did you donate organs to be used after death?
 Yes No Not sure
20. If your answer to the previous question is 'no', would you like to donate an organ?
 Yes No Not sure
21. Do you know where and how organ donation is made?
 Yes No Not sure
22. Would you recommend organ donation to your family and friends?
 Yes No Not sure
23. If a relative of yours dies, would you donate their organs?
 Yes No Not sure
24. Do you want your relatives to donate your organs after you die?
 Yes No Not sure
25. Do you find the studies on organ donation sufficient?
 Yes No Not sure
26. Do you trust the organ distribution system of the Ministry of Health?
 Yes No Not sure
27. Do you think you have the right to cancel the decision after organ donation?
 Yes No Not sure
28. Is it necessary to be completely healthy to be an organ donor?
 Yes No Not sure
29. What do you think is the most effective method to increase the rate of organ donation?
 Media School Family Religious Organizations
 Healthcare Institutions All
30. Have your views and ideas on organ donation changed with this survey?
 Yes No Not sure