

Perceptions and attitudes of Saudi adult population toward organ donation, Taif, Saudi Arabia

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Abstract

Background: Islam supports concepts of transplantation that provide the strongest positive influence for organ donation both during life and at death.

Objective: To determine the public knowledge and attitudes toward organ donation, and to identify the factors that influence organ donation consent and refusal in KSA.

Materials and Methods: A cross-sectional study was carried out including Saudi adults who attended the outpatient clinics in Prince Mansour Family and Community Hospital in Taif city throughout the study period. An Arabic-language questionnaire was designed to capture information relevant to the study. It was filled in by the researcher through face-to-face interviews of the selected participants. The questionnaire comprised sociodemographic information, questions to explore knowledge of the participants about organ donation, and questions to assess participants' attitudes regarding organ donation during the life and after death.

Result: The study included 400 Saudi adults aged between 18 and 60 years (mean = 32.68 ± 9.17 years). Most of them (72%) were males. The majority (85.8%) of the participants has heard of—and was aware of—the organ donation programs. Almost two-thirds (62.4%) of the participants had their information about organ donation from the media whereas 37.6% and 33.8% from newspapers/magazines and the Internet, respectively. Only 12% had their information regarding organ donation from health-care workers. The knowledge score and attitudes toward organ donation increased gradually with the increasing educational level of the participants ($p = 0.001$). Almost 30.3% respondents were willing to donate an organ whereas 237 (59.3%) refused organ donation. Fear of complications and lack of proper post-donation care were the main reported reasons for non-willingness of organ donation in 54.9% participants.

Conclusion: Negative attitudes toward organ donation reported by this study are justified by the inadequate information acquired by the public about this significant issue.

KEY WORDS: Organ donation, perception, attitude, adults, Saudi Arabia

Introduction

One of the basic aims of Islam is saving life. This is a fundamental aim of the Shariah and Allah greatly rewards those who save others from death in the world and the Day of

Judgment. It is a kind of “sadaqa jariya,” which is essentially an act of charity whose benefits continue after a person passes away. For that, Islam supports concepts of transplantation that provide the strongest positive influence for organ donation both during life and at death.^[1] Organ donation is the gift of an organ to help someone else who needs a transplant. There are two types of organ donation. The first is organ taken from a live donor. The second is cadaveric organ donation. Death is defined as either cessation of heart beat or brain death. Brain death is the irreversible end of all brain activities (including involuntary activity necessary to sustain life) due to total necrosis of the cerebral neurons following loss of brain oxygenation.^[2]

The first resolution of the Islamic Council in the Kingdom of Saudi Arabia (KSA; Senior Ulama Commission) about

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organ donation and transplantation was issued in 1982. It permitted tissue and organ transplantation from both living and cadaveric donors. This resolution marked a new era in organ transplantation in KSA, leading to the formation of the Saudi Center for Organ Transplantation (SCOT).^[3]

The SCOT was established by the government of KSA in 1984 as a national organ procurement center that supervises all activities of organ donation and transplantation in KSA.^[4] The program aims to serve humanity by ending the suffering of those with end-stage organ failure by providing viable organs in a manner that is not only beneficial to the patient but also to donor families, the health-care professionals, and the members of the public.^[4] Also, it aims to improve awareness of the public and medical communities about the significance of organ donation and transplantation including opinion surveys, distribution of donation cards, training courses, and hospital visits.^[4] The SCOT achieved considerable success rates and its efforts benefited a significant number of patients.

According to the figures published by the SCOT, the number of cadaveric organ donors in KSA in 1995 was 82. However, the number of patients on dialysis in 1996 was about 5000.^[5] In 2009, there were 6000 sick Saudis across KSA awaiting organ transplants,^[6] something that has in recent years become difficult due to an annual decrease in the number of organ donors in the region and we often hear stories about many Saudis who leave KSA to get some kind of organ transplant. As a result, severe organ shortage has been associated with increasing number of patient deaths and increasing number of commercial transplants and transplant tourism.

In recent years, there are steady increases in the total number of organ transplantation with each passing year as the treatment of choice for patients with end-stage organ disease.^[5] Studies on knowledge and attitudes toward organ donation had shown that the source of information about organ donation was the television, and the contribution of health-care providers in providing knowledge about organ donation and transplantation was “none” or “little.”^[7] Although there is a significant lack of knowledge, 67% people are willing to donate.^[5]

Other study observed that many Saudi families are unwilling to donate organs when they were approached. Reviewing the psychological aspects of organ donation showed that several knowledge and religious beliefs influence an individual's decision to donate their organs after death.^[4]

Various organs had been transplanted in KSA in the past few years. Despite the success of the Saudi program, there have been public and medical obstacles that have obviated the full benefit of cadaver donors. The medical obstacles are encountered in emergency services and intensive care unit (ICU) services. There is an inadequate number of emergency room (ER) staff in many hospitals, and an inadequate quantity and quality of paramedics on road emergency services. Moreover, there is inadequate awareness of paramedics and doctors in the ER about the importance of transplantation and the concept of brain death. Doctors in the ICU still have

problems related to late recognition, diagnosis, and inadequate maintenance of brain death cases. Late diagnosis is usually due to an inadequate number of neurologists, who are usually in large centers, and inadequate equipment. Sometimes there are administrative obstacles that can mitigate the process of organ donation: inadequate communication systems in hospitals, improper eligibility of admissions to hospitals, and inadequate cooperation from local health authorities. Public obstacles include inadequate awareness of some of the leaders of Islamic religion and the importance of organ donation and transplantation. Moreover, a greater number of people would agree to donate organs if they are supported by religious communities and leaders. Accordingly, family and patient characteristics, their attitudes and beliefs about organ donation, place of residence, and inadequate awareness of the concept of brain death are associated with the decision to donate organs.^[7]

The purpose of this study was to explore the current public knowledge, opinions, and attitudes toward organ donation and studying factors that affect them. Study practices that can aid in better planning for future awareness programs in the Saudi society have significant impact on the crucial need for donation of organs. Factual knowledge allows individuals to refute false beliefs, which increases the willingness to donate organs.

Materials and Methods

A cross-sectional approach was applied on adults (either patients or their accompanies) who attended outpatient clinics (OPD) in Prince Mansour Family and Community Hospital (PMFCH) in Taif city, which is considered the first point of contact between the general public and the health-care system. It is therefore an ideal location to obtain a more representative sample from people with different sociodemographic and cultural characteristics. Taif city is located in western region of KSA. It had an estimated population of 1,011,613 in 2010. Saudis represented 82.5% of them.^[8]

Completion of $\geq 80\%$ of the survey questions (16 valid responses) was necessary for inclusion in the study in addition to age ranged between 18 and 60 years, both sexes.

Using Epi Info software, version 7 (StatCalc—Epi calculator), the study sample size of population was determined. Assuming that around 30% people were willing to donate, at 95% confidence level, sample size was found to be as 383 participants. To account for nonresponders and achieve reliable and precise results, we increased the sample size to 400 participants.

We interviewed the patients and/or those who accompanied them in the vital signs room and filled the questionnaire during assessment of patient vital signs. A systematic sampling approach was adopted in this study. Approximately, 1200 patients, at least, checked in at the family medicine OPD during 10 days duration (average 11 patients/clinic/day \times 12 clinics/10 working days, i.e., Saturday to Wednesday). Using

the formula $1/k = n/N$ (where k is the spacing unit between selected numbers; n the sample size, which is 400; N the total population, which is 1200), the third care seeker to show up at the family medicine OPD on day 1 of the research was our index subject. Next, every third care seeker was interviewed, on consent, to maximize the probability that every individual has an equal opportunity of being selected until 400 participants had been interviewed.

The survey instrument is an Arabic-language questionnaire designed to capture information relevant to the study. The questionnaire was filled in by researcher through face-to-face interviews of the selected participants. The questionnaire consisted of three sections with a total of 24 items; sociodemographic information (e.g., age, gender, level of education, and marital status), 4 items; questions exploring knowledge of the participants about organ donation (e.g., have you ever heard about organ donation program? Do you know the meaning of brain death, and others), 10 items; and statements to assess participants' attitudes regarding organ donation during the life and after death, 10 items. The responses for the items on knowledge are in "yes" and "no" and often "don't know" form. Items on respondents' attitudes about organ donation are scored on a five-point Likert scale ranging from "strongly agree" to "strongly disagree."

A number of steps were taken to increase the validity of the questionnaire. First, a review of the relevant literature was carried out to select some statements pertaining to respondents' knowledge and attitudes. Second, seven academic consultants reviewed the questionnaire and their suggestions were incorporated into the final form. Finally, a pilot survey was conducted before data collection and modifications were made based on the pilot testing results.

The reliability of the questionnaire was determined by retesting 40 participants. An average coefficient of correlation of 0.94 was obtained. (Data of the pilot study were included in the actual study because no significant variations were found.)

Approval for the study was obtained from the research and ethics team, Armed Forces Hospitals, Taif city. Approval was also obtained from the PMFCH administration before starting the study.

The data were verified by hand then coded and entered into a Microsoft program in a personal computer. The SPSS software, version 18, was used for data analysis. Discrete variables (knowledge and attitudes scores) were presented as arithmetic mean and standard deviation whereas categorical variables (age, gender, educational level, marital status, and source of information) were presented as frequencies and percentages. Participants' knowledge score regarding organ donation was calculated as follows: the participants were asked to answer 18 questions about organ donation, its importance, brain death, Islamic regulations, organ donation by site, and functions of Saudi Center for Organ Donation. Right answer was given the highest score. The overall score was calculated in a way that the higher the score, the higher

the knowledge regarding organ donation (the score ranged between 0 and 18). Participants' attitudes score toward organ donation was calculated as follows: the participants were asked to answer questions regarding their attitudes toward organ donation. Positive attitudes were given the highest score. The overall attitudes score was calculated in a way that the higher the score, the higher the attitudes toward organ donation (the score ranged between 7 and 36).

Bivariate analysis of the means of organ donation knowledge and attitudes scores with regard to independent variables was performed by Student's *t*-test for comparison of two groups and one-way analysis of variance (ANOVA) statistical tests for comparison of more than two groups. Least significance difference test was used for post hoc comparisons of ANOVA. Significance was determined at *p*-value of <0.05.

Results

The study included 400 Saudi adults who attended the OPD in PMFCH, Taif city, throughout the study period. Their sociodemographic characteristics are presented in Table 1. Their age ranged between 18 and 60 years with a mean of 32.68 ± 9.17 years. Most of them (72%) were males. Almost two-thirds (64.5%) of the participants were married. Approximately one-third (35.5%) of them were secondary school graduates whereas 44.5% were university graduates.

The majority of the participants (85.8%) has heard of—and was aware of—the organ donation programs. Almost two-thirds (62.4%) of the participants had their information about organ donation from media whereas 37.6% and 33.8% had their information from newspapers/magazines and the

Table 1: Sociodemographic characteristics of the participants ($n = 400$)

Sociodemographic variables	Number	%
Age (years)		
≤25	94	23.5
26–35	177	44.3
36–45	91	22.7
>45	38	9.5
Range (years)	18–60	
Mean ± SD (years)	32.68 ± 9.17	
Gender		
Male	288	72.0
Female	112	28.0
Marital status		
Single	133	33.3
Married	258	64.5
Divorced/widowed	9	2.2
Educational level		
Illiterate/primary schools	26	6.5
Intermediate schools	54	13.5
Secondary schools	142	35.5
University	178	44.5

Table 2: Factors affecting knowledge score of the participants about organ donation (0–18)

Variables	Mean	SD	p-Value*
Age (years)			
≤25 (94)	7.64	3.62	0.660*
26–35 (177)	8.14	3.95	
36–45 (90)	8.07	3.96	
>45 (38)	7.50	4.03	
Gender			
Males (288)	7.88	3.87	0.597**
Females (112)	8.11	3.91	
Educational level			
Illiterate/primary (27)	5.96	3.70	0.001* [‡]
Intermediate (54)	7.53	3.79	
Secondary (142)	7.57	3.66	
University (176)	8.69	3.96	
Marital status			
Married (258)	8.30	3.90	0.023* [‡]
Single (133)	7.38	3.69	
Divorced/widowed (9)	5.89	4.83	
Heard about organ donation			
Yes (343)	8.24	3.87	<0.001*** [‡]
No (57)	6.16	3.43	
Source of information			
Friends/relatives (32)	6.84	3.76	0.009* [‡]
Newspapers/magazines (32)	8.16	3.80	
Media (85)	7.02	3.47	
Internet (26)	8.73	3.54	
Health-care workers (12)	11.00	3.44	
Others (5)	9.00	6.98	
More than one source (208)	8.16	3.96	

*ANOVA test; **Student's *t*-test; [‡]statistically significant.

Internet, respectively. More than one-quarter (25.1%) of the participants had their organ donation information from their relatives or friends. Only 12% had their information regarding organ donation from health-care workers.

Most of the participants (79.3%) recognized the importance of organ donation and 61% of them have recognized the proper definition of brain death as an irreversible cessation of brain activities. Slightly more than one-half (51%) of the participants reported that organ donation is accepted by

Islamic regulations whereas only 7.5% reported that Islam is against organ donation.

Only 47 participants (11.8%) were aware of the presence of organ donation registration center in Taif city. One-half of them knew the exact place for organ donation registration.

Regarding their knowledge about organs that could be donated, the majority of the participants (93%) recognized that kidney could be donated. Two-thirds (66.7%) of them recognized that liver could be donated. Slightly more than one-half of them (52%) recognized that cornea could be donated. Heart, bone marrow, lung, pancreas, and skin could be donated as mentioned by 43.5%, 34.8%, 31.3%, 28.5%, and 22.8% of the participants, respectively. Less than one-half of the participants (41.3%) have heard about the SCOT. Of them, 48.7%, 41.8%, 44%, and 36.5% reported organization/supervision, community health awareness, exchange of information, and distribution of donation cards, respectively, among the functions of the SCOT.

Table 2 shows the factors associated with participants' knowledge about organ donation. The knowledge score increased gradually with increasing educational level of the participants, being highest among university graduates (8.69 ± 3.96) and lowest among illiterate/primary educated participants (5.96 ± 3.70). This difference was statistically significant ($p = 0.001$). Organ donation knowledge score was significantly higher among married (8.30 ± 3.90) and single participants (7.38 ± 3.69) as compared to divorced or widowed participants (5.89 ± 4.83; $p = 0.023$). Organ donation knowledge score was significantly higher among those who have heard about organ donation compared to those who have not heard about it ($p < 0.001$). Regarding source of information, the knowledge score was highest among participants who had their information from health-care workers (11 ± 3.44) and lowest among those who had their information from friends or relatives (6.84 ± 3.76). This difference was statistically significant ($p = 0.009$). Respondents' age and gender were not significantly associated with organ donation knowledge ($p > 0.05$).

Table 3 shows that 25.5% of the respondents believed that organ donation causes body deformities. The majority of them (89.5%) agreed that organ donation saves life of others. Almost one-half (49.8%) of the participants are willing for organ donation to family members only whereas only 24.6% are willing for organ donation to others, during their life. Slightly less than one-half (45.3%) of the participants are

Table 3: Responses of the participants to the questions about their attitudes toward organ donation ($n = 400$)

Statements	Strongly disagree No. (%)	Disagree No. (%)	Equivocal No. (%)	Agree No. (%)	Strongly agree No. (%)
Organ donation causes body deformities	30 (7.5)	117 (29.3)	151 (37.8)	56 (14.0)	46 (11.5)
Organ donation saves life of others	1 (0.3)	6 (1.5)	35 (8.8)	126 (31.5)	232 (58.0)
Willing for organ donation during life to relatives only	33 (8.3)	69 (17.3)	99 (24.8)	108 (27.0)	91 (22.8)
Willing for organ donation during life to others	58 (14.5)	113 (28.3)	131 (32.8)	77 (19.3)	21 (5.3)
Willing for organ donation after death to others	52 (13.0)	64 (16.0)	103 (25.8)	104 (26.0)	77 (19.3)
Looking for donor, if you need an organ	4 (1.0)	26 (6.5)	46 (11.5)	187 (46.8)	137 (34.3)
Supporting organ donation of brain dead people	36 (9.2)	63 (15.8)	95 (23.8)	105 (26.3)	101 (25.3)

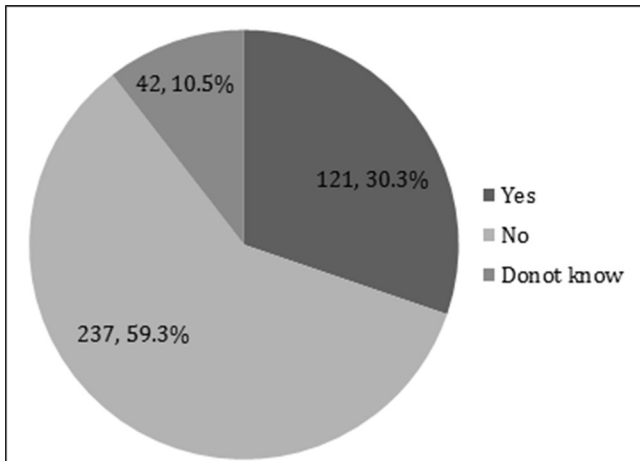


Figure 1: Participants' willingness for organ donation.

willing for organ donation to others after death. Most of the participants (81.1%) agreed that they will look for donor, if they got diseases and need organ transplantation. Slightly more than one-half (51.6%) of them supported organ donation of brain death people.

Figure 1 shows that 30.3% of the respondents are willing to donate an organ whereas 237 (59.3%) individuals refused organ donation. As clear from Figure 2, fear of complications and lack of proper post-donation care are the main reported

reasons for non-willingness for organ donation (54.9%). Insufficient information regarding organ donation, family refusal, and being against Islamic regulations are reported by 32.9%, 28.7%, and 12.7% of the respondents, who refused organ donation, respectively.

Table 4 shows the factors associated with participants' attitudes toward organ donation. The attitudes score increased gradually with increasing educational level of the participants, being highest among university graduates (25.24 ± 5.10) and lowest among illiterate/primary educated participants (22.44 ± 5.51). This difference was statistically significant ($p = 0.034$). Organ donation attitudes score was significantly higher among those who believed that Islamic regulations support organ donation (26.94 ± 4.30) as compared to those who believed that Islam is against organ donation (18.17 ± 3.62 ; $p < 0.001$). Respondents' age, gender, marital status, knowledge about organ donation, and history of organ donation/reception were not significantly associated with organ donation attitudes ($p > 0.05$).

History of organ donation was given by five individuals (1.3%) whereas only three (0.8%) had a history of organ reception.

Discussion

This study aimed to determine the knowledge and attitudes regarding organ donation in a selected adult population of Taif city, KSA. Our analysis of the collected data showed an interesting set of findings.

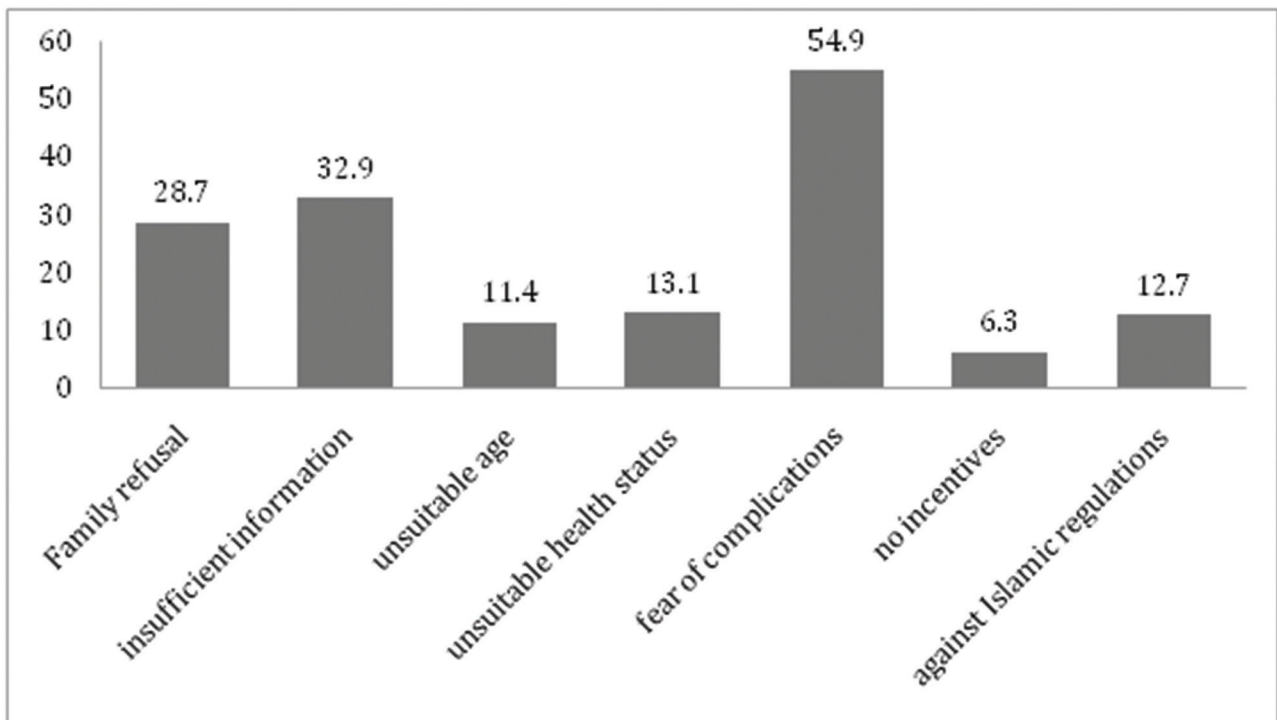


Figure 2: Causes of refusal of organ donation ($n = 237$).

Table 4: Factors affecting attitudes score of the participants toward organ donation (7–36)

Variables	Mean	SD	p-Value*
Age (years)			
≤25(94)	24.60	4.62	0.202*
26–35 (177)	25.21	5.15	
36–45 (90)	23.92	5.11	
>45 (38)	24.03	5.35	
Gender			
Males (288)	24.56	4.97	0.528**
Females (112)	24.92	5.20	
Educational level			
Illiterate/primary (27)	22.44	5.51	0.034* [±]
Intermediate (54)	24.25	4.90	
Secondary (142)	24.94	4.85	
University (176)	25.24	5.10	
Marital status			
Married (258)	24.67	5.32	0.680*
Single (133)	24.75	4.60	
Divorced/widowed (9)	23.22	3.60	
Hearing of organ donation			
Yes (343)	24.66	5.05	0.971**
No (57)	24.68	5.09	
History of organ donation/reception			
Yes (7)	27.33	4.84	0.192**
No (393)	24.62	5.05	
Belief that Islamic regulations support organ donation			
Yes (203)	26.94	4.30	<0.001* [±]
No (30)	18.17	3.62	
Don't know (166)	23.05	4.46	

*ANOVA test; **Student's t-test; [±]statistically significant.

In this study, almost one-third of the participants reported that they had insufficient information about organ donation and transplantation. These findings are comparable with those reported from neighboring countries.^[9,10] Also, studies conducted in the West^[11,12] and KSA,^[4,13–15] all indicate the importance of public education about the importance of organ donation.

In accordance with a previous study conducted in Pakistan,^[16] our study showed no significant association of the willingness to donate with gender or age. A study from Nigeria showed that the willingness to donate an organ was significantly associated with younger age ($p = 0.002$) but not with gender ($p = 0.47$).^[17]

People who believed that religion does not allow organ donation showed negative attitudes toward organ donation. This study also showed that among reasons behind the refusal to donate was a “presumed forbiddance in religion.” This could be because of the unawareness of the population regarding religious edicts concerning organ donation. A number of Islamic organizations and institutions around the globe have issued fatwas and edicts in favor of organ donation describing it as “an act of merit.”^[18–20]

This study identified that the main source of information regarding organ donation was media, mainly television. The same has been reported by Alghanim.^[7] Generally, studies had shown the importance of visual media in increasing the awareness of the public about organ donation.^[18,21–22]

It is a disappointing trend to note that only 12% people had heard about organ donation through health-care workers. A comparable result has been reported in Pakistan.^[18] Efforts to judiciously increase the participation of doctors in the process should start at the root level. As a first step, the medical curriculum should increase medical students' awareness of the organ shortage problem and how it can be effectively addressed.^[23] A study conducted in California showed that speaking to a physician about organ donation positively influenced the likelihood to donate an organ.^[24] Although we have no study from KSA that assesses the knowledge and attitudes of physicians regarding organ donation, studies from other regions showed that over 95% of the physicians who responded to a questionnaire-based survey supported organ donation in principle. Physicians responded correctly on average to 68.3% of the questions testing knowledge.^[25]

More than one-half (54.9%) of the participants who did not encourage organ donation were concerned about fearing of complications and not receiving adequate health care after donation. Therefore, it is possible that establishing legislations that will guarantee the donors better health care and easy access to health facilities might encourage people to donate organs during their lifetimes. Respondents reported “lack of incentives” as one of the reasons for not willing to donate. Accordingly, financial and nonfinancial incentives should be considered to encourage the public to donate organs. The results of this study showed that respondents reported family refusal as one of the main limiting factors for donating organs. Efforts should be made to increase discussions about organ donation among the family members. Previous researches had reported direct correlation between willingness to donate and family support^[7,26] and indicated that appropriate public exposure to knowledge about organ donation would result in more family discussions and more frequent declaration of one's wishes to donate, decreasing uncertainty at critical times of brain death of a loved one and would likely to increase organ donation. In this study, 61% participants recognized that brain death means irreversible cessation of brain activities.

Measures should be taken to educate people with relevant information, including the benefits of organ donation and possible risks as well, so that people can make informed choices in the future. In the absence of adequate baseline information, it is indeed difficult to comment on whether the general population is already aware of this simple facet. Almost 37% people in this study disagreed that organ donation carries any risks. People have a right over their bodies; they should therefore be fully educated about the future repercussions of removing any part of their bodies. With full disclosure of such information, they can then make the choice of donating an organ to another human being in the noblest spirit of munificence and benevolence.

Our study findings are similar to data from other developing countries such as Nigeria where only 30% of the respondents expressed a willingness to donate in one survey.^[17] In a study from Ohio, over 96% of respondents expressed favorable attitudes toward donation.^[27] In Pakistan, 62% individuals were willing to donate an organ.^[16]

Television, newspapers, and doctors can be used as efficient sources of information. The communication gap between patients and doctors should be bridged for the generation of more favorable attitudes toward organ donation in the population. Policy-makers should also involve religious scholars for the mobilization of a favorable public opinion toward organ donation. In addition, a publicly chartered organization may be established to coordinate live organ donation, including donation by altruistic strangers.

Among strengths of this work, up to our knowledge, this is the first study to examine the relationship between respondents' knowledge and attitudes about organ donation and their sociodemographic characteristics in KSA. In addition, this study comes at a point in time when organ donation is an actively debated bioethical and medical issue in KSA. Therefore, our research is relevant and timely. This will create a fertile ground for promoting awareness campaigns in the country. Through our study and its results, we hope to be in a better position to clarify certain ethical issues regarding organ donation in KSA. The awareness regarding organ donation in the country can certainly be improved and this in turn can impact the motivation of the people toward organ donation. We state this because our study and previous studies conducted in other regions of the world have shown that awareness and motivation go hand in hand. Better awareness of organ donation and its various facets can be expected to improve the motivation to donate. Religion is one vehicle that can be used to motivate people toward organ donation. This survey showed the immense influence of religion in fashioning opinions toward organ donation. We hope that people will translate these statistics into an aspiration to help others through organ donation. The extremely low level of organ donation seen in this survey should serve as an important revelation that despite the increasing prevalence of end organ diseases in the country, not many organ donations are being carried out in a legitimate manner. The opinions of the people in this survey can help shape future policies regarding organ donation; their wishes, preferences, and reservations can all be actively debated at higher forums before germane policies are engineered. This study can also help create more motivation among the people for organ donation; this being one of the major hurdles organ transplantation is facing today.

One major limitation of this study is that it does not claim to be comprehensive because the study took place in Taif city only. Accordingly, the results may have limited applicability to other regions in the kingdom. Second, the information was acquired via a face-to-face interview, which was based on a questionnaire. Although this may have led to higher rates of completion of the forms because of interviewer's encouragement for optimum completion, it may also have introduced

interviewer's bias in the process of data collection despite all efforts to minimize it. Nevertheless, this study forms an important baseline document for future studies and a qualitative tool can be used in further studies to gauge requisite information.

Conclusion

In conclusion, negative attitudes toward organ donation reported by this study are justified by inadequate information acquired by the public about this significant issue.

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