

Awareness, Beliefs and Barriers of Organ Donation among Saudis in Madinah City, Saudi Arabia

Ghaida Jabri*, Alaa Sandokji, Nourah Alzughaihi, Ibrahim Alsehli, Hanan Neyaz, Khadijah Alhusaini, Mohammed Jabri and Mohammed Kareems

Faculty of Medicine, Taibah University, Kingdom of Saudi Arabia

Abstract

Background: Although organ transplantation is considered as the only preferable treatment for end-stage organ disease, there are not many organ donors among Saudis.

Objectives: To assess knowledge and attitude of Saudis in Madinah, Saudi Arabia, towards organ donation and to determine factors intervene with willingness of family to donate a member's organ.

Methods: A cross-sectional study, data were collected through a valid structured interview questionnaire from 290 participants during organ donation campaign in May 2015. The questionnaire included socio-demographic data and data about participants' awareness and knowledge on organ donation. Data were analyzed and compared by participants' sex using appropriate statistical tests.

Results: Of the interviewed 385 Saudis, 290 agreed to participate in the study with a response rate of 76.3%. The mean age of the participants was 27.2 ± 8.8 years. The study revealed 74.1% of the participants were willing to donate their organs with no significant differences between males and females, although only 2.7% of them reported to have a donation card. Religion, money, and age of the recipient appeared to have no role in their willing of organ donation. However, lack of awareness (21.7%), family refusal (20.6%) and fear of unknown (19.7%) were the most important barriers of organ donation.

Conclusions: The study showed a considerable number of participants were willing to donate their organs that religion and financial reasons were not factors. More organ donation campaigns are needed to maximize public positive beliefs.

Keywords: Awareness; Knowledge; Organ donation; Saudi Arabia

Introduction

The development of organ transplantation in the second half of the 20th century has been a remarkable achievement [1]. Recently; organ transplantation is one of the most effective options for those with an end-stage organ failure [2]. Its success has been basically dependent on public awareness, support and active participation. Without these factors, the efficiency of organ transplantation and the consequent saving or extension of lives would have undoubtedly suffered adversely [3].

In Saudi Arabia, the Saudi Center for Organ Transplantation (SCOT), established in 1984, and it was known as National Kidney Foundation with the objective to observe activities of organ donation and transplantation in Saudi Arabia. SCOT has many strategies that included research works, donation cards distribution, health professionals' education and public awareness [4-7]. Despite huge efforts of education and motivation of public about organ donation, the organ donors still not covering the growing waiting list [8-10], and insufficiency of organ donation in Saudi Arabia still a major barrier for transplantation.

Although organ transplantation has brought new horizons of hope to save many patients life, it is accompanied with a variety of cultural, ethical, and religion-related problems [11]. A systematic review of eighteen studies that involved 1019 participants, has detected eight prominent factors that affect the individual's decision about organ donation [12]. These factors include relational ties, religion-related beliefs, cultural influences, family refusal, body probity, health-care system interaction, knowledge about organ donation, and reservations about the process of organ donation [12]. Of these eight factors, the

family refusal is found to be the most effective one. Family refusal, however, could be modified with educational and informative incentives where the donation is recognized socially, as a gesture of otherness and solidarity [13].

As the first step in designing and planning interferences in order to increase the acceptance of organ donation, it is necessary to determine the influencing factors on organ donation. By identifying these factors, healthcare team, managers, and planners can help families in their decisions regarding their loved one's organ donation to go through this agonizing decision much easier. Therefore, the goal of this study was to appraise the knowledge and attitude of Saudis in Madinah city, Saudi Arabia, towards organ donation and to determine factors that may facilitate the willingness of family to donate a member's organ.

Methods

During "Organ Donation" campaign on the first tow days of May 2015, a cross sectional study was conducted over a sample Saudi male and female visitors of AL Rashid mall, the largest shopping center

*Corresponding author: Ghaida Jabri, Medical Student, Faculty of Medicine, Taibah University, Kingdom of Saudi Arabia, Tel: 00966543836066; E-mail: ghaid2@hotmail.com

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in Madinah city, Saudi Arabia, and aimed to raise the community awareness about the importance of organ donation. All participants were Saudis and of at least 18 year of age, who visiting the site of the campaign between 6 pm to 10 pm for two days, were interviewed at the entrance before heading to the awareness part of the organ donation campaign. Of the interviewed 380 subjects during the campaign, 290 subjects agreed to participate in this study and filled the study questionnaire, with a relatively high response rate of 76.3%. The information was collected using face to face interview based on a structured pilot tested questionnaire. The used study questionnaire was adopted and modified from previous national and international studies [10-14]. Questionnaire was translated and verified and the instrument was initially tested and any areas of disagreement were resolved with the cooperation of translators and the research team. The validity of the used Arabic questionnaire was obtained with the help of epidemiologist and family and community medicine consultants. The questionnaire included two basic sections; one comprising the socio-demographic data and the other section including data about knowledge, attitude, practice, and factors that affect the decision of organ donation. Socio-demographic data included age, gender, marital status, education level, and economical status.

Knowledge of the responders was assessed by questions regarding the meaning of the term “Brain death”, awareness of the concept of organ donation, knowledge of the Islamic fatwa regarding organ donation, sources of information and the best ways to raise knowledge and awareness in their opinion. Attitude of the respondents regarding organ donation was determined through questions regarding opinions on the willingness to donate organs after death, family member’s willingness to donate organs, holding an organ donor card, and the factors influencing their decision for donating their own organs or granting a family member well of donating. Enquiring about actual donation of any organ or holding an organ donation card was used to assess participants’ practices.

SPSS program (version IBM SPSS statistics 19) was used to analyze the data. Data was presented using frequencies, mean and standard deviation as appropriate. Awareness and attitude of participants towards organ donation were assessed, analyzed and compared by participants’ sex and age categories using appropriate statistical tests (chi square or Fischer exact test). P values ≤ 0.05 were used as indicators of statistical significance differences between the groups of the study. Research approval was taken from Taibah University, College Dentistry Research Ethics committee (TUCD-RE). In purpose to avoid physical or emotional harm and to ensure confidentiality and privacy of the collected data ethical consideration was considered.

Results

The socio-demographic characteristic of studied 290 Saudi participants was presented in Table 1. The mean age of the studied participants was 27.2 ± 8.8 years, of them 9.3% were above the age of 40 years. Of the studied cohort, 39.3% were females and 60.7% were males. About two-thirds the studied cohort (64.7%) was of university and higher educational level. Less than one half of them (43.4%) were students, 40.3% were employers and 16.3% were none employers. Three-fourth of the participants reported monthly family income of less than 10000 SR. Single participants of the study were representing 63.1%, while 33.2% were married and 3.7% were divorced and widow. Almost all of the studied participants in the sample has heard about organ donation. 4.7% of participants defined organ donation as “taking the tissues of the human body from a cadaver” while 1.1% defined it

as “taking tissues from a living human body donor” and the rest of the participants (94.1%) were defined donation as “taking tissues from human body for transplantation to another person either from living donor and/or” cadaver (Table 2).

Of the studied 290 participants, 215 (74.1%) were willing to donate their organs with significant higher rate was among males ($p=0.03$). Nearly one half of the studied participants (140 participants (48.3%)) were willing to donate their organs or their family member and the lower percent was among female participants, although not statistically significant. Only 2.7% of the studied participants reported to have had donated an organ (5 males (2.8%) and 3 females (4.3%)). Also, a low percent of the studied sample (4.1%) was reported to have donor card, where only 7 males (3.9%) and 5 females (4.3%) have this card. The majority of the studied participants (82.8%) perceived organ donation as saving lives and which more significantly marked among female participants ($p=0.03$). The most important factors affecting participant’s donation to an organ were the recipient’s health condition (50.6%), relation to the recipient (41.1%), religion of the recipient (3.5%) and age of the recipient (4.5%), with no significant differences between males and females, however male participants reported the relation to the recipient was of greater importance.

Table 3 presented the knowledge and belief of the studied participants on organ donation by their sex. Two hundred and eighty-two participants (97.2%) were belief that the most organs can be donated is the kidney with a significant more belief about that organ among males. For donation from living, the respondent’s belief the great importance of donor personal consent before donation with a significant difference between males and females ($p=0.01$), while for donation from cadaver, the need of family consent was an important for 69% of respondents, with statistically significant difference between males and females ($p=0.03$). More males in comparison to females’ participants with a statistically significant differences reported that the donated organs should be promoted and there is need for having effective laws to protect the organ donation process. Two hundred

Characteristics*	N=290
Age in years, mean \pm SD (range)	27.2 \pm 8.8 (19-60)
Age in years (categories)	
≤ 40	263 (90.7)
>40	27 (9.3)
Participant’s sex	
Male	176 (60.7)
Female	114 (39.3)
Educational level	
Illiterate	5 (1.5)
Less than university	98 (33.8)
University and higher	187 (64.7)
Occupation	
Students	125 (43.4)
Employed	116 (40.3)
Unemployed	49 (16.3)
Monthly family income (SR)	
<10000	219 (75.0)
10000-15000	43 (14.9)
>15000	28 (10.1)
Marital status	
Single	182 (63.1)
Married	96 (33.2)
Divorced and widow	12 (3.7)

Table 1: Characteristics of studied Saudi participants (n= 290). *Data are presented by mean \pm SD or by n (%).

Attitude and awareness questions	Total n= 290 No. (%)	Male n= 176 No. (%)	Female n= 114 No. (%)	P value
1. Willing to donate your organs				
No	30 (10.3)	14 (7.9)	16 (14.0)	0.02*
Yes, under special circumstances	70 (24.1)	40 (22.7)	30 (26.3)	
Yes, irrespective of circumstances	145 (50.0)	100 (56.8)	45 (39.4)	
Not decided	45 (15.6)	22 (12.5)	20 (17.5)	
2. Donate your organs to				
Family member	140 (48.3)	90 (51.1)	50 (43.8)	0.18
Friend	120 (41.4)	80 (45.5)	40 (35.1)	
Anyone	30 (10.3)	6 (3.4)	24 (21.1)	
3. Have you ever donated an organ?				
Yes	8 (2.7)	5 (2.8)	3 (4.3)	0.61
No	282 (97.3)	171 (98.9)	111 (97.4)	
4. Do you have organ donor card?				
Yes	12 (4.1)	7 (3.9)	5 (4.3)	0.61
No	278 (95.9)	169 (96.1)	109 (95.7)	
5. Your perception of organ donation				
To save someone's life	240(82.8)	142 (80.6)	98 (85.9)	0.03*
Out of compassion/sympathy	30 (10.3)	24 (13.6)	6 (8.6)	
For money	15 (5.2)	8 (4.5)	7 (6.2)	
As a responsibility	5 (1.7)	2 (1.1)	3 (4.3)	
6. Factors holding you to donate your organs				
Age of recipient	13 (4.5)	8 (4.5)	5 (4.3)	0.32
Religion of recipient	10 (3.5)	5 (2.8)	5 (4.3)	
Health status of recipient	147 (50.6)	83 (47.2)	64 (56.2)	
Relation to recipient	120 (41.4)	80 (45.5)	40 (35.2)	

Table 2: Awareness of the studied participants about organ donation by their sex. *Significant.

	Total n= 290 No. (%)	Male n= 176 No. (%)	Female n= 114 No. (%)	P value
1. Organs could be donated				
Kidney	282 (97.2)	171 (98.9)	107 (93.6)	0.01*
Blood	240 (82.8)	142 (80.6)	90 (78.9)	0.60
Heart	145 (50.0)	85(48.2)	60 (52.6)	0.06
Eyes	130 (44.8)	80 (45.4)	55 (48.2)	0.06
Liver	220 (75.9)	130 (73.9)	82 (71.9)	0.75
Skin	135 (29.3)	40 (22.7)	39 (34.2)	0.01*
Bone marrow	265 (57.5)	87 (49.4)	60 (52.6)	0.08
Lungs	224 (48.5)	88 (50.0)	57 (50.0)	1.00
2. Who give consent for living donation				
Donor	270 (93.1)	160 (90.9)	110 (96.5)	0.01*
His family	15 (5.2)	12 (6.9)	3 (2.6)	
His spouse	5 (1.7)	4 (2.2)	1 (0.9)	
3. Who give consent for donation after death				
Family	200 (69.0)	126 (71.5)	74 (64.9)	0.03*
Spouse	70 (24.0)	40 (22.8)	30 (26.3)	
Friend	20 (7.0)	10 (5.7)	10 (8.8)	
4. Should organ donation be promoted?				
Yes	258 (88.9)	150 (85.2)	108 (94.7)	0.01*
No	32 (11.1)	26 (14.8)	8 (5.3)	
5. Effective laws to govern the process of organ donation are necessary				
Yes	273 (94.1)	168 (95.4)	107 (93.8)	0.20
No	17 (5.9)	8 (4.6)	7 (6.2)	
6. Promoting organ donation could be by				
Monetary benefit to donor family	30 (10.3)	10 (5.6)	20 (17.5)	0.23
Giving awards	3 (1.0)	2 (1.1)	1 (1.0)	
Free health treatment for donor family	70 (24.2)	30 (28.3)	40 (35.0)	
All of above	187 (64.5)	134 (63.3)	53 (46.5)	

*Significant

Table 3: Knowledge and belief of the studied participants towards organ donation by their sex.

and seventy-three participants (94.1%) did belief that effective laws are necessary to promote the process of donation, with no significant difference between males and females. Also, to promote donation, the studied participants suggest the monetary benefit to donor family and free health treatment for donor family, with a very few participants suggesting giving money.

Table 4 presented the distribution of the reasons and barriers intervening with organ donation by the studied participants. No reasons were reported by 70 participants (24.1). However, the most important reasons were lack of awareness on organ donation among 63 participants (21.7%), refusal of family members among 60 participants (20.6%), fear of unknown among 57 participants (19.7%), religious

Barriers and reason	Total n= 290 No. (%)	Male n= 176 No. (%)	Female n=114 No. (%)	P value
Lack of awareness	63 (21.7)	40 (22.7)	23 (20.2)	0.23
Fear of unknown	57 (19.7)	34 (19.3)	23 (20.1)	
Religious reasons	20 (6.8)	14 (7.9)	6 (5.2)	
Refusal of family members	60 (20.6)	35 (19.9)	25 (21.9)	
Cultural reasons	20 (6.8)	12 (6.9)	8 (7.1)	
No reasons	70 (24.1)	41 (23.3)	30 (26.3)	

Table 4: Barriers and reasons for not donating organs by donors.

reasons among 20 participants (6.8%), and cultural reasons (6.8%). These percentages were similar between both studies male and female participants with no statistically significant differences.

Discussion

The study findings revealed that 74.1% of the participants were willing to donate their organs with significant higher rate being among the studied males (79.3%). This rate appeared higher than that observed in a recent Saudi study [15] where 66.7% of the study respondents were willing to donate an organ and this rate was decreased to 42.8% among the rural respondents, and similar low willing rate was also reported in the previous Saudi studies [4,15-17]. The detected high rate in this study might be explained by the high literate rate (98.5%), and in particular the university and higher education 64.7% among the study participants. Studies from neighboring countries reported low rate of willingness toward organ donation [18,19] as well as studies of Western countries [20,21]. All the above-mentioned Saudi and non-Saudi studies have revealed education as a main factor in increasing public awareness toward organ donation. Concerning these variations, it was observed that higher awareness and willingness to donate organs were more among people who reported higher educational level. In this study, the rate of university and higher education among the participants was high. Similarly, willing of organ donation was correlated with education and socio-economic status in a similar study from Pakistan [22]. Also, a previous study conducted in Turkey [23] has reported that education and training significantly motivate public for organ donation.

The perception of organ donation as to “save someone life” was reported by the majority of the studied participants and it was marked among females (85.9%). Perception of organ transplantation as “a way for money collection”, however, was very among all studied participants (5.2%), particularly among males (4.5%). This finding has been reported in Scottish study [24], and is thought to be because financial payments appear to undermine the individual and cast doubt over their intentions to donate [25].

The most important factors holding the studied participants to donate were the health status of the recipients (50.6%), and the relation with the recipients (41.4%). The age and religion of the recipient, however, was representing very low motives for participants in this study to donate an organ. Similarly, religion and cultural reasons appeared to have no role in other studies concerned with eye and kidney donation [26,27]. In contrast to these findings, however, the religious beliefs were found to be the most important motivation factor to donate in the previous Pakistan study [22]. Other reported factors were worries about decreasing the level of the received healthcare after donation, lack of family support, and lack of information about organ donation were the primary reasons for lack of willingness to donate [15].

Most of Saudis in the study have appeared to know the different

organs which can be donated. The highest level of knowledge about this item was for kidney, liver, blood, bone marrow and heart. The majority of study participants (93.1%) reported the mandatory of donor consent for living donation and 69% reported the necessity of family consent for donation after death. Again, the fact that most of the respondents were literate individuals, a factor made them well educated about organ donation and understood what was displayed in the mass media. Mandatory consent for donation expressed before the death of the donor should ideally form the basis for donation. However, in the case of unavailability of such consent, consent from adult family members of the deceased donor should be obtained for organ donation. In a study done on the responses of relatives of post-mortem cases, it was revealed that out of the potential post-mortem donors, 44.3% of relatives of such cases gave consent for donation after intensive counseling [15].

The study participants have acknowledged some measures to be presented by government to promote organ donation. These measures include; monetary benefit to donor family, giving awards, and free health treatment for donor family. Therefore, it is possible that starting legislations and regulations which will guarantee the donors best health care and easy access to health facilities could encourage people to donate organs in their lifetimes. In a previous study, financial and non-financial support has been reported by their participants to encourage public for organ donation [15].

The study findings have revealed that the most important barriers of not donating organs among the studied participants were lack of awareness (21.7%), and refusal of family members. On the other hand, however, religious (6.8%), and cultural (6.8%) appeared to have a minimal role in this respect. Family members continue to play a prominent role in donation decisions at time of death. In a previous Spanish study, Martinez et al. [28] found that donation was less likely when there is more family conflict. In similar previous studies, adequate knowledge and adequate understanding of the process of organ donation and brain death have been thought to be essential for obtaining donation consent in previous studies [29,30].

The present study appeared to have a number of strengths. The anonymous and comprehensive questionnaire and face-to-face interview that insured correct and complete method for data collection. The study questionnaire has also been tested by a pre-test study and validated by experts. To the best of our knowledge, this study is the first to study the awareness and to explore different barriers intervene with organ donation among Saudis in Madinah city, with a relatively high response rate of 76.3%. Moreover, and unlike other similar studies, this study has analyzed awareness and barriers intervene with organ donation according to participants' sex.

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As a limitation of this study, as this study was limited by the organ donation day, the study sample was relatively small size that future large and national studies are needed before generalization of these results can be assumed. Furthermore, though this study has probed the awareness and attitudes of general population towards organ donation, studying these issues among terminally ill patients are needed as these sectors of population represent the potential donors in most number of cases. This important point has to be considered in future research to assess awareness and attitudes of palliative care and terminally ill patients towards organ donation.

In conclusion, the study showed a considerable number of participants were willing to donate their organs. Religion and financial factors appeared not to have much effectiveness on organ donation decision among the studied participants. Lack of awareness and family refusal were the most important barriers intervene with organ donation. These findings highlight the need for continued public education through several organ donation campaigns to maximize positive beliefs on organ donation.

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