

Organ Donations from Deceased Persons in the Saudi Arabian Population

Saleh Al Shehri,¹ Faissal AM Shaheen,¹ Abdulla A Al-Khader²

Objective: We aimed to determine the factors that influence organ donation consent and refusal in Saudi Arabia and see if they are different from those reported elsewhere. By determining these, we hope to introduce strategies to enhance donor consent by families of deceased persons.

Methods: We examined next-of-kin records of Saudi brain dead persons who had been approached for consent for donation during 1998. These same next of kin were approached in 2004 and asked to fill out a questionnaire examining demographics, awareness, and emotions regarding their decision to donate a family member's organ(s). In addition, data related to the deceased persons also were recorded.

Results: During 1998, 41 Saudi next of kin had been approached for permission to obtain organs from their deceased relatives. Of these, 16 consented and 25 did not. We obtained responses from all the consenters (group 1) and from 16 of the nonconsenters (group 2). The consenters were more educated; had positive feelings about donation and still do; and had keener knowledge regarding organ donation, religious standpoints about donation, and the results of transplantation.

Conclusions: The results demonstrate that consent for donation depends on prior knowledge and awareness of the various aspects of organ donation. Public education methods used to encourage organ donation need review. We found no differences in economic status or age between consenters and nonconsenters. The relationship between the deceased person and the next of kin does not

appear to play a role in determining consent or refusal. On the other hand, consent was less likely when death was caused by a motor vehicle accident than it when other factors led to death.

Key words: Organ donation, Deceased person, Consent

There is a universal shortage of organs available for donation. The supply of organs has basically plateaued, whereas the demand for organs has increased. In the Kingdom of Saudi Arabia, there are 4200 patients on the waiting list for kidney transplantations, whereas only 1000 kidneys are transplanted annually [1].

To deal with the increasing gap, there has been a worldwide increase in live donations and use of what has come to be called *marginal* or *suboptimal* organs retrieved from deceased persons [2, 3]. In the United States, 99% of the organs used in transplantation are obtained from deceased persons [4].

By 1999, the number of patients in the United States on waiting lists for organs was 72,110. Of these, 6143 (8.5%) died before they could receive the needed organ. Half of those who died needed a kidney transplant [4]. At the same time, there is evidence that only a third of all potential organs are actually harvested for donation [5, 6, 7]. This discrepancy is partly due to an inability to identify or to approach families of deceased persons [8] and partly because some next of kin do not give consent for donation. Among the factors for refusing to consent are dissatisfaction in the care given to the deceased and poor knowledge about brain death and organ transplantation [9].

To determine why some relatives consent and why others refuse to donate, we performed this study among Saudi Arabian persons who had either given or refused consent for organs to be donated from a deceased family member. By determining the factors associated with consent and refusal, we

¹Saudi Center for Organ Transplantation, Riyadh, Saudi Arabia

²Division of Nephrology, Hypertension 7 Renal Transplantation, King Abdulaziz Medical City, Riyadh, Saudi Arabia

Address reprint requests to: Dr. Abdulla A. Al-Khader, King Abdulaziz Medical City, PO Box 22490, Riyadh 11426, Saudi Arabia

Phone: 00 96 61 252 0011, Ext 4191 E-mail: aaalkhader@yahoo.com

hope to be able to introduce strategies to enhance donor consent by families of deceased persons.

Materials and Methods

Records from the Saudi Center for Organ Transplantation (SCOT) showed that during 1998, 41 relatives had been approached for permission to obtain organs from their deceased relatives. Of these, 16 consented (group 1) and 25 did not (group 2).

In 2004, an attempt was made to contact via telephone the same relatives of the deceased donors who had been approached at the time of the potential donor's death and who had been the primary decision maker for consent or refusal. A survey was conducted and performed by the same interviewer (SS) in all cases.

The survey questions were designed to examine the following variables in the respondents: the causes and motivations for consenting (in group 1) or refusing (in group 2); their feelings about their decisions at that time (1998) and now (2004); their immediate and subsequent feelings about the death of their loved ones; their immediate and subsequent feelings about being approached to consent to donate; their responses if they were asked to consent for donation again; their feelings about accepting an organ to be transplanted should they ever need one; their knowledge about brain death and organ donation at the time of their relative's death; the effect of prior knowledge on whether or not consent was given; the effect of prior knowledge regarding the existence and functions of SCOT on whether or not consent was given; and what their opinions and ideas are regarding the best ways to enhance organ donation in the Saudi Arabian public? Respondents also were asked if there were any associations between consenting and refusing and the following: cause of death; age of the next of kin at the time of death; length of time the donor had remained in the intensive care unit (ICU); educational or economic status of the next of kin; prior knowledge of the Islamic scholars' view on the permissibility of donation during life and after death; and the time between receiving news of the death and requesting consent for donation.

Between-group comparisons were made for each variable to detect significant differences. The Wilcoxon rank sum and chi-square tests and comparison of proportions were used to assess statistical differences. Values for *P* less than 0.05 were considered

statistically significant.

Results

All persons (100%) who had originally given consent for donation participated in the study, while only 19 of 26 who had originally refused to give consent for donation participated (76%).

Table 1 shows the demographics of the respondents in the 2 groups. Table 2 summarizes and compares the data obtained from the records of the SCOT, especially regarding causes of death and length of stay in ICU prior to harvesting or cessation of the heart beat. Table 3 shows the responses related to emotions, feelings, and mind-set in the 2 groups and how they felt about the death of their loved ones and about being approached for donation. And Table 4 records the responses of the 2 groups regarding prior awareness and viewpoints of the next of kin.

Discussion

All families with a relative with brain death are approached and given the option for organ donation [10]. This is ethically important, as it gives equal opportunity to all families. It is not acceptable to forgo such a request, for example, because the medical staff says that the family is grief stricken or that they are likely to be angered by the request. In this scenario, the transplant coordinator and the physician must have a strategy that combines sympathy with compassion, while still putting forth the option of donation [11].

It is important that whoever approaches the family understands that their job is not task-focused (the task being obtaining an organ) but instead is process-focused. The clinician should view their job as helping the relatives through their ordeal and giving them the opportunity to offer the deceased person's organ(s), should they wish to do that.

Consent rate is also significantly affected by any hospital experiences the next of kin might have had prior to the death of their relative [12]. The clinician should be well trained on how to approach bereaved families. Good training has been shown to increase the rate of consent [13]. The consent rate also will be significantly enhanced if the clinician is trained in end-of-life decision-making communication techniques [14, 15, 16].

Responses related to demographics (Table 1)

The mean age of the responders was similar in both groups. Age in this study was not an important factor in willingness to consent, and this agrees with the results of previous studies [17].

Educational level affects willingness to consent for donation. This is evidenced by the fact that there were more university graduates in group 2 than there were in group 1 ($P = 0.023$). This, too, agrees with the findings of previous studies [18].

In the current study, economic status was not different between the groups and thus appears not to be related to willingness to consent. Similarly, there was no significant difference regarding the relationship of the decision maker and the deceased. There was, however, a trend that would suggest that siblings were less likely to give consent for an organ donation than were parents of the deceased ($P = 0.08$)

Data obtained from the SCOT records (Table 2)

When the cause of death was a motor vehicle accident (MVA), the chances of consent were reduced ($P = 0.025$). This may be related to the fact that an MVA is very sudden and thus, there is little time for the family members to consider their options. Moreover, most MVA victims are young, which makes the loss that much harder to bear [18].

Interestingly, duration of the relatives' ICU stay was significantly longer for persons in group 2 than it was for persons in group 1 ($P = 0.0004$). This is thought to be due to the fact that the decision for consent is followed by immediate organ harvesting. On the other hand, at least in our society, very often the ventilators are not switched off when the diagnosis of brain death is made. Instead, ventilation continues until the heart stops.

The consent rate was higher when there was a time interval between being informed of the brain death and being asked for consent to donate an organ, and when the next of kin was asked for consent simultaneously with being told of the brain death ($P = 0.05$). This agrees with the results of other centers [19]. There was a strong positive association between consent rate and requesting the donation after a reasonable time had elapsed between the request and notification of the family member's brain death [8, 20]. If the request is made at the same time as the news of the loved one's death, the consent rate diminishes by 32% to 37% [21].

Responses related to emotions, feelings, and mind-set (Table 3)

Feelings experienced by the family members after being told of their loved one's death were similar between the 2 groups. However, they differed

Table 1. Demographic Responses

Economic status	Group 1 n = 19	Group 2 n = 16	P
Excellent	18.8%	5.3%	0.22
Good	50%	78.9%	0.082
Satisfactory	6.3%	15.8%	0.39
Poor	25%	0	0.027
Relationship to the deceased			
			P
Parents	68.8%	57.9%	0.51
Siblings	6.3%	26.3%	0.13
Children	12.3%	15.8%	0.77

Table 2. Data Obtained from SCOT Records

	Group 1	Group 2	P
Mean age (years)	41.9	40.5	ns
Education levels			
Primary school	31.3%	34.1%	0.86
Intermediate school	6.3%	21.2%	0.22
Secondary school	12.5%	31.6%	0.19
University	37.6%	5.3%	0.023
Did not go to school	12.5%	8.9%	0.73
Length of stay in ICU			
More than 3 days	15%	81.6%	0.0004
Less than 3 days	85%	18.4%	0.0004
Cause of death			
	n = 19	n = 16	P
Motor vehicle accident	57.9%	18.8%	0.025

SCOT: Saudi Center for Organ Transplantation

Table 3. Responses Related to Emotions, Feelings, and Mind-Set

Feelings when asked for donation			
	Group 1	Group 2	P
Satisfied/comforted	85%	0%	0.0006
Hostility/resentment	0%	47.4%	0.0031
Irritated	0%	31.6%	0.019
Annoyed/disturbed	31.3%	21.1%	0.5
None defined	12.5%	0%	0.122
Current feelings about the decision			
			P
Satisfied	81.3%	42.1%	0.0244
Happy	0%*	5.3%	0.34
Annoyed/disturbed	6.3%	0%	0.27
None defined	12.6%	52.6%	0.018
Would you donate in the future if faced with the same situation?			
			P
Yes	80%	1%	0.0001
No	20%	46.4%	0.11
Don't know	0%	52.6%	0.0016

substantially in their feelings when asked to consent to donation ($P = 0.02$). For persons in group 1, the feelings were more of comfort and satisfaction ($P = 0.0006$), whereas the feelings of those in group 2 were characterized by hostility and resentment ($P = 0.0031$). Additionally, for persons in group 1, there was less feeling of irritation ($P = 0.019$). Similar findings have been reported from Europe and the United States [22].

It is interesting to note that among those in group 1, the feelings of satisfaction and comfort persisted for 6 years after the decision to donate had been made ($P = 0.024$) [22]. This agrees with the finding that more than 80% of those in group 1 reported that they would make the same decision were they faced with a similar situation in the future. Conversely, only 1% of those in group 2 said that they would allow donation in the future ($P = 0.0001$). The persistence of these opinions over time in the 2 groups suggests that the mind-set of persons in both groups is shaped by strongly held, preconceived ideas, and that lack of knowledge of brain death and transplantation outcome was an important factor in the decision-making process for the persons in group 2. On a positive note, however, is the fact that more than half of those in group 2 (52.6%) said that they didn't know what their position would be if they needed a transplant in the future.

Other studies have demonstrated that families that consent to donation have a high degree of satisfaction regarding their decision (94%) [23], and this is similar to the findings in our study.

Responses related to awareness (Table 4)

A very significant finding was that more persons in group 1 knew that kidney transplantation is associated with excellent outcome ($P = 0.024$). This indicates that prior knowledge of the excellent results of transplantation has a positive impact on decision making and further supports the need for intensive public education. It is not surprising, therefore, to find that more persons in group 1 would be willing to receive an organ for transplantation should they require it at some point in the future ($P = 0.0001$).

Another extremely important finding was that 93.8% of the persons in group 1 knew that Islamic teachings permit organ donation from the living, whereas only 36.9% of those in group 2 knew this fact ($P = 0.002$). Similarly, 93.8% of the persons in

group 1 versus 52.5% of those in group 2 knew that Islam permits donation after death ($P = 0.011$). Along the same lines, other studies have shown that donor families have an understanding of brain death prior to being asked for donation [7]. This is similar to our observations. Clearly, then, it is incumbent on us as transplant physicians to educate the public about the Islamic standpoint on organ donation. This is, of course, highly important in religious societies such as ours.

Of similar significance is the crucial finding that only 10.5% of those in group 2 had heard of the existence of the SCOT compared with 68.8% of

Table 4. Awareness

From an Islamic perspective, is donating a kidney during life permitted?			
	Group 1	Group 2	P
Yes	93.8%	36.9%	0.002
No	0%	5.3%	0.36
I don't know	6.3%	57.9%	0.003
From an Islamic perspective, is donating a kidney after death permitted?			
			P
Yes	93.8%	52.6%	0.011
Don't know	6.3%	42.1%	0.022
Did not specify	0.0%	5.3%	0.36
How would you rate the results of kidney transplantation?			
			P
Excellent	37.5%	5.3%	0.024
Very good	37.5%	31.6%	0.72
Good	12.5%	10.5%	0.85
Poor	0%	5.3%	0.36
I don't know	12.5%	36.8%	0.11
None specified	0.0%	10.5%	0.19
What would you do if you needed an organ transplantation?			
			P
I would seek another opinion	6.3%	52.6%	0.006
I would not accept an organ	0.0%	21.1%	0.059
I would accept an organ	93.8%	0.0%	0.0001
Did not specify	0%	26.3%	0.34
Have ever heard about SCOT?			
			P
Yes	68.8%	10.5%	0.001
No	31.2%	84.2%	0.003
Did not specify	0.0%	5.3%	0.34
What in your view is the best way to increase organ procurement?			
			P
Intensive media coverage	48.8%	15.8%	0.043
Advertise the role of SCOT more	6.3%	5.3%	0.9
Don't know	12.5%	10.5%	0.85
Advertise religious permission	25%	0.0%	0.027
Did not specify	7.4%	68.4%	0.0009
Had you been told of brain death prior to being asked for consent?			
			P
Yes	81.3%	63.2%	0.05

those in group 1 ($P = 0.001$). Again, this stresses the importance of continual media campaigns that promote organ donation.

More persons in group 2 than in group 1 (68.4% vs 7.4%) had no views or opinions about ways to improve procurement of organs ($P = 0.0009$). This also would indicate that persons in group 2 already had a mind-set opposed to donation and had not learned enough or thought enough about it. Conversely, persons in group 1 suggested that organ procurement would benefit from intensive media coverage ($P = 0.043$) and by advertising the positive religious viewpoint of organ donation ($P = 0.027$). The influence of prior awareness on the rates of consent has been reported elsewhere [24].

Conclusion

The results of the current study show that rates of donation are dependent on prior knowledge and awareness about the various aspects of organ donation, indicating an urgent need to review public education methods to better encourage organ donation. No differences were found in economic status between consenters and nonconsenters, nor were there any differences in their ages. The relationship between the deceased person and the next of kin does not appear to play a role in determining consent or otherwise. On the other hand, when death is caused by an MVA, consent is less likely than when death comes as the result of other causes.

Similar studies should be done in different countries with different cultures to compare the results and find out how others might induce higher rates of consent. Such studies could be done prospectively as this would give the results and recommendations greater support.

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