 DOI: 10.4176/090405

Original Article

Reasons for Unwillingness of Libyans to Donate Organs After Death

Alashek WA[1], Ehtuish EF[2], Elhabashi A[2], Emberish W[2], Mishra A[2]

[1]Department of Community Medicine. [2]Department of General Surgery. Faculty of Medicine, Alfateh University for Medical Sciences, Tripoli, Libya

Received for publication on 28 December 2008. Accepted in revised form 11 February 2009
Key words: Reasons, Unwillingness, Libyan, Deceased organs, Donation.

ABSTRACT
Introduction: Organ transplantation in Libya depends exclusively on donations from live relatives. This limitation increases mortality and prolongs the patients' suffering and waiting time. **Objectives:** The aims of this study were to explore willingness to donate organs after death and to identify the reasons for refusal. **Methods:** A population-based cross-sectional study was conducted from April to July 2008 on a cluster sample of 1652 persons (58% males and 42% females). The questionnaire included demographic information and mainly enquired about willingness to donate organs after death and the reasons for refusal when applicable. **Results:** About one-third (29.7%) of participants were in favor of donating their organs after death, 60.1% refused and 10.2% were undecided. Willingness was significantly associated with being male, younger age, having a college or graduate degree, and being single ($P < 0.05$ for all). Lack of adequate knowledge about the importance of deceased organ donation and uncertainty about its religious implications were the most predominant reasons for refusal (43.8% and 39.5%, respectively). Other reasons included ethical concerns about retrieving organs from dead bodies (37.9%), preference for being buried intact (28%), and uneasiness about the idea of cadaver manipulation (33%). **Conclusion:** There were a considerable resistance to deceased organ donation, especially among females, those of older age, married people, and those with a low education level. The barriers to cadaveric donations were lack of adequate knowledge, unease about body manipulation, and concerns about religious implications. Public educational campaigns should be coordinated with religious leadership.

INTRODUCTION

Organ transplantation has become an established therapeutic option for most types of end-stage organ failure, but transplantations are limited by shortage of donated organs [1]. Many patients die or experience prolonged dependency because of lack of organs [2]. Live organ donation offers a valuable opportunity for transplantation, but cadaveric organ donation extends the possibility for reducing the gap between patients' needs and the organ supply [3].

In Libya, an organ transplantation program was established in 2004 [4]. For approximately four years, kidney and liver transplantations were performed only from living, related donors, which restricted the transplantation activities and prolonged patient suffering and waiting time [5].

Transplantation of organs from human cadavers has steadily increased in many countries in the past decades [1], including many Middle Eastern countries, in which the culture resembles that in Libyan society [6-8]. Nevertheless, Libya has not been able to initiate cadaveric organ transplantation yet.

Various factors have been associated with unwillingness to donate organs after death, including age, gender, level of education, knowledge regarding organ donation, and awareness of organ shortage [9-11]. Reports from Turkey, Mexico, Brazil, USA, and Spain determined some criteria in favor of deceased organ donation. It included younger age, female gender, and higher level of education [9-14]. Other research related the disinclination to religious reservations about transplanting organs from dead people [15-18]. This study aims to explore the state of willingness to participate in organ donation after death and to identify the major reasons for refusal. The results could help in

developing strategies for establishing a deceased organ donation programs in Libya and in directing educational organizers to better approaches for building a favorable public opinion.

METHODS

This study was planned as a population-based cross-sectional study. It was conducted from April to July 2008 in four Libyan cities after obtaining approval from the Organ Transplantation Research Committee. A cluster sample of 1652 participants was recruited (58% males and 42% females; from approximately 370 to 550 persons from each city). They were randomly selected from 10 public facilities (universities, schools, companies, banks and post offices). Each group was considered as a cluster. From each selected facility, a list of the reference population was obtained. It included the names (codes) of all employees/ students/ teachers and/or workers in that facility. Then a random selection of 200 persons was done. Cities included in the study were Tripoli (600 persons), Benghazi (600 persons), Sabha (400 persons) and Gharyan (400 persons). The populations surveyed were mostly urban.

The researchers visited the public facilities and orally got consent from those who were included in the sample to participate in the study by fulfilling a self administered anonymous questionnaire sheet. The questionnaire was written in Arabic. Respondents informed verbally about the shortage of local data.

The structured questionnaire was developed from the literature [9-14]. It included information about respondents' age, gender, educational level, occupation and marital status. The central question was about willingness of the respondent to donate his or her organs after death and the reasons for refusal for those who were unwilling to donate.

The validity of the questionnaire's content was judged by a team of psychologists, sociologists and an organ transplant surgeon. The reliability of the questionnaire, as determined by the test-retest method, was 0.83. A pilot study was conducted on February 2008 on 73 randomly selected individuals from Banks in Tripoli to assess the phrasing of the questionnaire and the time required to complete it.

Table 1: The questionnaire. (Translated from Arabic; the Arabic version is available upon request).

Information gathered about	
Age	Years
Sex	a) Male b) Female
Education (Highest level achieved)	a) Less than high school graduate b) High school or associate bachelor's degree c) College graduate d) Postgraduate degree
Occupation	a) Student b) Professional/employee c) Business d) Unemployed/Retired/Housewife
Marital status	a) Single b) Married
Do you agree to have your organs donated after death	a) Yes, I agree b) Un-decisive c) No, I don't agree
If you disagreed to donate your organs after death, what could be the reason?	a) I do not have enough knowledge about the importance of deceased organ donation. b) I am not certain about the religious standpoint. c) I feel uneasiness about the idea of corpse manipulation. d) I would like my body to be buried intact. e) I believe that retrieving organs from dead bodies is ethically unsound. f) I never thought about organ donation before. g) I do not wish to give a reason. h) I have other reasons. Please specify …….

The finalized Arabic questionnaire (Table 1) consists of seven items. It was divided into two parts. The first part included information about age, sex, educational level, occupation, and marital status. The second part consisted of the question assessing the willingness of the respondents to be organ donors after death, and provided a choice of six different reasons for refusal, plus a space where they could mention any other reasons.

The question format (yes I agree, no I don't agree, and I have not decided) was used for the item exploring the willingness of the responders to be an organ donors. The time needed to fill out the questionnaire form was not supposed to exceed four minutes based on the pilot study. Permissions were obtained from the public facilities to administer the questionnaire.

After the questionnaire sheets were filled out, the data were checked manually. The data were analyzed with SPSS version 11.5. Percentages, mean ± 2, standard deviations, and ranges were calculated. The Chi-square test was used to determine the statistical significance of association between categorical variables. Statistical significance was defined as $P \leq 0.05$.

RESULTS

The response rate, after exclusion of uncompleted questionnaires and those filled by respondents who were less than 20 years of age, was 82.6%. Mean age was 35±12.6 years, with a range of 20–76 years. Of the 1652 participants, 491 (29.7%) agreed with donating their organs after death, 993 (60.1%) expressed refusal, and 10.2% were undecided.

Table 2: Distribution of respondents according to demographic variables and their opinions about deceased organ donation.

Demographic variable	Number (percent)	Opinion			X^2 (P value)
		Agree Number (percent)	Undecided Number (percent)	Do not agree Number (percent)	
Sex					
Male	958 (58)	323 (33.7)	102 (10.6)	533 (55.6)	X^2= 20.342
Female	694 (42)	168 (24.2)	66 (9.5)	460 (66.3)	(0.000)
Age group					
20-29	722 (43.7)	275 (38.1)	88 (12.2)	359 (49.7)	
30-39	440 (26.6)	124 (28.2)	50 (11.4)	266 (60.5)	X^2 = 89.714
40-49	207 (12.5)	42 (20.3)	19 (9.2)	146 (70.5)	(0.000)
>50	250 (15.1)	7.9 (3.16)	10 (4)	201 (80.4)	
Education					
-Less than high school graduate	125 (7.6)	16 (12.8)	3 (2.4)	106 (84.8)	
-High school or associate bachelor's degree	458 (27.7)	120 (26.2)	57 (12.4)	281 (61.4)	X^2 =132.468 (0.000)
-College graduate	842 (51)	278 (33)	91 (10.8)	473 (56.4)	
-Postgraduate degree	94 (5.7)	54 (57.4)	14 (14.9)	26 (27.7)	
Occupation					
Student	428 (25.9)	169 (39.5)	55 (12.9)	204 (47.7)	
Professional/Employee	803 (48.6)	253 (31.5)	87 (10.8)	463 (57.7)	
Business	120 (7.3)	33 (27.5)	18 (15)	69 (57.5)	X^2 =137.036 (0.000)
Unemployed/Retired/House wife	171 (10.4)	3 (1.8)	3 (1.8)	165 (96.5)	
Marital status					
Single	974 (59)	334 (34.3)	108 (11.1)	532 (54.6)	X^2 = 42.454
Married	546 (33.1)	135 (24.7)	56 (10.3)	355 (65)	(0.000)

Table 2 shows the willingness rate in relation to demographic variables. Willingness to donate organs after death was significantly ($P<0.05$) more frequent among males (33.7%) than females (24.2%). Younger participants were more accepting of donating organs after death than older participants: 38.1% of those aged 20-29 years agreed to donate organs after death compared to only 3.2% of those who were 50 years or older ($P<0.05$). On the other hand, strong unwillingness to donate organs posthumously was observed among

the older age groups; the refusal rate was 70.5% and 80.4% in the 40-49 and the >50 year categories, respectively.

Willingness to donate organs posthumously was positively related to educational status. The most willing were holders of postgraduate degrees (57.4%) while the least willing were those with less than a high school education (12.8%) (Table 2); the difference between these groups was significant (P<0.05).

Moreover, students were more willing to donate their organs after death than the other categories (P<0.05). Conversely, rejection of this type of organ donation was more frequent among the unemployed, the retired, and housewives (96.5%).

Another statistically significant relation (P<0.05) was observed with marital status, where 34.3% of single respondent agreed to donate organs as compared to 24.7% of married respondents.

Table 3: Frequency of different reasons given for refusing deceased organ donation.

Reason for refusal	Frequency N=993	%
Lack of satisfactory knowledge about the importance of deceased organ donation.	435	43.8
Uncertainty about religious standpoint	392	39.5
Considering that retrieving organs from dead bodies is ethically unsound.	376	37.9
Uneasiness about the idea of cadaver manipulation	328	33
Never thought about organ donation	283	28.5
Preferring body integrity at burial	278	28
Lack of knowledge about the rules and regulation of organ donation	62	6.2
Unfamiliarity with the idea of deceased organ donation	41	4.1
No reason given	167	16.8

Table 3 illustrates the reasons given by the respondents for refusing deceased organ donation. Many respondents selected more than one reason. Lack of adequate knowledge about the importance of deceased organ donation and uncertainty about its religious standing were the most predominant responses (43.8% and 39.5%, respectively). Other reasons included ethical concerns about retrieving organs from dead body (37.9%), preferring to be buried intact (28%), and uneasiness about the idea of cadaver manipulation (33%). Noteworthy, more than one quarter of the respondents had never thought about organ donation, and 16.8% of those who refused to donate gave no reason.

DISCUSSION

In Libya, organ transplantation activities are seriously limited because it depends exclusively on living donors [5]. The deceased organ donation program could not be established yet. The strategies of the Libyan Organ Transplantation Program to initiate deceased organ transplantation activities included advocacy, which helped in obtaining legal approval of organ donation and transplantation besides organizing and publishing meetings with the religious leaders in the country to facilitate the passage of a religious ruling “official proclamation” of religious acceptance. It also included launching many educational campaigns through the media to familiarize people with the concept of deceased organ donation and motivate them to participate. These efforts can benefit from an assessment of the reasons behind current resistance to cadaveric donation, and the knowledge gained would help decision makers to plan more effective strategies to address the obstacles.

We found that less than one third of the surveyed individuals were willing to donate their organs after death. This result is far lower than the results reported by other studies, which ranged between 46-75% [9,10,19-21]. The present low willingness rate is similar to that published by Bilgel et al. in Turkey during in 1991, in which only 33.7% of the surveyed individuals were willing to donate their organs after death [22]. However, in Turkey the willingness rate rose to 57% after 12 years [12], which indicates that concepts and attitudes of people toward this issue change over time as a result of well planned educational programs.

Although it was observed that willingness to donate organs does not guarantee that the individual will obtain a donor card [10,23], the level of willingness we observed indicates the presence of a substantial source of potential donors in the local community.

We also analyzed the relationship between different demographic variables and willingness to donate organs after death. We found that male respondents exhibited significantly stronger willingness than females to donate their organs after death. This finding is contrary to other observations in USA, Mexico, and Spain [10,13,14]. Our results point to the need to analyze why Libyan females have relatively more negative attitudes than males and indicate that they should be encouraged to discuss this topic.

Our results also showed that unwillingness to donate deceased organs increased with age. Younger people (20-29 years) exhibited more than ten-fold higher agreement rate than those who were 50 years of age or more. Younger people generally have more favorable attitudes and willingness to donate organs after death [9,13,14,24-26].

In agreement with other studies [9,13,20,24], we found that more educated people were more supportive of deceased organ donation. Additionally, students were more supportive of cadaveric organ donation than other employment categories. A previous work done by Östergren and Gäbel had emphasized similar observation [25].

Other significant finding of this study was the relationship between marital status and willingness to donate organs after death. Specifically, single respondents were more inclined towards organ donation than married ones. This finding supports what was observed by Conesa et al in Spain [13]. However, this observation warrants further social investigation and age standardization.

We found that the most prominent reason given for rejecting organ transplantation from cadavers was insufficient knowledge about the implication of deceased organs. Also, more than quarter of the refusing respondents had simply never thought about organ donation. In addition to that, many individuals stated that they knew nothing about the process of deceased organ donation and its regulation, including where and how to obtain a donor card.

Lack of knowledge about deceased organ donation had already been reported as the most important reason for refusing this type of donation in Australia, Hong Kong and Spain [13, 16, 27]. In Qatar, 31.6% of surveyed individuals had no idea about organ donation [28]. Certainly, lack of information about deceased organ donation questions the validity of the educational practices undertaken by the Libyan organ transplantation program and the role of major media outlets. It draws attention to the need to evaluate the impact of information resources in Libyan society. The short age of the Libyan transplantation program, the weak educational approach, and insufficient media converge about the project could be some reasons for poor population knowledge.

The second most frequent reason for refusal in this study was religious concern emanating from the inadequacy or ineffectiveness of an Islamic fatwa about the permissibility of cadaveric donation in the community. Most preceding studies, which focused on attitudes and willingness to donate cadaveric organs, showed that refusal because of religious concerns were frequent observation and that a clear official religious position in support of cadaveric donation is important for the spread of positive attitudes among Muslims [15,26-34].

Repulsion of the idea of cadaver manipulation and ethical concerns about deceased organ donation, in addition to concerns about intact body at burial were very well recognized reasons for unwillingness in the previous studies as well as the present study [13,35-37]. About one third of refusing individuals had reported such worries. In Mexico, Zepeda-Romero et al found out that bodily mutilation was the main reason for people's negative stand on cadaveric donation [14].

In conclusion, lack of proper knowledge, religious doubts and concerns about body manipulation act as barriers against deceased organ donation progress. These barriers indicate failure of delivering effectual message. Well-structured public educational campaigns should be implemented to modify the situation. This activity might be augmented by participation of religious leaders to tackle the debate about the issue experienced by the public.

ACKNOLEDGEMENTS
The authors thank Dr. Debra Budini, Dr. Ali Gosbi, Dr. Mohamed Algilani, Dr. Mohamed Elbaccush and Dr. Tamer Abdulmola for their thoughtful suggestions that resulted in developing the study questionnaire.

CORRESPONDING AUTHOR:
Wiam A Alashek, e-mail: wiam4ash@yahoo.com

REFERENCES

1. Organ Procurement and Transplantation Network (Accessed at http://www.optn.org/ on June 2008)
2. Howard R J. Organ Donation: Opportunities for action. Am J Transplant. 2007; 7(1):14- 6.
3. United Network for Organ Sharing. (Accessed at http://www.unos.org/ on June 2008)
4. Ehtuish E, Abouna G, Shebani A, Abdulmola T, Shawesh T. Kidney transplantation in Libya: A North African and Middle Eastern perspective. Exp and Clin Transplant 2006; 1: 425-8.
5. Usta A, Shawish T, Milud N, et al. Outcome of Libyan National Organ Transplantation Program in its third anniversary. JMJ 2008; 1:44-50.
6. Shaheen FA, Shouqiyyeh MZ, Attar MB, Alswailem AR. The Saudi Center for Organ Transplantation: an ideal model for Arabic countries to improve treatment of end-stage organ failure. Transplant Proc 1996; 28(1):247-9.
7. Masri MA, Haberal MA, Shaheen FA, et al. Middle East Society for Organ Transplantation (MESOT) Transplant Registry. Exp Clin Transplant 2004; 2:217-20.
8. Alsayyari. The history of renal transplantation in the Arab world: a view from Saudi Arabia. Am J Kidney Dis 2008; 6:1033-46.
9. Bracellos FC, Aranjo CL, Costa JD. Organ donation: a population-based study. Clin Transplant 2005; 19:33-7.
10. Gallop Organization. National survey of organ and tissue donation attitudes and behaviors. Washington DC 20004; 2005
11. Morgan S. Many factors of reluctance: African Americans and the decision (Not) to donate organs. J National Medical Association 2006; 5:695-703.
12. Bilgel H, Sadikoglu G, Goktas O, Bilgel N. A survey of the public attitudes towards organ donation in a Turkish community and of the changes that have taken place in the last 12 years. Transplant Int. 2004; 17(3):126-30.
13. Conesa C, Rios A, Ramirez P, et al. Psychosocial profile in favor of organ donation. Transplantation Proc 2003; 35:1276-81.
14. Zepeda- Romero L, Garcia G, Jauregui O. Results of a survey on organ donation and transplantation in Metropolitan Guadalajara, Mexico. Salud Publica de Mexico 2003; 1:1-4.
15. Kececioglu N, Tuncer M, Yucetin L, et al. Attitudes of religious people in Turkey regarding organ donation and transplantation. Transplant Proc 2000; 32:629-630.
16. Cheng B, Chung Ping Ho, Ho S, Wong A. An overview on attitudes towards organ donation in Hong Kong. Hong Kong J Nephrology 2005; 2:77-81.
17. Lauri MA. Attitudes towards organ donation in Malta in the last decade. Malta Med J 2006; 4:25-9.
18. Alam AA. Public opinion on organ donation in Saudi Arabia. Saudi J Kidney Dis Transpl 2007; 18:45-9.
19. Donmez L, Ozbey C, Aydogan S. Knowledge, attitudes and behaviors regarding organ transplantation in a primary health care region in Turkey. Dial Transplant 2003; 32:324-32.
20. Haustein S, Sellers M. Factors associated with (un) willingness to be an organ donor: importance of public exposure and knowledge. Clin Transplant 2004; 18:193-200.
21. Shahbazian H, Dibaei A, Barfi M. Public attitudes toward cadaveric organ donation. Urol J (Tehran) 2006; 4: 234-9.
22. Bilgel H, Bilgel N, Okan N, et al. Public attitudes toward organ donation: A survey in a Turkish community. Transpl Int. 1991; 4:243-5.
23. Morgan S, Miller J. Beyond the organ donor card: The effect of knowledge, attitudes and values on willingness to communicate about organ donation to family members. Health Communication 2001; 1:121-34.
24. McNamara P, Guadagnol E, Evanisko M, et al. Correlates of support for organ donation among three ethnic groups. Clin Transplant 1999; 13(1):45-50.
25. Östergren P O, Gäbel H. Influence of social support and study course on attitudes of 18-year-old students toward cadaveric organ donation and transplantation. Transplant Proc 1993; 1 Pt 2:1702-3
26. Boulware L E, Ratner L E, Sosa J A, Cooper L, Laveist A, Powe N. Determinants of willingness to donate living related and cadaveric organs: identifying opportunities for intervention. Transplantation 2002; 73:1683-91
27. Kerridge I H, Saul P, Lowe M, et al. Death, dying and donation: organ transplantation and the diagnosis of death. J Med Ethics 2002; 2:89-94
28. El- Shoubaki H, Bener A. Public knowledge and attitudes toward organ donation and transplantation: A cross- cultural study. Transplant Proc. 2005; 5:1993-7.
29. Cantarovich F. Influence of socioeconomic and ethical factors on people's behavior regarding the use of cadaveric organs. Transplant Proc 2005; 37:539-42.
30. Aswad S, Souqiyyeh M Z, Huraib S, et al. Public attitudes towards organ donation in Saudi Arabia. Transplant Proc 1992; 5:2056-8.
31. Gillman J. Religious perspectives on organ donation. Grit Care Nurs Q 1999; 3:19-29.
32. Lam WA, McCullough LB. Influence of religious and spiritual values on the willingness of Chinese-Americans to donate organs for transplantation. Clin Transplant 2000; 14:449-56.
33. Shaheen FA, Al-Jondeby M, Kurpad R, Al-Khader AA. Social and cultural issues in organ transplantation in Islamic countries. Ann Transplant 2004; 2:11-3.
34. Alkhaukri F, Stimson G, Warrens A. Attitudes toward transplantation in UK Muslim Indo-Asian in West London. American J of Transplantation 2005; 5:1326-31.
35. Randhawa G. An exploratory study examining the influence of religion on attitudes towards organ donation among Asian population in Luton, UK. Nephrol Dial Transplant 1998; 13:1949-54.
36. Sanner M. Attitudes towards organ donation and transplantation. A model for understanding reactions to medical procedures after death. Social Science and Medicine 1994; 8:1141-52.
37. Bagheri A, Tanaka T, Takahashi H, Shoji S. Brain death and organ transplantation: knowledge, attitudes and practice among Japanese students. Eubios J Asian Int Bioeth. 2003; 13:3-6.

To cite this article: Alashek WA, Ehtuish EF, Elhabashi A, Emberish W, Mishra A. Reasons for Unwillingness of Libyans to Donate Organs After Death. *Libyan J Med*. 2009; 4:158-163.