Original Article

An investigation into the factors effective in the consent of families with brain-dead patients candidates for organ donation in Isfahan, Iran in 2012-13

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Abstract

Background: Studies have shown that, with regard to social, cultural, and institutional contexts, several factors affect family decision-making on organ donation. This study aimed to investigate the effective factors in organ donation by family members with brain-dead patients.

Materials and Methods: This was a descriptive-comparative study in which a researcher-made questionnaire was used to collect data. The reliability of the questionnaire was obtained as 0.81 using Cronbach's alpha. The study sample consisted of 85 members of families with brain-dead patients in Isfahan, Iran in 2012–13. The collected data were analyzed using the Statistical Package for the Social Sciences version 20.0, and the level of significance was considered as <0.05.

Results: The obtained results indicated that factors such as age, marital status, level of education, and cause of brain death did not have any effect on their families consent, whereas factors such as gender, duration of hospitalization, having an organ donation card, personal view of the brain-dead patient, and the number of patient's children had a significant relationship with the consent on organ donation. In addition, the care and treatment team were effective in family decisions regarding organ donation.

Conclusions: In general, the necessary culture and increasing the population awareness and their knowledge can be a positive step in this regard and may bring about an easy and rapid acceptance of organ donation by the involved families.

Key words: Brain death, family consent, Iran, organ donation

Introduction

Determining the end of a life is important because it should be specified that what would be lost, according to which death would be determined. Brain death includes approximately 1% of the total deaths all over the world,[1,2] and implies the loss of all functions of the brain that is caused after a complete cessation of blood flow to this sensitive organ.[3-5] The issue of organ donation of brain-dead patients is one of the significant and challenging issues that is made based on the values and laws of different societies, cultures, and religions.[6]

Organ donation is a complex process used for patients with heart, liver, kidney, and pancreas failure that are in the late stages of their diseases.[7,8] Through donation of vital organs by brain-dead patients, lives of patients in need of these organs can be saved and the possibility of continuation of life for patients who are in the final stages of organ failure can be provided.[9]

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There is a high prevalence of brain death in Iran with the lowest prevalence of organ donation. Considering the high frequency of accidents in Iran at a rate of one death in 10 accidents and one brain death in each 100 dead people, there is a high rate of brain death in Iran than that in other countries; however, a low percentage of brain-dead patients are candidates for organ donation, which is not adequate.[10]

Over the past two decades, the need for organ donation has increased by 200%,[11] however, the consent to organ donation has still remained in a constant, low and insufficient rate for donors with favorable conditions in the world.[12] Studies have shown that one of the key factors of the crisis of organ shortage, and in fact, the most important limiting factor for the success of organ donation, is families' lack of consent.[10-13] To improve opportunities for organ denotation, studies are required to be conducted in this field.

In recent decades, researchers' experiences have demonstrated that, to improve opportunities for organ donation, studies are required to be conducted regarding family decisions about the organ donation of their brain-dead patients. In addition, the analysis of factors related to the person's consent to organ donation and the factors involved in family's decision is required. Concerning family decisions about the organ donation of their relatives, researchers have identified several reasons based on the causes of consent to or lack of consent to organ donation.[14]

Most non-donor families have a contradictory and incredible concept of brain death. They refuse to accept the reality of death of the brain-dead patient and hope that the patient will recover; something like a miracle that results in the return of the brain dead patient. However, families who believed in this and accepted the failure of the brain-dead patient to return, were sometimes pioneer for organ donation, even before they were asked to do so by the physician.[8]

A study by Kim *et al*. (2004) showed that misconceptions about brain death lead to dissatisfaction, and one of them is that they think they are selling the organs of their beloveds. Their decision is also affected by religious, cultural, social, educational, and experimental factors.[15]

A study conducted by Siminoff revealed that, if one of the family members has a desire to donate organs, others will have more desire.[16] In addition, the results obtained by Rice and Tamburlin (2004) revealed that there was an increased possibility to decide on organ donation in individuals with previous experience with organ donation, recipients of transplanted organs, or individuals who had registered on the waiting list compared to others who had no such experience.[17]

In the United States, Heather and Laura showed that the decision of the brain-dead patient on organ donation during their lifetime, such as having an organ donation card, would have a significant impact on his family's consent.[18]

In Iran, several descriptive studies have been conducted using questionnaires, surveys, and interviews regarding this issue, with the purpose of attitude, knowledge, or legal discussions. In this regard, the study by Shahbazian *et al*. indicated that age, sex, and socioeconomic status had no effect on the attitude of society whereas race, level of education, economic status, and having a person requiring organ donation in the family made individuals more prone toward organ donation.[19]

Awareness of the ideas of the deceased person about organ donation and knowledge about the conditions of individuals in need of those organs significantly influenced the consent to organ donation, as reported by Shamsi *et al*. Two categories affect the decision to donate, namely, public education of the community and provision of suitable conditions at the time of request for organ donation.[20]

Investigating the consent of people to donate organs of their relatives after death, Bromand and Asghari found that there was a direct relationship between the consent to organ donation of loved ones, considering the brain death as death, considering it irreversible, and the consent of the deceased during his lifetime.[21]

Although organ transplantation is associated with numerous cultural, ethical, and religion-related problems, it has provided new horizons of hope to save a group of patients. It may cause some problems for the family to care for a brain-dead patient and it is a difficult and complicated issue to make a decision on giving consent for organ donation for the family members, especially in Asian families, when their patients have healthy and proper organs for transplantation and are considered as appropriate candidates for organ donation.

The present study tried to find out the differences through determining and comparing factors affecting the consent or lack of consent of the families with brain-dead patients as candidates for organ donation and gain general knowledge by overcoming the existing challenges and finally taking a basic step to overcome these shortcomings, disadvantages, and problems via proper planning.

Materials and Methods

As a descriptive-comparative study, the study population consisted of all families with brain-dead patients in Isfahan in 2012–13. They were divided into two groups, that is,

families with a brain-dead patient as a candidate for organ donation including donor and non-donor families. The inclusion criteria were families with brain-dead patients in 2012–13, and the exclusion criteria were the death of the brain-dead patient from the declaration of brain death to the time of obtaining the consent, lack of suitable organs for organ donation, having malignancies in the brain-dead patient which was not suitable for organ donation according to the medical team, if the brain-dead patients were foreign nationals, or if the family denied to participate in the study.

Because of the limitation of the population size (96 families), all of them were considered as the study sample. Obtaining access to the names and the addresses from the statistic section of the hospital, we made a telephone call to the family and an appointment was made in the hospital if they agreed. The questionnaires were sent to the participants to be filled, and after presenting an introduction and a brief description of the objectives, if the participants agreed to participate in the study, the questionnaire was delivered to them, and we waited for an answer as much as possible. Alternatively, by coordination with respondents and based on the allocated time, they were referred again to receive questionnaires the next hour or day. If the participants were illiterate, interviewers honestly filled the questionnaires by asking them. After collecting the data, the sample size was considered to be 85, among which 11 families were not satisfied with the cooperation due to various reasons and one had one of the exclusion criteria.

A researcher-made questionnaire was used to collect data. The questionnaire was designed with the help of resources and texts and with an emphasis on localizing the items. According to the resources reviewed, texts and opinion of experts, and faculty members, the content validity was evaluated and its reliability was determined as 0.81 using Cronbach's alpha. In addition, the questions which reduced the reliability of the questionnaire were removed. The abovementioned questionnaire was made up of two parts, that is, the first part was devoted to the underlying questions and the second part was related to the factors affecting families' consent and lack of consent. All the questions were Multiple Choice Questions.

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) software version 20 and descriptive statistics. Data analysis was performed using independent *t*-test and analysis of variance (ANOVA), in which the level of significance was considered to be 0.05.

Ethical considerations

This study was approved by Isfahan university of medical sciences Ethical Committee with the code of 185051.

Results

In the present study, among all families with brain-dead patients in Isfahan in 2012–13, 54 families consented to organ donation whereas 31 families denied it.

The mean age of the brain–dead patient in the donor group with 30.37 ± 15.80 years was more than that of the non-donor group with 28.52 ± 17.2 years; however, due to the high dispersion of age, the difference was not statistically significant ($P > 0.05$). In the group of donor families, in terms of the sex of the brain-dead patient, males and females had a frequency of 37 (68.5%) and 17 cases (31.5%), respectively. However, in non-donor families, the males and females were 13 cases (415.9%) and 18 ones (58.1%), respectively, in which the difference was statistically significant ($P < 0.05$).In addition, factors such as marital status, level of education, and the cause of brain death in brain-dead patients had no effect on the consent of their families ($P > 0.05$). In contrast, factors such as duration of hospitalization, having an organ donation card, the personal view of the brain-dead patient, and the number of his children had a significant relationship with the consent to organ donation ($P < 0.05$) such that the families whose patients had an organ donation card and a positive view on this during their life-time consented to organ donation. It can also be stated that more the number of children of brain-dead patient, the more was the possibility of family's lack of consent with organ donation. Further, the frequency of family consent was lower in long-term hospitalization [Table 1].

The results of the investigation of factors affecting lack of consent in non-donor families indicated that in 86 cases (83.5%), lack of consent was personal followed by family opposition. Moreover, from the perspective of non-donor families, the manipulation of the corpse of the brain-dead person was not considered ethical, and hence, this to some extent affected lack of consent [Table 2].

Finally, the results from the evaluation of factors influencing the consent of donor families showed that the encourager of donation was the coordinator of organ donation team in 67 cases (38.5%) and the near and distant relatives in 63 cases (36.2%). After organ donation, 161 cases (92.5%) of donor families' members had the tendency to a satisfactory relationship and inner sense with the recipient of the organ and 31 (7.5%) of the families had a tendency to cut the relationship after organ donation. In addition, the family consent to the organ donation in 135 cases (77.6%) and 2 cases (1/1%) was due to the heavenly and ethical issues [Table 3].

Table 1: Frequency distribution of demographic characteristics of individual with brain death in both groups of donors and non-donors

Factor	Satisfied (*n*=54)	Dissatisfied (*n*=31)	*P* value
Age	30.37±15.80	28.52±17.20	0.616
Sex			
Male	37 (68.5%)	13 (41.9%)	0.022
Female	17 (31.5%)	18 (58.1%)	
Marital status			
Single	25 (46.3%)	14 (45.2%)	0.375
Married	28 (51.9%)	14 (45.2%)	
Divorced	0 (0%)	1 (3.2%)	
Widowed	1 (1.9%)	2 (6.5%)	
Educational Level			
Illiterate	1 (2%)	0 (0%)	0.076
Under diploma	27 (52.9%)	12 (44.4%)	
Diploma	15 (29.4%)	4 (14.8%)	
University	8 (15.7%)	11 (40.7%)	
Occupational status			
Housewife	12 (22.2%)	7 (22.6%)	0.040
Clerk	6 (11.1%)	6 (19.4%)	
Free	16 (29.6%)	5 (16.1%)	
Student	16 (29.6%)	9 (29%)	
unemployed	0 (0%)	4 (12.9%)	
other	4 (7.4%)	0 (0%)	
religion			
Muslim	54 (100%)	31 (100%)	-
Other	0 (0%)	0 (0%)	
Reason of brain death			
Accident	36 (66.7%)	22 (71%)	0.810
Diseases	18 (33.3%)	9 (29%)	
Organ donation card			
Yes	8 (14.8%)	0 (0%)	0.025
No	46 (85.2%)	31 (100%)	
Brain dead person's opinion about organ donation when alive			
Positive	16 (29.6%)	1 (3.2%)	0.013
Negative	1 (1.9%)	1 (3.2%)	
No opinion	37 (68.5%)	29 (93.5%)	
The number of Brain dead person's child			
Single	25 (46.3%)	14 (45.2%)	0.047
No child	8 (14.8%)	4 (12.9%)	
1-3	14 (25.9%)	13 (41.9%)	
≥4	7 (13%)	0 (0%)	
Duration of hospitalization (day)			
≤10	37 (68.5%)	13 (41.9%)	0.008
10-20	8 (14.8%)	15 (48.4%)	
21–30	7 (13%)	3 (9.7%)	
>1 month	2 (3.7%)	0 (0%)	

Table 2: Frequency distribution of factors affecting lack of families' consent for organ donation

	Factors	Frequency	Percentage
Not willing to donation reason	Family Opposition	17	16.5
	Religious limitations	0	0
	Personal reasons	86	83.5
Not ethical to manipulate the brain dead body	Positive	30	29.1
	No opinion	47	45.6
	Negative	26	25.2

Discussion

The present study aimed to investigate the factors influencing the consent of families with brain-dead candidate for organ donation. The results showed that the age of the person in donor group was more than that in the non-donor group, however, because of the high dispersion of age, the difference was not statistically significant. In contrast, the sex of the patient was effective in the consent to organ donation. In addition, factors such as marital status, level of education, and cause of brain death had no effect on the families' consent, whereas factors such as duration of hospitalization, having an organ donation card, patient's personal view, and their number of children had a significant relationship with the consent. In other words, families whose patients had organ donation card and a positive view consented. It can also be said that family's lack of consent increased with the number of children of the brain-dead patient.

According to our study, many studies mentioned the previous knowledge about organ donation,[22] brain-dead person's decision about organ donation during their lifetime,[18] organ donor age,[22-24] and families' interest and dependency to the dead persons and unexpected death may affect the family satisfaction about donation[14,22] may affect the family satisfaction about donation.

As mentioned before, these factors can have an important role in family decision, for example, if the dead person was aware about the process, it may cause the family to be more knowledgeable and knowing the dead person's satisfaction with organ donation and considering it as a useful and important act helps them to decide more confidently;

Table 3: Frequency distribution of factors affecting families' consent for organ donation

	Factors	Frequency	Percentage
Organ donation encouragement	Coordinator of donor team	67	38.5
	Doctor	26	14.9
	Social Worker	0	0 (0)
	Priest	4	2.3
	Near/far families	63	36.2
	others	14	8
Relation with organ Recipient after donation	No relation	13	7.5
	Relation with satisfaction	161	92.5
	Relation to remember the kindness	0	0 (0)
	Relation to meet the needs	0	0 (0)
Reason of satisfaction of donation	Material needs	9	5.2
	Heavenly rewards	135	77.6
	Help to needy people	28	16.1
	Ethical matters	2	1.1
Expectation from the recipient family	Nothing but Heavenly rewards	174	100
	Meeting the long-term needs	0	0 (0)
	Meeting the short-term needs	0	0 (0)
	Always be ready to serve of recipient family	0	0

whereas factors such as juvenile death or being an unexpected phenomenon shocked the family and affected their decision; however awareness and acculturalization may cause to control their feelings.

However, results from the investigations into the factors affecting the lack of consent in non-donor families indicated that this was due to personal causes followed by family opposition. Religious restriction was not the reason for lack of consent, and hence it may be said that, according to religion, one can easily consent to organ donation, as doners' families didn't ask anything from recipients and God's satisfaction is enough for them. Also, considering the manipulation of the corpse of the brain-dead person as unethical also affected the lack of families' consent to some extent.

Consistent with this study, other researchers have revealed that lack of consent and families' refusal to organ donation has to do with the lack of understanding with the concept of brain death.[25-28] For example Arjmand *et al*. (2007) found that the appropriate awareness and reasonable belief of individuals on the issue influenced the correct decision-making of family members.[29]

A study by Kim *et al*. (2004) showed that misunderstanding in the context of brain death resulted in the lack of consent and one of them is that families felt they have sold the body organs of their loved ones; moreover, it is hard to accept the brain death as actual death.[15]

The investigation of the factors affecting the consent of donor families showed that the encourager of the donor person was the first coordinator of the organ donation team, and therefore, has an important role in coordinating the team of organ donation and relatives in attracting the consent to organ donation.

Consistent with these results, James *et al*. (2010) found that 26% of subjects consented to organ donation at the time of interview and the first time of talking about organ donation, and the majority of these families, 74% of subjects, consented to organ donation after they had an investigation and obtained information. Medical team is the most important team who can encourage families to consent to organ donation by supporting them and explaining about the brain death.[14]

Conclusions

According to the study results, the level of awareness and knowledge of families along with their attitude can be effective in their decision regarding organ donation. In addition, the care and treatment team were effective in family decisions regarding organ donation.

Therefore, it can be stated that several factors affect organ donation. Exploration and explanation of these factors help policy makers and managers to plan and intervene in acculturalization and facilitation of organ donation. In addition, the nursing and medical personnel must attain

the skills to have a dynamic interaction with the brain-dead patient's family members, providing better attitude toward organ donation and getting organ donation card with more and deep understanding of brain death and organ donation process.

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Conflicts of interest

There are no conflicts of interest.

References

1. Brain death and organ harvesting of the language of with verses and hadiths. J Borhan and Mysticismd 2006;7:171-86.
2. Yousefi H, Roshani A, Nazari F. Experiences of the families concerning organ donation of a family member with brain death. Iran J Nurs Midwifery Res 2014;19:323-30.
3. Mori K, Shingu K, Nakao S. Brain Death in Miller RD, Millers Anesthesia. 6th edition, Philadelphia: Elsevier; 2005. pp. 2955-70.
4. Wayne P. Organ transplantation. Prog Transplant 2010;20:274-8.
5. Smeltzer SC, Brenda B, Hinkle JL, Cheever KH. Brunner and Suddarth's Textbook of Medical-Surgical Nursing (One Volume Set). 12th ed. Philadelphia; 2010. p. 2240.
6. Motavali Zadeh S, Kiani SH. Brain death and organ donation. Tehran: Charity Foundation for Special Diseases, published research, education and agricultural extension agencies, 2007.
7. Linda D, Kathleen M, Mary E. Critical Care Nursing. 6th edition. Elsevier eBook on VitalSource; 2010. Pp. 1206.
8. Manzari Z, Mohammadi A, Heidari A. Factors influencing family decisions about organ donation in brain dead patients: A qualitative study. Payesh J 2012;6:913-25.
9. Margot E, Capland C, Dionne J, Fudge B, Gay C. A clinical groups attempt to raise awareness of organ and tissue donation. J Prog Transplant 2010;20:33-9.
10. Ghadi Pasha, Nikian M, Tajodin Z. Evaluate the attitude and awareness of organ donation in brain death etiquette and procedure. J Forensic Med 2008;2:112-6.
11. Zamani F, AbediHydar Ali. A comparative study on effective factors on consent to organ donation among families of brain death victims in Isfahan, 2013. J Emerg Pract Trauma 2015;1:13-8.
12. Abouna GM. Organ shortage crisis: Problems and possible solutions. J Transplant Proc 2008;40:34-8.
13. West R, Burr G. Why families deny consent to organ donation. Aust Crit Care 2002;15:27-32.
14. James R, Danielle L, Jennifer K, Richard J. Family Initiated Discussions about Organ Donation at the Time of Death. Clin Transplant 2010;24:493-9.
15. Kim JR, Elliott D, Hyde C. The influence of sociocultural factors on organ donation and transplantation in Korea: Findings from key informant interviews. J Transcult Nurs 2004;15:147-54.
16. Siminoff LA, Lawrence RH, Arnold RM. Comparison of black and white families' experiences and perceptions regarding organ donation requests. Crit Care Med 2003;31:146-51.
17. Rice C, Tamburlin J. A confirmatory analysis of the organ donation readiness index: Measuring the potential for organ donation among African Americans. Res Soc Work Pract 2004;14:295-303.
18. Traino HM, Siminoff LA. Attitudes and acceptance of First Person Authorization: A national comparison of donor and nondonor families J Trauma Acute Care Surg 2013;74:294-300.
19. Shahbazian H, DibaeiA, Barfi M. Public attitudes toward cadaveric organ donation: A sSurvey in Ahwaz. Urol J 2006;4:234-9.
20. Shamsi A, Alizadeh Charandabi S. Compare opinions and refuse to families of brain dead patients degree of understanding of the underlying factors related to organ donation decision. Thesis for obtaining a master's nursing education, 2008;16:1-150. [Persian].
21. Boroumand MA, Asghari F. Relatives of organ donation after brain death, whether people agree with Tehran? J Med Ethics Hist Med 2011;5:52-8.
22. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. JAMA 2001;286:71-7.
23. Delmonico FL, Sheely E, Marks WH, Baliga P, McGowan JJ, Magee JC. Organ donation and utilization in the United States, 2004. Am J Transplant 2005;5:862-73.
24. Manzari ZS, Mohammadi E, Heydari A, Sharbaf HR, Azizi MJ, Khaleghi E. Exploring families' experiences of an organ donation request after brain death. Nurs Ethics 2012;19:654-65.
25. DeJong W, Franz HG, Wolfe SM, Nathan H, Payne D, Reitsma W, *et al*. Requesting organ donation: An interview study of donor and non-donor families. Am J Crit Care 1998;7:13-23.
26. Bormand MA, Asghari F. Do Tehran citizens agree with organ donation from a brain-dead family member? J Med ethics Hist Med 2011;5:51-8.
27. Burroughs TE, Hong BA, Kappel DF, Freedman BK. The stability of family decisions to consent or refuse organ donation: Would you do it again. Psychosom Med 1998;60:156-62.
28. Maloney G, Walker I. Messiahs, pariahs, and donors: The development of social representations of organ transplants. J Theory Soc Behav 2000;30:203.
29. Arjmand B, Aghayan HR, Godarzi P, Emami Razavi H, Ja'farian A. Knowledge and attitudes about organ donation and tissue donation card makers and members of connective tissue bank products (case/control). J Med Council Islamic Republic Iran 2008;26:30-5.