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A comparative study on effective factors on consent to organ donation among families of brain death victims in Isfahan, 2013

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Abstract

Introduction: According to the previous studies, several social, cultural, and organizational factors are involved in the decision of families of brain death victims for organ donation. The present study was performed to determine the effective factors in the decision of organ donation among families of brain death victims.

Methods: In this descriptive-comparative study data were gathered through a self-made questionnaire. The reliability of questionnaire was determined by calculating Cronbach's alpha (0.81) and the face and content validity were studied and approved by a number of experts. Statistical population included all family members of brain death victims in Isfahan/Iran during 2012-2013. They were divided into two groups of with and without consent to organ donation. The whole population was considered as the study sample. Data analysis were done through SPSS using independent T-test, ANOVA, and Chi-square tests.

Results: According to the present study, age and marital status of the victims have no effect on their families' consent to organ donation (P> 0.05); but sex, duration of hospitalization in the emergency department, having organ donation card ,and personal opinion of the brain death victim showed significant relationship with consent to organ donation (P< 0.05).

Conclusion: Since the rate of awareness, knowledge, and attitude of family members are effective in their decision for organ donation, improving cultural backgrounds required for this decision and increasing awareness and knowledge of people can improve the attitude of people in this regard and facilitate the acceptance of family members.

Keywords: Brain death, Organ donation, Family, Consent

Introduction

The need for organ donation has showed 200% increase during the last two decades (1). Decision for organ donation at the time of brain death is one of the important and challenging issues that vary in different societies, cultures, and religions based on their values and laws (2). Studies have shown that one of the key factors of organ shortage crisis and in fact the most important obstacle of organ donation is family members refusal (1,3).

According to Margot et al, by donating the organs of brain death victims, the life of many patients can be saved and it helps survival of those who are in the last stages of organ deficiency (4).

Body organs of brain death victims are the most important source of organ donation in different countries that have approved laws of organ donation of brain death victims and applied widespread advertisements in relation to organ donation. However, the gap between the number of people in the waiting list of organ transplantation and the number of donated organs has been increasing. The statistics of accidents in Iran is high and there is one death in each 10 accidents and one brain death per 100 accident-related deaths; although, Iran has the highest number of brain death compared to other countries, a small percent of brain death victims are candidates of organ donation (5).

Most of the family members of brain death victims who refuse organ donation, have a misunderstanding about brain death; for various reasons they cannot accept the death of their patient and hope for his/her recovery or expect something like a miracle happen to them (6).

According to the experience of researchers in recent decades, in order to improve the chances of organ transplantation, further studies and analysis in relation to the



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involved factors in decision of families of brain death victims for organ donation are required. Until now, researchers have gathered a number of reasons for the decision of family members of brain death victims in regard to accepting or refusing organ donation (7).

Siminoff et al have reported that consent of one of the family members for organ donation increases the tendency of other family members for organ donation of their relatives (8).

In Kim et al study in South Korea with the aim of studying the effect of socio-cultural factors on organ transplantation, misunderstandings in relation to brain death caused families' deny to organ donation. One of these misunderstandings has been related to some cases of selling dead person's organs. Furthermore, religious, cultural, social, and educational factors have been effective in people's decision (9).

The results of Rice and Tamburlin study in New York showed that the probability of decision for organ donation is more among those with previous experience of donating or receiving organs or those who are in the waiting list (10). Rodrigue et al have asserted that family members have an essential role in making decision for organ donation after their relative's brain death and factors such as age, sex, ethnicity, previous awareness about transplantation from corpus, previously expressed tendency of the deceased person for donation, and the discourse of members of organ transplantation team affect this decision (11).

The results of Rodrigue et al study in USA showed that healthcare providers are the most important persons in encouraging families for organ donation. Families who did not give consent included those who loved the victim very much or their loved one was a victim of a nontrauma cause. The frequency of consent to organ donation was higher among parents and those who were older (7). In Traino and Siminoff study, decision of brain death victim at time of life for organ donation, such as having a donor card had positive effect on families' consent (12).

In Iran, several descriptive studies have been performed through using questionnaires and interviews in order to investigate attitude, awareness or legal aspects of this issue. Rezai and Shakoor have shown that among over 15 year-old participants, mean score of awareness about organ donation compared to attitude was low and in fact, in spite of positive attitude of society toward organ donation, a participant with high attitude score did not have correct awareness about brain death as an irreversible death (13). According to Ahmadian et al study, knowing the opinion of the decease done about organ donation and awareness toward the conditions of demanders has significant effects on consent to organ donation. Moreover, two groups of factors have an impact on consent to organ donation; one group through general education of society and the other through providing appropriate conditions at time of demand based on the supportive and information needs of families as well as understanding their critical

conditions (14).

Bormand and Asghari found a direct significant relationship between families' acceptance of brain death as an irreversible death and consequently consent to organ donation of their loved one with the tendency of the deceased person at time of life (15).

The results of Manzari et al study showed that several factors affect organ donation. They believed that finding these factors and explaining them to policy-makers and managers are very beneficial in improving every planning and intervention in relation to facilitating organ donation. Furthermore, it has been recommended that healthcare team help families of brain death victims to find an appropriate perception of brain death concept and its irreversibility by giving clear information to them (6).

Considering the above-mentioned studies and the importance of this issue, the first step in designing any intervention and planning for increasing consent to organ donation is exploring the effective factors on giving or not giving consent to organ donation; therefore, in the present study, it has been attempted to determine and compare effective factors on consent of families of brain death victims for organ donation in order to obtain a comprehensive insight and eventually to plan for removing present challenges and problems.

Methods

The study population of this descriptive-comparative study included all families of brain death victims during 2012-2013 in Isfahan/Iran. They were divided into the two groups of with and without consent to organ donation. Inclusion criterion was being a family member of a brain death case during the study period and the exclusion criteria were the death of the brain death victim during the process of obtaining consent, lack of suitable organ for donation, the presence of malignancies making the case unsuitable for organ donation according to the physician's opinion, families initial refusal of receiving any explanation about brain death and organ donation, and being a foreign resident.

Because the study population was limited (96 families), the whole population was considered as study sample. Data gathering was performed using a researcher-made questionnaire. The questionnaire was designed using related literature with an emphasis on the localization of items. Content validity was confirmed using literature review and considering the opinions of experts. The reliability was confirmed after obtaining Cronbach's alpha= 0.81 and items decreasing reliability were omitted. The questionnaire consisted of two parts; the first part included demographic questions and the second one included multiple choice questions related to awareness and attitude of participants toward organ donation. After referring to the address of participants, the researcher presented his identification card and gave brief explanation about the study aims and by taking consent for participation the questionnaire was given to the participants. All the questionnaires were supposed to be obtained on the same day, but in case of not completing the questionnaires; a time was set in order to be collected by the researcher. For illiterate participants, the questionnaire was completed through an interview. Finally, 11 families were excluded due to either having one of the exclusion criteria or denying to participate, and 85 families were studied.

Data were analyzed through SPSS 20 using descriptive statistics. Inter-groups data analysis were performed using independent T-test, ANOVA, and Chi-square tests and P<0.05 was considered as statistically significant level.

Results

From 85 studied families, 54 families gave and 31 did not give consent for organ donation.

The age of brain death victim was more in the group with consent compared to that in the other group; even though, due to wide distribution of individuals' age, the difference was not statistically significant (P=0.616). In regard to the sex of brain death victim, in the group with consent to organ donation, the frequency of male sex was 37 (68.5%) and that of female sex was 17 (31.5%). In the group who did not give consent, 13 (41.9%) of brain death victims were male and 18 (58.1%) were female that showed a significant difference (P= 0.022). In other words, for male brain death victims, the rate of consent to organ donation was higher. This can be attributed to the fact that, generally males are more vulnerable to events and brain death. Moreover, the marital status of the brain death victim had no effect on consent of their families (P= 0.37). Conversely; factors such as duration of hospitalization in the emergency ward (P=0.008), having donor card (P=0.025), and personal opinion of brain death victim (P=0.013) showed significant relationships with consent to organ donation in a way that families of those with donor card and positive attitude toward organ donation at time of life had a tendency for more consent. In families of those victims with long period of hospitalization, the frequency of consent was lower (Table 1).

The rate of awareness and knowledge toward organ donation was moderate in most participants of the group with consent [47 (42.5%)], while it was poor in most participants of the group without consent [50 (48.5%)] and the two groups showed a significant difference (P=0.000). The best sources of acquiring information about organ donation are television, family, and friends (Table 2, Figure 1). In studying the attitudes of two groups with and without consent to organ donation, all families with consent showed good and desirable attitude [174 (100%)], while among families without consent, 1 case (1%) had poor attitude, 52 ones (50.5%) had moderate and 50 ones (48.5%) showed good attitude. According to Chi-square test, the difference between the two groups was significant (P=0.00); in other words, it can be said that the attitude of families toward organ donation is a very effective factor (Figure 2, Table 3).

Discussion and Conclusion

The present study was performed with the aim of studying effective factors on consent of families of brain death victims who were candidates of organ donation in Isfahan province/Iran. The results showed higher age of brain death victim in the group with consent, but due to the wide age distribution, the difference was not considered significant. In opposition, the gender of brain death

Table 1. Frequency of demographic characteristics of brain death victims in both groups

Variable		Consented	Not consented	P-value
Age		15.80 ± 30.37	17.20 ± 28.52	0.616
Sex	Male	37 (68.5%)	13 (41.9%)	0.220
	Female	17 (31.5%)	18 (58.1%)	
	Single	25 (46.3%)	14 (45.2%)	0.375
Marital status	Couple	28 (51.9%)	14 (45.2%)	
	Divorced	0 (0%)	1 (3.2%)	
	Widow	1 (1.9%)	2 (6.5%)	
Organ denor card	Yes	8 (14.8%)	0 (0%)	0.025
Organ donor card	No	46 (85.2%)	31 (100%)	
	Positive	16 (29.6%)	1 (3.2%)	0.013
Personal opinion of brain death victim about organ donation	Negative	1 (1.9%)	1 (3.2%)	
	Neutral	37 (68.5%)	29 (93.5%)	
	10≥ days	37 (68.5%)	13 (41.9%)	0.008
Duration of hospitalization in the emergency ward	11-20 days	8 (14.8%)	15 (48.4%)	
	20-30 days	7 (13%)	3 (9.7%)	
	≤1 month	2 (3.7%)	0 (0%)	

Table 2. Frequency of familys' awareness and knowledge of the two groups on organ donation

Auguaraa ku audadaa		Consented	Consented		ted		
Awareness, knowledge		Number	%	Number	%	P-value	
Familiar with organ donation	Yes	117	67.2	99	96.1	0.000	
	No	57	32.8	4	3.9		
The amount of information on organ transplantation	Not at all	25	14.4	0	0	0.000	
	Slightly	25	14.4	7	6.8		
	Poor	34	19.5	50	48.5		
	Moderately	74	42.5	45	73.7		
	Good	16	9.2	1	1		
How get information on organ donation	Magazine & newspaper	8	4.7	14	13.6		
	Family & friends	44	25.7	25	24.3	0.134	
	Internet	3	1.8	2	1.9		
	Training course	2	1.2	0	0		
	Book	2	1.2	2	1.9		
	Television	112	65.5	60	58.3		

victim was found to be effective in families' consent to organ donation. In addition, factors like duration of hospitalization in the emergency ward, having donor card, and personal opinion of brain death victim about organ donation showed significant relationships with consent to organ donation. In other words, the role of emergency



Figure 1. The percentages of the awareness about organ transplantation From the perspective of family members in the two study groups



Figure 2. The percentage of family members attitude towards organ donation

 Table 3. Frequency of family members' attitude of two groups on organ donation

Attitude	Consented	Not consented	– P-value
	Number (%)	Number (%)	- P-value
Poor	0 (0)	1 (1)	
Moderately	0 (0)	52 (50.5)	0.000
Good	174 (100)	50 (48.5)	

wards and the duration of hospitalization in them can affect the decision of families; therefore, healthcare personnel of emergency wards, due to having more relationship with the family members of deceased persons and their professional experience, can play a very effective role in increasing the knowledge of families on this issue.

In line with the present study, Siminoff et al have reported that various factors including socio-individual status, ethnicity, age, cause of death, and previous awareness on this issue can affect the rate of organ transplantation (16). According to Martinez et al study in Spain, personal intension of the dead person on organ donation can help the families very much and remove any conflict among family members (17). Also, Morgan and Miller have reported more consent to organ donation among families of those victims who had previously completed the donor card or had talked about this topic with their relatives (18).

In the Delmonico et al study, as opposed to the present study, the age of donors showed significant relationship with families' decision on organ donation (19). As it was said before, in the present study, in spite of age difference of victims in the two groups, due to the wide age distribution, this factor could not be considered as significant.

In line with the present study, Rodrigue et al showed the effects of age and gender of brain death victims on consent of families to organ donation (11). According to Rodrigue et al those who did not consent for organ transplantation either had loved the deceased person very much or the

cause of their loved death had been something other than trauma (7). The study of Traino and Siminoff in USA has also showed that the decision of brain death victim at time of life and measures such as filling donor card has great effect on families' consent (12).

Similar to the results of the present study, Shahbazian et al in their study in Ahwaz/Iran showed that age, gender, and socio-economic status have no effect on the attitude toward organ donation; while, ethnicity, educational level, economic status, and having a child needing organ transplantation among the relatives, increases the tendency of people for organ donation (20).

In the present study, the rate of awareness and knowledge of families on organ donation was mostly moderate in the group with consent and poor in the group without consent and the two groups showed significant differences in this regard; in other words, awareness and knowledge were effective in participants' consent to organ donation. According to the present study, the most beneficial sources of acquiring knowledge about organ donation are television, family, and friends. In Morgan et al study, family members had received important information about organ donation through media and unfortunately most of them were negative. They asserted that there are some obstacles in organ donation that are transferred by showing negative movies (21). Also, Moloney and Walker believe on the negative role of media in organ donation (22). It should be mentioned that the present study generally showed the effect of media on awareness, but did not investigate whether this effect is positive or negative.

In our final comparison of attitudes of families with and without consent, the two studied groups showed a significant difference; that is, families with consent had good and desirable attitude, while the other group had a moderate attitude. It can be concluded that the attitude of families is very effective in their decision making for organ donation. Similar to the present study, some previous studies have also showed that lack of knowledge and positive attitude are related to families denial to organ donation (22-25). For example, Arjmand et al have found that adequate awareness and logic belief about this issue cause good decision making; in other words, more awareness leads to better attitude and consequently consent of families (26). In this line and similar to the present study, Rosel et al showed that complete and clear awareness about brain death, the physicians' and nurses' manner, and discourse as well as hospital facilities are factors affecting families consent (27). Siminoff et al in their study comparing black and white families in regard to consent to organ donation, showed the significant effect of awareness and attitude of families on their decision for organ donation (8).

West and Burr believed that factors such as incorrect information about brain death, cultural misbelieves, and the personality of deceased person are the most important factors preventing consent of families to organ donation (3). Kim et al in their study on *"The influence of socio-cultural* *factors on organ transplantation*" concluded that misunderstandings about brain death resulted from the lack of awareness leading to denial of organ donation (9).

Generally, since several factors affect organ donation, exploring and explaining these factors to the policymakers and managers for planning interventions in relation to improving the culture of organ donation and facilitating its process can be very beneficial. Moreover, it is recommended that healthcare team provide families of brain death victims with clear and comprehensive information about brain death and make sure the understanding of families of the irreversibility of brain death.

Ethical issues

This study was approved by the ethic committee of Khorasgan Branch, Islamic Azad University of Isfahan.

Authors' contributions

First authors contribute to drafting/revise the manuscript, study concept or design, analysis or interpretation of data.

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