Original Article

Experiences of the families concerning organ donation of a family member with brain death

Hojatollah Yousefi[1], Asieh Roshani[2], Fatemeh Nazari[3]

Abstract

Background: In recent years, the lack of organ for transplantation has resulted in health planners and authorities in all countries, including Iran, paying serious attention to the issue. Despite the above-mentioned fact, families with a member affected by brain death are not interested in organ donation.

Objective: This study is aimed at making an investigation into the decision-making process of organ donation in families with brain death. Also, the research is aimed at investigating how the deterrent and facilitating factors in the process of organ donation can be made.

Materials and Methods: The current research is a qualitative study with descriptive exploratory approach. Data were collected through unstructured interviews with 10 family members who gave consent to organ donation of their family members in 2012. Purposeful sampling processes began in March 2012 and lasted up to June 2012. Simultaneously, thematic approach was used in analyzing the data.

Results: Data analysis led to finding 24 categories and 11 themes, which fell into two categories: facilitating and deterrent factors. The five main deterrent themes included the five themes of prohibiting factors that were shock, hope for recovery, unknown process, and conflict of opinions, and worrying association. The six main facilitating themes included humanistic desires, immortality, culture making, satisfaction of the deceased, assurance, and eternal honor.

Conclusion: The findings indicated that there is ambiguity and different interpretations on brain death. The research also showed that using the experiences of donator families can provide practical and applied solutions to facilitate the process of organ donation and solve the problems faced by the health care system.

Key words: Brain death, family, organ donation

Introduction

One of the controversial medical issues discussed in recent decades is brain death. This concept has been known for many years.[1] However, the term "brain death" was officially introduced by Henry Butcher, the chairman of medical school in Harvard University in 1968.[2] Brain death is the irreversible end of all brain and brainstem activities.[3] This concept is different from other types of acute brain disorders with changes in consciousness (coma and vegetative state). Having different imaginations about brain death among the people seems to be highly influenced by culture, religion, and experience.[4] Organ transplantation is associated with brain death, and has developed through technical advances in surgery and immunity system suppressing treatment.[5] Organ transplantation has improved patients' quality of life and their hope to future.[6] Based on estimates, about 17 patients (5-7% of the patients in organ donation waiting list) die daily as a result of no adequate donated organs while there is 70% increase in patients' organ demand.[7,8] The statistics of organ donation in brain dead patients is 34 out of a million in the world and 1.7 out of a million in Iran. These statistics reveal that there are a few brain dead candidates for organ donation whose number does not meet the existing demand.[9] Although organ transplantation has brought new horizons of hope to save a group of patients, it is accompanied with numerous cultural, ethical, and religion-related problems.[10] Brain dead individuals are among the patients who may cause some problems for their family, as making a decision on giving consent for organ donation becomes a difficult and complicated issue for the family members, especially in Asian families, when their patients have healthy and proper organs for transplantation and are appropriate candidates for organ

[1]Assistant Professor, Department of Adult Nursing, School of nursing and midwifery Nursing and Midwifery Care Research Center, Isfahan University of Medical Sciences, Isfahan, [2]Eisabne-Maryam Hospital, Isfahan, [3]Academic Member, Department of Adult Nursing, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

Address for correspondence: Fatemeh Nazari,
Department of Adult Nursing, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran.
E-mail: nazari@nm.mui.ac.ir

donation.[11,12] Families' avoidance of giving consent for organ donation is the main obstacle in this regard, so despite a higher number of brain dead patients detected, the ultimate goal of donation is not actually achieved when the level of donation consent is low. There are a few qualitative studies with appropriate extent and variation in relation with family's decision on organ donation in Iran. With regard to this issue, further studies on families' experiences seem essential. Therefore, a background for conducting the present study was made and it aimed to investigate families' decision-making process concerning organ donation of a family member with brain death, with the research question of what the families experience concerning organ donation.

Materials and Methods

This is a qualitative study with descriptive exploratory approach. The participants comprised available family members of brain dead individuals who signed the consent form to attend the study and had experienced organ donation process of a family member at least 40 days and at the most a year before the study started in Isfahan, Iran. The participants were selected through purposive sampling. The only inclusion criterion was being an immediate family member (parents or spouse). The study was conducted from April to June 2012. Researcher referred to Organ Donation Association in the Vice-Chancellery for Treatment and Medical Education of Isfahan University of Medical Sciences after getting a written letter of introduction from nursing and midwifery school. Research steps were approved by the related research committee concerning ethical considerations.

Participants were selected from the families who had experiences about the research concept (organ donation), and their contact addresses were taken from the related association. Firstly, they were called to coordinate an orientation meeting for explanation of the research design and goal and signing their consent forms. After attaining their trust, the second session to conduct the interview and record their experiences at their homes was set. The interviews started with almost similar open questions like "Can you introduce yourself?" In the next step, they were asked to explain about their experience of giving consent concerning their deceased member's organ donation. The interviews ended when the researcher believed all necessary information had been obtained from the participants and the data were saturated. Before each interview, the permission to record participants' voice was taken, and they were assured about confidentiality of their personal information and their use in scientific and research issues. A total of 16 members from 10 families underwent face-to-face open interviews. The length of interviews varied from 45 min to 4 h based on the participants' demand. The donors were nine Muslim men and one Muslim woman aged 17-42 years. Participants' descriptions concerning their experiences of their brain dead patient and organ donation were recorded in an MP4 device in the related open interview. Immediately after each interview, the recording was listened to, transcribed, and given to the participants for obtaining their approval. The researcher also took detailed notes about the part not recorded or the parts which were not recordable after each interview.

After the data were collected, all participants' explanations about the related concept were reviewed and main phrases were extracted in the form of primary codes. After the primary codes were defined, they were categorized into unique groups with similar context, and next, subthemes and main themes were formed. These themes were checked by primary codes. Main themes were again reviewed, and appropriate abstract names were selected for them. Eventually, a final and comprehensive report based on the research question and major and minor goals was provided, and the results were described. For rigor of the data, the researcher took advantage of consultation with her supervisor and counselor. The data were approved by participants during transcription and by the researcher's supervisor and counselor at the time of coding. Data collection and analysis were concurrently conducted through Aronson, a method described earlier.[13,14]

Results

Data analysis led to extraction of 402 primary codes of which 121 were for prohibiting factors and 281 for facilitating factors.

Finally, their reduction yielded 11 themes and 24 subthemes, which were divided into two groups of prohibiting and facilitating factors. Prohibiting factors included 5 main themes that emerged from 12 subthemes, and facilitating factors included 6 main themes that emerged from 12 subthemes [Table 1]. The five themes of prohibiting factors were shock, hope for recovery, unknown process, conflict of opinions, and worrying association. There are explained subsequently.

Prohibiting factors

1. **Shock:** Shock refers to a situation when the family members have just faced an unexpected situation and crisis and are imbalanced. This theme emerged from two subthemes of disbelief and shortage of time. Disbelief is a manner when the family has just faced the crisis. The family finds itself in a miserable situation and is in shock and disbelief and tries to escape from reality.

Table 1: Subthemes and themes related to prohibiting and facilitating factors

Facilitating factors		Prohibiting factors	
Themes	**Subthemes**	**Themes**	**Subthemes**
Humanistic desires	Altruism Spiritual motives	Shock	Disbelief Shortage of time
Immortality	Replacement Solacing transplantation	Hope for recovery	Prayer Healthy appearance Patients' condition
Culture making	Propaganda Respect Positive relatives and friends	Unknown process	Unknown death Shortage of information Distrust
Satisfaction of the deceased		Conflicts of opinions	Relatives' and friends' disagreement Concern about public belief
Assurance	Trust Accepting reality Visit Appropriate informing Awareness	Worrying Association	Recipients' position Lack of respect
Eternal honor			

"The day they told me my husband was brain dead, they talked to me to give consent. They told me I did not have much time. First, I did not accept, I was in shock I was out of my mind." (Wife)

On the other hand, when the families are in this dilemma and have not accepted the reality, they are asked for organ donation of their deceased one while there is a short time interval between brain death and making a decision on organ donation.

"When she said he is brain dead, I did not hear anything more … they told us his pulse was weak, his liver was dysfunctional, if you agree, hurry up to decide. … We had to decide quickly. Finally, we made up our mind in just one night. We did not realize anything at that time." (Father)

2. **Hope for recovery:** From three subthemes of healthy appearance, patient's condition, and prayer, the theme of hope for recovery emerged. Families hoped their patient would get cured and return to family. In most of the cases, healthy appearance of the patient was one of the reasons which reinforced the hope for recovery of the brain dead in families. In most of the interviews, the participants mentioned their patient was brain dead while she/he apparently had no signs of injury and this issue confused the family to accept the reality.

"You know, my son had no problem, I watched him, he was intact, just two sutures on his little finger, no broken head and no wound!" (Mother)

The position of the brain dead in the family reinforced the hope for recovery. Many individuals' key role in the family made it more difficult for family to accept their absence and they hoped for their recovery.

"My husband was hard working, he was the bread winner of the family, he was everything for me, and the whole life was based on him. It was too hard to accept." (Wife)

Praying, especially in difficult life situations, exists in all humans, especially in Iran, where there are deep and firm religious beliefs.

"We hoped he would wake up, I promised to always say my prayer, worship and go fasting, if my son would get ok." (Father)

3. **Unknown process:** This theme emerged from three subthemes of unknown death, shortage of information, and distrust, and reveals the unknown process of brain death and its roots in families and society.

"I first thought it was a coma, I made a mistake between coma and brain death, they never explained what brain death was." (Mother)

Another obstacle was improper manner of informing the families by the health team. This defect embarrassed the families and made them agree with health and transplantation team.

"They never explained what brain death was. If I actually knew there was no hope, I would have eagerly signed the form, but I gave consent with crying." (Mother)

Distrust included lack of reliance to treatment and transplantation team, which can be as a result of family's shock, confusion, and disbelief on the one hand and improper approach to families in this situation and not informing them about their patients' exact situation on the other. This leads to families' consultation with other physicians and, possibly, nurses out of treatment team.

"I kept hopeful to the last minute. My two sons brought a doctor from out of hospital, but he said the same thing as other doctors." (Mother)

4. **Conflict of opinion:** The theme of conflict of opinion, emerging from relatives' disagreement and concern, indicates a

situation when the family faces incoordination between its own thoughts and perceptions and those of its relatives and friends and the public. While the family tries to accept organ donation of their deceased beloved, at the time of decision making, disagreement of the relatives and friends can put the family in confusion, nervous breakdown, and conflict of opinions.

"Our relatives and friends did not agree. They objected why we gave consent for organ donation. They said, 'now they will dissect his body.' My mother did not permit it. My dad said, 'they intentionally did not take care of him to donate his organs.'" (Father)

Some relatives and people think that the family has sold the organs or have monetary expectations from the recipient's family. They always expressed their concern about the public opinion.

"First, all thought we sold his organs. As we had to change our house, they were more convinced that we had sold our son's organs." (Mother)

5. **Worrying association:** This theme emerged from two subthemes of recipients' importance and their ignorance of respect. Some donors' families expressed that the personality of the recipient was important for them.

"First we went to see who the recipient was. Do they (recipient's family) deserve? What family are they? Are they believers and religious?"

Some families need respect from others, especially from the side of the recipient. Meanwhile, ignoring the value of organ donation in the society either from the side of recipients or by other people, mass media, and related organizations can slow down the process of making the culture of donation among these social groups.

"Nobody came over to visit us after organ donation. Mass media did not contact us. Nobody asked how we would make ends meet now that our bread winner is gone. They left us." (Wife)

Facilitating factors

Six themes of facilitating factors included humanistic desires, immortality, culture making, satisfaction of the deceased, assurance, and eternal honor.

1. **Humanistic traits:** This theme emerged from two subthemes of sacrifice, and altruism and spiritual motives. Having traits of sacrifice, forgiveness, and altruism is one of the factors, and perhaps the most important factor in organ donation.

"From the aspect of altruism, we were happy that someone benefited from our son. When his healthy organs are to decay in grave, why not to donate." (Father)

Spiritual and religious beliefs and motives are among the facilitating factors in organ donation. In fact, they help them cope with the sorrow more easily. In all interviews, the families claimed to have donated the organ for the sate of God and for the peace of the deceased person's ghost.

"He was a gift from God and the Lord wanted to get him back. We dealt with God." (Mother)

2. **Immortality:** This theme emerged from two subthemes of replacement and solacing transplantation, and indicates that from the view of the family, organ donation is the symbol of their deceased patients' immortality and solaces the family. Based on participants' remarks, the recipients replace their deceased, and a feeling of belonging is formed in them.

"I tell my husband, imagine our son is grown up and now we communicate with him, when I hug him (the recipient), I feel he is my son who has suddenly grown up."(Father)

There is a high desire to communicate with the recipient's family from the side of organ donor's family. Some families seek for their deceased patients' immortality in the recipients, and the communication they make with the recipients brings them peace and solace.

"We insisted on visiting the recipient as we felt he had an organ of my husband in his body. We liked them to call us once in a while; this is a solace for us." (Wife)

3. **Culture making:** This theme emerged from three subthemes of propaganda, dignity, and relatives' and friends' positivity. One of the important issues about brain death is culture making in relation with organ donation.

Propaganda and informing the public, especially through mass media, plays an important role in this regard. In Iran, in recent years, production and broadcasting of TV series on the subject of brain death has increased. In fact, paying attention to these issues is valuing the subject of donation and donors' families. It can act as a facilitating factor.

"We were not familiar with brain death, but had watched it in movies. Now, we watch such movies and they seem ordinary to us." (Mother)

Relatives and, especially, immediate family members play a key role in decision making. The positive role of relatives and friends in provision of a peaceful atmosphere and

relaxing the family facing the disaster, as well as provision of psychological and mental help to make them take a decision is so important and effective.

"When our relatives knew that we wanted to donate, they all said it is the right thing. Now, all of them have organ donation card." (Mother)

Highlighting the position of donors' families and giving a respect to their action has a facilitating role in organ donation. When the issue of donation and donors' families gets brilliant, for instance, through mass media, especially TV, in fact, donation and donors' families are valued.

"That you are here is so good, that you talk to us is a relief and gives us peace. It is good for us." (Father)

Most of the families talked about authorities' attention and nationwide congresses on the subject of organ donation. Some emphasized on the necessity of receiving financial help from related organizations based on their financial status after their beloved passed away.

"They should insure the spouse and children of the brain dead and give them financial help. I wish the authorities could hear us to do something. I think families like us should be known more in the society and people should hear us more." (Spouse)

4. **Consent of the deceased:** Results of the present study showed that families' awareness of their patients' viewpoint in relation with organ donation is a facilitating factor in organ donation.

"We agreed as we knew our son liked it. He always said (when alive) 'mom, this body should not be buried with intact organs.' I knew he liked it."

5. **Assurance:** This theme emerged from five subthemes of trust, accepting the fact, visiting the patient, appropriate informing, and awareness. Reliance to treatment and transplantation team is one of the facilitating factors, as the families get the news of their beloved's death and irreversibility of his/her condition from them.

"Relatives asked, 'why did you agree?' We answered, 'doctors never tell lies, the doctors said, we do not do anything even if there is 1% chance of survival.'" (Father)

Families' visits to their patients during hospitalization and observation of unsuccessful trend of treatment and worsening of their condition all can help them accept the reality.

"We visited him every day. I went to his bed, he had a pulse but his eyes were not live and his body was cold. I said, 'he has just a pulse but is not conscious.' I knew there was no chance and his brain was dead." (Mother)

With regard to the reality of brain death and irreversibility of patient's condition, losing hope to go on with treatment and acceptance of the situation that had happened can act as an efficient factor for organ donation. When families knew the fact, they made their decision for organ donation more easily.

"We knew nothing about consciousness; transplantation doctor calmly explained that to us in detail, and then, we gave consent." (Father)

6. **Eternal glory:** Brain death followed by an organ donation was counted as death with glory by the families. This issue is more notable in Iranian society in which humanistic and spiritual values are more prevailing. Participants considered organ donation as an eternal glory which is reflected in donor's resurrection.

"God wanted us to give back his gift. We are happy, we finished it, and thank God, he (the deceased) had a glorious death and got immortal like a martyr." (Mother)

Discussion

The results of the present study showed that families experience some perceptions and emotions and show various reactions in the process of decision making when they are informed about diagnosis of brain death of their patients, and their organ donation, which can be divided into two groups of prohibiting and facilitating factors in the trend of organ donation. Shock indicated the conditions that are deeply stressful in which the family receives the bad news of their patient's brain death and remains in distress and confusion.

Knowing about brain death and the short time interval between the event and brain death is the main stressful factor experienced by donors' families. This theme is consistent with the theme of trial to accept death obtained by Manuel *et al.* They expressed that families' acceptance of the fact leaves them in shock, which is accompanied with a mixture of chaos and confusion and leads to a dysfunction in perception of information from the environment, especially the treatment team.[15,16] Mills, quoting from Long *et al.* and Wong and Chan, argues that disbelief and anxiety and acute psychological stress have been experienced in most of the families when faced with a brain dead member.[17,18] Medina *et al.* mentioned that the manner in which the brain death

was caused and its sudden and unexpected nature is an important factor that decides giving or not giving consent by the families.[19]

Khoddami Vishteh *et al.* expressed that patient's relatives avoided giving consent for organ donation in two-thirds of traumatic events due to the acute nature of these events.[20]

Praying for patients' return and recovery was among the issues of hope for recovery, which is latent in all humans in difficult situations of life, especially in Iranian society with deep and firm religious beliefs. In such conditions, families start praying and seek for a more magnificent power (God). Sadock *et al.*, quoting from Kaplan, mentioned the individuals in crisis are in sort of emotional imbalance and cannot access natural coping methods against pressure. Consequently, they are vulnerable concerning psychological status. In the phase of knocking off or dealing which is one of the steps in crisis, one deals with God through vow and worship.[21]

Healthy appearance of the patient, contrary to his/her internal severe injuries, increases the hope for recovery in the family. The more the patient has a key role in the family, his/her missing becomes more difficult for the family and the families hope for their recovery. From the viewpoint of participating families in the present study, the sorrow of missing a young member is more than that of an older member through brain death.

Dejong *et al.* reported that characteristics of the deceased individuals, their age, and key role in the family, the deceased person's will, and the family's perception of brain death are among the effective factors on donation.[22]

Manuel *et al*. explain that the deceased person's characteristics and his/her wishes and ideals are effective on his/her families' decision on organ donation.[15] Meanwhile, Ahmadian *et al.* and Tavakoli *et al.* showed that there was no significant difference in some of the deceased persons' characteristics such as gender, marital status, education, and occupation in two groups of donors and donation avoiders.[23,24] Although public awareness about brain death has increased in recent years due to various reasons including the effect of mass media, it is not enough. The obtained results show that yet, there are many obscure points among the people and even donors' families. Most of them did not know the difference between coma and brain death. Families' awareness, when facing such conditions, may result in their more realistic reaction. Long *et al.* emphasize that families' perception of brain death does not necessarily coincide with legal and medical definitions.[17] Manzari *et al.,* quoting from Franz and Oliver, state that most of the families do not have appropriate awareness about the meaning of brain death.[16] Public opinion and their wrong perception of organ donation can be counted as an obstacle in this regard.

The decision to donate an organ is a very tough decision for the family members of the brain dead. One of the major obstacles in this issue is relatives' and friends' disagreement, which has been already pointed out.

In this relation, Tavakohi *et al.* also state that in 77% of cases, incoordination among family members to make a decision and in 45% of cases, relatives' and friends' disagreement are the negative points of these families' donation.[24] The importance of the recipients' position from the side of donating families was obtained as a result in the present study, which is consistent with the finding of Ahmadian *et al.* who reported that 63.8% of donating families and 8.8% of avoiding families requested the transplantation team doctor for adequate explanations about the type of recipients' life, their life condition, and characteristics.[23] Motive and the reason for donation is a very important factor in organ donation about which participants frequently talked in their interaction with the recipients. Therefore, through supporting these humanistic motives and valuing them, donation is somehow spread in the society. In Iranian society, sacrifice and altruism are highly dominating among the people and, consequently, positively affect organ donation and can be considered as facilitating factors. In addition, religious beliefs are counted as a very effective factor in organ donation. Ahmadian *et al.* stated that the chance of donation increased by increase of one score in the domain of religious beliefs.[22] Alshehri *et al.* showed that donating families had deeper religious approach concerning organ donation.[25] Family members of brain dead patients, donating organs, expressed their intent and motive to donate as saving life of the people in need, better coping with the sorrow of missing their beloved, sate of God, and helping the people.

Willson *et al.* showed that individuals' and families' motive to donate an organ has been saving people's life and helping them.[26] Stouder *et al.* reported that 71% of donating families' motive and intent was enhancement of others' quality of life, saving others' life, and helping the people in need for an organ and their support.[27] The deep altruistic and religious beliefs in these families were notable in their study, which highly supported sacrifice and giving a new life to those in need for donation. The theme of immortality in the present study concords with the term of dominance in the study of Abedi *et al.* in which based on donors' families' idea, the success of transplantation was equal to the deceased person's immortality and living while

dead, and lack of success in transplantation was equal to a new sorrow for them.

Domination refers to the feeling of belonging and dependency by the donors' families toward recipients.[28] These families seem to need a sort of attention, although a few were after less others' attention. In other words, all families welcomed relatives', public and society's attention, although the sort of their desire was different. Some were after attention to transfer their own message and some others wanted to make culture among people. Meanwhile, a group of them was after drawing authorities' attention in addition to that of public. Roza *et al.* concluded that 63% of families mentioned that the support during funeral concerning their action of donation was appropriate, and a significant association was found between receiving low appreciation and support concerning donation during the above ceremonies and a new donation.[29] The results of the present study showed that organ donation of the deceased and their live organs in recipients' body somehow reflect immortality through which the families can better cope with the sorrow. Tavakoli *et al.* in their study on decrease of families' sorrow experiences reported no difference, as there was no difference in the level of depression among donors' families and donation avoiding families, although most of the donating families mentioned that being involved in organ donation process was effective on their sorrow reduction.[24]

Routasalo *et al.* showed that families buy themselves a chance to accept the reality of missing their beloved through organ donation and seek for the continuation of their life in recipients.[30] Our obtained results emphasize on the necessity of government and governmental and supportive organization management to this process, so as to value these families and prevent direct contact of donors' and recipients' families to stop possible abuses. Manual *et al.* indicate the importance of governmental organizations' support of organ donation and show the main role of government in culture making and propagation concerning supporting organ donation associations as well as donors' families.[15] Zohoor *et al.* stated that increase of public awareness concerning brain death and the phenomenon of organ transplantation changed the attitude and enhanced the percentage of organ donors.[31] The results of the present study showed that awareness of brain dead members' families about their patients' viewpoint concerning organ donation and brain death was a facilitating factor in organ donation, which is consistent with the finding of Tessmer *et al*.

They explain that families' awareness of their patients' agreement with organ donation facilitates their organ transplantation.[32] Our obtained results showed that assurance given to brain dead member families can be a facilitating factor. Trusting the treatment staffs and approval of diagnosis are among the assuring elements. On the other hand, accepting the reality assures the family that their patient is in an irreversible condition. Visiting their patients and seeing their critical condition can help the families accept the fact.

Therefore, in families with more awareness about brain death and those who experience longer period of time with their patients' injury, decision making is easier. The participants counted organ donation as a glorious death and remembered the deceased with wellness and considered them as the honor of the family. Manuel *et al.* extracted a theme of creation of an immortal memory, which seems to be consistent with eternal glory obtained in the present study. They believed that participating families believed organ donation to be effective in their gaining peace and consolation. They stated that the decision to donate an organ is the reflection of an internal desire and wish through which they changed a miserable event to something better and positive.[15] Our obtained results not only helped us to have a better understanding from families' experiences and the affective, emotional, and mental perceptions they are involved in, but also brought us a deeper and different perception in relation with the obstacles and facilitating factors in the trend of organ donation. The addressee group of our results is the public, related organizations, and supportive NGOs.

Nursing personnel should also attain necessary skills to attend a dynamic interaction with brain dead member families, and the public should be driven toward organ donation and getting organ donation card through their better and higher perception of brain death and organ donation process.

Conclusion

The study shows that there is ambiguity and different interpretations on brain death. Using the experiences of donator families can provide practical and applied solutions to facilitate the process of organ donation and remember to the health care system for more attention to these families.

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