

The Experiences of Family Members of Non-Organ Donors on the Crisis Rising From Patients' Brain Death

Mehran Tahrekhani,¹ and Heidar Ali Abedi^{2,*}

¹Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, IR Iran

²Department of Nursing and Midwifery, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, IR Iran

*Corresponding author: Heidar Ali Abedi, Department of Nursing and Midwifery, Isfahan (Khorasgan) Branch, Islamic Azad University, Isfahan, IR Iran. Tel: +98-9131022936, E-mail: drabediedu@yahoo.com

Received 2016 June 26; Revised 2016 September 26; Accepted 2016 September 27.

Abstract

Background: Brain death crisis as an overwhelming situation can create a critical state for families in which they are unable to make logical decisions for their patients with brain death.

Objectives: This study aimed to explore the experiences of family members of patients with brain death, who did not donate their patients' organs.

Methods: A qualitative study was conducted on nine non-donor family members of patients with brain death, selected using the purposeful sampling method. To collect data, deep unstructured interviews were held to reach data saturation. The interviews were transcribed verbatim and analyzed utilizing the phenomenology approach based on the seven-step Colaizzi's method.

Results: The participants of this study explained their situation as 'an overwhelming situation in families due to patients' brain death'. Also, the data analysis led to the development of four main themes as follow: 'overwhelming situation', 'perplexity factors', 'the sling loops of defect in consent for organ donation', and 'compatibility'.

Conclusions: The overwhelming effects of the patients' brain death on the family members and the crisis rising from it influenced the decisions made by family members for organ donation. Therefore, some measures should be taken to cultivate appropriate adaptive behaviors among family members for relieving their sorrow and pain. Moreover, healthcare team members should be informed of the crisis raised from patient's brain death and help family members make logical decisions with regards to organ donation.

Keywords: Life Experiences, Family Members, Brain Death, Organ Donation

1. Background

There are some misperceptions in families with regards to brain death. Some families cannot believe that a dead person may still have vital signs (1). Brain death is the loss of all brain functions without any chance for recovery (2), which occurs as a consequence of blood congestion in this sensitive organ. In other words, brain death may occur when blood and oxygen are not delivered to the brain (3, 4). The American neurology academy (ANA) defines brain death as the absence of brain's clinical functions without any known cause that is irreversible (5). According to a study by Khoddami et al. brain death constitutes one to four hospital deaths and 8-13% of mortalities at the intensive care unit (ICU) (6).

A paradox exists between families' perceptions of brain death and the legal and medical definitions of this phenomenon (7). Also, the sudden nature of brain death adds to the complexity of the phenomenon and renders it even more challenging to Asian families, particularly if patients were young and healthy (8, 9). Organ donation is a social action, which is conducted based on the individ-

ual's consent while alive. Moreover, it can be done under the consent of patients' family members upon their brain death to excise their body organs and tissues and donate them to those in need (10). However, in most countries, the donation process depends on the families' consent (11). In the study by Goh et al. it was found that the sudden death of a family member and donation issues imposed a substantial amount of pressure on family members (12). For instance, some family members may resist accepting the decedent person's death and remain hopeful for the patients' recovery. Some of them may even expect something like a miracle to happen and bring the patient back to normal life (11).

Quantitative research approaches have failed to explore the different aspects of people's experiences in this social phenomenon. In this respect, qualitative studies are able to provide valuable data on families' experiences about the crisis caused by brain death. It has been noted that the experience of family members of brain death is mixed with cultural and contextual factors. An earlier study investigated factors affecting the decision about or-

gan donation in brain dead patients' families; however, the meaning of brain death and the factors affecting decisions in families of non-organ donors have not been examined and to the best of our knowledge there are no studies on the crisis originating from brain death among families of non-organ donors.

The crisis experienced by the families of patients with brain death is so grave that may hinder them to accept this situation and many of them refuse donating the organs of these patients. Therefore, the questions that are concerned with this subject are, "what is the meaning of brain death for family members of patients with brain death, who refuse organ donation?" and "why some of the families resist organ donation?". Exploring the experiences of these families might help healthcare providers create an atmosphere for families to cope with this crisis.

2. Objectives

The aim of this study was to explore the experiences of family members of patients with brain death, who did not donate their patients' organs during the crisis of patients' brain death.

3. Methods

3.1. Study Design

A phenomenological approach was used in this qualitative study. According to Polit and Beck, the phenomenological approach investigates the meaning of human experiences and aims to explore the essences of life phenomena (13).

3.2. Sample and Settings

The population of this study included all the immediate family members of non-organ donor patients with brain death hospitalized at the Ayatollah Mousavi hospital, Zanjan, Iran. A purposeful method was used for sampling of the immediate families of these patients, who were willing to share their experiences on the crisis stemming from brain death.

3.3. Data Collection and Interviews

In-depth unstructured interviews were held with the participants from July 11th 2013 to September 22nd 2014. The interviews were continued until data saturation was reached and the new collected data did not add to the variations of the data analysis products (14). Ultimately, nine people participated in the study at their homes or workplaces, which ever was convenient for them. According to the purposive sampling method, they were selected from

youngest to oldest. This meant that the children of the patients with brain death were invited for initial interviews because this phenomenon was more tolerable for them and then their siblings were invited. Finally, their parents were interviewed. If more explanation for the participants' statements was required, another session for extra questions was held. The details of the participant's demographic characteristics are presented in Table 1.

All the interviews were tape-recorded and transcribed verbatim immediately after each interview. All the interviews were commenced with a general question: "What happened when you were informed about the patient's brain death?". The branching questions to improve the depth of data collection were as follow: "What did you do at that very moment?", "what was the meaning of brain death for you?" and "Will you explain it more?". Each interview session lasted between 30 and 40 minutes on average.

3.4. Ethical Considerations

This study was approved by the research council and the research ethics committee affiliated with the Islamic Azad University, Khorasgan branch, Isfahan, Iran (ethical approval code:493021, issued on the 16th of September, 2015). Before data collection, the study aim and method were explained to the participants. They were informed that participation in this study was voluntary and that they could withdraw at any time without being penalized. They were also assured of the anonymity and confidentiality of the data. Those who willingly agreed to take part in this study, were asked to sign an informed consent.

3.5. Data Analysis

The seven-step Colaizzi's method for phenomenological analysis was used. In the first step, all interviews were tape-recorded and then transcribed verbatim immediately after the interview. A sample of data analysis used in this study is presented in Table 2.

The researcher immersed the data to develop categories and themes, as hidden patterns from the content of data (15, 16). After each interview was transcribed verbatim, the transcriptions were read line by line several times to obtain a sense of the entire text. Next, the sentences, related to the research topic, were underlined and initial codes were extracted. The codes were extracted and classified in groups based on similarities and differences. At stage 4 to 6, the formulated meanings were placed into clusters of themes to extract the 'essential structure of the phenomena' and the results were integrated into an exhaustive description of the topic being studied and the essential structure of the phenomenon was formulated. At this stage, four main themes were emerged concerning experiences, thoughts and feelings related to the crisis

Table 1. Demographic Characteristics of the Participants

Order	Relationship with the Patient	Age	Residence	Marital Status	Occupation
1	Son	26	Urban	Single	Student
2	Brother	32	Urban	Married	Unemployed
3	Brother	23	Rural	Married	Driver
4	Father	59	Urban	Married	Retired
5	Mother	47	Urban	Married	Housewife
6	Sister	18	Urban	Single	Student
7	Son	23	Urban	Single	Auto body mechanic
8	Brother	33	Urban	Married	Employed
9	Mother	65	Urban	Married	Housewife

Table 2. Analysis Process Conducted in This Study

Participants' Statements	Underlined Units	Codes	Subtheme	Theme
I lost my mind upon hearing the news	I lost my mind upon hearing the news	Losing oneself		
A kind of feeling, which defies description	A kind of feelings, which defies description	Unpleasant feeling		
A feeling which you wish no one to experience	A feeling ,which you wish no one to experience	Unique experience		
The way the doctor broke the news and what we heard from the ICU staff made me lose my mind	The way the doctor broke the news and what we heard from the ICU staff made me lose my mind	Losing oneself	Overwhelming Situation	Overwhelming Situation
Because I was responsible to pay visits to the hospital	Because I was responsible to pay visits to the hospital	Being the caregiver of the patient		
Talking to the doctor and hospital staff concerning my father's affairs	Talking to the doctor and hospital staff concerning my father's affairs	Being the caregiver of the patient		
I was almost the first one who learned that my father had a brain death.	I was almost the first one, who learned that my father had had a brain death			
Truth be told, I did not completely lose hope and I had never experienced such a situation	Truth be told, I did not completely lose hope and I had never experienced such a situation	Initial hope for the patient's recovery		
I hope no one experiences such an incidence	I hope no one experiences such an incidence	Unique experience		
May God protect all families from such incidences	May God protect all families from such incidences	Unique experience		

caused by brain death. The researchers tried to present the social aspects of the phenomenon under study in a clear form. At stage seven, descriptive results were returned back to some of the participants to confirm if this analysis describes their experience. For bracketing (17), before data gathering, the first researcher documented his subjective ideas about the crisis caused by brain death within the families of the patients and during the study, he sought to avoid pre-judgments and subjective ideas throughout

the interviews and data analysis procedure, and tried to keep his sole concentration on the data obtained from the participants' experiences.

3.6. Rigor

The following measures were obtained to assess this study's rigor: credibility included activities that increased the probability that credible findings were produced. One of the best ways to establish credibility of findings was

to see whether the real ideas of the participants were presented in the findings of this study. This was confirmed through asking participants to verify our findings. Dependability was a criterion met once the researchers demonstrated the credibility of findings. Confirmability was a process criterion, in which the researchers documented the process of data collection and analysis over time for other qualitative researcher's future follow up. Transferability referred to the probability that our study findings were meaningful in similar situations. The researchers sought to select participants based on maximum variation in sampling and recorded their demographic characteristics. The findings were also shown to a few family members of patients with brain death, who did not participate in the research, and they confirmed the fit (15).

4. Results

4.1. The meaning of the Phenomenon

The meaning extracted from the data was 'an overwhelming situation in families due to patients' brain death'. Brain death created an overwhelming situation for the patients' families. It resulted in the creation of a failure chain loop, and discontent with organ donation. As the time passed, a type of compatibility was developed among them.

Also, the data analysis led to the development of four main themes as follow: 'an overwhelming situation', 'perplexity factors', 'the sling loops of defect in consent for organ donation', and 'compatibility'. Each theme consisted of two to five subthemes.

4.2. An overwhelming situation

According to this theme, the families experienced a difficult situation following the outburst of the news of patients' brain death. As a shocking incidence, it affected all aspects of their life. Five subthemes were identified for this theme including 'the shock stemming from brain death', 'keeping family members unaware', 'the collapse of the family after the patient's death', 'post-mortem problems', and 'untimely death'.

4.2.1. The shock Stemming From Brain Death

According to the participants' statements, the news of patients' brain death and the resulting shock was a catastrophic incidence. A participant commented: "upon hearing the news I totally lost my marbles. I cannot explain my feelings. This is a situation, which you never wish for anyone" (Participant 1, male, 26 years old). A female participant also commented: "I got shocked. The news broke our backbone. I informed my father, but could not keep him

calm. He was sad and hitting himself against doors and walls, then he fainted and we held him with lots of difficulty. I fainted at the hospital. I was totally unconscious" (Participant 5, 47 years old). Referring to her father's behavior in the funeral session of the patient, one of the participants said: "It was unbelievable. My father did not cry nor did he see anything. He called me and said he was bringing the meat of the sacrificed sheep dedicated to the soul of the patient. He told us: 'Don't cry. I am not crying either. Believe me. I am bringing the sacrificed mutton', which I was going to have for his wedding upon the bride's arrival at his house.' You know that there is a tradition to sacrifice a sheep upon the bride's arrival" (Participant 6, female, 18 years old).

4.2.2. Keeping Family Members Unaware

According to the participants, brain death was such an overwhelming incidence that they decided to keep families unaware of the news. One of the participants said: "I just wanted her [the patient's mother] not to go to the yard. If she did, she would ask the reason of our crying. He just wanted to know... whoever came over. I just asked them (the patient's close relatives) not to come to the hospital" (Participant 8, male, 33 years old). Another participant shared his experience by saying: "...then we took our mother to the hospital). Later my brother in law figured out the situation. He found out that the patient was brain dead. He took my mother aside and tried to prevaricate the incidence. He told her that the patient has been taken somewhere else, trying to put it in an unsuspecting way. He said to her that she would meet the patient later, but not now" (Participant 3, male, 23 years old).

4.2.3. The Collapse of the Family After the Patient's Death

The participants stated that following the patients' death, their family collapsed. It was characterized by a broken home and the patient's spouse's remarriage with someone else, starting a new family, and relationship disruption of the spouse with the bereaved family.

One of the participants said: "He got shocked [his family collapsed. His child left. The wife left. Who would have guessed that the bride would leave the home? Three people left this home. She got married and left. She took the baby and left...]" (Participant 9, female, 65 years old). Referring to the crisis of the patients' brain death to family members, a participant commented: "we are dead actually. My mother has lost her eyesight, because she cried a lot" (Participant 6, female, 18 years old). Another participant explained his experiences of his child's cerebral death after two years as follow: "I have grown worse... worse. I act like a maniac. I just wander around and moan" (Participant 4, male, 59 years old).

4.2.4. Post-Mortem Problems

The families stated that numerous problems arose after the patient's death, such as financial and psychology problems. A male participant said: "It was only me, who had to weather the storm, because my siblings are younger than me. Now, I am their supporter. I myself had newly established auto mechanic center and had to somehow deal with all these financial problems" (Participant 7, 23 years old). Another participant shared her experiences following her father's death as follow: "Life has imposed a burden on our mother... I do my best. I was a sophomore university student, but due to problems after my father's death, I had to drop out of university. Thank God. We are getting by, but naturally, my mother is dealing with life's burden. We see her and understand her, but nothing can be done about it. We can perceive from her talks. I mean I do my best, but no matter how hard I try; I will not be able to fulfill my duties and it will not suffice" (Participant 1, male, 26 years old).

4.2.5. Untimely Death

Sudden death had a devastating impact on the bereaved family members, which affected every single aspect of the family and was a massive shock for them. One of the participants said: "Imagine that two young family members pass away during one year. It is hard to tolerate" (Participant 8, male, 33 years old). The untimely death of a family member at adolescence was unbearable and unbelievable for the bereaved family members. One participant stated that the patient's brain death affected the whole family. "I purchased a car for my brother. He died and I was accused of killing him. My youngest sister gave the verdict, as I was a murderer" (participant 4, male, 59 years old).

4.3. Perplexity Factors

The families of patients with brain death fell into a bewildered, perplexed situation, where they lost their ability to make logical decisions. Three subthemes were extracted from this theme as follow: 'hopes and fears', 'bewilderment, and 'seeking to find the reasons of brain death'.

4.3.1. Hopes and fears

The participants were hopeful regarding the recovery of patients, when they saw the patients had vital signs. A participant commented: "... he lied there unconscious for 14 to 15 days. We were told that there would have been hope if he had come around, but if he had not, then... well... we were waiting every single day, every single hour for him to come back to life" (Participant 2, male, 32 years old). Another participant said: "You see his neck vessels? They throb very fast like this, very fast [opening and closing her

fingers into a fist to show the movements of vessels]. I said Dear God! Thank You! Dear God, if he recovers, I will sacrifice a bull! They were telling us that he was coming back" (Participant 5, female, 47 years old).

Upon hearing the brain death diagnosis and becoming sure that their patients would not recover, they became disappointed with their patients' recovery. A participant said: "The ward staff talked to me and told that there was no hope. They wanted our family to have their last visit with the patient and mark it as a farewell, since the life support system was attached to our patient and he was alive just because of the life support" (Participant 1, male, 26 years old). Another participant stated her experiences as follow: "The doctors told me that recovery was unlikely for brain dead patients. Therefore, we lost hope and resorted to God, but this did not work either" (participant 7, male, 23 years old).

4.3.2. Bewilderment

The participants were bewildered after the patient's brain death. A 32-year-old male participant commented: "... First, there was only silence, until we could find ourselves and figure out what had really happened. This happened several months after the brain death of our patient". Another participant shared her experiences as follows: "My younger daughter still seems crazy. Well, all of us have been somehow... She has been acting weirdly. When she enters home, she comes and asks where her brother is. She is uncontrollable. She has injured her head, hurts herself and so on" (Participant 5, female, 47 years old).

4.3.3. Seeking to Find Out About the Reasons of Brain Death

Following brain death, the participants tried to gain information about the causes of brain death. A participant said: "I researched about it, at least to find something about it; I tried to learn about brain death so that I do not get confused and to know what to do in such situations" (Participant 2, male, 32 years old). Another participant, who had no information on cerebral death, explained his experience about seeking to gain awareness on cerebral death as follows: "One of our residents, who works at the cardiovascular surgery ward informed me about the incidence (meaning cerebral death). He is more informed than us, you know. He said that he himself had signed organ donation form so that his organs would be given to other people in case he developed brain death. He said he had the organ donation card. He advised us to do so and donate our patient's organs. I suppose we received 80% of the information from him. Following my brother's death, two or three other people had cerebral death too, none of them recovered" (Participant number 3, male, 23 years). The same participant stated his awareness on cerebral death as follows: "Those who develop cerebral death will not recover.

Therefore, you must donate their organs, the heart, kidneys, and other organs. They will work in other people's bodies. Then you would feel that you brother's heart is throbbing in someone else's body and get some feeling of fraternity and affinity towards that person.

4.4. *The Sling Loops of Defect in Consent for Organ Donation*

Different cultural reasons such as being a rural resident, illiterate, having religious beliefs concerning death and the patient's corpse, and social and individual factors, influenced the families' discontent with organ donation. They were classified to the following five subthemes: 'discontent with organ donation during the critical period', 'wrong beliefs toward organ donation', 'a lack of awareness on brain death', 'a lack of awareness on organ donation', and 'bringing agony to the patient through consenting to organ donation'.

4.4.1. *Discontent With Organ Donation During the Critical Period*

Having heard the diagnosis of brain death and following the crisis, the families were unable to think and decide logically and give consent for organ donation. One of the participants commented: "It was not an ordinary situation for me to think logically. I mean I could not figure out what was going on. I could not concentrate. Under those circumstances I could not even consent for donation so that I could save another person's life through organ donation" (Participant 2, male, 32 years old). Another participant explained his experiences about this critical situation, during the time which the organ donation team was going to bring up the donation subject to his family, as follow: "The doctor did not try to convince me to donate the organs. They could not bring up the subject easily. I left the doctor's office and told my father about the incidence and about the team's suggestion for organ donation. My father got so morose" (Participant 3, male, 23 years old). Another participant also said: "As for the consent with organ donation at that time ... I don't think the answer would be yes, but since after a while I became aware of the significance of donation, I might have conceded with it" (Participant 6, female, 18 years).

4.4.2. *Wrong Beliefs and Unawareness About Organ Donation*

All the participants considered wrong beliefs of the society toward organ donation, as one of the main reasons for their discontent with organ donation. "Another colleague of mine came to me and told 'Mr. N, I heard that you have sold all of the organs.' I was so offended. Suppose that I had donated the organs for the sake of God. The medical team would have cut and stitched his body and people

would have seen his body, while doing ablution, then they would have thought that I had sold his body organs. People would have thought badly about my family" (Participant 8, male, 33 years old). Another participant shared her experience as follow: "Well, the undertaker said that they had washed the body, but they had not seen any stitches or abscissions on his stomach or anywhere. The patient's body was intact. I thought to myself that I had not consented to organ donation and people are gossiping like this. If I had, only God knows what stories they would have told about my family" (Participant 9, female, 65 years old).

4.4.3. *A Lack of Awareness About Brain Death*

One of the reasons of the participants' resistance against organ donation was a lack of information about brain death. A participant stated: "My family members and I knew nothing about brain death" (Participant 5, female, 47 years old). Another one said: "There was no such a thing in our family or among our relatives before. We had no idea about it in our village. There is little information and instruction on the authorities' side" (Participant 2, male, 32 years old). Referring to his lack of awareness about brain death, another participant commented: "I had no idea about brain death; I thought that brain death was treatable. I did not know that there was no hope for recovery. I did not know that brain death meant a real death and the patient was not treatable anymore" (Participant 3, male, 23 years).

4.4.4. *A Lack of Awareness About Organ Donation*

A lack of awareness about organ donation that stemmed from old age and lack of education resulted in discontent with organ donation. A participant said: "... because my grandma is old, she did not consent to organ donation ... then my grandma got sad, of course everyone got sad and she said no, because they are a family of rural origin" (Participant 1, male, 26 years old). Referring to the reason for disagreement with organ donation, another participant also commented: "... they were old and unaware of organ donation" (Participant 7, male, 23 years old). One of the participants explained his unawareness of organ donation and suggested some methods to prepare families to consent for organ donation: "there must be some consultations during brain death for family members. For instance, they should visit patients, who need organ donation, or there must be some instructional programs on TV or Radio so that people know what to do and how to deal with such situations" (Participant 2, male, 32 years old). Then the participant continued to share his experience as follows: "in that situation (meaning cerebral death of the patient) we did not have knowledge and we were not that aware of measures like organ donation

to gain mitzvot and save some other people's lives. I attribute our discontent only to unawareness, lack of information and no consultation on the hospital staff side.

4.4.5. *Bringing Agony to the Patient by Consenting for Organ Donation*

The participants did not give consent to organ donation due to the belief that their patients' body would be chopped off and hurt when their organs would be removed by the medical team. One of the participants said: "This would be like torturing the patient, but I did not know if they would hurt him. They might have conducted autopsy, removed his body parts, or something, and he would have gone to the hereafter like this" (Participant 7, male, 23 years old). Another participant also commented: "... because my child would have been cut apart and I did not want this. His wounds were enough. There was no need to give his heart away and ... they told me to donate his organs and I said no" (Participant 5, female, 47 years old).

4.5. *Compatibility*

The participants that could reach a certain type of compatibility with organ donation were able to tolerate the event and could surmount the problems of life. This theme consisted of two subthemes as 'comprise' and 'surmounting life problems'.

4.5.1. *Comprise*

After the patient's death, the family members developed a certain sort of compatibility. "My mental state has improved a little bit since then. I tried to somehow comprise; both my family and me. We must believe that this incidence was the providence of God (Participant 1, male, 26 years old). Another participant explained his mental state concerning his sister's brain death after two years as follow: "I am much better now. I acquiesce to God's will; Just that. Thank God and I just resort to Him. Nothing can be done (Participant 2, male, 32 years old).

4.5.2. *Surmounting Life Problems*

They also afflicted with the problems after the patients' death. According to the family members' statements, they could gradually overcome such problems. A participant commented: "Other problems still came about after it [brain death], which were overwhelming and I had to overcome them, while our father was gone... since he has gone, I have not had any support, and it is really hard for me to try and figure out how to cope with problems... I have to repair our house and my father is gone. I borrowed money from here and there to hold the funeral. I can cope with financial problems" (Participant 7, male, 23 years old). Another participant shared his experiences of overcoming

life's hardships as follow: "Thank God, I am just getting by. All the burdens of the family is on my mother's shoulders. I perceive it through the way she explains her feelings. I do whatever I can to be of an assistance" (Participant 1, male, 26 years old).

5. Discussion

The findings of the present study indicated that the diagnosis of brain death led to desperate reactions among family members. If appropriate measures are taken to relieve such families' bewilderment, the consent rate for organ donation may increase.

The participants were initially plagued by an overwhelming situation, which created an arduous and stressful circumstance for them. They were shocked since they did not have previous experiences with this incidence. A previous study on factors affecting the decision about organ donation in brain dead patients' families also revealed that they were shocked since this experience was abrupt, unprecedented and sudden (11).

Following the patient's death, manifold problems arose for the family members. A study revealed that after informing families about brain death of the patient, they faced many problems and were unable to think and decide logically (8, 18). Since most brain dead patients in this study had a parental role, following their death, the families were entangled with numerous financial problems and in some cases, this led to family collapse in a way that their spouses married someone else and forgot their previous spouses.

The second issue described by the participants was bewilderment, which happened because they were unaware of brain death and its irreversibility. They hoped that patients would come back and once they did not witness recovery signs, they became disappointed and bewildered. Our findings are supported by those of other studies. A study revealed that families had an unbelievable and paradoxical view of brain death. They resisted to believe their patient's death due to several reasons and were still hopeful for their recovery (11).

Another finding was about the sling loops of defect in consent for organ donation. The subjects stated that a lack of awareness concerning brain death, its irreversibility, as well as organ donation led to their resistance against organ donation. Montazeri et al. also reported that non-donors families did not have previous knowledge and awareness about brain death and most of them had previously not decided on organ donation (11). The research conducted by Kurz indicated misperceptions on brain death and a lack of knowledge concerning this phenomenon, increased families' discontent with organ donation (19). Other studies

also revealed that misconceptions on brain death and a lack of knowledge on this subject was associated with discontent with organ donation (11, 20, 21).

On the other hand, wrong beliefs in the society toward organ donation resulted in discontent with organ donation. Similarly, other studies reported that effective factors preventing organ donation were wrong information about brain death, improper cultural beliefs and the personal characteristics of patients such as their young age (22, 23). However, wrong beliefs such as selling the organs, among relatives and other people prevented the families from agreeing with organ donation. A study revealed that a vast majority of relatives and people suspected that families sold organs or had monetary expectations from organ receiving families (24).

Among the families that did not consent to donate their patients' organs, religious beliefs played a prominent role as well. Some related reasons were the necessity of respect toward the dead and the prohibition against corpus abscission in Islam, and fear of eschatologically physical defects in patients due to organ donation (11).

Finally, following patients' death, as the time elapsed, the families developed a kind of adaptation and relative compatibility with this incidence. After several years, the reminiscence of the incidence brought sorrow and bewilderment to the families in a way that they sought to evade the whole occurrence. Our findings explained the factors leading to the families' discontent with organ donation, which were not explained in previous studies. In general, the participants experienced a major crisis and bewilderment, which had a profound impact on all aspects of their life. They also may resist acceptance of the situation for several years or even forever. Therefore, if assistance is provided for these families, the consent rate of organ donation may increase, and they may better adapt with the crisis.

As for nurse education, courses and workshops on this phenomenon could be held to inform nurses of the crisis of brain death among families and the methods used for increasing the possibility of organ donation. Furthermore, the media could raise public awareness through giving information on brain death and organ donation for reducing wrong beliefs on organ donation, which often act as the most important barrier to organ donation.

Since the death of endeared people and the crisis rising from this incidence could be overwhelming and may affect the survivors' logical thinking and decision-making, some measures have to be taken to promote the organ donation culture. Moreover, the healthcare team should be aware of the crisis rising from brain death and help families adapt with this crisis.

As a limitation of the study, it was impossible to access all family members and collect data regarding their

perspectives. Also, some families were reluctant to share their perspectives and revitalize their painful memories and sorrow arising from this phenomenon. Future studies are needed to collect data about the perspectives of the family members of organ donor patients concerning the crisis of patients' brain death. Such data would be used for devising strategies that alleviate this crisis among family members. Other studies such as the exploration of the emotional needs of patients' families following organ donation and procedures for obtaining consent for organ donation are suggested.

Acknowledgments

The authors would like to express their sincere gratitude to all participants. The results of the present research were extracted from a Masters thesis in nursing supported financially by the Islamic Azad University of Isfahan, Khorasgan Branch (decree number = 493021).

Footnotes

Funding/Support: None declared.

Financial Disclosure: None declared.

References

1. Manuel A, Solberg S, MacDonald S. Organ donation experiences of family members. *Nephrol Nurs J.* 2010;**37**(3):229-36. [PubMed: 20629462].
2. Verheijde JL, Rady MY, McGregor JL. Brain death, states of impaired consciousness, and physician-assisted death for end-of-life organ donation and transplantation. *Med Health Care Philos.* 2009;**12**(4):409-21. doi: 10.1007/s11019-009-9204-0. [PubMed: 19437141].
3. Miller RD, Eriksson LI, Fleisher LA, Wiener-Kronish JP, Cohen NH, Young WL. Miller's anesthesia. Elsevier Health Sciences; 2014.
4. Goila AK, Pawar M. The diagnosis of brain death. *Indian J Crit Care Med.* 2009;**13**(1):7-11. doi: 10.4103/0972-5229.53108. [PubMed: 19881172].
5. Manzari ZS, Mohammadi E, Heidari A, Aghamohammadian Sherbaf H, Modabber Azizi MJ, Khaleghi E. Experiencing brain death diagnosis by patients' family members and organ donation: a qualitative study. *Iran J Med Ethics History Med.* 2011;**4**(6):63-74.
6. Khoddami Vishteh HR, Ghorbani F, Ghobadi O, Shafaghi S, Barbati M, Rostami Louyeh A, et al. Causes and follow-up outcomes of brain dead patients in Shahid Beheshti University of Medical Sciences hospitals [in Persian]. *Pejouhandeh.* 2010;**15**(4):Pe171-8.
7. Long T, Sque M, Addington-Hall J. Conflict rationalisation: how family members cope with a diagnosis of brain stem death. *Soc Sci Med.* 2008;**67**(2):253-61. doi: 10.1016/j.socscimed.2008.03.039. [PubMed: 18442874].
8. Stone JT, Wyman JF, Salisbury SA. Clinical gerontological nursing a guide to advanced practice. Philadelphia: WB saunders company; 1999.
9. Bosnell R, Madder H. Concepts of brain death. *Surgery.* 2011;**29**(7):289-94.
10. Niazi M, Shirazi M. The role of social and cultural factors in organ donation among citizens Kashan. *J Contemp Sociol.* 2010;**2**(2):51-83.

11. Montazeri ZS, Mohammadi E, Heydari A. Factors affecting the decision about organ donation in brain dead patients' families: a qualitative study [in Persian]. *J Payesh*. 2011;**11**(6):913-26.
12. Goh AY, Mok Q. Clinical course and determination of brainstem death in a children's hospital. *Acta Paediatr*. 2004;**93**(1):47-52. [PubMed: [14989439](#)].
13. Polit DF, Beck CT. Nursing research: Generating and assessing evidence for nursing practice. Lippincott Williams & Wilkins; 2008.
14. Holloway I, Wheeler S. Qualitative research in nursing and healthcare. John Wiley & Sons; 2013.
15. Speziale HS, Streubert HJ, Carpenter DR. Qualitative research in nursing: Advancing the humanistic imperative. Lippincott Williams & Wilkins; 2011.
16. Polit DF, Beck CT. Essentials of nursing research: Appraising evidence for nursing practice. Lippincott Williams & Wilkins; 2013.
17. LoBiondo-Wood G, Haber J, Berry C, Yost J. Study Guide for Nursing Research: Methods and Critical Appraisal for Evidence-based Practice. Elsevier Health Sciences; 2013.
18. Rantanen A, Kaunonen M, Astedt-Kurki P, Tarkka MT. Coronary artery bypass grafting: social support for patients and their significant others. *J Clin Nurs*. 2004;**13**(2):158-66. [PubMed: [14723667](#)].
19. Kurz RS, Scharff DP, Terry T, Alexander S, Waterman A. Factors influencing organ donation decisions by African Americans: a review of the literature. *Med Care Res Rev*. 2007;**64**(5):475-517. doi: [10.1177/1077558707304644](#). [PubMed: [17881619](#)].
20. Naghneh M, Taghvaei D, Kashefi P, Dastani-Hoseynabadi A. Factors affecting family's consent in brain-death candidates for organ donation. *J Isfahan Med Sch*. 2015;**33**(344):1233-8.
21. Quick BL, Lavoie NR, Scott AM, Bosch D, Morgan SE. Perceptions about organ donation among African American, Hispanic, and white high school students. *Qual Health Res*. 2012;**22**(7):921-33. doi: [10.1177/1049732312439631](#). [PubMed: [22395297](#)].
22. West R, Burr G. Why families deny consent to organ donation. *Aust Crit Care*. 2002;**15**(1):27-32. [PubMed: [11979987](#)].
23. Lawson AD. Presumed consent for organ donation in the United Kingdom. *J Intens Care Soc*. 2008;**9**(2):116-7.
24. 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**(3):323-30. [PubMed: [24949074](#)].