Original Article

Reluctance to organ donation in Iran's brain-dead families: a case study of Shiraz city

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Abstract

Background: In Iran, a large number of people in need of organ transplants die every year and many families are not willing to donate organs. The question is here why do such families refuse to donate deceased brain-dead organ(s)?

Method: This study was carried out using grounded theory. The research population was 23 individuals who refused to donate organs and dwelled in Shiraz City which they have selected by snowball sampling.

Results: Some reasons behind their decisions: traditionalism, non-cognizance of brain-dead individuals, normative pressure, trust, religious beliefs, patriarchal attitudes, significant others, disbelief in the death of a loved one, hope of recovery, compassion for the one's patient and inability to make decisions

Conclusion: Results showed that cultural and social barriers factors play pivotal roles in not donating deceased brain-dead organs. In this way, medical advances in organ transplantation can only be useful if the factors mentioned are soundly discussed.

Keywords: Brain Death; Grounded Theory; Iran; Organ Transplantation.

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Introduction

Organ transplantation in today's modem world has brought many people to better health condition and saved many families from worry and hardship. Data from the Global Observatory of Donation and Transplantation in 2018 disclosed 140,964 organ transplants worldwide(1).

Transplantation is seen as a kind of gift of life (2); that is associated with many challenges for society and the medical community regarding moral values and social complexities (3). One of the most important issues in this regard is organ shortage, which indicates the gap between the number of brain-dead individuals and the list of people waiting for their organ. Regarding the amount of organ donation, different countries have different status and scenarios, for instance, in Wales (constituent unit of the United Kingdom) organ donation rate reported to be 48.5 to 53.6%, but in Spain the rate has been 80 to 85% over the same period of 2013 to 2015 (4). However, in other countries, especially in Asian countries, donation rate has been much lower. Reports have shown that in Iran in 2009, out of every 25,000 in-need

individuals of a waiting list, one individual has died every two, three hours. In the same year, out of 2,000 donors who could donate, 7,230 transplantable organs were buried. This trend has caused the number of donations per million population (PMP) per year index in Iran, to be 14.3, while in a country like Spain, the PMP index has been 49.6 (5). In Iran, a large number of people die every year due to car accidents and work accidents and the deceased brain-dead organs are not generally donated. According to available reports, the main important reason for non-donation is the objection of the deceased families (6). This issue has not been not specific to Iran and can be seen in other countries (7–9). Research has shown that refrying from organ donation has less to do with medical condition. Rather, it goes back deeply in social and cultural conditions. World-wide researches on organ donation shown that many families are reluctant to donate (10–12) due to many factors, including relatives' beliefs about the deceased's wishes concerning donation(13), lack of awareness and knowledge; especially the inability to diagnose the difference between coma and brain-dead condition (14–16); religious believes(17–20); social values and taboos of death; values and norms about respect for the corpse and death-related rituals (3,6,21,22), social trust in general, trust in the people and the health system; trust in nurses and physicians and transplant staff (19,22), and conditions of organ request(23). Thus, it is necessary to pay more attention to the interaction of medical technologies with social and cultural conditions (7,8,18). Considering the above arguments, this study was undertaken to shed more light on why deceased brain-dead Iranian families don't actively patriciate in organ donation. Given high level of having deceased brain-dead individuals in Iran, the results of this study can help many other Iran – like conditions in terms of how to tackle this social and demographic patterns of health-related issue.

Methods

Given that decision-making regarding organ donation from brain-dead patients is a very complex issue and largely deals with the inner intentions of human beings, it must certainly be studied in its natural environment. Moreover, the lack of a specialized theory in the organ donation field, the necessity of specifying the various dimensions of this phenomenon, and identifying the causal, contextual, and intervening factors, it has generally forced researchers to adhere to the qualitative method e.g. grounded theory strategy. The participants in this research were 23 people. The sampling method will be explained shortly latter. After obtaining the necessary ethical code from Shiraz University of Medical Sciences, given the lack of cooperation from the relevant authorities to introduce families who have not agreed to organ donation, in the first step, the target families were identified through snowball sampling. In this way, after identifying the first family and interviewing them, they were asked to introduce another family they knew. At this stage, seven families were identified.

In the next stage, we tried to gain their trust by having a conversation with each family and convince them to participate in the interview. In this step, we explained the research rules, as well as the ethical principles governing this research, such as maintaining the anonymity of the interviewees, not disclosing the information and content of the interview, and the interviewee's right to withdraw at any stage of the research. In the next stage, the snowball sampling was used within each family. In other words, we asked the interviewees to introduce another person who played a key role in the decision not to donate an organ. The sampling process continued until the theoretical saturation was reached. Due to the research field, the members of a family were in one cluster. so we tried to purposefully interview the key decision-makers with the maximum

diversity based on criteria such as age, gender, education level, and the person's status within the family. Additionally, to prevent overlapping responses, individual interviews were conducted with each of the interviewees. At the end, we interviewed a total of 23 key decision-makers.

After each interview, the task of analysis was performed through the open, axial, and selective coding process of the collected data. The place of the interview was chosen based on the interviewers' suggestions. Since not all interviewees allowed us to record their audio or video, we were to take transcripts during the interview. Each interview lasted between 60 and 90 minutes. Research data were analyzed using MAXQDA software.

Results

A total of 7 brain-dead individuals were used in this study, including 3 females and 4 males.

More than half of the respondents were illiterate or had elementary education. Only 17% had a bachelor's degree. Through the analysis of the interview, 213 initial codes were extracted. Then, in the axial coding stage, 22 axial codes were identified which we will explain below, taking into account the conceptual and semantic similarity of the original codes. Also, it turns out that around a third of the decision-makers were women, though, it was generally men who were the decision-makers.

Contextual conditions

The conceptual and semantic similarities of the initial codes pointed to the contextual conditions for reluctance to donate organs as a condition that already existed and may present in different people. Traditionalism and traditional thinking were frequently

Table 1 Participant Characteristics

Code	Interviewee	age	Marital status	Education	Brain dead patient
1	Father	50	Married	Bachelor	First brain-dead 24, female Single Bachelor
2	Mother	49	Married	Bachelor	
3	Brother	23	Single	Bachelor	
4	Uncle	52	Married	Diploma	
5	Father	66	Married	Associate Degree	Second brain-dead 49, female married Associate degree
6	Sister	40	Married	Diploma	
7	Brother	28	Single	Elementary	
8	Father	58	Married	Associate Degree	Third brain-dead 28, male married bachelor
9	Brother	40	Married	Diploma	
10	Wife	28	Married	Elementary	
11	Grandpa	65	Married	Diploma	Fourth brain-dead 20, male Single Diploma
12	Father	40	Married	bachelor	
13	Mother	35	Married	Diploma	
14	Mother	47	Married	Elementary	Fifth brain-dead 20, female, Married, Diploma
15	Father	50	Married	Junior high school	
16	Girl	21	Single	Diploma	Sixth brain-dead 42, male, Married Diploma
17	Father	70	Married	Elementary	
18	Son	18	Single	Junior high school	
19	Wife	41	Married	Illiterate	
20	Sister	52	Married	Elementary	Seventh brain-dead 43, male Married Junior high school
21	Father	48	Married	Elementary	
22	Son	75	Married	Illiterate	
23	Wife	43	Married	Elementary	

seen in the statements and behaviors of the respondents, or rather, the respondents justified the decision not to donate an organ through the channel of traditions. One of the examples of traditionalism can be seen in the lack of attention to innovation and support for new methods. Respondent code 14 pointed:

"It used to be good that there was no such thing. The dead had more respect then".

The existence of patriarchal views and the traditional status of men were effective in making decisions in this case. Respondent code 1 pointed:

"His uncle decided not to donate. No one can say anything more. After all, he is an uncle, and his respect is everyone's duty".

Life in the world of traditions is associated with collectivism and the fear of being judged and rejected by others. Thus, normative pressure is felt by everybody. Respondent code 18 told us:

"If we donated an organ of my father, in the city, our families would destroy us with their eyes, and they would all reject and cut off their association with us".

Also in the traditional world, there is a traditional interpretation of religion that the whole body has a special place and belief in the bodily resurrection is so important that it prevents the removal of organs from the body of individuals. Respondent code 20 pointed out:

"We did not want to see our brother live in that world without the heart and kidney".

Poor knowledge of brain-dead meaning and lack of information in this area has an important influence on decision-making; when a doctor announces that a patient is brain-dead, some families do not accept or doubt the quality of the doctor. Respondent code 13 pointed:

"There was someone who was in a coma for 8 years, after 8 years he regained consciousness and now I realize that coma is not brain --death".

Intervening conditions

Intervention conditions are conditions that intensify the orientation towards non-donation of organs. It can be temporal and spatial situations or the reaction and intervention of others. According to interviewee code 6:

"A large number of people had already come out of the hospital to ask for organ donation, and a hell had been set up. Thinking of the scene now, my hands and feet are trembling. I don't want to see that scene at all".

According to the interviews, significant others, that is, people who are considered important to decision-makers, are influential in the bereaved family's unwillingness to donate organs. According to the respondents, the elders of the family created obstacles and tried to persuade families not to donate. Interviewee code 14 said:

"The elders of the family, whose words are very important to us, said that you should not donate".

Technical errors or dissatisfaction with general medical diagnosis has been a reason for worry about organ donation, especially when decision-makers saw doctors

disagreeing. Some decision-makers also expressed distrust of the hospitals over the uncertainty of the purpose of organ donation. According to respondent code 15:

"It is hard to trust hospitals and their employees. The hospital collects money by selling my son's organs".

According to respondent code 14:

"We would love to help individuals, but hospital staffs do it for their individuals, and if they do not sell to friends and relatives".

The interviewees' decisions not to donate organs were influenced by their awareness of the deceased patient's views on organ donation, either through direct statements made by the patient or the decision-makers understanding of the patient's position on the matter. Bereaved family member code 3 said:

"My sister cared about the beauty of her body. She cared a lot about the beauty of her face. We did not touch my sister's eyes and face".

Decision-makers may sometimes perceive their responsibility towards the patient as the patient's own choice. This mindset is often observed in families who have failed to provide support to brain-dead individuals during difficult times, or when brain death coincided with feelings of rejection and hopelessness.

Causal conditions

These causal categories include events that directly lead to the occurrence or growth of a phenomenon (Corbin & Strauss, 1998). Disbelief in death, inability to diagnose coma from brain death, and inability to accept the death of a patient with a heartbeat and breath are very effective in this regard. Respondent code 17 notes:

"My son was still breathing; he was still alive. I did not want anyone to touch his body. The doctor was lying".

Also, it was seen that some had hope of a miracle that will lead to the patient's return and recovery or to find a medicine that can help in this regard. Respondent code 10 notes:

"I heard that the deceased came back to life in the morgue, and I was still waiting for the last moment. Maybe my wife too".

Also, the belief in the necessity of the fullness of the corpse and the prevention of intentional removal of the corpse were other factors in this regard. Inefficiency and inability to make decisions, especially when the decision-maker was faced with a huge amount of different emotions, was another factor that interviewees pointed out.

Action strategy

The actions and behaviors that a person shows when confronted with this phenomenon are called action strategies. Decision-makers experienced a range of passivity to pragmatism and reacted in different ways. Some reported strong emotional feelings such as fear or shock, while others were more active in using actions such as verbal and physical assault to force them to leave the place. Respondents code 11 said:

"When they said that the transplant team wanted to come from the hospital, we all closed the door together and all the mourners did not even answer the phone".

Respondents code 22 noted:

"When the doctor said to donate, losing my control, I assaulted and pushed him away".

Some, who were skeptical, sought information from sources such as the Internet, books, friends and colleagues. Others resorted to the supernatural, such as referring to prayer writers and fortune tellers and occult, religious practices, such as going to shrines, praying, appealing to the saints, and making vows as a strategy of action.

Consequences

The consequences here refer to the decision not to donate an organ by the decision-maker and the family of the deceased brain-dead. Some of these consequences were positive and some are negative. The main themes obtained in this section can be divided into two broad categories: personal and family consequences. Some psychological consequences were reported in the personal and family arena: the feeling of having negative effect on others, being indifference to fellow human beings, feeling depressed, Nihilism, losing of calm within the family, feeling tired and restless, frustration in personal life and being cold-hearted about social interactions, to name a few. Some interviewees also pointed out to behavioral consequences, such as not attending rituals, not going to the cemetery alone, and mourning. Mainly, in the behavioral dimension, there was a tendency for isolation among decision-makers. Respondent code 1 said:

"The younger brother lived like crazy, and his mother did not become normal even a year later; she was receiving treatment and did not participate in any rituals".

It should be noted that not all consequences necessarily hurt individuals and families. For example, some decision-makers were proud of their decisions their action increased emotional attachment and family cohesion. Respondent code 20 said:

"I didn't allow my child to be torn to pieces. I feel good. What do these doctors say? I thank God, I was not wrong at the time. All families respect us because we were able to maintain the dignity of our family".

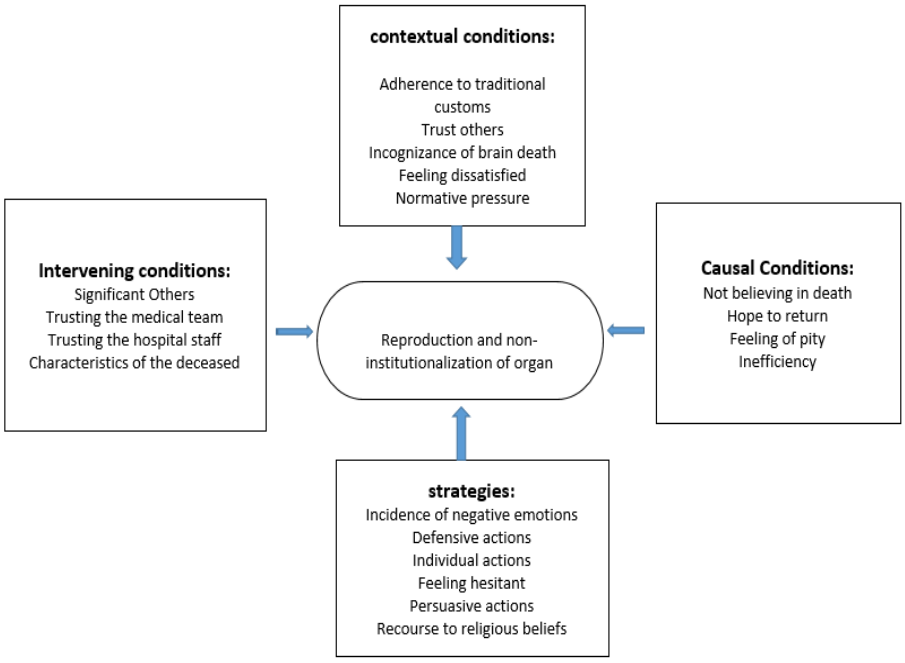

Figure 1 Paradigm model of respondents refusing organ donation in this study.

In general, the phenomenon resulting from the interaction of the conditions described in the previous lines indicated the reproduction of the non-institutionalization of the culture of organ donation. This means even though some abjections arose during the decision-making process, however, these abjections did not have enough power to cast doubt on the decision-maker's will, in a way that many of them may have been proud of their decisions and actions. In other words, they consider this decision as a way to maintain cohesion and honor for their family.

Discussion

The aim of this study was to explore the reasons for not donating organs in deceased brain-dead families in Shiraz City, Iran, by adopting qualitative method e.g. grounded theory. In general, the findings of this study showed that the reluctance to donate organs of deceased individual was not only a medical issue but also social and cultural factors play a big role. Therefore, there is an urgent need to pay attention to and address the relationship between medical technologies with social and cultural factors. This finding of the present study was consistent with many other studies (4,7,8,18). According to the analysis conducted in this study, and by the views of sociologists and social psychologists, it was determined that the decision not to donate organs from deceased individuals was influenced by social conditions and circumstances, in addition to being a personal choice, with both subjective and objective effects. The analysis of the interviews showed that some personal factors such as non-cognizance of brain death and lack of sufficient information or incorrect information about organ donation have been effective factors among decision-makers. This result has been confirmed in many previous studies(15). The possibility of miracles leading to the patient's return and recovery, or obtaining drugs that can help in this area, was another factor that prevents organ donation on a rational level(22). The belief in the necessity of the corpse being perfect and the feeling of compassion for the patient and the protection of his body, although seemingly personal and psychological, is rooted in people's traditional thoughts. This has been confirmed in many studies(6,21,22).

The most common factor paving the way for non-organ donation is the spirit of traditionalism and collectivism. People were worried about organ donation because it strongly affected them. Regarding the evaluation of others, they may look at others in a negative light. Numerous social psychology theories have illustrated how groups can impact individuals, as well as how individuals often make decisions based on the influence of others. Especially in this field, the role of clergy and religious organizations is obvious. These individuals and organizations can be very effective by providing information about organ donation and promoting it among the population. Many studies have shown that the negative impact of the growing distrust in Iranian society has led to the loss of the moral virtues of organ donation on the one hand, and concerns about possible rumors about the sale of the organs of brain-dead patients on the other. Personal mistrust in related organizations and individuals minimizes the context of organ transplantation(19,22). Based on the findings of this study, it seems that creating or increasing the level of general and inclusive trust among people as well as the health system is one of the most important prerequisites for promoting organ donation. In this study, some decision-makers referred to the timing and location of the proposal, which was raised during the instability of the family mood, and that those conditions influenced the decision as not to donate. The research of the victim and his colleagues also shows that families should take the necessary measures to prepare people for organ donation to a time long before brain death(22). According to social psychology theories, one could argue that to promote organ donation as a

behavior, efforts should be made to alter the attitudes of individuals across different sectors, thereby fostering a culture of organ donation within society. Changing the cognitive and emotional dimensions of attitudes can be done by giving the right cognitive information to members of the community in general and not just when confronting a brain-dead patient to eliminate a lot of ignorance or misinformation. Increasing awareness can be very effective in using the capacity of important others (McGlade & Pierscionek, 2013). Stimulating people's feelings and emotions and reminding the moral and human aspects of organ donation would be an important stimulus to promote this action. However, since cognition and emotions do not necessarily lead to action, according to later social psychologists, people can change their attitudes and emotions by adhering to behaviors. For example, special programs can persuade people to donate organs voluntarily, while obtaining a driver's license or applying for employment.

In this study, it was concluded that the patriarchal view was very decisive in whether deceased dead-brain families undertake organ donation or not in Shiraz City. We genially expect that with the entry of women into this field of family decision-making, the process of institutionalized organ donation and saving the lives of patients will be elaborated in times to come.

Conclusion

Results showed that cultural and social barriers factors played pivotal roles in not donating brain-dead organs. Some of them were social conditions and situations, lack of sufficient information or incorrect information, miracles leading to the patient's return and recovery, or obtaining drugs, traditional thoughts about corpse perfection, normative pressure, religious beliefs incompatible with organ donation, organizational mistrust, and significant others. In the end, considering the women's presence in society and the weakening of patriarchal views, we can hope that the level of organ donation will increase in the future. In this way, medical advances in organ transplantation can only be useful if factors mentioned above are soundly discussed.

Ethical Considertions

This research was conducted under the supervision of Shira University of Medical Sciences ethics , with ID code: IR.SUMS.REC.1399.1120

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Authors' contributions

Beheshty and Moradi developed the study concept and design. nouzari acquired the data. Beheshty and nouzari analysed and interpreted the data. Beheshty wrote the article. Beheshty and nouzari contributed to the discussion Beheshty and Moradi provided administrative support.

Conflict of interest

The authors declared no conflict of interest.

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