Exploring families’ experiences of an organ donation request after brain death

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Abstract
This qualitative research study with a content analysis approach aimed to explore families’ experiences of an organ donation request after brain death. Data were collected through 38 unstructured and in-depth interviews with 14 consenting families and 12 who declined to donate organs. A purposeful sampling process began in October 2009 and ended in October 2010. Data analysis reached 10 categories and two major themes were listed as: 1) serenity in eternal freedom; and 2) resentful grief. The central themes were peace and honor versus doubt and regret. The findings indicated that the families faced with an organ donation request of a brain-dead loved one experienced a lasting effect long after the patient’s demise regardless of their decision to donate or refusal to donate. In conclusion, this study highlights the importance of family support and follow-up in an efficient healthcare system aimed at developing trust with the families and providing comfort during and after the final decision.

Keywords
Brain dead, families experiences, organ donation, organ request, qualitative content analysis

Introduction
Sudden and unexpected death is identified as one of life’s most stressful experiences and, in such a complex situation, request for organ donation can be very difficult and traumatic. After a patient’s demise, survivors feel overwhelmed with grief and cannot make such a profound decision as to donate an organ. Despite the advances in research on decision-making processes for organ donation, relatively few studies...
have examined the psychological consequences of the decision to donate organs. Most studies have focused on stress, coping, and the needs of organ recipients and their families. There has been less emphasis on the donors’ families and how they survive their emotional trauma. Moreover, most of the research studies that address the relatives of potential donors, mainly focus on consent issues when families decide on organ donation, and bypass the psychological aspects of organ donation for the surviving family members. In fact, few studies have offered insight into the family conditions following donation request and how consenting families or those who declined a donation request have managed their lives positively faced with the potential conflict for refusing to donate.

Researchers reported that dissonance, conflict and anxiety are the outcomes of decision making for organ donation. The decision-making process has been described as an experience revolving around conflict and resolution according to the Theory of Dissonant Loss. Researchers from Switzerland have demonstrated that the long and traumatic memories of grieving relatives are influenced by the features of their decisions (transparency versus uncertainty) and the interaction quality of the care team with family members. These findings indicate that the essence of family experiences includes some degree of uncertainty and ambiguity, but their perception and beliefs are background dependant. Certainly, for better understanding of an intense situation, the nature of a traumatic event on the mental state of the family and the interaction and dynamic process of organ donation should be comprehensively examined. Obtaining more information on this phenomenon can help facilitate the presentation of professional opinions on how to better care for the patients and their family members, and could also help them overcome their grief easier following the patient’s demise.

Despite earlier passing of the regulatory bills on organ donation and transplant in Iran, public acceptance has not been reached. Organ donation rate in Iran is lower than many countries per global figures, perhaps due to newness and an uninformed public. Since the impact of organ donation on Iranian families has not been previously investigated, this qualitative study examined the issue and its cultural framework with the aim of discovering the family of a brain-dead patient’s experiences when faced with a request for organ donation.

**Methodology**

Content analysis method was used to discover the experiences of the family of brain-dead patients when deciding in favour of or against organ donation. This qualitative approach is an appropriate selection for exploring daily experiences of human emotions and feelings.

**The samples**

Participants in the study were 14 families of brain-dead patients who were candidates for organ donation and consented to donate organs. Families were recruited at the onset and three months after the patient had died. In addition, 12 families who declined to donate organ were recruited at the onset and at least six months after their patient had died.

The brain-dead patients were six females and 18 males ages 12–52. Reasons for brain death state were: accidents (19 cases); convulsion (1 case); subarachnoid hemorrhage (3 cases); and unknown (1 case). Time passed for families who consented to donate was 3–15 months, while for families who declined to donate it was 6–18 months. Thirty-five participants took part in the study. This included 11 couples (parents of unmarried patients), one sister, and three brothers. In the case of married brain-dead patients (9 cases), their wives and children were interviewed. In three cases parents and also two brothers were interviewed. The interview location was chosen by participants who mostly preferred their own homes. A purposive sampling included families who had already witnessed brain death and organ donation and
were willing to retell their experiences. The sampling process began in July 2008 and ended in December 2010. Accordingly, 24 unstructured, face-to-face in-depth interviews using open-ended questions were conducted. Fourteen informal interviews brought the total interviews to 38 in addition to field notes. Each interview variably lasted about 1–3 hours. The researcher listened to participants’ descriptive recollections of their experiences and offered encouragement to speak freely on all related subjects. The researcher was committed to maintaining the state of ‘openness’ contrary to what was constantly enforced among family members.

The researcher avoided filtering data through presuppositions and presumptions. Active listening and discovering the real intent of the participants in their living environment helped in understanding how participants dealt with the issue or solved their problem. The researcher started with open and general questions such as ‘could you please tell me how your beloved had an accident?’ And based on the answers given by the participants, the researcher gradually helped move to the experience of organ donation by probing questions like ‘please explain more’ or ‘what do you mean by . . .?’ or ‘could you describe an instance which would help me better understand the details of your experiences?’ As the study progressed, the interviews were directed by the subsequent questions and the researcher directed his/her questions based on a specific category. The sampling continued until data saturation was achieved or until no new codes were derived in the three final interviews and all the conceptual levels were completed.

Data analysis

Content analysis approach was used to analyse data after each interview. The recorded interviews were immediately transcribed for stated comments and nonverbal gestures such as crying, shedding tears, smiling, sighing, remaining silent and so on. The text of the interviews were read and reread multiple times. Data were transformed into units of meanings in the format of related statements. The units of meanings were also reviewed several times and then encoded. Later, codes were categorized according to the meaning or content similarities to be minimized and compacted as much as possible. This trend continued throughout the analysis units until the main and sub-categories emerged.

Finally, data were categorized by common patterns and content meanings as themes were identified (Table 1). Necessary modifications were made to find content and category titles. The analysis process was repeated by adding each interview and modifying categories. Irrelevant expressions were deleted from the interviews. Memo writing by the researcher was a key factor for recording the insights to facilitate data analysis. At each interview or field observation, data were compiled and memos were prepared.

Ethical considerations

The Institutional Review Board (IRB) granted permission to conduct research according to the ethics committee review at the medical research office of Tarbiaat-e Modaress University through a formal presentation of the research proposal. Later, a written consent form was devised to state voluntary participation in interviews. An informed consent form was signed by each participant after being clearly briefed on the research goals and purposes. Participants were also informed that interviews would be tape recorded. Families were assured that their conversations would be kept confidential and their anonymity preserved. Since the researcher was interviewing family members in mourning, and anticipated emotional tension, participants were advised that should they experience emotional distress they could have access to a counsellor.
Data credibility

For data efficacy and credibility, an attempt was made to review and modify interview focus per units of analysis while extracting implications through supplementary views and suggestions given by each participant. In addition, two qualitative research experts supervised and evaluated the entire data gathering process. Furthermore, confirmability, credibility, and transferability of data were enhanced by triangulation method using interviews and field notes along with maximum variance sampling in which there were interviews with people at various ages, genders, social status, education, and their relation to the deceased. Other factors that increased the credibility of the research were the allocation of sufficient time to the study and forming an open and empathetic relationship with the participants in such a way that some of them indicated that for the first time they had an opportunity to express their hidden worries and find some emotional relief.

The findings

Content analysis of data from interviews and field notes generated 272 codes, 10 categories, and two themes. Themes were: 1) serenity in eternal freedom; and 2) resentful grief (Table 2).

Theme 1: Serenity in eternal freedom

As the main theme among different classes, serenity in eternal freedom represented desirable and pleasant experiences of families after organ donation. Family members expressed feelings of ‘peace and calm to manage grief’, ‘comforting feedback’, ‘improved knowledge, attitude and persuasion toward organ donation’.
Peace and calm to manage grief. Consenting families experienced peace and calm at the funeral for donating rather than burying patient’s organs. Despite feeling grief over their loss, they expressed subsiding sadness and emotional turmoil once the decision for donation was made, which decreased further after the burial. Thus, consenting to donate was perceived as effective in reducing psychological problems after the funeral, as consenting participant (No. 5) stated:

During the burial, we were the only calm persons. At that moment, God really gave us comfort and peace of mind. I said maybe our calm was related to donating the organs . . . I really meant it . . .

Families pointed to the positive and consoling impact of organ donation on coping with grief and loss. Their consent for donation had given them more relief to manage their loss. Furthermore, some of the families believed that organ donation had relieved their suffering and helped them regain normalcy and get back to work quickly. Two consenting family members remarked:

I feel the donation has made it possible for me to tolerable the loss easier. Maybe it is a source of comfort or solace . . . (No. 10)

I found strange solace after the donation. I got back to work so promptly that all my colleagues were surprised . . . (No. 5)

Comforting feedback. All of the families, without exception, received comforting and encouraging feedback from others for their decision to donate organs. They expressed feelings that their decision to donate was valuable and acceptable in generating positive feedback and praise from everyone. It made them happy, proud of themselves and pleased at being useful to humanity. A consenting participant recalled:

Whenever others praised me, I thought to myself what I did was great. It was really worthwhile and pleasing . . . (No. 6)
Improved knowledge, attitude and persuasion toward organ donation. All of the consenting families agreed that other family members had a positive attitude towards donation after it was carried out. Donation had a positive influence on the immediate and distant family members as their attitudes changed as stated below:

My opinion about donation has positively changed. I have even registered as a donor and picked up my donation card . . . (No. 13)

Some families reported that they not only signed an organ donation card for themselves, but encouraged others to do so. This had encouraged people around them to sign an organ donation card while living and well. A sense of pride at showing kindness to others dominated the expressions. As a participant mentioned:

My family members and friends have urged their parents’ permission to become an organ donor in case this happened to them . . . (No. 8)

All families expressed that they were willing to donate their organs if something happened to them as stated below:

Let me say that I will do it again if it happened to my other children . . . (No. 2)

Closeness to God and being favoured by Him. One of the experiences reported by most families was spiritual achievement, in the sense of a deeper relationship with God and closeness to Him. They believed donation was a gift for them and for the deceased. They thought that because of the donation, the deceased was under the spiritual and divine protection of God in the Hereafter and they were in the same situation for consenting to donate. They also interpreted the donation process as a divine assessment of their faith and felt proud for consenting to donate as stated below:

Recently we had a serious accident. Although it was terrible, nobody was hurt . . . All family members even those who had disagreed with donation came to believe that we were protected from harm for consenting to donate organ . . . (No. 4)

Spiritual and emotional presence and connection with the deceased. Some families experienced the feeling that the donor was still alive and present everywhere. They believed their emotional and mental relationship with him/her was still continuing after his/her demise. They perceived that their family member was more alive after donation compared to being in a brain-dead state. Satisfied and pleased, family members shared the following sentiment:

I can still feel his presence . . . maybe because I know some organs of his body are alive in other bodies . . . they are alive and they can breathe . . . (No. 9)

Among the donated organs, the heart was particularly important to the families; therefore, most of them felt good the deceased’s donated heart was still beating and alive following heart donation. For them, it was a symbol of his/her presence. As commented here:

I really like the boy whose heart is actually my son’s heart . . . I can smell my son. I have a special relationship with him and feel my son in his presence more than anywhere else . . . (No. 13)

Effective interaction with the recipients and the importance of successful transplant. Most of the families were inclined to meet with the recipients, because they enjoyed seeing them in good health and sensing the presence of the deceased – despite the stated reluctance to meet them while consenting to donate. As one participant declared:
Well, it is certainly pleasurable to see someone who has recovered to a healthy life, although I am not claiming credit or saying that we did it . . . (No. 3)

However, some of the families urged not to be introduced to the recipients for personal reasons and found it difficult to meet the recipient family. Other families were unhappy because the recipients did not contact them. For example, as expressed here:

I want to see them, but if we go to see them, they may think that we are regretful about the donation . . . If they wanted to meet us, they could call us . . . (No. 6)

An important finding of this study was family concerns about the process efficiency of transplantation after donation. Families felt maximum satisfaction and pleasure could be obtained if they were informed that the transplant was successful and the recipient was well. As stated below:

It was important for me to know and be sure that the transplant had been successful. Although the operation results were not related to us, my mind was always busy with the result . . . (No. 14)

**Theme 2: Resentful grief**

This theme detailed two sides of family reactions for declining to donate after the patient’s death: experiencing regret, sorrow, attitude change and dissonance for the decision made; and feeling no regret and content with the decision. The experiences of consenting families who have disturbed memories from viewing the body after organ harvesting, and families receiving negative feedback and having doubts after death, are also explored. The main theme derived from family reactions was the feeling of resentful grief in families who consented and declined donation. This theme extracted five main classes including: ‘devastation after viewing the harvested body’, ‘the effects of negative feedback by others’, ‘feeling sorrowful regret versus contentment’, ‘change in perspective and attitude after the patient’s death’ and ‘doubts and dissonance in decision making’.

**Devastation after viewing the harvested body.** The anguish and sorrow of some families who agreed with donation intensified after they viewed the body of the deceased and on seeing the physical changes to the body. They were unhappy and worried that their decision to donate disturbed the deceased. As stated here:

I wanted to see him for the last time, but they didn’t allow me. When I found out that it was for the eye surgery, I felt I had annoyed him . . . (No. 14)

**Feeling sorrowful regret contentment.** Despite all the difficulties and problems, none of the consenting families had regrets about their deliberate decision. As a participant expressed:

It was very difficult for me, but generally speaking, I am satisfied with my decision and I thank God . . . (No. 11)

However, some of the families who did not agree to donate organs later felt regretful about their decisions. They felt remorseful because they had not used the opportunity to save another life and to do something with spiritual reward. They wished to go back in time and change their decision. They admitted that if it happened again, they would consent to donate. For example, as mentioned here:

I wish I could go back in time and agree with the donation . . . (No. 2)

In contrast, more than half of the families who disagreed with donation believed that their decision was right and felt no regret. As a non-consenting participant shared:
I feel no regret. My decision was quite right and logical. If I’m going to decide a hundred times, I’ll do the same . . . (No. 9)

The effects of negative feedbacks by others. Most of the families who agreed to donate had to encounter negative feedback by others. There were hints at a mother’s cruelty who had agreed to donate or let her child’s body be cut into pieces and sold. A consenting participant shared:

They accused me of selling my child in exchange of money . . . (No. 7)

Such feedback caused distress, demoralization and regret for all family members. Some of them experienced feelings of guilt and shame as stated below:

I thought maybe I was wrong . . . (No. 11)
I felt guilty . . . (Nos 7 & 13)

Participants stressed that compared to positive feedback the negatives had hurt the feelings of and demoralized families. As mentioned here:

Honestly speaking, many people praised me but I can just remember one who blamed me . . . (No. 6)

However, the negative feedback did not cause feelings of guilt and blame in families who were fully informed about the nature of brain death. For example:

I was very upset, but I thought they don’t know the difference between coma and brain death. We had done the right thing and they were wrong . . . (No. 5)

Change in perspective and attitude after the patient’s death. Some of the families who at first disagreed with donation changed their views after the patient’s death and on learning that she/he was not going to be revived. They believed that their decision was made when overcome with prejudice and emotions that clouded their reasoning and logic. After the patient’s death, they understood that organ donation was a suitable choice, but had lost the opportunity to help others and to receive God’s blessing. As a non-consenting participant shared:

At the time, I believed that what was happening was according to God’s will and we had no right to interfere in God’s affairs by donating organs, but now I think God wanted us to help those who were in need . . . so, it was better for us to consent . . . (No. 6)

Doubt and dissonance in decision making. Both family groups experienced uncertainty and dissonance after making the final decision. Some of the families who agreed to donate suffered from uncertainty and dissonance regarding the organ donation process. In reference to hurting the deceased and not giving him/her the opportunity to revive, families felt guilty and ashamed. This was mainly because of their confusion and misconceptions about brain death versus coma as stated here:

Sometimes I think that I should have kept him . . . maybe he would have recovered from the coma. Sometimes I ask myself if I was on the wrong side . . . (No. 5)

Facing the possibilities of the patient’s chance of revival (after watching movies and receiving negative feedback), families suffered from severe stress and psychological trauma as a result of emotional struggles and negative feelings of potentially having made a hasty decision. As commented below:
Once, I saw a girl in a TV program who came back to life after a few years... I cried so much because I feared for destroying my son’s life... (No. 12)

However, this feeling of uncertainty and conflict was also created in families who declined donation who regretted their decision. These were families with prior knowledge that the deceased had previously decided to donate organs and yet his/her request was not honoured by the family. These families experienced uncertainties and suffered from emotional conflicts. As one non-consenting participant stated:

It was possible for me to change my decision. Maybe it was better to agree with donation, especially because he was satisfied with it... I fear his soul is annoyed because of my decision... (No. 3)

Discussion
The results of this study revealed two themes in relation to the experiences of families of brain-dead patients facing requests for organ donation. The themes were: 1) serenity in eternal freedom; and 2) resentful grief, which asserted the nature of families’ experiences with the organ donation process. Themes reflected on the emotional paradox, reactions and consequences of decision making to consent or decline organ donation. Both family groups experienced immense suffering but, for those who consented to donate, there was some relief and consolation after the emotional storm, as some family members felt paradoxical senses of peace and calm despite resentment, doubt and uncertainty regarding their decision. Conflicting feelings were stronger and more prevalent in families who declined to donate.

The serenity and consolation for eternal freedom is a new found and unpublished thematic concept. Other categories related to this theme that reflect the positive effects of family experiences as pleasant memories after donation despite loss and grief are also never published or reported in other studies as a series of independent categories.

There is a published study\textsuperscript{14} on the positive effects of donation that states that families who once agreed to donate organs were more likely to donate their own organs to overcome their grief. In another study\textsuperscript{15} researchers reported positive motives for donation including a sense of spiritual reward for helping others, an appreciation for the sanctity of life and having insurance companies provide financial support for family members who consented to donate organs and publicize their decision in favour of organ donation.\textsuperscript{1} It is noteworthy that organ donation is totally free in Iran and no money is paid to the donor’s family.

Similar to the results of the current study regarding the impact of organ donation on the attitude and behavior of the family and others, researchers\textsuperscript{15} have found that some of the families were interested in promoting organ donation programs. But, unlike the results of his study in which some of the families received anonymous letters and were emotionally unable to answer them,\textsuperscript{15} this study, showed most of the families were inclined to interact with the recipients and those who were able to do so, described a very positive and pleasant effect. Dissimilar to our findings, another study\textsuperscript{16} demonstrated that agreement or disagreement with donation had no effect on the grief process and the main variables affecting the mourning process were similar in both consenting and non-consenting families. The differences in the study results may be related to participant’s cultural and religious differences as well as study focus. Because participants in this study viewed their experience from a spiritual dimension by feeling close to God and favoured by Him, they mourned differently.

The resentful grief concept was extracted from data to reflect the difficulties associated with the natural grief process for consenting and non-consenting families when faced with agonizing decisions to donate organs. In some studies, conflict has been introduced as a consequence of organ donation.\textsuperscript{6,17} In this study, consenting families encountered conflict and resentment after the patient’s death and experienced
devastating psychological effects despite having positive feelings after organ donation. The main reasons
given were the unanswered questions, uncertainties and contradictory information regarding brain-death
diagnosis, the patient’s chance for revival and coming back to life. Families were conflicted over the possi-
bility of failing or neglecting the patient.

A published study\textsuperscript{18} on family grief also stated that brain-dead patients’ families are at high risk of
paradoxical consequences of grief such as guilt and love at the same time. Another study\textsuperscript{19} has shown
parents’ unanswered questions or misunderstanding of the nature of the brain-death state and organ dona-
tion could provoke grief by challenging family life and its normalcy. Similar results were found indicat-
ing families left with unanswered questions, especially on brain-death and its prognosis, grieved with
resentment after the patient’s death. The unanswered questions have become increasingly difficult for
families over time\textsuperscript{20} and making the decision to donate organs without knowing the patient’s prognosis
was found to be directly associated with anxiety and conflict.\textsuperscript{21,22} In line with some of these findings,
researchers\textsuperscript{6,23} have asserted that a lack of understanding on brain-death contributed to conflict and dis-
sonance. This study also found that families who properly understood the concept of brain-death felt less
conflict, guilt or uncertainty, and, dissimilar to other findings,\textsuperscript{20} our participants did not report increased
distress over organ donation. One must consider the current approach to organ donation and cultural fac-
tors when comparing study results.

In recent years, the way the Iranian healthcare system enrolls new volunteers to donate organs is not con-
sidered ethically sound. Lack of support and understanding is offered to families in extreme distress and a
major organizational and structural revision is deemed appropriate. Unlike this study, researchers\textsuperscript{24} have
found that consenting families experience more psychological distress compared to non-consenting
families. We found consenting families who had a full understanding of the meaning of brain death had less
distress. In this study, consenting families with partial knowledge and understanding of the brain-dead state,
suffered from confusion and uncertainty after the patient’s death.

A qualitative approach in this study disallowed comparing levels of distress among consenting and non-
consenting families, but it was obvious that non-consenting families who understood what brain-dead
meant, experienced more distress, tension and conflict after the patient’s death. Researchers\textsuperscript{1} reported the
negative effects of a request for organ donation on families included their concerns about the deceased’s life
after death, stress associated with family debates and decision-making process, others’ negative feedback
regarding donation, inability to perform daily activities, and inability to get back to work.

In our study, none of the families reported inability to perform daily tasks or getting back to work. In fact,
consenting families returned to work faster after donation. A unique finding was the degree of distress and
conflict in non-consenting families after the patient’s death mainly due to the negative remarks by others
and learning about the patient’s prognosis after death. Thus, request for donation without consideration for
families and offering concrete test results and prognosis could lead to distress and conflict in families.
Therefore, healthcare teams must recognize family needs, offer comfort and support, and assist during deci-
sion making before the patients’ death.

In spite of the difficulties, none of the consenting families who participated in this study expressed regret,
but five non-consenting families were regretful about their decision. Similarly, another research study\textsuperscript{25} has
indicated that none of the consenting families reported regret, but three non-consenting families expressed
regret about their decision. Researchers\textsuperscript{2} have also illustrated that a significant proportion of consenting
families were unsatisfied with their decision and did not want to repeat it again. Moreover, families who
understood brain-death and could explain its meaning were more satisfied with their decision. Other studies
asserted that most of the consenting families felt no regret but were deeply dissatisfied and sometimes con-
 fused by the dissonance resulting from the technical and practical nature of donation process. Family mem-
bers, similar to participants in this study, needed support and did not receive comfort or support from the
people involved.\textsuperscript{2}
Conclusion

The findings of the study indicate that a request for organ donation has a significant impact on families with lasting effects after the patient’s death depending on the decision made in various circumstances. Consenting and non-consenting families experience the positive effects of their decision by feelings of comfort and satisfaction alongside negative experiences such as tension, conflict and psychological strain. Therefore, organ donation is a complex and life changing experience for families involved in any decision made.

However, considering the global crisis regarding lack of donor membership, organizations have to revise their objectives by considering positive and negative family experiences in order to increase the number of consenting families. Organ donation is a multifaceted issue with psychological, ethical, moral, cultural, financial and legal components. Observing and improving every aspect could be important to the organizational success. Above all, family needs must be met when a request for donation is presented.

Based on the results of this study, it is necessary to continue supporting the families after their decision. Providing accurate information on the correct diagnosis of brain-death and assuring families of the prognosis by differentiating the brain-dead state from coma can help them in recognizing the irreversible brain damage and remove family misperceptions about the possibility of return to life. Families faced with such psychological turmoil should not have any ambiguity, misperception or misunderstanding about coma and biological life instead of brain-death state. There should be no lingering doubt for families when a donation request is made. Family support through precise information and reassurance are essential before and after the patient’s death. In fact, the organizational goal should not be focused on the safe removal of the organs and saving recipients’ lives, but the human aspects of the process for both sides. Regard for the sanctity of life applies to both family groups as one gives and the other receives life. The healthcare team must promote open expression, answer questions truthfully, attempt to gain trust, maintain confidence and help families to make the best decision.

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Conflicts of interest

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