

# Iranian nurses' experiences of brain dead donors care in intensive care units: A phenomenological study

Shayesteh Salehi<sup>1</sup>, Tahereh Kanani<sup>2</sup>, Heidarali Abedi<sup>1</sup>

## ABSTRACT

**Background:** Care of brain dead donors is complex, critical, and sensitive and has a direct and positive impact on the end result of organ and tissue transplantation process. This study describes the nurses' experiences of care of brain dead donors in intensive care units (ICU).

**Materials and Methods:** This research was performed by phenomenological method that is a qualitative approach. Purposive sampling was used to gather the data. The researcher reached to data saturation by deep interviews conducted with eight participants from ICU nurses in Isfahan hospitals who cooperated in care of brain dead donors. Data analysis was performed according to Colaizzi analysis method.

**Results:** Interviews were analyzed and the results of analysis led to "Excruciating tasks" as the main theme formed by psychological effects of facing the situation, heavy and stressful care, defect of scientific knowledge, conflict between feeling and duty, outcome of attitude change in behavior, emotional responses to perceived psychological afflictions, doubt to medical diagnosis, spiritual perceptions, and biological responses when faced with the situation.

**Conclusion:** Caring of brain dead organ donors is difficult and stressful for intensive care nurses and can be a threat for nurses' health and quality of nursing care. So, providing suitable physical, mental, and working conditions is necessary to make suitable background to maintain and increase nurses' health and quality of care and effective cooperation of this group of health professionals in organ procurement process.

**Key words:** Brain dead donor, nurses' experiences, organ donation, organ procurement, intensive care unit, Iran

## INTRODUCTION

Nowadays, organ transplantation is considered as the best treatment for patients with end stage dysfunction of organs.<sup>[1]</sup> It has caused a great advance in the promotion of these patients' quality-of-life after receiving donated organs.<sup>[2]</sup> From the time neurological definition of brain death was suggested in medical sciences in 1970s, and when brain dead patients were considered as potential organ donors<sup>[3,4]</sup> until now, donation has had a rapid pace.<sup>[1]</sup>

Although present advances in surgical techniques, organ preservation procedures and immune suppressive medications have caused an improvement in quality-of-life among organ recipients, inadequate vital organs for

donation is considered as a restrictive factor for a low number of lives, saved by organ donation.<sup>[5]</sup> The gap between the number of critical patients with end stage organ dysfunction whose lives depend on receiving donated organs, and the number of available organ donating brain dead patients has been the main determinant for the yearly number of organ transplantation. The imbalance between the demand for donated organs and the supply results in a higher number of patients who die while waiting in an organ transplantation list.<sup>[6]</sup>

It is so that for instance, in US, 18 patients are added to organ transplantation national waiting list each 12 min, and approximately 18 patients die of not on time accessibility to donated organs each day.<sup>[5]</sup> In Iran, from 15,000 annual brain deaths resulted from car accidents, the rate of donation is only two organ donations from brain dead patients out of a million while a lot of patients in organ transplantation list die as a result of a shortage in donated organs.<sup>[7]</sup>

Low number of organ donors is associated to factors such as expiration of donor due to instability, metabolic or cardiopulmonary instability and delayed or lack of detection of progressive brain death.<sup>[6]</sup> Meanwhile, a group of authors have emphasized on vital position and role of

<sup>1</sup>Nursing and Midwifery Faculty, Khorasgan (Isfahan) Branch, Islamic Azad University, Isfahan, Iran, <sup>2</sup>Department of Nursing, Shahid Chamran Hospital, Isfahan University of Medical Sciences, Isfahan, Iran

**Address for correspondence:** Mrs. Tahereh Kanani, Nursing and Midwifery Faculty, Khorasgan (Isfahan) Branch, Islamic Azad University, Isfahan, Iran.  
E-mail: tk88ir@yahoo.com

nurses in critical care units in detection of potential donors, taking care of them and improvement of organ donation accessibility.<sup>[1,8,9]</sup> Clinical support of brain dead donors is considerably different from other patients in critical condition and needs skillful and experienced caregivers such as nurses and physicians who are professional in taking care of donors.<sup>[10]</sup> Based on estimations, 17-25% of retrieval and transplantation organs are lost because of inappropriate management of donors during the critical and vital period of intensive cares.<sup>[11]</sup> In this direction, a study has explained how nurses in critical care units do their best through taking care of the donors and preservation of the donated organs (for the recipients in the waiting list) to make a positive environment for organ donation.<sup>[12]</sup>

In other researches, nurses described this responsibility as a stressful and valuable experience.<sup>[13,14]</sup> In addition, there are evidences showing that just knowledge and attitude do not affect and satisfy the health providers (including nurses) in their participation in organ procurement process, and the stress resulted from that. Their experiences also may play a more significant role and somehow negatively influence the above-mentioned process and slow down the trend of organ donation.<sup>[15]</sup> As in Iran in recent years, the rate of organs donation has increased under the influence of world-wide medical sciences advancements in relation with organ and tissue donation on one hand, and the rapid pace of chronic diseases and consequently higher number of patients needing organ transplantation on the other hand,<sup>[16]</sup> health providers including nurses are more involved in organ preparation process in brain dead patients. In addition to the importance of care in brain dead patients who are the potential donors to preserve function of donated organs is a sophisticated, vital and sensible process that can be fulfilled just with high quality intensive nursing care, and can absolutely affect the final outcome of organ and tissue transplantation process;<sup>[17]</sup> recognition and consideration of nurses' experiences in this regard was considered as an important issue, and the present study aimed to investigate Iranian nurses' experiences of brain dead donors care in intensive care units (ICU).

## MATERIALS AND METHODS

This is a qualitative study with descriptive phenomenological method to describe experiences of nurses who were taking care of brain dead donors in ICU. As detection of emotions, feelings, attitudes and humanistic values is difficult through quantitative research methods, which focus on objectivism and details orientation, qualitative research methods are adopted in these regards.<sup>[18]</sup> This study was conducted from November 2011 to April 2012 after getting a letter of introduction from vice-chancellery for research in Azad

University, Branch of Khorasgan and passing the official process and getting needed permissions in three special and sub-special selected hospitals affiliated to Isfahan University of Medical Sciences in Isfahan. There were the patients with diagnosis of brain death as candidates for organ donation or other brain dead admitted patients to be prepared for organ donation in ICU of aforementioned hospitals.

Sampling was purposive and inclusion criteria were having at least BS of nursing, working in an ICU, having participated in caring of a brain dead donor at least once and giving an informed consent to attend the study. Exclusion criterion was the lack of interest to continue the research. Sampling continued until data saturation, which ended with eight participants in the present study. In depth unstructured interviews were adopted. Firstly, necessary explanations concerning the goal and design of research were given to the participants.

After getting their consent to run the interviews, an appropriate time, and location were determined to their convenience. Face-to-face interviews were conducted in the mentioned wards and in a peaceful and convenient environment (staffs lounge room). The participants permitted their interviews to be recorded by a digital voice recorder. The interviews started by an open general question about the study phenomenon (what was your experience from the time you faced a brain dead organ donating patient until the end of his/her care and how it affected you?). Next questions were made based on the participants' responses (what did you think of?). In case of any ambiguity in responses, further questions were asked in the same field. Each interview lasted for 20-40 min. In order to gain participants' trust and reliance, a couple of minutes were devoted to greeting and starting daily conversations with the participant before interviews started. After each interview, the recorded interview was carefully listened and transcribed word by word. The obtained data were analyzed based on the seven step Colaizzi method including reading protocols to acquire a sense of whole, extracting significant statements from each protocol, formulating meanings from significant statements, organizing themes from formulated meanings, integrating themes into an exhaustive description of the studied phenomenon, formulating a complete and clear description of the studied phenomenon, and finally, validation of the results through referring to the participants.

It was so that, firstly all the transcribed materials were carefully studied and reviewed and participants' significant statements were extracted to have a sense of the whole. Then, the meaning of each statement was formulated and organized into themes and these themes referred to primary

protocols (interviews). Next, themes were integrated into an exhaustive description, which was changed to a more general concept, which was close to essential structure of the phenomenon resulted from data analysis. Finally, essential structure of the phenomenon was formed, and the results were combined and formulated in the form of a complete description of the studied phenomenon.

Eventually, the findings were referred to the participants for validation and checking ambiguity. The rigor of the data were considered by four components suggested by Moule and Goodman (2009) including, credibility, dependability, confirmability and transferability.<sup>[19]</sup> It was so that in the present study, credibility was confirmed by member checking. Indication of other participants to the codes in former interviews confirmed dependability. To achieve confirmability, different stages of data analysis were checked by a panel of experts and an agreement was made on accuracy and meanings of the data. In order to gain transferability, it was tried to include maximum variation of sampling through the selection of the participants from various hospitals, with different education levels, work experience and ages as well as preparation of complete and reach explanations given to them.

Ethical considerations such as getting permission to attend the research environment, giving a complete explanation about the research and attaining participants' informed consents, attaining the permission to record the interviews and keeping their information confidential were considered in the present study.

## RESULTS

Participants' age ranged between 27 years and 47 years and their length of work in ICU was between 2 years and 22 years. From a total of eight nurses attending the study, seven were female and one was male with education levels of BSc and MSc [Table 1]. The theme of excruciating tasks was yielded from the data obtained about the experience

Participant	sex	age	Level of educations	Unit	Years of Experience
Participant No 1	Female	33	MS	ICU	7
Participant No 2	Female	27	BS	ICU	2
Participant No 3	Female	34	BS	ICU	8
Participant No 4	Female	39	BS	ICU	10
Participant No 5	Female	32	MS	ICU	7
Participant No 6	Male	47	BS	ICU	22
Participant No 7	Female	28	BS	ICU	3
Participant No 8	Female	39	BS	ICU	12

of taking care of a brain dead donor with subthemes of psychological and mental effects of facing the situation, heavy and stressful care, defect of scientific knowledge, conflict between feeling and duty, outcome of attitude change in behavior, emotional responses to perceived psychological afflictions, doubt to medical diagnosis, spiritual perceptions, and biological responses when faced with the situation [Table 2].

**Table 2: Thematic categories and sub themes constituting the main theme "Excruciating tasks"**

Thematic categories	Sub themes	Main theme
Psychological pain	Psychological and mental effects of facing the situation	Excruciating tasks
Preoccupation to situation		
Duality of feelings		
Fear		
Curiosity		
Donated organ preservation	Heavy and stressful care	
Heavy load of care		
Caring process stress		
Donated organ outcome		
Disturbances in the ward conditions		
The nature of brain death		
Organ preparation process		
Defect of scientific knowledge	Defect of scientific knowledge	
Conflict between feeling and duty	Conflict between feeling and duty	
Attitude change outcome in facing organ donations	Attitude change outcome in behavior	
Culture making concerning organ donation		
Reflection of thoughts change in verbal dialogue		
Responses to psychological afflictions	Emotional responses to perceived psychological afflictions	
Facing emotional reactions to the situation		
Impressibility by appearance of a donor		
Doubt to medical diagnosis	Doubt to medical diagnosis	
Perception of supernatural powers	Spiritual perceptions	
Feeling of donors' continuation of perceptions		
Biological responses when faced with situation	Biological responses when faced with situation	

### Psychological and mental effects of facing the situation

This subtheme was formed by thematic categories of psychological pain, preoccupation to situation, duality of feelings, and fear and curiosity. Facing the situations such as the donors', their families,' and relatives' condition caused numerous psychological and mental effects among the participants. These effects have been reported in the form of psychological pain such as sadness and sorrow, distress, depression, hatred, despair and hopelessness, and duality of feelings and fear with various severity and degree depending on issues such as patients' age and appearance and the extent of their injuries. Participants mentioned their preoccupation to the patients' condition, sadness, and sorrow imposed to their families and their emotional status as well as their patients' agonizing fate as some of their mental concerns leading to their psychological pain. It should be noted that participants' experienced psychological pain has been more in their first exposure to these patients, and it gradually decreased through their frequent exposure.

One of the participant states:

*"...when I faced the body of the donor, I feel sorry and I think deeply about his/her family, I imagine if she/she were one of my family members, I would feel so sad and depressed. I cannot forget that patients even after a couple of shifts."* (Participant No. 1)

Another participant states:

*"...being exposed and thinking about such a fate relieves me from my own sadness and problems to some extent. On the other hand, it depresses me and diminishes my life expectancy."* (Participant No. 5)

### Heavy and stressful care

This subtheme was formed from thematic categories of donated organ preservation, heavy load of care, caring process stress, donated organ outcome, disturbances in the ward conditions, the nature of brain death, and organ preparation process. Participants, in the present study, indicated that taking care of the donor in order to preserve the transplantation organs and preparation of the donor for organ harvesting surgery are important and sensitive issues and the related care is heavy and stressful. The disturbance made by the medical team's attendance in the ward to approve brain death and to do necessary coordination in the ward increased the toughness of the condition. In addition, one-way communication, perceived by nurses during taking care of the patient, and the experienced feeling based on the sensitivity of sharing in ending a human's life, and in return, bringing another human to life worsened the condition of care. A participant concerning caring tasks of a donor said:

*"...taking care of this patient is very stressful for me as they should be cared well. We try to take care of them well for the recipient; their organs should not have any problem so as to function well after transplantations..."* (Participant No. 2)

Another said:

*"...taking care of a brain dead patient whose organ should be carefully preserved by us is stressful and takes a lot of come and go and footwork..."* (Participant No. 7)

A participant concerning the mess in the ward said:

*"...presence and come and go of brain death approval team and transplantation coordinator are tiresome for me as the ward gets crowded and loses discipline. It disturbs the ward tasks and care of other patients. I like them to finish their work and leave the ward as soon as possible..."* (Participant No. 5)

### Defect of scientific knowledge

In the present study, defect of scientific knowledge in relation with necessary cares of the donors to preserve and prepare for organ harvesting was mentioned as an effective factor for increase in stress during care. One of the reasons for this defect was reported to be associated to inadequate knowledge given to the staffs during their education in nursing school concerning facing process of donation and transplantation. Participants claimed to have received their needed knowledge and information by frequent exposure with the situation and through their experienced colleagues, physicians of transplantation and coordination team as well as specially designed educational courses. One of the participants said:

*"...as I had not worked in neurology and trauma ICU, I had no scientific information about some of the related cares. My knowledge and information, obtained during my education, was not adequate either, but the physicians were available and guided me..."* (Participant No. 8)

### Conflict between feeling and duty

Emotional pain resulted from patients' care, made some of the participants speed up and facilitates brain dead patients' death while they knew this action was out of their job description. A participant about this issue stated:

*"...sometimes, I think, if I were permitted and could, I would dispatch the patients from the device to stop the suffer they have to tolerate just to donate their organs..."* (Participant No. 1)

### Attitude change outcome in behavior

This subtheme was the product of combination of thematic categories such as attitude change outcome in facing organ donations, culture making concerning organ donation, and reflection of thoughts change in verbal dialog. Being

involved with the brain dead donor led to behavioral reactions due to participants' exposure to the subject of organ donation. These reactions seem positive in some cases and negative in some others, but can influence the level of public acceptance of organ donation and consequently, provision of transplanted organs. Some remarks of a participant are:

*"...I would not resist before, if my family would like to donate organs, but when I saw the donors and the recipients and as the process does not go as well as we believe, especially for the recipients, I disagreed with them. Even they wanted to get a member, but I disputed with them..."* (Participant No. 3)

*"...I personally have completed organ donation form, but if I tell my family, I did it, they do not agree. I recommend them to be a candidate for organ donation, but they do not accept, but my husband completed the form and got a candidate..."* (Participant No. 1)

### **Emotional responses to perceived psychological afflictions**

Responses to psychological afflictions, facing emotional reactions to the situation, impressibility by the appearance of a donor were thematic categories to form this subtheme.

Some participants reported that discharge and manifestation of feelings were helpful, which can be an evidence for the need for emotional support among the nurses involved in taking care of brain dead donors.

One of the participants concerning sharing her feelings with her colleagues said:

*"...when I talked with my colleagues about it (donor), I felt better sometimes, they felt sorrier than I did. That I shared my feeling with them convinced me that I was not the only one to have this feeling..."* (Participant No. 2)

Facing with emotional reactions of donors' families was also reported painful and weird and some nurses seemed not to be adequately prepared to face these reactions.

As a participant said:

*"...emotional reactions that the family show toward their patients, especially, their worship and vow, are so weird and not appropriate for a person whose patient is brain dead, I do not know what to do that time and how to tolerate..."* (Participant No. 8)

### **Doubt to medical diagnosis**

Existence of some medullar reflexes in brain dead patients made the participants doubtful about the accuracy of medical diagnosis made by the physicians. Some

participants' state:

*"...When he/she lifts his/her hand up as a reflex, one suddenly thinks, he/she may wake up, what if he/she is back, they should not be in a hurry, perhaps he/she wakes up. I can say, I rely on diagnosis by 80%..."* (Participants No. 4)

*"...When I saw some movements in his limbs, for example at the time of blood sampling when he withdraws his hand, I doubt it. At the beginning, I would suddenly lose heart that it may not be a brain death, but the physicians assured me that they were medullar reflexes. Even now, when I see, they do few examinations, again, I doubt it, I expected them (physicians) to spend more time on something so important and examine the patient more carefully as it is a case of life or death and is different from other diagnoses..."* (Participant No. 6)

### **Spiritual perceptions**

This subtheme was made by thematic categories of perception of supernatural powers and feeling of donors' continuation of perceptions. Some participants, experienced feeling of donors' ghost presence and his/her continuation of perceptions. These feelings can have roots in participants' religious beliefs in relation with human's ghost and its connection with the body. Such perceptions led to fear among some participants, considered in subtheme of psychological and mental effects.

A participant stated:

*"...I feel there is a supernatural power, for example, I feel the ghost of the patient is around me, I feel the patients are aware of the decision, which has been made for them and can see me and everything I do, and may be disappointed with me and suffer from what I do..."* (Participant No. 2)

Another participant in relation with the question in her mind about the continuation of patients' perceptions said,

*"...I like to know what feelings they (the donors) have about the decision, which was made for them! Do they feel anything?"* (Participation No. 3)

### **Biological responses when faced with situation**

Biological responses were among other experienced items. These responses were reported mostly in forms of emotional fatigue, sleep disorders including preoccupation at the time of sleep leading to problems in falling asleep, night mares and digestive disorders such as nausea and loss of appetite. Frequent exposure to the situation decreased the severity of the disorders. Some participants in this regard stated that:

*"...It was a night shift, when I went for the rest, I felt his ghost in the room, I was scared to death. When I slept, I dreamed the donor did not like to donate his heart and said*

*I am healthy, I am alive, but the organ harvesting physicians shouted at him that you are dead and should donate your heart, liver etc. The donor ran in the ward and I suddenly woke up...*" (Participant No. 3)

*"...when I was by the patient, I had these negative feelings, it sometimes caused me to feel nauseous..."* (Participant No. 6)

## DISCUSSION

The findings of the present study showed that the care of a brain dead donor was experienced heavy and stressful by the caring nurses and involved them in direct touch with the patients. During this direct relationship, nurses' mind was often involved in patients' condition and fate, their families' conditions and the type of occurred event and was affected by mental and psychological factors and sometimes showed biological responses.

In addition, during the care, nurses faced some reactions of their colleagues and the donors' families in relation with the donors' condition, which played a major role in the severity of psychological and mental effects imposed to them. They also experienced a conflict between their feelings and professional duty, and patients' psychomotor responses, which made them doubtful about the diagnosis of brain death. Their beliefs about the association between the ghost and body led to their experience of spiritual perceptions.

Feeling such as sadness and sorrow, anger, depression, hopelessness and curiosity in relation with donors' personal relationships and life, studied under subtheme of mental and psychological effects in the present study, have been also reported in the study of Carter-Gentry and McCurren.<sup>[20]</sup>

More difficult aspect of exposure to the situation, when facing a young donor and thinking about his/her personal life in such a situation, is consistent with the study of Flodén and Forsberg.<sup>[21]</sup> In addition, the balance between participants' experienced concerns in the present study compared to the sudden sadness and sorrow imposed to the donors' family, and donors' families' feelings has been confirmed in other studies.<sup>[22,23]</sup> As the health of donors' organs highly influences the outcome of organ transplantation and the health of the recipients, preservation of these organs is of great importance and needs precise care of the donor in an ICU. The participants in the present study understood this issue well and tried to achieve this goal although they described it as a difficult and stressful task. In this relation, the nurses attending in the study of Pelletier-Hibbert emphasized on the point that the family's decision to donate organs is the beginning of a chain of

events which diverts nurses' care focus from saving the donors' life to the preservation of their donation organs and stated that they experienced a stressful situation in relation with preservation of the donors until harvesting their organs.<sup>[24]</sup> Administration of intervention in taking care of a donor, based on nurses' awareness and belief in ending a human's life to save other individuals' life through organ donation and transplantation has been also emphasized in the study of Flodén and Forsberg.<sup>[21]</sup>

Experienced conflict between feeling and duty, obtained in the present study, which indicates nurses' desire to speed up and facilitate donors' death due to their perceived emotional suffer as a result of the donors' miserable condition and their professional responsibility has been also reported in the study of Pearson *et al.*, This finding was obtained through observing brain dead donors' families sadness, sorrow and anxiety and with respect to the fact that the goal of taking care of the donors was just preservation of donation organs health.<sup>[25]</sup> Behavioral outcomes as a result of the formed attitude in confrontation with brain dead donors, caused a lack of interest and sometimes disagreement with others' donation in some of the participants. On the contrary, it caused the desire and encouragement of other toward organ donation in some other participants. Meanwhile, in the study of Sotillo *et al.*, health providers' encouragement to make individuals interested in organ donation and transplantation was reported among the variables affecting acceptance of organ donation, and consequently, higher rate of organ donation and transplantation.<sup>[22]</sup> There are other studies on emotional responses to participants' perceived psychological afflictions consistent with the present study, which reveal the need of the nurses taking care of brain dead donors concerning emotional support and their inadequate emotional preparation to face donors' families' emotional reactions. In the study of Carter-Gentry and McCurren, the participants agreed that talking about the events related to preparation of organs made it easier to cope with its miserable conditions.<sup>[20]</sup> Bloomer *et al.*, pointed out to inadequacy and defect of ICU nurses' preparation in dealing with sorrow and misery existing in donors' families.<sup>[26]</sup> Doubt in medical diagnosis is another finding of the present study, which concurs with that of Regehr *et al.*, as in their study one of the concerns of the participants (nurses) was a lack of assurance concerning donors' death.<sup>[17]</sup> Meanwhile, psychomotor responses, even the sophisticated ones, are possible among patients with absolute diagnosis of brain death. These are medullar reflexes, which may be initiated spontaneously or because of stimulation in 33-35% of the cases.<sup>[27]</sup>

Sometimes, muscle relaxants are needed during organ harvesting surgery due to such movements.<sup>[28]</sup> Therefore,

with regard to clinical signs of brain death and the length of time and frequent tests that the medical team consider based on brain death diagnosis protocol, to diagnose and announce brain death, this doubt may be resulted from affective and emotional aspects as well as a defect of knowledge. Participants' expectation for a more precise and careful investigation of medical team in administration of examinations and lack of reliance of some participants to medical diagnosis can have led to an increase in such a doubt.

In accordance with the finding of spiritual perceptions in the present study, Pelletier-Hibbert also reported the unique finding of their study as the feeling of some participants concerning the presence of ghost after brain death.<sup>[24]</sup>

The perceived need for education concerning necessary cares given to the donors to preserve the organs and preparations for organ harvesting, obtained in the present study, was also emphasized in study of Mascia *et al.*, Participation in educational seminars, education of clinical skills and regular hospital focused education in relation with brain death and process of organ donation have been reported effective.<sup>[29]</sup> Organ donation preparation in brain dead patients is a new issue in Iran. Although, there are studies on awareness and attitude of health providing personnel in relation with organ donation, no domestic study was found about their experience in relation with organ preparation including taking care of donors in ICU to let us compare its results with those of the present study. In comparison with results of foreign studies, it seems that despite the differences in occupational, environmental, cultural, religious, and traditional aspects of nurses' experiences about the phenomenon studied in the present study, the findings of these two studies were close to each other. Generally, it can be concluded that with regard to the findings of the present study, taking care of the donors with brain death is a heavy and stressful issue for ICU nurses. Negative mental and psychological and physical effects and the experienced stress can threaten nurses' mental and physical health and lead to their occupational burnout through time.<sup>[30,31]</sup> In addition, it can somehow negatively affect the progress in the trend of organ donation process.

## CONCLUSION

The results of the present study showed that ICU nurses experience a difficult and stressful process during taking of brain dead donors. Facing such heavy and difficult caring tasks often result in negative mental and psychological effects and various reactions to the issue of organ donation among them. Meanwhile, they perceived defects in their knowledge concerning taking care of the donor and psychological preparation to face such a caring situation.

With regard to the obtained results of the present study and in order to improve ICU nurses' occupational conditions and empowerment of nursing services quality during organ donation process, provision of post-traumatic stress disorder cares such as psychological counseling and emotional and spiritual supports for related nurses by the related organization seems necessary. It is essential for the nursing board authorities to include higher level of theoretical and practical knowledge in relation with the concept of brain death, taking care of brain dead donors and efficient coping mechanisms in critical condition in outline of nursing curriculum as well as related continuing education.

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