

Original Article

The Nursing Challenges of Caring for Brain-dead Patients: A Qualitative Study

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ABSTRACT

Background: Caring for brain-dead patients is one of the hardest duties for nurses, particularly in Intensive Care Units (ICUs). **Objective:** This study aimed to explore the nursing challenges of caring for patients diagnosed with brain death. **Methods:** The present study was conducted as a qualitative conventional content analysis, and data collection was carried out by field notes and 15 semi-structured and in-depth interviews with nurses working in the ICUs. Data analysis co-occurred simultaneously with data collection. **Results:** Seven themes were extracted from the data: uncertainties and conflicts between physicians and nurses, tensions in breaking the news of patient's brain death to families, stressful experience of caring for the first time, nurses' physical and psychological afflictions due to complex care tensions, stress of being blamed by patients' family, difficulty in tackling the emotions of patients' family, and finally, a sense of lack of support and protection in care. Finally, the main theme of turbulent confrontation with successive chains of tension in caring brain-dead patients was abstracted. **Conclusions:** Since nurses confront chain of tensions while caring for a brain-dead patient, this can affect the quality of this vital role to keep the transplantable organs viable; furthermore, authorities should implement special support programs for nurses.

KEYWORDS: Brain death, Terminal care, Nurse, Qualitative research

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INTRODUCTION

Brain death denotes irreversible conditions, i.e., perfect loss of brain and its stem functions while signs of life still exist in patients. Studies indicated that 1%–4% of deaths occur in hospitals, and 10% of mortalities in Intensive Care Units (ICUs) are reported because of brain death.^[1]

In Iran, >15,000 brain deaths are reported every year, about 10% of which are in the donor group.^[2] In 2013, 48% of the transplants were performed using brain-dead donors in Iran.^[3] Actual deceased organ donors were reported to be around 8.4 per million population in Iran as of 2014, according to IRODaT.^[4] Therefore, the

waiting list is still expanding,^[3] and 7–10 Iranians die every day while they are enrolled on the waiting list for transplantation.^[5]

Nurses play a vital role in caring for dying patients.^[6] It is often the nurses who first recognize the clinical signs of de-compensation and suspect the possibility of

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assigning a patient as a potential organ donor.^[5,7] Studies have shown that nurses play several roles including the identification of potential organ donors, effective follow-ups for the needs of brain-dead patients' families, public education, and providing nursing care for patients with multiple organ donations,^[8-10] which are extremely vital for the success of organ donation process.^[11]

Moreover, caring for brain-dead patients is so cumbersome that it requires professional higher-order skills.^[6,12] First, it defies the nurses' previous beliefs about death and dying.^[13] Second, caring of patients in critical conditions and dealing with the stresses imposed by relatives aggravate the situation.^[14,15] A recent study in Iran has investigated the experiences of the family members of patients with brain death;^[16] however, despite the sensitivity of ICU caregiving and the need for a complete care plan for brain-dead patients, the nurses' challenges in caring for brain-dead patients have not been comprehensively taken into account.

Objectives

This study was conducted to explore the nursing challenges of caring for brain-dead patients.

METHODS

A conventional content analysis approach was employed. Purposive sampling was conducted from March 2014 to June 2016, and the participants were recruited from among nurses working in hospitals affiliated to Universities of Medical Sciences in Mashhad, Neyshabur, and Sabzevar, Khorasan Razavi, Iran. The criteria for inclusion were as follows: possessing a BSN degree, a minimum of 1-year working experience in the ICU, a history of caring for brain-dead patients, lack of psychiatric illnesses, and participants' willingness to participate in the study. The first participant was interviewed, and then other participants were invited to the study based on the codes which emerged from the previous interviews.

Semi-structured, face-to-face interviews, accompanied by field notes, were conducted for the data collection. General open-ended questions were asked, such as "How did you feel when you were assigned to take care of a brain-dead patient for the first time?," "Could you please explain each caring situation precisely and in detail?," "How did you feel in each situation?," "What challenges and problems did you encounter?," and "How did you get along and tackle those challenges?" All of the interviews were conducted by the first author in a quiet and private room located in each hospital, with the duration of 45–90 min based on the richness of the participants' experiences. The interviews were recorded using a digital voice recorder and transcribed verbatim on the same day. The data collection continued up to

the saturation point, where the richest description of their experience and perspectives were obtained.^[17] Data saturation occurred after fifteen interviews; however, three more interviews were conducted for further confidence.

Ethical considerations

This study was approved by the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.REC.1394.58). The participants were provided with adequate information about the study objectives before the interviews. They were all assured of data confidentiality, their voluntary participation, and the rights to withdraw from the study at any point. Before recording their verbal interviews, they signed written consent forms.

Data analysis

Data analysis was carried out by qualitative content analysis of conventional type as recommended by Hsieh and Shannon.^[18] Each interview was transcribed and double-checked for accuracy on the same day, along with participants' nonverbal communications such as cries, smiles, and silence. Then, they were reviewed repeatedly to achieve a sense of the whole. Further, they were reviewed word-by-word to explore key thoughts and concepts. Units were normally coded using either the exact expressions from the text or original words and statements under the researcher's influence. The semantic units were also reviewed several times, and the codes appropriate to each semantic unit were written and then classified, reduced, and condensed based on their conceptual and semantic similarities. Afterward, codes which were conceptually similar were located in one cluster which was more general and conceptual, and finally, the categories (themes) were abstracted. Later, according to the codes and clusters in each theme, subthemes (subcategories) were identified. The analysis process was repeated with more interviews and the categories were corrected in this respect.^[19] With development of the main themes, definitions for the themes and subthemes were developed, and examples for each code and theme were identified from the data to report the findings.

The data trustworthiness was achieved using the Guba and Lincoln criteria which include credibility, confirmability, dependability, and transferability.^[19] To achieve credibility, we employed a member-checking technique. For this purpose, transcripts, interviews, and units of analysis, along with initial extracted codes, were presented to participants to obtain their confirmation and complementary comments. In addition, the interviews, initial codes, and themes

were reviewed by a co-researcher and two professors in the field of qualitative research. The sampling with maximum variance (i.e., interviews with different individuals in terms of age, gender, employment status, working experience, and workplace) verified the data transferability. Spending enough time for the study and intimate relationships with participants along with numerous and long-term reviews and analysis during a year were the factors which increased the reliability of the data.

RESULTS

Fifteen participants took part in this study, including eight nurses, two head nurses, two staff nurses, two transplantation committee coordinators, and one organ procurement unit personnel (10 female and 5 male participants) in the age range of 30–49 years, whose working experiences ranged from 2 to 13 years. The themes and subthemes derived from the participants' perspectives and experiences are described as follows.

Theme I: Uncertainties and conflicts between physicians and nurses

Uncertainty on the diagnosis by physicians for brain death has made nurses concerned and obsessed. They ask themselves, "whether the physicians' diagnosis on the brain-dead patient is true or not" (Participant 12 [P12]). "Such uncertainties regarding the diagnosis of brain death would raise doubts about patient's death and lead to disconnection of patients from the vital signs devices, giving rise to unfavorable emotional states while transferring patients (P1)." Participants believed that "most doctors are less inclined to sustain noncandidate brain-dead patients because of the lack of empty beds in ICUs (P5)."

Some nurses were also doubtful about patients' death since they had observed vital signs in brain-dead patients. One of them commented as follows: "sometimes, you can see their hearts are working while they receive no dopamine. Even when the rate of the device is reduced, you can see s/he is living with 4-degree blood pressure (P1)."

Nurses felt a sense of disability due to dubious brain death diagnoses during their caring hours; in fact, they reported a sense of confusion and anxiety. One of them said, "I did the cardiopulmonary resuscitation three times although they had told me not to do so. If I resuscitate the patients, they could still be alive I did not know whether to let them die or to revive them (P1)."

Theme II: Tensions in breaking the news of patients' brain death to families

Breaking the news of brain death, which is expected to be done by the donation committee coordinator,

falls on the nurses' shoulders, as reported from some hospitals. This issue made the nurses feel stressed so that they frequently commented as follows: "it is not good to give such distressing news to patients' family ... it is really difficult (P4)." "I have never liked to do it. I think that it is the worst news you can give to others (P2)." Nurses preferred, instead physicians or donation committee coordinator to break the bad news; "when the consulting physician confirms brain death, the physician is the first person who must give the news to dead-brain patients' family members (P15)."

Theme III: Stressful experience of caring dead-brain cases for the first time

When a nurse accepts caring for a brain-dead patient for the first time, s/he would experience a stressful situation where great tension haunts both experienced and inexperienced nurses. This experience is specifically difficult when the patients' vital organs should be sustained viable. One of the participants stated that "it was really so difficult; I was somehow afraid to get close to the patient. In fact, it is difficult for everyone for the first time. It was really stressful (P2)." Evidence from another participant confirmed that "it is so important to revive the patient and avoid cardiac arrest that may cause lots of stress for the first time (P1)."

Theme IV: Nurses' physical and psychological afflictions due to complex care tensions

The participants declared that they had encountered physical, emotional, and psychological problems while caring for patients whether as a donor candidate or nondonor. One of them contended, "I still remember where my patients were exactly hospitalized, their beds and their date of death (P13)."

They also claimed that donation candidates caused more emotional tension as families had disputes over donation. "Caring for brain-dead patients had impacts on me and made me nervous. I used to fly off handles by the smallest words my husband uttered (P7)."

Such tensions threaten the physical health of nurses too. "Since I started my shift, I've been recharging patients' dopamine and checking their tests frequently. Suddenly, I found I am starting to suffer spinal disc herniation (P3)."

They must keep the organs of the candidate patients safe and vital until the transplantation is conducted; they are also obliged to simultaneously care for other ICU patients properly. All these issues are associated with lots of stress for nurses.

Theme V: Stresses of being blamed by patients' family

According to the participants, caring for a brain-dead patient is really stressful; the difficulty lies in communicating with their families which intensifies their anxiety because most families are not well informed about brain death. They usually hope for the patients' recovery and always confuse brain death for coma. One of them said, "Once, during the suction of a patient, several cerebral reflexes were observed. Her family members were all excited and thought she was recovered (P4)."

Sometimes, brain-dead patients' family members treat nurses negatively and stressfully; frequently, nurses are afraid of being blamed by patients' family members. A nurse stated that "although such curses have no impact on the caring process, it mentally disturbs me and makes me anxious (P1)." Another participant also said, "I am really frightened by the extremely agitated relatives of the candidates who feel you are the culprit (P6)."

Theme VI: Difficulty in tackling the emotions of patients' family

As most participants declared, communicating with families of donor candidates is so stressful, in a way that most nurses shed tears while remembering those situations. "One of the patients' husbands asked his baby to look at her mom while she did not know that she cannot see her mother forever. Such feelings are so painful (P5)."

Some of the families also considered donation as a kind of piercing the patient. The use of these terms by families was very unpleasant to nurses. "You get your kid's body pierced. They are doing it to remove the organs. It is terrible and nerve-wracking (P14)."

In some cases, nurses start sympathizing with the grief-stricken family and put themselves in the shoes of families with dead-brain patients. "I am really concerned about his children because I have kids too (P11)."

Theme VII: A sense of lack of support and protection

Despite all the tensions for the nursing of brain-dead patients, nurses had a miserable sense of lack of support by the healthcare system, which could lead to additional stress in their practice. This was extracted from the following three categories: fear of possible complaints despite proper care, worries about lack of support from the healthcare system, and unpleasant feelings due to being overlooked.

Referring to the fear of possible complaints, one of the participants said, "All the documents related to each brain-dead patient should be preserved because patients'

families might complain legally and you must not forget your careful recording at all times (P2)." Otherwise, nurses would feel that their professional efforts and caregiving may be ignored by both the health system and the patient's family.

The participants also claimed that "no one considers the physician as the culprit, but everybody blames the nurses. They even sometimes curse the miserable nurses and wish the same situation for our family (P8)." A feeling of being overlooked was also running in nurses so that one of them stated that "the worst thing is that no one sees us. When a patient dies or comes to brain death, we are cursed and feel uncomfortable mentally (P1)."

DISCUSSION

The results of this study revealed the most salient challenges affecting nursing care of the brain-dead patients. It was argued that "turbulent confrontation with successive chains of stress in caring for brain-dead patients" was the most influential concept, considered to be the central theme covering other subthemes in the study.

The present study showed that caring for brain-dead patients was absolutely stressful for nurses. The findings are consistent with the findings of the previous studies; however, they had sporadically highlighted a few different aspects of such themes. Studies by Keshtkaran *et al.*^[1] and Salehi *et al.*^[20] also revealed that there were uncertainties in terms of diagnosis and confirmation of brain death for nurses which was pictured as a halo of ambiguities, uncertainties, and doubts. Thus, the diagnoses were accompanied by nurses' concerns and stressful tension. The study by Salahuddin *et al.* also showed that uncertain decisions followed by conflicts between physicians and nurses were easily observed in the process of the disconnecting patients from the vital signs devices.^[21]

The process of caring for brain-dead patients was not merely limited to the patients but also included meeting the special needs of patients' significant others experiencing a clinically critical, complex, and stressful situation which made it really stressful to break this bad news to them. Nurses are indeed required to understand general aspects in the diagnosis of brain death as regards patients and their families,^[13] to fully brief them about brain death.^[22] Majority of families are not well informed about brain death,^[14] and this exacerbates the tension of breaking the brain-death news to patient's family.

Other studies also show that caring of brain dead patients is among the hardest tasks, and stressful conditions, specially when nurses try to disclose situation to the families.^[23] Thus, most nurses tend to believe they still

lack the preparedness to care for patients who were a candidate for organ donation.^[9,20] Furthermore, caring brain-dead patients and interactions with their families could lead to heavy workload pressure and psychological stress in nurses.^[24] In the studies by Ronayne and Watkinson, the category of “cognitive incompatibility in nurses” was identified; furthermore, it was concluded that such feelings could interfere with the care quality of brain-dead patients and lead to impoverished states in nurses.^[8,25] Another category associated with the given theme was the lasting memories of candidate patients. Despite the nurses’ knowledge of body physiology and brain death, the awful experiences of caring for brain-dead patients remained stressful for the nurses.^[22,25] In this situation, the nurses might be recommended to analyze their emotional responses to death, losses, and catastrophic cases they encounter.

Living with the predominant stress of being blamed by patient’s family was another theme obtained from the present study. In a study by Orøy *et al.*, the themes of challenging conversations and conflicting expectations from patients’ families were also identified.^[26] Presumably, the acceptance of brain death is basically difficult for most patients’ family members, some of whom unreasonably start finding fault with nurses when they are asked by the healthcare system to agree with organ donations.

Another major theme extracted from this study was difficulty in tackling the emotions of the patients’ family. Since most of the patients quite suddenly come to brain death, there is no time for families to adapt themselves to this undesirably unwanted loss; therefore, acceptance of such a fact is really problematic for patients’ families.^[27-29] Another study showed that nurses were likely to get through personal and professional conflicts in such circumstances; thus, they were required to understand their own feelings to provide acceptable care for patients and, at the same time, provide support and advice to patients’ families.^[22] In the study by Pearson *et al.*, nurses’ experience of dealing with the emotional grief of the families were highly depressing, accompanied by emotional requirements.^[23]

The last theme was nurses’ feeling of lack of support and protection by the healthcare system. Although it was not established as an independent theme in the literature, the importance of supports to nurses caring for brain-dead patients was highly desired. Studies revealed that nurses were required to be aware of this stressful situation because they, as well as their colleagues, needed occupational support.^[22] The study by Karimi-Moneghi *et al.* indicated that nurses experienced serious problems in dealing with dying patients; thus, they were in need of organizational support to cope with such threats, and ignorance of their

needs could be expected to have adverse effects on patients too.^[30] Moreover, a supportive working environment can increase nurses’ abilities to use knowledge and skills at work. Therefore, plans to provide support in the workplace to improve the quality of care and efficiency of nursing practice are of utmost importance.^[31]

As a limitation to the present study, the participants were volunteer nurses from only nine hospitals affiliated to Universities of Medical Sciences in Khorasan-e-Razavi province, Iran, as mentioned earlier. Replication of the same study either in other hospitals or in other regions might provide further insight in exploring a bigger picture of the phenomenon in perspective.

CONCLUSION

The results of this study revealed that nurses caring for brain-dead patients are facing numerous care challenges, so nursing authorities should pay more attention to the needs of nurses, plan necessary changes, and provide organizational support for them. Establishment of a psychological counseling system in clinical settings might be helpful in alleviating the nurses’ emotional and psychological problems, particularly as regards brain-dead patients.

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Conflicts of interest

There are no conflicts of interest.

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