The ethical obligation to provide care to patients diagnosed with brain death until the end stages based on grounded theory

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Abstract

Nurses are faced with tremendous pressure when providing brain-dead patients with care. There is limited guidance for nurses on the care of these patients. The present study aimed to report the experiences of nurses regarding the care of patients diagnosed with brain death.

Semi-structured interviews were conducted with 31 nurses and other stakeholders, and the observations and field notes were analyzed using continuous and comparative analysis based on grounded theory.

The qualitative analysis of the data resulted in extraction of six final categories, including 'facing increased tensions and conflicts', 'organ donation: a distinct care element', 'inconsistency of care management', 'effective care requirements', 'challenges, rights and duty requirements', and 'moral obligation to provide holistic care until the last minute'. Data analysis identified 'Challenges, rights and duty requirements' as the main issue and showed that the nurses managed this issue using the strategy of 'moral obligation to provide holistic care until the last minute' as the core variable.

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According to the results, it is recommended that the healthcare system (especially hospital management) take supportive action for nurses in various fields of care of brain-dead patients to resolve educational, moral and legal challenges.

Keywords: Brain death; Nurses; Advance care planning; Tissue donors; Grounded theory.

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Introduction

Care provision is the essence of the nursing profession, an important aspect of which is the care of dying patients (1). Brain death refers to the irreversible loss of all brain functions, particularly the brainstem (2). According to statistics more than 10 % of deaths are due to brain death (3) In Iran, brain death is a major consequence of road accidents with a mortality rate that is significantly higher than the global and regional average. According to the Iranian Society of Organ Donation report, 5,000 - 8,000 potential brain deaths have been reported in 2017, with 2,500-4,000 cases identified as possible organ donors (4).

The care process of brain-dead patients involves several challenges. Numerous studies have focused on the challenges and ambiguities that nurses encounter in the care of brain-dead patients (5 - 6), reporting issues such as uncertainty about the concept of brain death (7 - 11), problems about care and communication with the patients' families (12 - 16), religious, ethical, and cultural challenges regarding the acceptance of brain death and organ donation (4, 17 -19), inadequate knowledge (20 - 22), and lack of mental preparation for the care of potential organ donors (9, 16). While the care process of the brain dead patient remains unclear, the understanding and exploration of this process is essential to the maintenance of body organs for donation.

In this regard, special attention must be paid to the actual experience of nurses under such challenging circumstances. In the present study, the grounded theory was used to determine nurses' experiences in the care process of patients diagnosed with brain death.

Methods

It is clear that selection of proper research methodologies depends on the phenomenon under investigation. The grounded theory could be used effectively to discover social processes and comprehend the conditions leading to them, as well as the causative agents of the conditions (23). This qualitative research was conducted based on the grounded theory. Data collection started in March 2014 and gradually continued until data saturation in 2017. Sampling was performed via in-depth, semi-structured interviews with 31 participants, including 18 nurses, three family members of the patients, three physicians, and other stakeholders (head nurses, shift supervisors, organ donation committee coordinators, and head of the donation committee in Khorasan Razavi province, Iran). The participants were recruited from among the nurses (36% male and 64% male) working in hospitals affiliated to Universities of Medical Sciences in Mashhad, Neyshabur and Sabzevar in Khorasan Razavi, Iran. The mean age of the participants was 31.84 In addition, two complementary interviews were conducted until theoretical saturation in November 2017. The interview began with an open and general question: "Could you describe the care of brain-dead patients that you have actually experienced in the ICU (Intensive Care Unit)?" Based on the obtained responses, other questions were asked. The duration of the interviews was 45

- 90 minutes. After obtaining the permission of the participants, the researcher recorded the interviews and occasionally took notes. The time and place of the interviews were agreed upon by consulting the participants, and the interviews were conducted individually in a quiet environment. All the interviews were directed by the same researcher (first authors) and the recorded interviews were immediately transcribed word-by-word and reviewed repeatedly. Data analysis was initiated with the first interview.

Data analysis was performed using the Corbin and Strauss approach (2008), and included examination of the concepts, context, process and consequences, and finally the integration of categories to build the theoretical framework (23). The emphasis of the analysis was on the formation of concepts based on the data obtained in each stage of data analysis. Coding and analysis were used to form a concept from the beginning of data collection. At this stage of the analysis, the primary classification of similar codes was also performed, and a primary subcategory was formed. In the open-coding process, the researcher aimed to discover the main issue to determine its solution based on the participants' viewpoints (23). For this purpose, the researcher could identify the factors that constituted the context of the study phenomenon through enquiry (who, what, where, when, and why). After data analysis and development of the categories and the main issue, the process was analyzed in order obtain strategies to and

consequences. The researcher tried to integrate the categories into the paradigm by creating a story line, doing diagrams and rereading memos with the intention of discovering the core variable and developing a theory. The researcher recorded the observations of the nurses regarding care provision for patients diagnosed with brain death in order to collect objective data.

Data Reliability

The quality of the present study was assessed based on the criteria proposed by Corbin and Strauss (2008) (23). To this end, the researcher used long-term follow-up, continuous member check, search for negative items, integration, peer debriefing and a survey by researchers who were familiar with qualitative studies in order to ensure the reliability of the data. For this purpose, the interview transcripts and extracted codes were presented to the participants to obtain their confirmation and complementary comments. In addition, the interview transcripts, the initial codes and the categories were reviewed by a coresearcher and two professors with ample experience in the field of qualitative research.

Theoretical sampling (i.e., interviews with diverse individuals in terms of age, gender, employment status, work experience and workplace) verified data transferability. Moreover, the duration of the study was three years. At all stages, the researcher tried to present the findings to healthcare providers of various educational and clinical positions (especially nurses) in the most meaningful manner.

Ethical and Research Approvals

The study was approved by the ethical committee of our institution, Mashhad University of Medical Sciences, Iran.

(Code: IR.MUMS.REC.1394.58).

In accordance with national regulations, written informed consent was obtained from each enrolled subject. The participants were informed about the ethical considerations of the study prior to the interviews and assured of confidentiality. Participation was voluntary, and subjects were assured that their statements would not be disclosed to anyone, except the researcher.

Result

The qualitative analysis of the interview data, observations and field notes led to the extraction of 1.270 initial codes, 12 subcategories, and 6 final categories. The six categories extracted from data analysis duty included 'challenges, rights and requirements', 'facing increased tensions and conflicts', 'organ donation: a distinct care element', 'inconsistency of care management', 'effective care requirements', and 'moral obligation to provide holistic care until the last minute'. The findings will be presented according to the analysis as context. process or strategy. and consequences, to guide the reader.

The Main Issue: Challenges, Rights and Duty Requirements

The majority of the participants emphasized two issues in every situation: 'the tension of keeping the organ donor alive until donation ' and 'fear of punishment and failure'. These phenomena were indicative of the main issue in the viewpoint of the participants since all the nurses were stressed about keeping the organ donor alive through all the care stages. In non-candidate patients, despite the lack of survival stress, the nurses still believed that they should take care of the patients until the last minute.

The Tension of Keeping the Organ Donor Alive until Donation:

This category indicated that nurses deal with stresses such as keeping the patient alive and maintaining the health of donation organs during the care of these patients. These concerns add to the difficulty and sensitivity of care due to changes in the conditions of the patients.

Below are some of the statements made by the participants in this regard.

"All the team members were trying to keep the organ donor alive, and the family of the patient gave their consent for donation, which is why the care of the patient was extremely sensitive. Suddenly tachycardia occurred, and the patient's blood pressure decreased.... In other words, all parts of the patient's body must be meticulously monitored until the last moments before donation...." [Participant No. 7]

"My concern is to keep the organ donor alive, especially the body organs. That is why I closely monitor the patient and will immediately notify the attending physician in case of problems.... Despite all this monitoring to the last minute, there is still the stress of keeping the patient alive until donation...." [Participant No. 5]

The comments above demonstrate the dimensions of 'obligation to keep the organ donor alive', which was repeatedly pointed

out by the nurses as the main issue in the care of organ donors.

Fear of Punishment and Failure:

This category indicated nurses' concerns regarding the care of brain-dead patients, such as fear of insufficient time, inability to maintain the health of organ donors, and loss of the organs. Understandably, the nurses were faced with the feeling of guilt in the care of non-candidate patients

"It is true that some brain-dead patients are non-candidates, but as human beings, they have the right to receive care. I would feel guilty if the ward was crowded and I was unable to care for these patients...." [Participant No. 3]

According to the nurses, caring for noncandidate patients was perceived as futile by physicians and even the healthcare system. Meanwhile, most nurses felt guilty after inefficient care, discontinuation of medications, and weaning of patients from the ventilator.

"Some say you should not take care of noncandidate patients... there is no such thing in our culture. I have never been able to not care for non-candidate patients because I would feel guilty." [Participant No. 1]

The mentioned issues highlighted the dimensions of 'duty requirements to maintain the health of organ donors' and 'right requirements to care for a non-candidate patient'. The concepts of these categories were grouped together as they seemed to relate to each other. Finally, the main issue of 'Challenges, rights and duty requirements' was extracted.

Context: Inconsistency of Care Management

After determining the main issue, the subcategory of 'inconsistency of care management' was extracted and explained as the context for the 'challenges, rights and duty requirements'. The context (in which nurses are confronted with the care process of brain-dead patients) consists of two categories: 'defects in the efficient healthcare system' and 'perceived conflicts in the acceptance of the situation'.

Defects in the Efficient Healthcare System

The healthcare system emphasizes the importance of care provision to brain-dead patients and increasing the rate of donations. However, there has been no planning to increase the quality of care and maintain the health of potential donation organs, which causes tension in nurses .

"The organ donor was about to be transferred to the transplant center during my shift. At the same time, I had a critically ill patient and had to take care of the two of them simultaneously, so I was constantly stressed about keeping the organ donor healthy until donation." [Participant No. 8]

"I still do not know how to care for organ donors. I do not even know which organs must be properly monitored and what laboratory tests must be quickly performed. But the head nurse does not pay attention to my lack of training on the care of brain-dead patients." [Participant No. 14]

Perceived Conflicts in the Acceptance of the Situation

Nurses experience conflicts from the moment they encounter brain-dead patients to the confirmation of brain death and transfer of the organ donor to the transplant center, and even afterwards. These conflicts are mainly caused by the 'duality of emotions about organ donation' and 'doubts and conflicts between physicians and nurses in understanding the treatment and care'. In addition, nurses have the fear of punishment and failure.

"If a brain-dead patient does not meet the donation criteria, I am never sure the diagnosis is correct; I would feel guilty if I did not care for these patients and discontinued dopamine and other drugs...." [Participant No. 2]

"Several other patients could have a new life if the organs of brain-dead patients are donated. Therefore, I am very sensitive about their care and constantly stressed whether they live or die until donation." [Participant No. 15]

An example of the recorded observations is as follows:

"The organ donor was supposed to be transferred to the operating room for donation in half an hour. The attending nurse was extremely stressed during this time and meticulously cared for the organ donor. Her level of stress was totally understandable...." [Participant No. 2]

Strategies: Success and Tranquility despite Physical and Mental Exhaustion

The extracted categories were indicative of the challenges faced by nurses in the care process of brain-dead patients. In this process, nurses use the following strategies to eliminate the main issue: 'diligent care efforts to successfully carry out the 'conscientious donation'. care'. 'care keeping provision while human and emotional considerations in mind, 'moral commitment to provide care even when death is imminent', and 'organ donation: the most distinctive element in life-saving care'.

Consequence: Success and Tranquility despite Physical and Mental Exhaustion

Consequences of these strategies were classified into two categories of 'threat to physical and mental health' and 'internal satisfaction and spiritual self-control following proper care'. It may be concluded that these strategies can lead to tranquility despite physical and mental exhaustion.

Integration of Categories

In line with moving from mere description theorization. the researcher toward constantly attempted to develop a storyline based on the core variable, and the final category and subcategories were the basis for the theoretical structure. All the interactions were focused on 'challenges, rights and duty requirements', and nurses used 'moral commitment to holistic care until the last minute' to deal with this main concern. This strategy emerged from the listed categories as the core variables with the required criteria, ultimately leading to "success and tranquility despite physical and mental exhaustion". Other categories emerging from analysis of the results appear below.

The concept of 'facing increased tensions and conflicts' indicated the circumstances that nurses were faced with, including the tension of the initial care, the hopelessness following confirmation of brain death, and dealing with the emotions of the families of the patients in the care process. Therefore, a major challenge for nurses is to overcome these stresses so that they can care for the brain-dead patient.

The concept of 'organ donation: a distinct care element' affects how nurses care for brain-dead patients as an intervening factor. Organ donation strengthens motivation for care, and conversely, when donation is not an option, nurses' desire to care for a noncandidate patient diminishes. 'Effective care requirements' are intervening conditions in process pertaining the care to the 'challenges, rights and duty requirements'. Targeted communication between the healthcare team and the patients' relatives also plays a key role in the provision of care to organ donors. Therefore, nurses need adequate knowledge to provide effective care to brain-dead patients (Table1).

 Table 1- Concepts/categories developed from the data at the integration stage

Subcategory	Category	Final Category
The tension of keeping the organ donor alive until donation Fear of punishment and failure The tension of giving bad news to the family	Challenges in patients' rights and duty requirements	
The stressful experience of the first care Difficulty in dealing with the family's feelings Sense of lack of support in care The stress of being blamed by the family Disappointment and sadness following confirmation of brain death	Turbulent confrontation with successive chains of stress	Facing increased tensions and conflicts
The physical distress caused by stressful care The psychological distress and family problems of nurses following stressful care Satisfaction with the life-giving care	Threat to physical and mental health	Success and
Success and satisfaction The tranquility following careful and human care Paying attention to the passing of life and the gift of life Moral development	Internal satisfaction and spiritual self-control following proper care	tranquility despite physical and mental exhaustion
Conscientious care Moral commitment to provide care even when death is imminent	Care based on ethical and conscientious values	Moral commitment to holistic care until the
The effect of patient status and characteristics on the care provider Nurses' emotional distress following care Respecting the rituals for dying patients Being less sensitive to non-candidate patients' care	Care provision while keeping human and emotional considerations in mind Futile care of non-candidate	last moment
Feeling uselessness of care when donation is not an option Giving life: an incentive for increased effort to receive the family's consent for donation Organ donation: the stimulus and result of careful care Organ donation: the most distinctive element in life-saving care	patients Organ donation serving as a motivation booster and giving meaning to care	Organ donation: a distinct care element
Duality of emotions about organ donation Doubts and conflicts between physicians and nurses in understanding the treatment and care	Perceived conflicts in the acceptance of the situation	Inconsistency of care
Defects in efficient organizational management Ineffective and non-targeted structure of care	Defects in the efficient and targeted healthcare system	management
Facilitating communication with the family in deciding about donation The role of communication with patients in understanding care Effective care as a result of teamwork	The effect of multifaceted care- centered communications on the donation process	Effective care
Nurses' need for education in order to provide effective care Nurses' need for sufficient knowledge and skill in order to provide proper care The necessity of impartiality and full support of the family	The necessity for adequate knowledge and skill in providing care	requirements

Theory of Moral Commitment to Holistic Care until the Last Moment

The theory developed after analyzing the data from this study explains that nurses face increasing stress and conflicts in the care of brain-dead patients, and the main issue of the 'challenges, rights and duty requirements' is formed by the inconsistency of care management. Nurses lack sufficient understanding about the concept of brain death and experience conflicts about organ donation. They face interventional measures (e.g., donation), which affect the care of brain-dead patients, so they have to dedicate all their efforts to finishing the task through 'moral commitment to holistic care until the last moment'. The consequence of this ethical and moral commitment to care is success and tranquility despite physical and mental exhaustion. In fact, in the face of these problems, nurses attempt to provide holistic care until the last moment to gain inner tranquility (Figure 1).

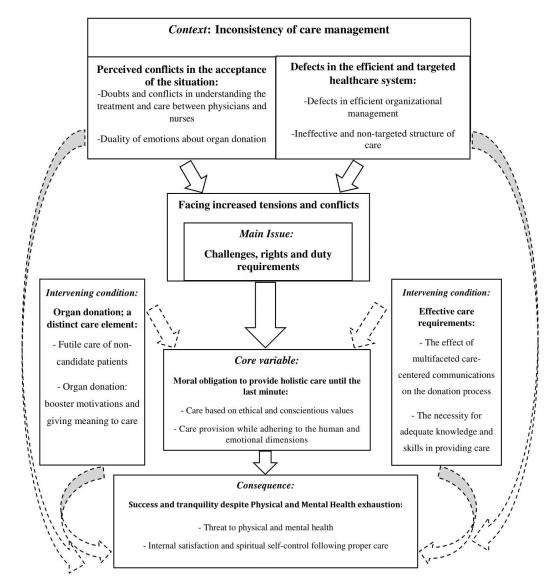


Figure 1- The theory of "Moral obligation to provide holistic care until the last minute"

Discussion

In this qualitative research, we evaluated the nursing care of patients diagnosed with brain death using the grounded theory approach, reaching the theory of 'moral commitment to holistic care until the last moment'. Therefore, the results were assessed by focusing on this core variable in order to solve the main issue (challenges, rights and duty requirements). While no study has pointed out this core variable and categories specifically. Simonsson et al. assessed the ICU nursing experience of caring for potential donors. The nurses stated that the organ donation process is emotionally challenging, supporting the patient's family is a difficult and demanding duty, a complex and multidimensional process should have a high level of liability, and respectful care must be provided based on respect for the potential organ donor (6). Forsberg et al. showed that nursing care strives to preserve respect for the organ donor and relatives within an atmosphere of tranquility (24). These studies have paid special attention to precise care provision and respecting organ donors as live patients, as well as their relatives, which is consistent with the subcategory of the core variable in the present study.

In studies that were mainly focused on the experiences of nurses in the care of braindead patients, the only concept assessed was the tension of keeping the patient alive until donation, and nurses' experiences in the care of non-candidate brain-dead patients and the related concerns were not evaluated. For example, in the study by Salehi et al. nurses' experiences showed the sensitivity of the care of organ donors due to its role in maintaining the health of the donation organs, which was described as an "excruciating task" (21). This is congruent with the category of 'tension of keeping the donation organs alive until donation' as one of the dimensions of the main issue in the present study.

Vijayalakshmi et al. recommend continuing training to enhance nursing knowledge and skills, as well as sensitivity to social, cultural, moral and religious issues, and support in the area of organ donation (9), which is in line with the main issue of the present study. This consistency is indicative of the importance of organ donation as part of the ICU culture, and shows that nurses carry out their responsibilities for the health of vital organs regardless of geographical physiological boundaries. Maintaining performance is possible by focusing on keeping the organs alive for reutilization while providing care to organ donors (25). Different studies have shown the significance of the care of organ donors as the most important aspect of the nursing care of patients before transfer to the operating room for donation (9, 16).

Keshtkaran et al. showed the lack of trust in diagnosis and verification of brain death as a "halo of ambiguity and doubt", so that nurses did not announce the brain death of patients and hoped for their cure. Such doubts make nurses uncomfortable and reinforce denial in the families of patients (8). Victorino aimed to evaluate the care management of organ donors by nurses when the latter had doubts about the diagnosis of brain death due to different cultures and beliefs (19). These findings are consistent with the concept of the main issue and context in the present research.

One of the stressful factors was the tension of giving bad news to the family. In a research, Yousefi et al. extracted concepts such as shock, hope for recovery, unknown process, conflict of opinions, and conflict of opinions (26). According to Foresberg, et al. communication with patients' families was very difficult for the nurses and could be associated with emotional reactions due to their sensitive emotional state (24).

The concept of 'defects in the efficient care system' was another underlying contextual factor for the main issue of the present study. In Sweden, the rate of organ donation has been on the rise since 2001, which shows the improvement of the organizational structure (27). In 2017, the actual donation rates in Iran were 900-1.000 based on the statistics, while 7-10 patients on the transplant waiting list are reported to die daily (4). Therefore, it could be inferred that the organizational management is still faulty, and high-quality care must be provided to donors so that the organs can be maintained in good condition. A review of the studies showed that the care of braindead patients and interaction with their families imposed tremendous pressure on nurses, resulting in cognitive dissonance (21). Under such circumstances, nurses become frustrated and inefficient due to the stressful care of brain-dead patients, which leads to the decreased quality of patient care (5). Therefore, nurses consider the care of brain-dead patients as a big challenge (21). Our findings presented the consequence of 'internal satisfaction and spiritual selfcontrol following meticulous care', which showed the excellence of the nurses caring for brain-dead patients in various personal and spiritual aspects. In addition to the aspects of the patient care process by nurses, the theory used in our research also considered the experiences of the other stakeholders involved in the care process.

Limitation

The limitation of this study was that nurses' statements had to be translated from the original language of the interviews into English.

Conclusion

The results of the grounded theory confirmed that nurses felt a moral commitment to care for organ donors and non-candidate patients despite all tensions, so that holistic and careful care could be provided until the last moment. Nurses tried to complete the care of potential organ donors meticulously based on ethical and conscientious values and regardless of the patient's prognosis, and even despite the futility of care of brain-dead patients. According to the results, nurses faced many

ambiguities regarding the ethical and legal aspects of brain death, and providing care to organ donors caused them a lot of tension, leading to their gradual mental and physical exhaustion. Therefore, "moral commitment to holistic care until the last moment" was the main strategy of nurses and the turning point of the study in the multidimensional process of caring for the brain-dead patient to overcome the phenomenon of "challenges in patients' rights and duty requirements".

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Conflict of Interests

None declared

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