

## Nurses' Challenges in Caring for an Organ Donor Brain Dead Patient and their solution strategies: A Systematic Review

### Abstract

**Background:** Caring for brain dead patient is one of the most troublous duties of an Intensive Care Unit (ICU) nurse. This study aimed to determine nursing challenges based on recent literature and identify the strategies to overcome these challenges. **Materials and Methods:** In this systematic review, the standard systematic review guideline of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used with articles published in PubMed, Science Direct, Scientific Information Database (SID), and Google Scholar databases during 2000–2018 on the keywords “brain dead OR brain death” and “nurses OR nursing.” After the primary search, 212 articles were found. Eventually, 21 articles were selected for the final evaluation. **Results:** According to the results, the challenges included the concept and diagnosis of brain death, religious, and cultural beliefs opposing organ donation, lack of knowledge about the care process, interactions with the families. The proposed strategies were providing medical and nursing interventions to maintain a brain dead patient for organ donation, providing working conditions that maintain nurses’ health, and increase the quality of care. **Conclusions:** Nurses play an important role in the care process of brain dead patients; therefore, recognizing their challenges can be the first step in increasing holistic care and maintaining organ vitality for transplantation. It is suggested that nursing authorities commence special educational programs with the aim to increase the knowledge of nurses about the care process of brain dead patients.

**Keywords:** Advance care planning, brain death, nurses, systematic review, tissue donors

### Introduction

At the second half of twentieth century, the term “brain death” defined as “irreversible cessation of brainstem function.”<sup>[1]</sup> Harvard Ad-Hoc (Committee of the Harvard Medical School to examine the definition of brain death) Committee of brain death expressed its criteria as documents in 1968 for the first time. It is an irreversible condition, and the complete loss of brain and brain stem function occur while there still may be signs of life in the patient. Previous studies indicate that brain death is the cause of 1–4% of deaths in hospitals and 10% of deaths take place in Intensive Care Units (ICUs).<sup>[2]</sup> Recently, research has focused on the important role of nurses in brain death and the organ donation process.<sup>[3]</sup> Nurses are important professionals in this area because they measure the vital signs of patients, and maintain hemodynamic stability so that donor organs remain viable.<sup>[4]</sup>

Studies have indicated that only half of physicians, nurses, and general practitioners have enough knowledge about the concept of brain death and organ donation while critical care nurses play an important role in the diagnosis of brain death and preparation of the patient for organ donation.<sup>[5]</sup> To care for brain dead patients who are kept alive to serve as organ donors, nurses need both technical-scientific skills, and the ability to handle situations that do not match the traditional concepts of nursing care.<sup>[6]</sup> They are in a position to inform families, and ask them to donate organs, and also to inform potential donors.<sup>[7]</sup> In addition, results of previous studies have shown that nurses play several roles in this regard such as identifying potential organ donors, effectively following-up on the needs of brain dead patients’ families, educating the public, and care of possible organ donors.<sup>[3,6,8]</sup> The latter may be extremely important to the success of organ donation.<sup>[9]</sup>

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Nurses do not attempt to encourage organ transplants due to their fear of enhancing the psychological pressure on the patient's family members, in addition to legal issues in this regard.<sup>[10]</sup> Since the concept of brain death has been misinterpreted repeatedly among health professional respondents, the nurses' attitudes toward transplantation have been negatively affected.<sup>[11]</sup> Therefore, nurses should be aware of medical, moral, and legal questions in dealing with this situation and understand the concept of brain death well. Lack of awareness of these issues will have unintended effects on nurses and patients and can affect the quality of care for brain dead patients which plays an important role in the improvement of organ donation rate. Thus, through a systematic review, the present study attempted to identify and evaluate the care challenges faced by nurses in dealing with brain dead patients.

## Materials and Methods

This study was a systematic review aiming to investigate the challenges nurses may face in providing care to brain dead patients in ICUs. This study was designed based on the Preferred Reporting Items for Systematic Reviews And Meta-Analyses (PRISMA) checklist.<sup>[12]</sup> This literature review was conducted on texts published from 2000 until December 2018.

These studies have been selected through searching on electronic search engines including PubMed (150), Science Direct (2), Scientific Information Database (SID) (5), and Google Scholar (53). The title and abstract of the studies were searched for the main study search phrases including brain dead, brain death, nurses, and nursing. In the first stage, we searched for "brain dead or brain death" and "nurses or nursing." The results were combined by using the Boolean operator "AND." The inclusion criteria of papers included the publication of the papers in credible scientific research journals, language of the paper (English), and accessibility of the full text of the paper.

The articles presented in conferences and seminars, case reports, and letters to the editor were excluded. A researcher-made data extraction form based on the study objectives was used for analysis of the papers. Details including the author's name, publication year, article type, study methodology, and the information relevant to "brain dead," "brain death," "nurses," "nursing," and the papers' final results were collected using this form. In terms of research design, the study classification included quantitative (cross-sectional, analytical, and descriptive studies) and qualitative studies (content analysis, phenomenography, grounded theory, phenomenology, and ethnography). It must be noted that article search was conducted by two independent researchers and all the studies reviewed (title and abstract) to find eligible articles. Any disagreement between these two researchers was resolved through discussion and by considering the

goals of the study, and the opinion of a third author was requested if necessary.

The target population consisted of nurses who cared for brain dead patients in ICU. In this study, the main question was presented as "Based on the results of studies, what are the challenges nurses may face in providing care to brain dead patients?"

The full texts of the selected abstracts were subsequently screened. After the primary search of different databases, 212 articles were found. The extracted articles were evaluated according to the inclusion criteria in two steps. During the first step, 164 articles out of 212 were eliminated because of being a duplicate or having the exclusion criteria. During the second step, 27 articles were eliminated for having irrelevant titles and goals and due to lack of accessibility of the full text. Eventually, 21 articles including 7 qualitative and 14 quantitative studies were selected for final evaluation [Figure 1].

## Ethical considerations

The authors committed themselves to avoiding plagiarism in the entire article, refraining from deliberately manipulating the data or analyses, and data making or fabrication, and maintaining honesty, objectivity, integrity, and caution.

## Results

After reviewing the results of studies, nursing challenges, and the strategies for the elimination and resolution of these challenges were categorized into 6 classes of (1) concept of brain death and brain death diagnosis, (2) discrepancies between physicians' and nurses, (3) religious and cultural beliefs opposing organ donation, (4) lack of knowledge about the care process for brain dead patients, (5) interactions with families, and (6) psychological, mental, and emotional challenges. A summary of the results is provided in Table 1.

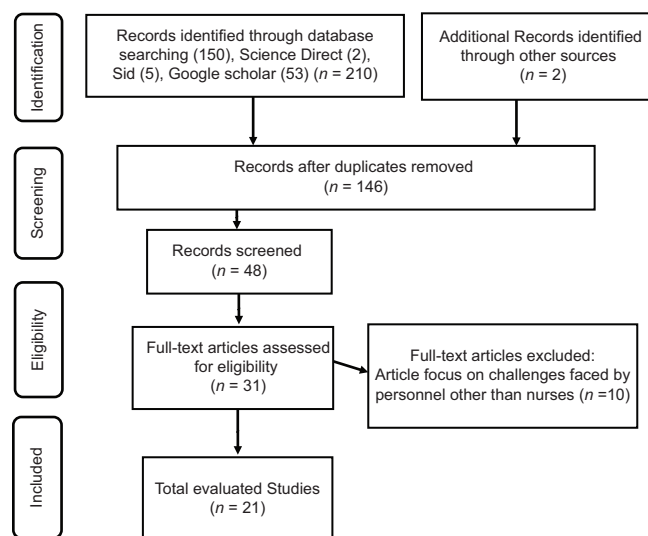


Figure 1: PRISMA\* flow diagram

\*Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**Table 1: Characteristics of included studies**

Article title	Authors	Type of study	Place	Sample size	Publication date	Strategy	Result (challenges)
1 Explaining nurses' experiences of caring for brain dead patients: A content analysis	Yazdi Moghaddam <i>et al.</i> <sup>[13]</sup>	content analysis	Iran	21	2018	Supportive model designed for ICU* nurses	Turbulent confrontation with successive chains of tension
2 The core of after-death care in relation to organ donation - A grounded theory study	Forsberg <i>et al.</i> <sup>[14]</sup>	grounded theory	Sweden	29	2014	Provision of technical, medical, and nursing interventions to enable organ donation from a brain dead patient	The process of care included the period from notification of a possible brain dead person until finding a possible organ recipient.
3 Intensive care nurses' perceptions of brain death	White <sup>[15]</sup>	naturalistic and descriptive study	Australia	40	2003	Offering supportive environments and promoting managers knowledge	doubts about perceptions of the concept of brain death
4 ICU nurses' perceptions of responsibilities and organization concerning organ donation-A phenomenographic study	Flodén <i>et al.</i> <sup>[16]</sup>	phenomenographic study	Sweden	15	2011	Managers responsibilities include providing education on the diagnosis of brain death, care process, and interaction with families	Diagnosis of brain death, the ambiguity and various perceptions of brain death diagnosis, and nurses' perceptions of their professional responsibility regarding organ donation
5 Iranian nurses' experiences of brain dead donors care in intensive care units: A phenomenological study	Salehi <i>et al.</i> <sup>[17]</sup>	phenomenology	Iran	8	2013	Providing suitable physical, mental, and working conditions to maintain nurses' health and increase the quality of care in organ donors	The difficult and stressful process of caring for brain dead donors, disturbances in the ward conditions
6 ICU nurses' knowledge, attitude, and practice towards their role in the organ donation process from brain-dead patients and factors influencing it in Iran	Masoumian Hoseini <i>et al.</i> <sup>[9]</sup>	cross-sectional analytical study	Iran	90	2015	Providing educational courses on the organ donation process	Inadequate knowledge and practice regarding their role in the organ donation process
7 Approaching families on the subject of organ donation: A phenomenological study of the experience of healthcare professionals	Orøy <i>et al.</i> <sup>[18]</sup>	hermeneutic phenomenological study	Norwegian	32	2013	providing understandable information and an appropriate manner of a request to families	Challenging interactions with families and facing conflicting expectations during the organ donation process

*Contd...*

Table 1: Contd...

Article title	Authors	Type of study	Place	Sample size	Publication date	Strategy	Result (challenges)
8 Deceased-donor organ transplantation: knowledge and attitudes among health care professionals managing critically ill patients in Karachi	Siddiqui <i>et al.</i> <sup>[19]</sup>	descriptive study	Pakistan	243	2012	Education regarding religious concerns to persuade families to increase donor consent rates	56.80% had concerns of religious rulings against organ donation, Only 42.70% and 37% were willing to approach families for consent for an organ donation
9 Psychological symptoms in family members of brain dead patients in the intensive care unit in Kerman	Hosseinrezaei <i>et al.</i> <sup>[20]</sup>	cross-sectional study	Iran	224	2014	Education interaction with the families	76.80% and 70.10% of family members reported high levels of anxiety and stress
10 The attitude and knowledge of intensive care physicians and nurses regarding organ donation in Hungary-it needs to be changed	Smudla <i>et al.</i> <sup>[21]</sup>	cross-sectional study	Hungary	282	2012	Education on brain death, donor management, and interaction with families	Inadequate knowledge and inappropriate attitude
11 Australian emergency doctors' and nurses' acceptance and knowledge regarding brain death: A national survey	Marck <i>et al.</i> <sup>[22]</sup>	cross-sectional survey	Australia	811	2012	Education to improve knowledge on brain death and facilitate organ donation	ambiguity and lack of knowledge about brain death
12 Attitudes to organ donation among Swedish ICU nurses	Flodén <i>et al.</i> <sup>[23]</sup>	descriptive study	Swedish	702	2011	Education on brain death diagnosis, interpersonal relationships, and interaction with relatives	Brain death diagnosis and interaction with relatives
13 Stressor experienced by family members in the process of organ and tissue donation for transplant	Cinque <i>et al.</i> <sup>[24]</sup>	descriptive-exploratory study	São Paulo	16	2010	Training courses to prepare nurses in all stage of the process to provide support and reduce distress	Facing family anxious in the donation process
14 Stressors in the nursing care delivered to potential organ donors	Guido <i>et al.</i> <sup>[30]</sup>	exploratory-descriptive study	Brazil	19	2009	Minimizing the effects of stressors with social support, spirituality, and separation of work from personal life	Stressful situations in interacting with families
15 Do nursing students understand the meaning of brain death?	Martínez Alarcón <i>et al.</i> <sup>[4]</sup>	exploratory-descriptive study	Spain	721	2009	Raising awareness regarding the organ donation process and improving education	Lack of knowledge about the concept of brain death

Contd...

**Table 1: Contd...**

Article title	Authors	Type of study	Place	Sample size	Publication date	Strategy	Result (challenges)
16 End of life in the intensive care unit: knowledge and practice of clinicians from Karachi, Pakistan	Salahuddin <i>et al.</i> <sup>[1]</sup>	cross-sectional study	Pakistan	137	2008	Providing ethics educational programs in the curriculum of nurses	Confusions in the definition of brain death,-discrepancies between physicians and nurses, perceptions of the withdrawal of life support
17 The maintenance care of potential organ donors: an ethnographic study on the experience of a nursing team	Lemes <i>et al.</i> <sup>[25]</sup>	ethnographic study	Brazil	17	2007	The education of cultural values for the provision of knowledge by the nursing team	Understanding the meaning of brain death, and determinant cultural values in caring for organ donors
18 Knowledge levels of Korean intensive care nurses towards brain death and organ transplantation	Kim <i>et al.</i> <sup>[26]</sup>	cross-sectional analysis survey	Korean	520	2006	Developing an education program on the concept of brain death, organ donation, and interaction with families	Insufficient knowledge about the criteria of brain death
19 Intensive care nurses' experiences of caring for brain dead organ donor patients	Pearson <i>et al.</i> <sup>[27]</sup>	the phenomenological approach described by Van Manen	Australia	20	2001	Further research to uncover the experiences of nurses in organ donation	Conflicting in the diagnosis of brain dead and ambiguity of the death
20 The nurse's knowledge, awareness, and acceptance of tissue-organ donation	Ozdogan <i>et al.</i> <sup>[7]</sup>	a prospective and semi-analytical study	Turkey	25	2001	Need for education about all aspects of brain death and organ donation	Lack of knowledge and education
21 Nursing care for brain dead patients who are potential organ donors	Cavalcante <i>et al.</i> <sup>[28]</sup>	a descriptive and qualitative approach	Brazil	30	2014	Addressing the technical dimensions of care for organ donors and their families	A significant concern for technical procedures of keeping the organ donor hemodynamic to accelerate the process

\*Intensive care unit

### Concept of brain death and brain death diagnosis

This category of challenge includes doubts about perceptions of the concept of brain death, uncertainty, and ambiguity about understanding the concept of brain death,<sup>[1,15,27]</sup> ambiguity and various perceptions of brain death diagnosis,<sup>[13,21,23]</sup> in addition to the diversity of its diagnosis.<sup>[23]</sup> This complicates the perception of the concept and diagnosis of brain death by nurses and affects the process of brain death care.

### Strategies

Strategies for resolving this challenge include supportive working environments facilitating the expression of dissonant perceptions,<sup>[15]</sup> and managers' responsibility in the organizational framework for providing education regarding the concept of brain death and its diagnosis and knowledge concerning brain death.<sup>[13,21,23]</sup>

### Discrepancies between physicians and nurses

This category of challenge includes conflicts between the doctors and nurses due to stress caused by doubts about the diagnosis of brain death and various aspects of donation in nurses, to the extent that some nurses experience mental preoccupation, and fear of failure. Discrepancies between physicians' and nurses' perceptions of the withdrawal of life support, result in disturbances in ward.<sup>[1,17]</sup>

### Strategies

The strategy for resolving the challenge of discrepancies between physicians' and nurses includes a plan which consists of studying interpersonal relationships along with interactions with physicians.<sup>[23]</sup>

### Religious and cultural beliefs opposing organ donation

This category of challenge includes the influence of cultural background and religious beliefs on individuals'



attitudes, beliefs, and behaviors. They are influenced by concerns of religious rulings opposing organ donation,<sup>[19]</sup> and determinant or influencing cultural values in caring for organ donors.<sup>[8,29]</sup>

### Strategies

A strategy to resolve this challenge is the managers responsibility in the organizational framework for education on reforming current legislation for organ donation<sup>[16]</sup> and regarding religious concerns to obtain families' consent, and consequently, increase donor consent rates,<sup>[19]</sup> and combining of cultural and religious differences in nursing ethics curricula in addition to the postgraduate curricula,<sup>[1]</sup> educational programs emphasizing ethics and combining cultural and religious differences in their ethics curricula for nurses.<sup>[1]</sup>

### Lack of knowledge about the care process for brain-dead patients

This category of challenge is related to the care process including technical procedures for the hemodynamic maintenance of a possible organ donor,<sup>[14,25,28]</sup> interrelation between other units and the nursing team,<sup>[19]</sup> lack of knowledge about the care process for brain death, nurses' perceptions of their professional responsibility, and role regarding organ donation.<sup>[7,9,16,21,22,26]</sup> These issues cause severe care tensions in nurses, lack of knowledge can lead to prolongation of the patient care process, and negatively affect the quality of care provided for organ donors.

### Strategies

Strategies for the resolution of this challenge include providing technical, medical, and nursing interventions to prepare a brain dead patient for organ donation,<sup>[14]</sup> managers' responsibility in the organizational framework including support to care dying patients,<sup>[16]</sup> provision of knowledge concerning brain death<sup>[7]</sup> and the donor process,<sup>[21]</sup> provision of support to medical institutions in terms of supplementary training and post-graduation courses with the aim to prepare nurses for professional performance and providing effective care to the families of these patients,<sup>[24,28]</sup> and an action plan which includes studying interpersonal relationships along with team interactions<sup>[23]</sup> and a refresher course every fifth year.<sup>[21]</sup>

### Interactions with families

This category of challenge includes challenging interactions with families and confrontation with conflicting expectations during the organ donation process, and anxiety and stress in family members of brain dead patients.<sup>[13,23,18,20,24,30]</sup> However, due to their inability to interact with the family, nurses are unable to provide emotional support to the family, and therefore, experience extreme tension.

### Strategies

Strategies for the resolution of these challenge to interacting with families include nursing efforts to form

a close relationship with the family within an atmosphere of peace and tranquility,<sup>[14]</sup> managers responsibility for the organizational framework and education on support and communication with the families of these patients (26),<sup>[18]</sup> knowledge enhancement during the care process to prepare nurses for professional performance and providing effective care to the families of these patients.<sup>[24]</sup>

### Psychological, mental, and emotional challenges

This category of challenge includes difficult and stressful situations during the care process of organ donors, and the psychological and mental effects of facing this emotionally demanding situation.<sup>[17,27]</sup> Due to the serious problems nurses experienced in caring for brain dead patients, they had emotional needs during this process.

### Strategies

Strategies for the resolution of psychological, mental, and emotional challenges include providing suitable physical, mental, and working conditions to maintain nurses' health and increase the quality of care in the organ donation process,<sup>[17]</sup> minimizing the effect of stressors by physical activities, social support, spirituality, separation of work from personal life, and addressing the technical and bioethical dimensions of care for better qualification and emotional maturity.<sup>[28,30]</sup>

### Discussion

The present study determined the workload and psychological stress of ICU nurses when providing care to brain dead patients and their families the challenges of which have been described. The most important challenges included doubts about perceptions of the brain death concept and diagnosis of brain death, and lack of knowledge about the care process for brain dead patients.

According to the articles studied, the challenge of "ambiguity of the concept and diagnosis of brain death for nurses" can even lead to failure in donation. Pearson *et al.* found that the ambiguity of a "death statement" is considered to be an area of conflict for nurses in which "no hope of recovery" simply means "real" death.<sup>[27]</sup> Keshtkaran indicated that nurses did not have confidence in the diagnosis of brain death, and thus, were inflicted by a sense of confusion and hesitance.<sup>[2]</sup> Studies demonstrated that the majority of nurses believe they are not well-prepared to provide care for potential organ donors and are worried about maintenance and organ vitality.<sup>[8,11]</sup> Consequently, prolonging the care process can lead to death or loss of vital organs due to the specific and vulnerable conditions of organ donors.<sup>[21,31,32]</sup>

The results of previous studies showed that discrepancies between physicians and nurses in terms of understanding were evident in the process of the disconnection of the patient from mechanical ventilation.<sup>[1,17]</sup> Uncertainty on the diagnosis of brain death by physicians has been the

cause of concern and obsession in nurses and has led to the disconnection of patients from vital signs devices, giving rise to unfavorable emotional states while transferring patients.<sup>[13]</sup> The results of the study showed that one of the challenges for nurses was religious concerns about brain death and organ donation.<sup>[19,29]</sup> Ignoring these issues can lead to a prolonged process and would have unintended effects on the quality of care for brain dead patients.<sup>[9]</sup> Interactions with families were the most stressful situations for nurses during caring for brain dead patients<sup>[18]</sup> because the organ donor was considered as a disappointing tragedy for a number of nurses.<sup>[33]</sup> Studies have shown that nurses suffered from a sense of hopelessness and inefficiency due to the stress of caring for these patients and such feelings could negatively affect the quality of patient care and lead to sense of punishment and failure of nurses.<sup>[13]</sup>

To overcome these challenges, the results of studies showed that providing suitable physical, mental, and working conditions through minimizing the effects of stressors with physical activity, social support, spirituality, and separation of work from personal life is necessary to maintain nurses' health and increase the quality of care in the organ donation process.<sup>[13]</sup> The study by Ozdag *et al.* showed that providing education about all aspects of brain death and organ donation<sup>[7]</sup> with a refresher course every fifth year is a matter of great necessity.<sup>[21]</sup> Therefore, recognizing and determining such challenges can be an important step in taking accurate care of brain dead patients, and consequently, ensuring the viability of the organs for transplants.

The limitation of this study was that only publications in PubMed, Science Direct, SID, and Google Scholar databases from 2000 to 2018 were evaluated, and articles published in other databases and outside of this timeframe were not included.

## Conclusion

The results of this study revealed that nurses are faced with challenges and tension in the process of caring for a donor brain dead patient. Therefore, despite the fact that nurses must be able to manage care to preserve the organs, these challenges create limitations in the process of care for these patients by threatening the health of organs for donation or causing the loss of the organ donor in some cases due to discrepancies. Moreover, transplantation statistics are still low due to the number of brain deaths, and maintaining the health of organs for transplantation. Therefore, identification of challenges in managing and understanding, supplying nurses with medical, clinical, and ethical educational programs to increase their knowledge, and providing them with special support programs regarding brain death can be effective in the quality of care for brain dead patients and accelerate the donation process. Furthermore, it is recommended that further research, in particular qualitative research based on the experiences of

nurses, be performed to explore the challenges faced by nurses during the process of care for brain dead patients.

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## Conflicts of interest

Nothing to declare.

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