Meaning of nursing care to brain dead potential organ donors

Significados do cuidado de enfermagem ao paciente em morte encefálica potencial doador

Significados de cuidado de la enfermería al paciente en muerte encefálica potencial dolor

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ABSTRACT
Objective: To understand the meanings of care to brain dead potential organ donors for nurses, develop and construct a theoretical model.

Method: Qualitative study based on the Grounded Theory approach. Data were collected through structured interviews with 12 nurses, distributed in three sample groups in a university hospital in northeastern Brazil, from December 2010 to June 2011.

Results: The phenomenon Unveiling multiple relationships and interactions of nurses in the complexity of patient care in brain dead potential donors is supported by the interrelationship of five categories and results from the need to organize care practices in the context of the intensive care unit, considering the factors involved in the relationship between nurses, staff and family and reveals challenges for nurses imposed by the complexity of the care process.

Conclusions: The meaning of care to brain dead potential donors involves understanding the complexity of this patient who can save somebody’s life through organ donation.


RESUMEN
Objetivo: Comprender los significados de cuidado al paciente en muerte encefálica potencial donador para enfermeras, y construir un modelo teórico.

Método: Estudio cualitativo sustentado en la Teoría Fundamentada nos Dados, realizado en diciembre/2010 a junio/2011, por medio de entrevista abierta con 12 enfermeras de Hospital Universitario, distribuidos en tres grupos amostrales.

Resultados: El fenómeno Revelando múltiples relaciones e interacciones de las enfermeras en la complejidad de la atención al paciente en muerte encefálica potencial donador sustenta-se por cinco categorías y emerge de la necesidad de organización de las prácticas de cuidado en el contexto de la unidad de terapia intensiva, considerando los factores involucrados en la relación entre enfermeras, equipo y familia y revela desafíos para el enfermero diante de la complejidad del proceso de cuidar.

Conclusiones: El significado del cuidado al paciente en muerte encefálica potencial donador está en entender su complejidad para además de un ser muerto, mas como gerador de vida por medio de la doación de órgans.

INTRODUCTION

Care originates from the desire to perpetuate our species. It is a value, a social asset, the product of an organizational care system, that involves multiple human interactions established between nurses and patients, their families, as well as with other professionals, to assist humans in their health-disease process(1), as well as in their death.

The setting of the Intensive Care Unit (ICU) is characterized by advanced technological equipment, critically-ill patients and frequent life-threatening situations. At the ICU, nurses must establish relationships with other professionals to deliver effective care.

In this critical environment, nurses provide care to patients affected by various pathologies such as stroke, as well as to patients with multiple injuries who sometimes progress to brain death, requiring intensive and specific care(2).

It is estimated that the percentage of cases of brain death is 60 per million inhabitants per year, corresponding to 12% of the deaths occurring in the Intensive Care Unit of a large general hospital. In Brazil, 7,981 cases of brain death were reported until September 2017(3).

Researchers(4) report that caring for brain-dead potential organ donors requires greater physical and mental demands from health professionals compared to other patients admitted to ICU.

Regarding brain death, some studies(5-8) have focused more on the care to potential organ donors and on the pathophysiology of brain death, to the detriment of the nurses’ perception of care to such patients. It should be stressed that nursing care to these patients is essential, especially in the management of pathophysiologic changes inherent in brain death and in hemodynamic monitoring, and this is directly associated to the effectiveness of organ donation.

Other studies reported that the different perceptions of nurses who deliver care to brain-dead patients may impact the probability of conversion of potential donor organs into to effective donors(9-10).

Also, a study conducted in Iran(11) reported that nurses are involved in an atmosphere of ambiguity and doubt when they care for brain-dead potential organ donors. There is confusion and hesitation about the diagnosis of brain death, and this may even lead to hope in reversing the patient’s condition. It is as if they were waiting for a miracle.

Therefore, the research problem was defined based on the following question: What does it mean for you to take care of the patient in brain death?

The process for composing the sample is called theoretical sampling. In this process the researcher collects, encodes and analyzes their data, deciding what data to collect next and where to find them. The groups of participants or sample groups are selected progressively to integrate the sample and are formed according to data analysis, the hypotheses generated and the construction of the categories(12). Three sample groups were formed in this study.

The inclusion criterion used for selection of the participants was nurses’ experience in the care of patients with a diagnosis of brain death, and the exclusion criterion was nurses who performed their activities in ICU or in the tissue and organ procurement service at a University Hospital in Northeastern Brazil, from December 2010 to June 2011. For the collection of data was used the open interview, being guided by the following question: What does it mean for you to take care of the patient in brain death?

METHOD

Article extracted from the master’s dissertation titled “Unveiling relationships and multiple interactions of the nurse in the complexity of care to brain dead patients in ICU”(12) submitted to Universidade Federal de Santa Catarina.

Qualitative research based on the Grounded Theory (PDT) methodology that seeks to understand the meaning of relationships and interactions in the data collected based on the exploration of social phenomena. The process of data collection and analysis is interdependent and occurs concurrently with the objective of identifying, developing and relating concepts, allowing greater involvement of the researcher with the research problem(13).

The research was carried out with the participation of nurses who performed their activities in ICU or in the tissue and organ procurement service at a University Hospital in Northeastern Brazil, from December 2010 to June 2011. For the collection of data was used the open interview, being guided by the following question: What does it mean for you to take care of the patient in brain death?

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Individual interviews (which were recorded on a digital device) were conducted in the workplace or in a location selected by the respondents. Subsequently, the interviews were transcribed and re-submitted to the study participants in order to allow the data to be validated by them, for corrections and additions if they deemed necessary. Data collection and analysis occurred simultaneously, based on comparative analysis, following the steps proposed by the Grounded Theory of open, axial and selective coding (13).

In open coding, the data were analyzed line by line in order to identify each idea / incident / event. At this stage, the preliminary codes were formed. Then, these were grouped according to their similarities and differences, and the conceptual codes were created. In axial coding, the conceptual codes were regrouped to form the subcategories. These, after a new stage of regrouping, formed the categories of analysis, to provide a comprehensive explanation on the phenomenon of care to patients with brain death. In selective coding, the subcategories and categories found were compared and reordered for their integration and association, and for refining the theoretical model, for the emergence of the central category (13).

The paradigmatic model of Strauss and Corbin was used to classify and organize the emergent associations between the categories. This model establishes a relationship between the categories based on the following components: phenomenon, context, causal and intervening conditions, strategies and consequences (13).

According to the analysis process recommended by the Grounded Theory, five categories and twelve subcategories emerged. Interrelated, these categories support the phenomenon “Unveiling relationships and multiple interactions of nurses in the complexity of the care to patients with brain death”.

The study observed the recommendations of Resolution 196/96 (in force at the time of project approval) and 466/2012 of the National Health Council and was approved by the Research Ethics Committee of the hospital where it was conducted under protocol no 3936/2010. An informed consent form was signed by the participants. To preserve participants’ anonymity, their names were replaced by a code, i.e. letter “E” followed by the interview order number (E1, E2, E3, ... E12).

### RESULTS

The understanding of the meaning of care to patients with brain death by nurses of a university hospital allowed to reveal the phenomenon “Unveiling relationships and multiple interactions of nurses in the complexity of care to brain dead potential organ donors”, which was defined by the interrelationship of five categories, as described in figure 1.

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**Figure 1** - Graphical representation of the paradigmatic model. Florianópolis, SC, 2011.
Providing care to patients in ICU

This category was considered the context where the phenomenon develops, being constituted by subcategory “Recognizing the ICU environment as a reference service for the maintenance of patients with brain death who are potential organ donors”. The nurses recognize that the ICU is a reference service for the maintenance of the patient in brain dead potential donor. They emphasize that the partnership with the Intra-hospital Organ Donation and Transplant Tissue Commission (CIHDOTT) is essential because the delivery of care to such patients is facilitated by the presence of nurses from the referred Commission, as they monitor and systematize the assistance, providing care to the patients, and achieving the goal of saving lives through organ donation.

So I think this partnership, the presence of the Commission, is important because it monitors, systematizes care and achieves the goal of saving lives through organ donation (E9).

Being responsible for organizing care practices in the ICU targeted to patients with brain death

This category triggers the phenomenon and is delimited by the following subcategories: “Establishing the difference between the care delivered to patients with brain death and critical patients” and “Organizing care practices in the ICU.”

According to the nurses, in order to establish care relationships, it is necessary to identify the patients admitted to the unit. The ICU environment includes several types of patients: critically ill patients, patients with potentially recoverable conditions or with negative prognosis, such as patients with brain death requiring permanent care.

The difference in caring for a patient with brain death and a critical patient is related to the motivation of nurses. Such motivation is associated to the prognosis of the patient, as described in the following statement:

[...] when we hear that a patient has a favorable prognosis, the entire team invests in prescriptions or medications. [...] And when we hear a patient has brain death we cease to invest in that patient (E2).

The care to patients with brain death is defined by the nurse as sensitive, difficult to perform, requiring full attention. Moreover, the implementation of such care (support practices) should not be delayed, in order to prevent failure in the organ donation process.

Patients with brain death require constant care. And it has to be done fast, because every moment that is lost and not taken care of, the failure of the process of donation and transplantation is more likely. Patients with brain death need constant care and full attention (E5).

Given the differences between the care required for patients with brain death and critical patients, nurses must organize the care practices in the ICU. To maintain the hemodynamic stability of the patient in brain dead potential donor, both ICU nurses and CIHDOTT nurses organize the care practices for these patients.

Intervenient conditions in the care to patients with brain death

This category is an intervening condition in the process of care to patients with brain death. It is composed of the following subcategories: “Identifying the elements that facilitate care to patients with brain death” and “Listing the elements that complicate care to patients with brain death.”

Nurses’ reports point to several elements that facilitate the care to patients with brain death, with emphasis on professional training, interaction and reception of the patient’s family, motivation to care, support of the Brazilian legislation to organ donation and transplant, presence of the CIHDOTT in the ICU and increased awareness of organ donation among health professionals, according to the following reports:

And to ensure the stability of the patient with brain death, in addition to the administration of drugs and the use of supportive devices, attention and perception of the professional are extremely important [...] And this stability also depends on the attention, the perception, the agility and the activities performed with him (E1).

I believe that well play the role as nurses is a matter of training on the use of techniques and procedures (E2).

I think that it is easier to care for a patient with brain death who is a donor. [...] When the patient is a potential donor, when the family accepts the donation, it is easier because I feel more motivated. This patient will benefit other people (E3).

The legislation on brain death was a way for the Ministry of Health to standardize so that all speak the same language concerns. Standardized procedures facilitate the delivery of care (E5).
I think there has been a breakthrough in the care to patients with brain death. Firstly, because the tissue and organ procurement service raised the awareness of nurses on this issue, and due to the presence of these commissions in the ICU. [...] People are more aware of this issue and are adopting this routine of systematization of care to patients with brain death (E9).

The nurses reported emotional and physical overload, inadequacy of the human resources dimension in the ICU, duality (person x professional lives of the nurse), lack of training to perform technical procedures and lack of emotional preparation to deal with these patients, logistics of the donation process and training of health professionals as aspects that complicate the process of caring for patients with brain death.

Managing a patient with brain death is a little bit difficult for me. [...] When a bond is established with the patient, it is worse. And I didn’t know exactly what to do. What are the parameters for blood pressure, diuresis, etc.? We were not taught how to manage patients with brain death in college [...] The information provided was very superficial (E3).

The first obstacle in the process of care to brain dead patients is the lack of intensive care physicians. The second obstacle is the lack of equipment to monitor the patient (E8).

Another difficulty reported by the respondents is that the care process is permeated by the distance between health professionals and the patients. There are situations in which these patients are overlooked and receive insufficient care. There is a weak bond between nurses and patients. This occurs more frequently when these patients are not donors, and it is characterized by nurses as a failure in care.

I noticed this lack of care with brain dead patients at the ICU. Over time I realized that this care was not appropriate and right. One explanation for this situation is the unwillingness of nurses to spend so much time and efforts in brain dead patients (E2).

The ICU nurses recognize that such situation is not caused by neglect, but rather by lack of knowledge and inadequate emotional preparation to deal with the patients. The respondents emphasized that such inadequate care provided to patients with brain death jeopardizes the organ donation process.

Incorporating strategies to care for patients with brain death

The subcategories “Incorporating scientific knowledge into care to patients with brain death”, “Pointing care attitudes of the nurses and the staff regarding patients with brain death”, “Incorporating attitudes to mitigate the frustrations of the process of care to patients with brain death” and “Ensuring care to patients with brain death through the tissue and organ procurement service of the hospital” are considered strategic elements incorporated by nurses to deliver care for these patients.

The ICU nurses incorporate the scientific knowledge and attitudes in their care practice to deliver high quality care to in order to maintain the stability of brain dead patients. The respondents stressed that all their activities are carried out with responsibility, dedication and professionalism to preserve hemodynamic conditions favorable to the transplant. They said they do the “best they can” to provide effective care. They take care of these patients with dignity, respect and professionalism, and feeling “emotionally strong” to provide better assistance to them.

We are responsible for keeping the patients stable [...] the success of the transplant will obviously depend on our actions. We are supposed to maintain all the vital conditions favorable to the transplant, we must do our best. [...] In the case of the patients with brain death who are potential organ donors, I always feel responsible for maintaining and stabilizing the patients. We do our best. We do everything we can (E1).

So I had to study and gain knowledge on the process to ensure the maintenance of that life (E3).

And to manage these patients with brain death we must be much stronger emotionally (E10).

The subcategory “Ensuring care to patients with brain death through the tissue and organ procurement service of the hospital” addresses the role of the nurse in the CIHDOTT and in the Transplant Center. In summary, it depicts the strategies used to organize the care provided to brain dead patients such as active search of this patient in ICU, interaction with the multidisciplinary team, implementation of care protocols, clinical case discussion by the health team and educational activities on brain death. Nurses recognize that education is the primary strategy for organizing care.
The strategies used to organize the care to patients with brain death concern the active search in daily practice [...]Education is the primary strategy to organize the care practices in the management of these patients. We have taught some classes in the ICU and we have already noticed that this has made the difference in the care provided by the team (E5).

There are other strategies for organizing care practices to manage brain dead patients such as clinical case discussions; not only lectures, but classes on the subject. [...] I think clinical case discussion by the multidisciplinary team is essential. Education is important (E6).

The protocol contributes to the systematization of care to patients with brain death. When there is a protocol of brain death to be followed, we know what it has to be done with this patient (E9).

Emergence of the complexity of care to brain dead potential organ donors

This category is a consequence of the phenomenon supported by the following subcategories: “Emergency of feelings and reactions of nurses in the process of care to brain dead potential donors”, “Pointing out the complexity of care to brain dead potential donors” and “Advances in care practices to brain dead potential donors”.

In subcategory “Emergency of feelings and nurses’ reactions to the process of care to brain dead potential donors”, ICU nurses report the emergence of feelings of well-being, frustration, sadness, anguish and several other responses in this care relationship. The professional called them “miscellaneous feelings”, as described in the following statement:

There [in the ICU] we don’t cry because there is so much to be done and we spend a lot of time in those activities [...] When we perform these activities, we feel good, but we also experience sadness; in fact, we experience miscellaneous feelings and emotions (E1).

In subcategory “Pointing out the complexity of care to brain dead potential donors” we realize that the complexity lies in understanding why a dead patient requires so much care from health professionals. Moreover, this complexity being requires the complementary action of a multidisciplinary health team in the process of organ and tissue donation and transplant. This teamwork is valued by the nurses who compare it to a gear system.

Patients with brain death were no longer seen as easy-to-handle patients that were about to die and began to be perceived as patients that demand a lot of care. I remember that once there was only concern with support practices. Control of central venous pressure, mechanical ventilation. [...] Now careful hydration and fluid replacement is performed whenever necessary. That is, now these patients require much more care than some critically-ill patients (E5).

I realize that people have a different view of the care to be provided to brain dead patients. I think it’s much better now. In the past, health professionals were not very concerned with these potential donors (E6).
The participants described the ICU as an environment that favors the maintenance of patient with brain dead potential organ donors. Studies corroborate this finding and show that care to these patients should preferably be performed in the referred sector, as it provides specialized and continuous care, materials and technologies necessary to the diagnosis, monitoring and treatment of patients with brain death. When they experience the possibility of donation is not taken into account the healthcare team is less likely to invest in care to these patients. To ensure proper maintenance, it is necessary to organize the care practices, which includes the management of care and the work team.

The organization of care practices by the CIHDOTT nurse involves identifying the needs of the potential donor; implement, evaluate and monitor care results. These steps do not differ from those traditionally conducted in the care to critical patients. However, the difference lies in the agility and the “race against time” faced by health professionals in the process of caring for brain dead patients, because the pathophysiological and hemodynamic disorders related to brain death are variable and are directly related to the success of the process of organ donation and transplant.

The care provided to patients with brain death does not differ from that provided to other patients and requires sensitivity, involvement, empathy, attention, perception and scientific knowledge of health professionals. This ensures efficient and resolute care to the patients and their families. Qualification, as well as learning and on the job training of ICU professionals also facilitates the delivery of appropriate care to these patients.

A conflicting issue for the nurses interviewed was the diagnosis of brain death. It is difficult to understand this diagnosis, as well as accept brain death because these patients are declared dead but exhibit signs of life - heartbeat, warm skin and lung movement - even if these signs are maintained through artificial means.

This situation generates a feeling of confusion, and is a major source of stress for nurses, which may interfere with their actions, as demonstrated in other studies.

Also, some nurses do not prioritize potential tissue and organ donors because they think that recoverable patients deserve more attention. Nurses tend to neglect brain dead patients because of their irreversible condition.

In addition, caring for this patient embodies the dichotomy between life and death. When they experience the process of care to brain dead patients, nurses become aware of the fragility of their lives, of their own finitude and the possibility of experiencing this situation with their relatives and friends. Thus, it is difficult to accept death as part of the human condition. This difficulty is maximized when links are established between nurses and patients.

The lack of material resources, equipment, medicines and even qualified professionals prevents the team from providing adequate care. The lack of a good doctor-nurse relationship also interferes directly with the care provided. These complicating factors demonstrated here are consistent with the literature.

ICU and CIHDOTT nurses, as well as the other members of the multidisciplinary health team should have technical and scientific knowledge to ensure the maintenance of the hemodynamic stability of potential donors, providing better care, with dignity and respect, to turn brain dead patients into effective organ and tissue donors. Moreover, health professionals should be aware of the care process and of the adequate execution of all the steps, to ensure that well-preserved organs and tissues are available for a safe transplant process. Education is a determining factor for the success or failure of the donation and transplant process, with the training, courses and lectures being key strategies to the operationalization of care.

The experience of taking care of patients with brain death arouse “miscellaneous feelings” in the nurses, which include emotions that pervade all care actions. Similar findings identified in a study carried out in southern Brazil. Ambiguous feelings can be related to the multidimensionality of nursing professionals who incorporate physical, biological, social, cultural, mental and spiritual aspects that impact the process of care.

The respondents perceive brain dead potential donors as dead persons who must be connected to different devices and equipment, requiring the same level of care provided to critical patients, to ensure their hemodynamic stability for the purpose of organ and tissue donation. The nurses’ challenge is to change the perception of these patients as individuals who no longer need care because they were declared dead, recognizing them as potential life-saving donors. The complexity of care to brain dead patients consist in becoming aware that these patients simultaneously incorporate life and death.

The actions of nurses of the CIHDOTT targeted to complex patients such as brain dead potential donors of organs and tissues must be integrated to those of the interdisciplinary team of the ICU to ensure integral care that meet the specificities of these patients. In fact, nurses must go beyond the limits of their technical knowledge and seek
dialogue with the other health professionals, who are supposed to participate in the care process to ensure integral care to the referred patients.

Thus, the phenomenon “Unveiling relationships and multiple interactions of nurses in the complexity of care to patients with brain death” emerges as a synthesis and response to the care actions performed in a university hospital. The nurses recognized that the experiences of caring for patients with brain death have changed the conception of care and professional attitudes, as they incorporated new attitudes, knowledge and skills to the process of care to these patients.

CONCLUSION

The present study investigated the meaning of care to brain dead potential organ donors for nurses of a university hospital, which allowed the formulation of an explanatory model for the phenomenon “Unveiling relationships and multiple interactions of nurses in the complexity of the care to patients with brain death”.

This model is defined by the context of ICU care, motivated by the organization of ICU care practices in patients with brain death. Its intervening conditions that facilitate the delivery of care to these patients are professional qualification, interaction and reception of patient’s family, motivation to care, support of the Brazilian legislation for organ donation and transplants. The greatest obstacle to the implementation of this care is the distance between the health professional and patients with brain death. The component strategy stressed the incorporation of attitudes of responsibility and dedication to address the complexity of these patients. The component consequence was identified through the revelation of the complexity of the patients and the need for interdependence of care practices.

The complexity of this care suggests a change in the way potential brain dead donors are seen and cared for: that is, they are no longer perceived as patients declared dead but rather as generators of life through organ donation. Thus, the complexity of care to patients with brain death allows to glimpse new possibilities and adopt different attitudes concerning the delivery of care to the referred patients.

Although this study is based on the experience of health professionals, its limitation is methodological, as it concerns the specific context of a university hospital in northeastern Brazil, not allowing generalization of its results. It is believed that future studies in other scenarios with different characteristics (considering that our country has continental dimensions) will encourage discussions about the influence of these results on the relationships of care to patients with brain death, especially organ donors. Such discussions may generate a solid theoretical framework to guide teaching, research and care practices for these patients, also contributing to advances in the theoretical knowledge on nursing, health and best practices to patients with brain death and on the process of organ donation.

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