



ORIGINAL


Factors that influence the care of family members of patients with brain death

Fatores que influenciam no cuidado dos familiares de pacientes em morte encefálica
Factores que influyen en el cuidado de los familiares de pacientes con muerte encefálica


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ABSTRACT

Objective: to understand the intervening factors resulting from nursing care to family members of patients diagnosed with brain death. **Methods:** this is a qualitative study with theoretical and methodological contribution in Grounded Theory (PDT). The study scenario was the Intensive Care Unit of a reference hospital in the care of patients in brain death and in organ and tissue donation in southern Brazil. Data collection occurred from September to November 2014, composing the theoretical sampling of 23 participants distributed in three sample groups. **Results:** the intervening factors identified were: the family members did not have clarity about the diagnosis of brain death and, consequently, the whole process of organ and tissue donation. The recognition of these factors evidences nursing as an indispensable profession and science in this context. The Intra-Hospital Commission for Organ and Tissue Donation for Transplants is an important resource for the instrumentalization of Nursing, in the care and approach of family members of patients diagnosed with brain death. **Conclusion:** the recognition of these factors by nurses can guide and optimize clinical nursing practice in this context, contributing to more agile, safe and assertive processes.

Descriptors: Brain Death. Nursing. Nursing Care. Family.

RESUMO

Objetivo: compreender os fatores intervenientes decorrentes do cuidado de Enfermagem aos familiares de pacientes com diagnóstico de morte encefálica. **Métodos:** estudo qualitativo com aporte teórico e metodológico na Teoria Fundamentada nos Dados (TFD). O cenário do estudo foi a Unidade de Terapia Intensiva de um hospital referência no cuidado ao paciente em morte encefálica e na doação de órgãos e tecidos no Sul do Brasil. A coleta de dados ocorreu de setembro a novembro de 2014, compondo a amostragem teórica 23 participantes distribuídos em três grupos amostrais. **Resultados:** os fatores intervenientes identificados foram: os familiares não possuíam clareza acerca do diagnóstico de morte encefálica e, conseqüentemente, de todo o processo de doação de órgãos e tecidos. O reconhecimento desses fatores evidencia a Enfermagem como profissão e ciência indispensável nesse contexto. A Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos para Transplantes é um recurso importante para a instrumentalização da Enfermagem, no cuidado e abordagem dos familiares de pacientes com diagnóstico de morte encefálica. **Conclusão:** o reconhecimento desses fatores pelo enfermeiro pode orientar e otimizar a prática clínica de enfermagem nesse contexto, contribuindo para processos mais ágeis, seguros e assertivos.

Descritores: Morte Encefálica. Enfermagem. Cuidados de Enfermagem. Família.

RESUMÉN

Objetivo: comprender los factores intervenientes resultantes del cuidado de Enfermería a familiares de pacientes diagnosticados con muerte encefálica. **Métodos:** estudio cualitativo con apoyo teórico y metodológico Teoría Fundamentada en los Datos (TFD). El escenario del estudio fue la Unidad de Cuidados Intensivos de un hospital de referencia en el cuidado de pacientes con muerte encefálica y en la donación de órganos y tejidos en el Sur de Brasil. La recolección de datos ocurrió de septiembre a noviembre del 2014, componiendo la muestra teórica de 23 participantes distribuidos en tres grupos de muestra. **Resultados:** los factores intervenientes identificados fueron: los familiares no tenían claro el diagnóstico de muerte encefálica y, en consecuencia, de todo el proceso de donación de órganos y tejidos. El reconocimiento de estos factores destaca a la Enfermería como profesión y ciencia indispensable en este contexto. La Comisión Intrahospitalaria de Donación de Órganos y Tejidos para Trasplantes es un importante recurso para la instrumentalización de la Enfermería, en el cuidado y abordaje de los familiares de pacientes diagnosticados con muerte encefálica. **Conclusión:** el reconocimiento de estos factores por parte de los enfermeros puede orientar y optimizar la práctica clínica de enfermería en este contexto, contribuyendo para procesos más ágiles, seguros y asertivos.

Descriptor: Muerte Encefálica. Enfermería. Atención de Enfermería. Familia.

INTRODUCTION

Nursing is a science and profession that has individual and collective ethical and social responsibilities, based on the care and protection of human needs. In addition to integrating knowledge, techniques and other medical and technological aspects into its practice, it should transform them, aligned with science and innovation. ⁽¹⁾ Another important aspect of nursing's performance in human health care is the continuous presence at the bedside, which configures these professionals as indispensable in the health care of the population. ⁽²⁾

The nursing education and their respective professional practice are guided, according to National Nursing Curriculum Guidelines and Law/Decree of Professional Nursing Practice in humanistic and ethical principles, with social responsibility, commitment to citizenship and to integral and holistic health, as it recognizes the multidimensionality of the human being. This approach implies caring for the individual in its entirety, comprising the brain and spirit, body and mind, reason and emotion, as a singular and plural individual that is part of a dynamic and interconnected whole. ⁽³⁾ Therefore, nurses, when caring for human beings in their practice, imply to care even for their relatives regardless of the context of care.

In the context of Brain Death (BD), the care provided to family members is redoubled, because in addition to all the complexity of the pathophysiology of BD, they are part of the process of organ and tissue donation for transplants. The BD is characterized according to Resolution No. 1,480 of the Federal Council of Medicine, the irreversible loss of known cause of the brain and its confirmation should be performed by means of neurological examinations over the specific time interval, including elements such as: apperceptive coma, fixed and unreactive pupils, absence of corneal-eyelid reflex, absence of oculocephalic reflexes, absence of responses to caloric tests, absence of cough reflex and apnea. ⁽⁴⁾ Complementary tests should unequivocally present no electrical, metabolic and cerebral perfusion activities. ⁽⁵⁾

Faced with a positive diagnosis for BD, all the efforts of the multidisciplinary team and even nursing are to enable organs and tissues for the donation and transplantation process. Thus, in addition to the actions of nurses and the health team, it is necessary to stabilize and not compromise this organism, and also to communicate the family members and question them about the permissiveness to start the donation process, as provided for in Law 10.211/2001. ⁽⁶⁾

Although several advances have been made in recent years in this field of the health sector in Brazil, evidencing it as a country with excellent rates and even reference of organ and tissue donation for transplants in the world, the discrepancy between the number of potential donors and real donors is still evident. This is mainly due to the refusal of family members of patients in brain death. ⁽⁵⁾

Thus, the importance of family members in this context of acceptance of organ and tissue donation for transplants is indisputable and studies in this reality become indispensable over the time. In the face of the above, the present study aims to recognize and understand the interventions resulting from nursing care to the relatives of patients diagnosed with brain death.

METHOD

This is a section of the study entitled "Meaning of Patient Care in the Brain Death Process for Nurses of an Intensive Care Unit in Florianópolis/SC", which had as theoretical-methodological contribution the Theory Based on Data from the Straussian aspect, which allows us to understand the social phenomena from the perspective of the meanings of actions, relationships and interactions between the subjects of certain realities. ⁽⁷⁾ That is, this is a qualitative study.

Data collection was developed in an ICU of reference hospital in the care of patients in Brain Death and in the donation of organs and tissues for transplants in southern Brazil, through open and individual interviews, in the participants' workplace, reserved environments, recorded with the aid of an electronic voice audio device. The theoretical sampling of this study was composed of 23 participants distributed in three sample groups.

The first sample group was composed of nine nurses who met the inclusion criteria: being an intensive care nurse, who has been working in the sector for at least six months and who already has experience in patient care in BD. The opening of the dialogue with this sample group was guided by the question: "How do you mean the care directed to the patient in the process of brain death in the ICU?".

From the analysis of the data of the first sample group, it was possible to perceive the constant performance in the team of the Intra-Hospital Committee for Organ and Tissue Donation for Transplants (CIHDOTT) and the importance of these professionals for patients, nursing and health. Besides to facilitating the operationalization of the brain death process. Thus, the second sample group was composed of four nurses who met the inclusion criteria: nurses working at CIHDOTT for at least six months. The opening of the dialogue was preceded by the question: "How do you, a nurse at CIHDOTT, mean and experience the process of caring for a patient in BD?".

The data analyzed from the second sample group emphasized the nurse's academic education. Thus, in order to understand the importance of nursing education from the perspective of caring for patients in the process of BD and achieving greater theoretical consistency, the third sample group was made up of ten participants, among which five newly graduated nurses who met the inclusion criteria: having experienced BD during training, and five professors of the Undergraduate Nursing Course of a public university who met the inclusion criteria: experience in ICU and patient care in BD. The interview with new-graduates were based on the

question: "Talk about your experience in the process of patient care in BD during graduation". With the teachers: "Tell me about your experience in the process of patient care in brain death from the teaching perspective".

The exclusion criterion adopted for the development of this study was to be away from work/course, for any reason, during the period of data collection. The repetition of information about the studied phenomenon and the absence of new important elements for the analysis and consolidation of categories and subcategories in their properties and dimensions made it possible to obtain the theoretical saturation of the data.

The data analysis process took place concomitantly with data collection, and began with open coding, followed by axial coding and finally selective coding, as recommended by TDF. The NVIVO® 10 software was used to organize the collected data and contribute to the analysis and coding processes. The analytical process, systematized according to the paradigmatic model, consists of five components: context, causal conditions, intervention conditions, strategy and consequence. ⁽⁷⁾ These components explain and support the phenomenon: "Recognizing multi-professional work as a potentiator of organ and tissue donation for transplants". Considering the relevance of the findings identified in the "Intervention" component, represented by the category "Caring for family members of patients diagnosed with Brain Death", we chose to explore and deepen their concepts and discuss them with the scientific literature. It is noteworthy that the study sought to respect the items of recommendations of the Consolidated criteria for reporting qualitative research (COREQ).

The development of this study met the precepts of Resolution No. 466 of 2012 of the Brazilian National Health Council and was approved by the Research Ethics Committee of the State Health Secretariat (SES) of Santa Catarina under protocol no. 2014/0010. The participants were informed about the objectives and methodology of the study, as well as signed the Free and Informed Consent Form (TCLE). ⁽⁸⁾ To maintain anonymity, their speeches were identified by letter of the alphabet - letter E corresponding to nurses; C, to nurses of CIHDOTT; EG, to nurses who experienced BD during graduation; and D, for nursing professors - followed by the number of interviews.

RESULTS

The data analyzed showed important intervening factors in the care provided by care nurses in the Intensive Care Unit (ICU) to the relatives of patients diagnosed with Brain Death (BD).

Regarding to the subcategory "Perceiving the misunderstanding of family members about the diagnosis of BD", the participants when caring for family members perceive that they have difficulty in understanding the diagnosis of BD, especially due to signs such as respiratory movements and heartbeats are still present in their relatives, even after the

diagnosis given by the health team, according to the following reports.

It is a very painful moment for the family and complicated, because with a beating heart, which is culturally the expression of life, how to pass on to this family that that relative is dying? (ED1)

We realize that families have difficulty understanding, even understanding this diagnosis. Especially when they notice heartbeats, breathing movements, warm hands. And they question us if the diagnosis is true. (EI3)

This difficulty in understanding the diagnosis of BD by family members contributes to the slowness and bureaucratization of the process of organ and tissue donation for transplants, because furthermore to experiencing grief, family members also experience the uncertainty of death, since they are unaware of the pathophysiology of BD. Thus, it is even more difficult for care nurses to approach family members about organ and tissue donation for transplants.

A challenge is having to inform them about organ donation, I think it's a difficult time for both the team and the family. Above all, because of the sadness and grief they experience due of the death of a family member. Uncertainty is also present, precisely because of the diagnosis of brain death. They don't know the physiology of brain death, right? (E4)

I find a role that very difficult, right? Of you being approaching the family, requesting that in this moment of mourning, loss of the family member she may be agreeing and accepting the donation of an organ, part of the loved one. (ED1)

In this sense, the data also pointed out that it is of paramount importance to keep family members informed about the whole process of BD, to suppress anguish, anxiety and improve the understanding of the whole process. The participants stated that the better the understanding of the whole process for the family member, the better the acceptance of organ and tissue donation, especially because it is the responsibility of the family members to accept or refuse the donation of organs and tissues for transplantation purposes.

As nurses, we need to be clarifying and informing all procedures for this family, all step by step, in order to reduce anguish, anxiety, uncertainty, including sadness. (EI6)

Clarifying the family, informing it to understand the diagnosis of brain death, the protocol, and the process of organ and tissue donation for transplants, I believe that the process has everything to work. (EI9)

Table 1 - Study Summary: Category and subcategories Florianópolis, SC, Brazil, 2014

INTERVENTION COMPONENT	SUBCATEGORIES
Caring for family members of brain death patients	Perceiving the misunderstanding of family members about the diagnosis of BD
	Evidencing nursing in caring for the relatives of patients diagnosed with BD
	Instrumentalizing to care for the relatives of patients diagnosed with BD

Source: Elaborated by the authors, based on the study data.

The subcategory "Evidencing Nursing in caring for family members of patients diagnosed with BD" reveals that it is up to the care nurse to inform, guide and care for the relatives of patients diagnosed with brain death, because they are experiencing a moment of pain and mourning, providing respect and qualified listening, thus contributing to humanized nursing care in the ICU. Another aspect reported by the participants is that to the detriment of the other professionals of the ICU health team, the nurse is the professional who has the most ties with family members, largely because of the inherent characteristics of the profession.

Care, I think nursing has more this part of humanization, of the family, of talking, of I think that this concern ... [...] I think we also have to know how to listen a lot, have a qualified listening, because sometimes the family is more distressed like this, because they have to leave, respect their pain, listen to their opinion. (E19)

The differential of nurses in relation to other professionals in patient care in BD is to have more contact with the family, I think it is more related to the family, the nurse has more this communication with the family, [...] we learn this. Learn to take care of the patient as a whole, with holistic gaze. And family is part of it. (E17)

However, one factor that directly influences the care of family members is the work overload of ICU care nurses. The data showed that the nurse tries to spend time to care for family members, nonetheless, because of the work overload, care nurses understand that this time spent to care for family members will never be enough, given the complexity that is to care in this context.

We don't realize it's the attention to this family, not that we don't stop and don't go to the family, don't go to talk, but it's never enough, it's never enough, because I think families would need more attention, only we can't handle it. (E10)

The nurse has tasks such as managing the nursing team, managing material and physical resources of the ICU, articulating the entire multidisciplinary team in the ICU, in addition to performing care activities directly to patients. Because of all the demands of nurses, here in the ICU, it is a little difficult to give a more comprehensive, more complete attention, let's say so. Understand? Because of this overload of assignments. (E16)

Additionally, the following reports evidenced the lack of preparation of nurses to deal with the relatives of patients diagnosed with brain death. In general, the training of nurses does not contemplate the process of brain death or prepare them for the communication of bad news in a substantive way and, consequently, the communication of brain death is also compromised.

I believe that it should be better cited and clarified as the protocol happens and clarified, especially as is the process of giving bad news. (E2)

The graduation does not prepare, I would like to take a preparatory course of bad news and read more about the subject to know how to act with family members in these cases. (E2)

I do not feel prepared to dialogue with the patient's family in BD. I think the graduation left a little to be desired. (E3)

Finally, the subcategory "Instrumentalizing to care for family members of patients diagnosed with BD" unveils that it is common for health professionals, especially nurses, to seek to improve their knowledge about brain death, to better instrumentalize this scenario or use other instruments to assist them in this process, such as the Intra-Hospital Commission for Organ and Tissue Donation for Transplantation (CIHDOTT), multi-professional team, qualified to deal with and operationalize brain death processes and, mainly, the donation of organs and tissues for transplants.

Our difference is the management with the family member who, often, the care nurse does not have the “tino”, does not have the profile of attending this type of family member and we are trained for this. (C3)

The CIHDOTT knows how to be following this family, so they have this training, they are more involved with this reality, they are the most educated to do so. (E16)

The data shown below also elucidate that taking care of the patients' relatives in the brain death process in a way that meets their expectations, means enabling a possible acceptance in the process of organ and tissue donation for transplants. Thus, communication, when not performed adequately can negatively influence the decision of organ and tissue donation of the family member who is in brain death.

We also have to be careful about how we are treating the family, how we are communicating, how we are taking this diagnosis of BD to family. How we're approaching this family. (E13)

Thereby, the communication and awareness of and with family members is not the responsibility only of care nurses and/or health team professionals, but of all professionals who are inserted in the hospital environment. It is of paramount importance that all these professionals are also sensitized about brain death and the importance of organ and tissue donation for transplants in the country's health context, as reported below.

I think everyone has to be trained, from the people who have this first contact with family members, the bookkeeping, the issue of porters, doctors, nurses, technicians, I think this guidance, this awareness, this care that people should have with family members, how to talk, how to act, I think this could contribute to better support, acceptance in the decision of these family members to donate the organs. (E15)

DISCUSSION

The present study showed, in general terms, the intervening factors resulting from nursing care to family members of patients diagnosed with brain death, among them, the misunderstanding of family members regarding the diagnosis of BD, particularly due to signs such as heartbeat and respiratory movements if present. In addition to this perspective, a systematic literature review carried out with the objective of understanding the support given to the family of patients diagnosed with brain death performed by the nursing team, showed in its results that the understanding and acceptance of the

family of the diagnosis of brain death becomes more difficult when the patient shows signs of life as breathing, body heat, blood pressure and heartbeat, as these cause confusion and promote life expectancy in family members. ⁽⁹⁾

Keeping family members informed about the diagnosis of BD and the organ donation process is fundamental, because the better the understanding of the family, the greater the chances of acceptance of organ donation. The family's understanding of the diagnosis of brain death is considered a critical point in the care of this patient, and the lack of information provided by professionals makes the diagnosis insufficiently clear, making it difficult and stressful to understand family members. ⁽⁹⁾ A Canadian study conducted with 27 family members who made the decision in the organ donation process showed in their results that the lack of information needed to understand this process, or the lack of understanding about the information make it difficult to make decisions. ⁽¹⁰⁾

Furthermore, to providing care to patients diagnosed with brain death, it is up to the nursing team to guide and care for the patient's family members, who go through grief and experience the pain of the loss of a loved one, thus enabling a possible acceptance in the process of organ and tissue donation for transplants.

The work overload was listed as a fact that directly influences the care provided to patients and their families. Aspects, such as, the logistics of the organ donation process, human resources dimensioning, inadequate ICU, lack of emotional and technical preparation to deal with the diagnosis of brain death and the organ donation process contribute to the physical and emotional overload of nurses, hindering the care provided. ⁽¹¹⁾

As in the present study, a recent integrative literature review showed that few findings demonstrated high knowledge of nurses about the diagnosis of brain death and organ and tissue donation for transplants. ⁽¹²⁾

Thus, instrumentalization throughout the career is considered fundamental, as well as by the participants of this study. Improving and updating technical and scientific knowledge about brain death contributes to the feasibility of a work process with greater safety. Of 353 intensive care nurses participating in a study conducted in Turkey, 77.4% stated that they underwent training and qualification on brain death and organ donation in parallel to the service. ⁽⁴⁾ In other words, education is still the most effective way to contribute to the increase in the number of organ and tissue donations, mainly to improve the communication of the health team and nurses with family members and, thus, to counter the data from studies that link the refusal of organ and tissue donation to non-effective communication by family members. ^(11, 14-15)

This and other studies state that the undergraduate/training of nurses does not exhaust and is not enough to provide subsidies for the practice of nurses in the face of this reality. Thus, in addition to the inclusion of more contents about brain death in nursing education, continuing

education in these themes can also be important strategies for filling this gap. ^(12, 16)

In view of these gaps found, a study developed in Santa Catarina reveals that the presence and support of the Intra-Hospital Commission for Organ and Tissue Donation for Transplantation (CIHDOTT) is pointed out as positive, since these professionals monitor and systematize the care of patients diagnosed with brain death, enabling organ capture and lifesaving. ⁽¹¹⁾

The care provided to patients diagnosed with brain death and their families contributes to the humanization of ICU care, and a study conducted with 14 nurses and eight physicians working in the ICU in São Paulo, highlights in its results that empathy offers fundamental support and care to family members, and the way in which care for patients with brain death is provided, tends to contribute to the family consent of organ donation, so that donation is configured as a mechanism of comfort and support for the donor's relatives in the mourning process. ⁽¹⁷⁾

Although there is refusal, even in view of all the efforts made to give organs and tissues for transplants, nurse and nursing team are also indispensable in this scenario of care and action in the face of patients in brain death and family members. Death and dying is implicit in the process of living human. This reality needs attentive and sensitive listening. The object of study and work of the nurse is the patient, family and community, from before birth until after death. ⁽¹⁸⁾

It is evident in this context that all efforts to qualify nurses and the nursing team in relation to the process of diagnosis of brain death and organ and tissue donation for transplants show that nurses, and nursing team, in particular, are the most competent professionals in process management, and have the dexterity when relating to other team members and the patients' families, may favor, speed up and make it even safer. ⁽¹⁹⁾

This study presented limitations related to the scenario because it is a single reality studied, which does not allow the generalization of the results. On the other hand, it is a reference hospital in the care of patients in brain death and reference in the collection of organs and tissues for transplants, allowing to evidence important and specific data of this type of scenario.

As a contribution, the Grounded Theory itself stands out, because it allows to deepen in aspects that other qualitative methods could not achieve, in particular, the multiplicity of meanings given to a single question.

CONCLUSION

The intervening factors resulting from nursing care for family members of patients in brain death were, in general, the misunderstanding of the diagnosis of brain death. This misunderstanding implies more time and bureaucracy with regard to the acceptance of family members and the donation of fact. As a result, nurses reported some challenges,

such as the gaps in training about the context discussed here.

For these reasons, it is common for these professionals to seek instrumentalization through CIHDOTT, with a view to effecting acceptance in organ and tissue donation for transplants, through effective communication of nursing, the health team and all professionals inserted in the hospital context.

Thus, for the transposition of the challenges presented, it is recommended the inclusion of disciplines related to this theme in the undergraduate studies of nurses to further strengthen this body of knowledge and the use of continuing education to further deepen this important theme in these care scenarios. It is also recommended to respect the refusal of family members even in the face of the efforts of the whole team, including respect the patient in the process of death and dying.

Finally, it is expected that this study will contribute to the reflection of the professional training and practice of nurses and influence the development of more studies related to brain death, especially with regard to family care and communication of bad news by nurses.

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