

THE BRAIN DEATH PROCESS: MEANINGS GIVEN BY INTENSIVE CARE UNIT NURSES

PROCESSO DE MORTE ENCEFÁLICA: SIGNIFICADO PARA ENFERMEIROS DE UMA UNIDADE DE TERAPIA INTENSIVA

PROCESO DE MUERTE ENCEFÁLICA: SU SIGNIFICADO PARA ENFERMEROS DE UNA UNIDAD DE TERAPIA INTENSIVA

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Objective: to understand how nurses signify the care provided to patients with brain death in the Intensive Care Unit. **Method:** this was a qualitative study based on grounded theory. Data collection took place in an intensive care unit in a hospital in the South region of Brazil, between September and November 2014. Twenty-three nurses participated in the study, distributed in three sample groups. The first step of data analysis was open coding, followed by axial and selective coding, according to grounded theory. **Results:** data analysis resulted in the phenomenon “Recognizing multiprofessional work as promoting organ and tissue donation for transplantation”, sustained by five categories. **Conclusion:** the care provided to patients with brain death was signified by the nurses as generating an opportunity for a new life for multiple recipients.

Descriptors: Nursing Care. Brain Death. Nurses. Intensive Care Unit.

Objetivo: compreender como os enfermeiros significam o cuidado prestado ao paciente no processo de morte encefálica em uma Unidade de Terapia Intensiva. *Método:* pesquisa qualitativa com aporte teórico-metodológico na Teoria Fundamentada nos Dados. A coleta de dados foi realizada em uma Unidade de Terapia Intensiva de um hospital no Sul do Brasil de setembro a novembro de 2014. Participaram do estudo 23 enfermeiros distribuídos em três grupos amostrais. A análise teve início com a codificação aberta, seguindo para a codificação axial e para a codificação seletiva, conforme a Teoria Fundamentada nos Dados. *Resultados:* emergiu da análise dos dados o fenômeno “Reconhecendo o trabalho multiprofissional como potencializador da doação de órgãos e tecidos para

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transplantes”, sustentado por cinco categorias. Conclusão: o cuidado prestado aos pacientes em processo de morte encefálica é significado pelos enfermeiros como gerador da oportunidade de uma nova vida aos múltiplos receptores.

Descritores: Cuidados de Enfermagem. Morte Encefálica. Enfermeiros. Unidade de Terapia Intensiva.

Objetivo: comprender el significado que le dan los enfermeros a la atención brindada al paciente en proceso de muerte encefálica en una unidad de terapia intensiva. Método: investigación cualitativa con aporte teórico-metodológico de la Teoría Fundamentada en los Datos. Datos recolectados en una unidad de terapia intensiva de hospital del sur de Brasil, de setiembre a noviembre de 2014. Participaron 23 enfermeros, divididos en tres grupos muestrales. El análisis se inició con la codificación abierta, mudando luego a codificación axial y codificación selectiva, conforme la Teoría Fundamentada en los Datos. Resultados: del análisis surgió el fenómeno “Reconociendo el trabajo multiprofesional como impulsor de la donación de órganos y tejidos para trasplantes”, respaldado por cinco categorías. Conclusión: la atención brindada a los pacientes en proceso de muerte encefálica recibe de los enfermeros un significado generador de la oportunidad de una nueva vida para los múltiples receptores.

Descriptores: Atención de Enfermería. Muerte Encefálica. Enfermeros. Unidades de Cuidados Intensivos.

Introduction

Brain death (BD) is the undisputed full and irreversible cessation of brain functions of unknown cause, manifested by an unperceptive coma, with absence of supraspinal motor responses and apnea. The main causes are intracranial bleeding, brain trauma, and ischemic brain injury. Its diagnosis necessarily includes complementary clinical tests that prove the absence of brain electrical activity or absence of brain metabolic activity, or absence of brain tissue perfusion registered on a BD declaration by two physicians, who do not need to be neurologists, in a specific time frame for different age groups⁽¹⁻²⁾.

According to data from the Brazilian Organ Transplant Association, most BD diagnoses are given in intensive care units (ICU). Providing care during the BD process is complex and can result in various harmful complications for potential donors. Thus, the different professionals involved in this process, especially nurses, must be capable of carrying out important procedures relative to patients' hemodynamic and hydric control and monitoring. These procedures are necessary for organ donation to occur adequately⁽³⁻⁵⁾.

The notification of possible organ and tissue donations for transplantation has been growing worldwide. As shown by Brazilian and international studies, Brazil is a reference in the field because it has the largest public transplantation service in the world; consequently, it stands out in the

world context of organ and tissue donation for transplantation. In 2017, 10,629 cases of BD were notified, resulting in 3,415 donations. The South region of Brazil presented high figures, with 2,467 BD notifications and 1,004 donations. The state of Santa Catarina saw a 10.9% growth in donors between 2016 and 2017, with 282 donations performed in 2017. The donations carried out in the last five years have contributed to the increase of more complex organ transplantations, such as heart, lungs and bone marrow. Between 2010 and 2017, Brazil registered a growth of 69% in the number of organ and tissue donors, surpassing international standards^(1,6-7).

The aim of the care provided to patients diagnosed with BD is to maintain their body in favorable conditions for organ and tissue donation through precise and complex practices performed by multiprofessional health teams. These procedures are essential to save the lives of other people on transplant waiting lists^(6,8-9).

In this context, nurses are responsible for planning, executing, coordinating, supervising and evaluating the nursing procedures carried out with possible organ and tissue donors⁽¹⁰⁾. With BD patients, all nursing duties center around optimizing organ and tissue donation for transplants. Nurses are an intrinsic part of the care provided to these patients, given that they provide these patients ongoing care^(3,9-10).

Considering the importance of nursing in this context, the aim of the present study was to understand how nurses signify the care delivered to patients with brain death in the ICU.

Method

This was a qualitative study based on grounded theory (GT), which provides an understanding of social phenomena from the perspective of the meanings of relationships and interactions among subjects⁽¹¹⁾. The data were gathered from an ICU in a hospital that is a reference in organ and tissue donation and transplantation in the South region of Brazil. Data collection took place between September and November 2014 through open-ended and individual interviews with nurses at their workplace. These interviews were audio recorded for later transcription. The theoretical sampling of this study consisted of 23 participants distributed in three sample groups.

The first sample group comprised nine nurses who met the following inclusion criteria: being an ICU nurse, of any gender, working in the ICU for at least six months, with experience in caring for patients with BD. The interviews were based on the following guiding question: "How do you signify the care provided to patients with BD in the ICU?"

The analysis of data from the first sample group showed the need to include nurses from the Intra-Hospital Committee for Organ and Tissue Donation for Transplantation (CIHDOTT), because these professionals participate in BD patient care in the ICU and also facilitate the process of organ and tissue donation for transplantation. Thus, the second sample group consisted of four CIHDOTT nurses who met the following inclusion criterion: nurses working in the CIHDOTT for at least six months. The interviews were based on the following question: "How do you, as a CIHDOTT nurse, signify and experience the process of caring for BD patients?"

The data gathered from CIHDOTT professionals highlighted academic nursing education. Thus, the researchers found it necessary to understand

the importance of the nursing education process from the point of view of BD patient care. In this direction, to reach greater theoretical consistency, a third sample group was made up of five recent nursing graduates who had been exposed to BD during their training, and five nursing professors of a public university who had experience in the ICU and with BD patient care. The interviews with new-graduates were based on the following guiding question: "What was your experience when providing care for patients with BD during your undergraduate training?" With professors, the guiding question was: "What was your experience with BD patient care from the teaching perspective?"

Professionals who were on leave from work for any reason during the data collection period were excluded. Data saturation was reached when information about the phenomenon began repeating itself and there were no new elements relevant to the analysis or to consolidate the categories and subcategories in terms of their properties and dimensions. The first step of data analysis was open coding, followed by axial and selective coding, as recommended by the GT⁽¹¹⁾.

NVIVO® 10 software was used to organize data for the analysis and coding processes. The analytical process, systematized according to the paradigmatic model, consisted of five components that explain and sustain the phenomenon, namely: context, causal conditions, intervening conditions, strategy, and consequences.

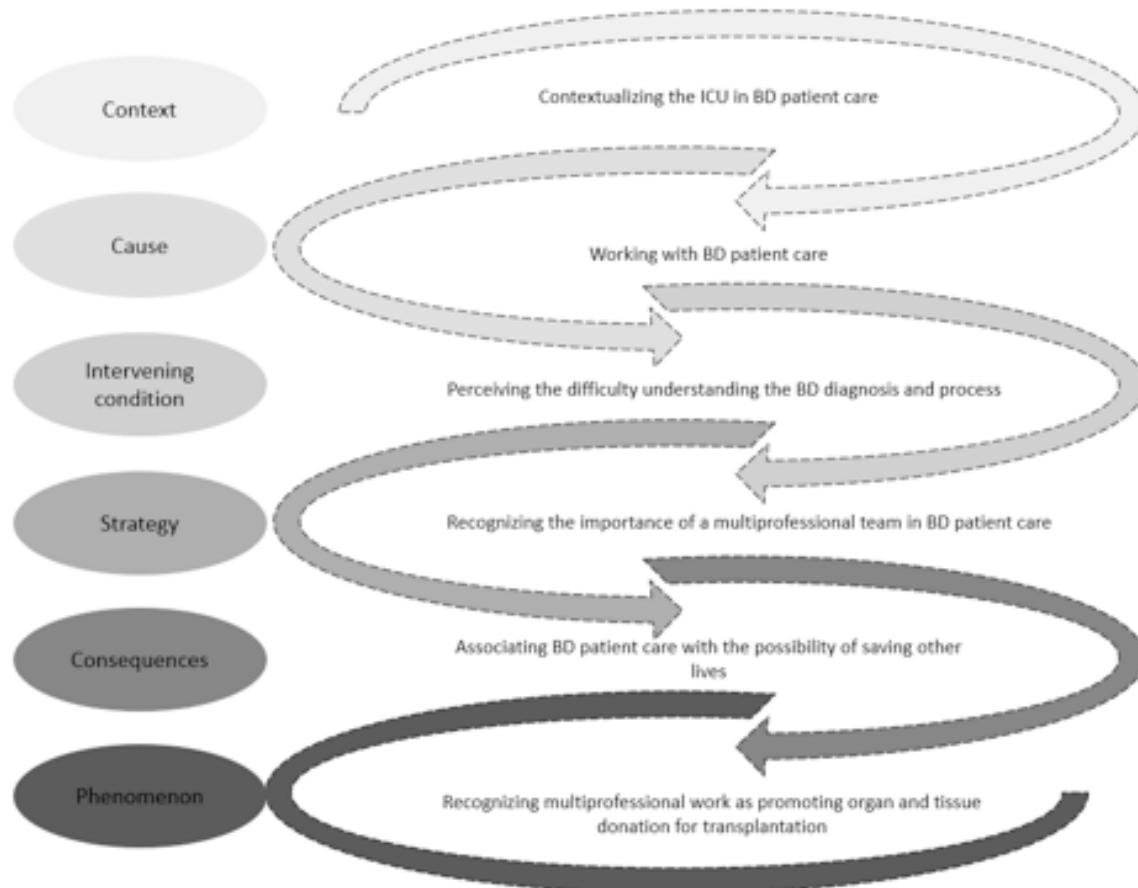
This study abided by the ethical precepts set forth by Resolution no. 446/12 of the Brazilian National Health Council⁽¹²⁾ and was approved by the Research Ethics Committee of the State Secretariat of Health (SES) of Santa Catarina, under protocol no. 2014/0010. After being informed about the study objective and methodology, the participants signed informed consent forms. Interviews were identified with letters: E for nurses; C for CIHDOTT nurses; EG for nurses who had been exposed to BD during undergraduate training; and D for nursing professors - followed by the number of the interview.

Results

The relationship between the categories and subcategories that emerged from the data revealed

the phenomenon “Recognizing multiprofessional work as promoting organ and tissue donation for transplantation,” as illustrated in Figure 1.

Figure 1 – Representation of the central phenomenon based on the paradigmatic model: recognizing multiprofessional work as promoting organ and tissue donation for transplantation



Source: Created by the authors.

The first category, “Contextualizing the ICU in BD patient care” refers to the context component. Because the ICU is permeated by technologies, intensive care and continuous presence of specialized professionals, it is an appropriate hospital setting to provide safe and quality care to patients with BD. This occurs mainly because these patients require constant care and specific and necessary technology for a BD diagnosis and to preserve their body for possible organ and tissue donation.

The ICU is the adequate setting. It has all the necessary materials, necessary technologies and necessary qualified staff to handle the reality of a patient with BD. There is

no other place in the hospital as well suited for this, to provide quality care. (E7).

The data show that the care provided by ICU professionals to patients diagnosed with BD was in accordance with the recommendations of the Brazilian Association of Intensive Care Medicine (AMIB) and the Brazilian Association of Nursing and Intensive Care (ABENTI), which are based on Brazilian legislation and national and international scientific evidence-based practices.

Our care is based on science. According to AMIB [Brazilian Association of Intensive Care Medicine] and ABENTI [Brazilian Association of Nursing and Intensive Care] recommendations, which follow international standards.

There is no question about the quality of the care provided here in the ICU. (E2).

The data also showed that, despite the specificities of the care provided to patients who are brain dead, it was considered no less important than that provided to patients with treatment options, especially so as not to discriminate or prioritize one or the other, because according to the humanized approach that permeates nursing care, everyone is equally important in terms of care.

The care provided to BD patients is just as humanized as that provided to patients with treatment options. We don't make this distinction. The only distinction is in the intensity of care to keep these organs "alive". (E9).

The second category, "Working with BD patient care" refers to "causal condition". It revealed that nurses possess the technical-scientific competences to recognize a BD diagnosis and provide direct care to these patients, as part of a multiprofessional team, because they have the appropriate training to develop clinical thinking in this situation.

We must develop clinical thinking to notice the clinical signs of BD and to think clinically, communicate this to physicians so that they can begin the protocol. This is all very complex. We can raise a hypothesis based on clinical thinking, actually contribute to this care. (E10).

Furthermore, the data show that nurses have the competences to assess not only the diagnosed hypothesis, but also to constantly evaluate the clinical conditions of BD patients and effectively contribute to direct patient care and, consequently, to the organ and tissue donation process for transplantation.

We perform hemodynamic monitoring of these patients, assess tissue perfusion, ventilation, lung and heart auscultation, ongoing vital sign monitoring and take the appropriate measures when these are not stable. Last, we constantly assess their clinical status, so that these patients can remain as stable as possible so their organs are viable for donation. (E10).

The third category, "Perceiving the difficulty understanding the BD process", was associated with intervening conditions. It showed that some professionals, who were unprepared about the specificities of BD care, acted as if they were caring for deceased patients. Thus, they did not

understand the need to provide these patients with ongoing care.

A lot of people say, "We're caring for a dead patient, so why are we giving antibiotics to a dead patient?..." As I said, there's a bit of backward thinking here, when they say, "I'm caring for a deceased patient". (E1).

In the same way that some of the professionals who provide direct care to BD patients do not understand this condition, family members also have a hard time understanding the diagnosis, especially because of the presence of a heartbeat and respiratory movements, as well as the organ and tissue donation process for transplantation.

I think families have a hard time understanding it [...] They ask, "The heart is still beating but there's nothing that can be done"? Accepting BD is difficult; accepting there is no more life there. (E9).

The fourth category, "Recognizing the importance of a multiprofessional team in BD patient care" refers to strategies. This category showed that nurses have several technical responsibilities, regarding direct care to patients with BD, in addition to coordinating the interpersonal relationships of all those involved in this context and supervising the technical nursing team during the care provided to BD patients. Their participation consists primarily of ongoing presence throughout the entire process in terms of the other professionals.

Nurses are essential. They mediate the entire situation, in terms of the family, what is necessary for the diagnosis, and guiding and supervising the nursing team. They will also mediate these situations. (E1).

Nurses monitor these patients 24 hours nonstop. There will always be a nursing technician or nurse at that patient's side, contrary to other professionals, such as physical therapists, physicians; they are not here all the time. Even though they are in the ICU, they do not stay with patients the entire time. (E4).

The data also show that the CIHDOTT is made up of a qualified multiprofessional team with suitable competencies to handle this reality. Consequently, they make a difference in the care provided to patients with BD, and the implementation of this committee had introduced significant changes to the hospital.

The professionals who make up this multiprofessional team are extremely prepared [...] They use very clear language, are very competent and committed to the organ donation process. It's amazing! I think they [CIHDOTT

team] are well prepared and are always willing to provide information. I think that organ transplant in the state has improved greatly with the CIHDOTT. (D3).

The fifth category, "Associating BD patient care with the possibility of saving other lives" was associated with the "consequences" component. It emphasizes that the purpose of intensive and ongoing nursing care provided to patients with BD is to maintain the organism to ensure the viability of organ and tissue donation and consequent transplantation.

I take care of this patient intensively to ensure organ donation. All this control, this rigor and thoroughness are for the purpose of organ donation. All this constant and intense care only exists because of the possibility of organ donation. Otherwise, we would care for these patients, but not as intensely as we do now. After all, they would be deceased. We would care for them with quality and respect, but not so intensely. (E6).

However, the outcome of organ donation is determined by the family, who has the power of decision over the process. In this direction, all of the professionals directly and indirectly involved in BD patient care are responsible for providing care and respect to the families of possible donors to generate a positive response to organ and tissue donation.

I think everybody has a part in raising awareness, so that the family can later consider donating the organs of the person who is in here. (E5).

The data also showed that, through the process of donation, caring for a BD patient means recognizing the possibility of changing the lives of other people on the organ and tissue transplantation waiting list. Delivering adequate care to BD patients and their families provides the opportunity to give a new life to other people.

Caring for BD patients means providing the family with the opportunity to do a good deed for other people, giving organs so that other people can live longer, or with a better quality of life [...] It especially means seeing other people have a better life, in better conditions, with an organ received through donation. (C1).

When we care for a patient with BD, we are giving viability to several people. You provide other people to improve their life, if you take proper care of that individual. (E10).

Discussion

The results of the present study point to the ICU as the adequate setting to care for

patients with BD. This finding corroborates the literature, which has confirmed BD as a diagnosis that is caused by potentially severe clinical conditions that, for the most part, are treated in ICUs, departments that allow for the ongoing monitoring of severe patients or those who are suffering from the decompensation of one or more organ systems. The care provided to BD patients in this unit is considered safe and effective because of the specific characteristics of the ICU and the constant presence of a qualified multiprofessional team providing patient care. To maintain organic stability, it offers cardiocirculatory, ventilatory, endocrine, metabolic and hemodynamic support⁽¹⁴⁻¹⁵⁾, enabling the final outcome of the entire process. However, in some realities, both in Brazil and in other countries in the world, such as Iran, patients with BD are cared for in emergency departments, environments that also offer technological and professional devices suited to handle this reality⁽⁶⁾.

Brazilian and international studies have shown that caring for patients diagnosed with BD requires the care of multiple highly qualified professionals to work continuously and as a group to provide intensive and rigorous care to preserve organs and tissues for transplantation^(6,16). Nurses, especially ICU nurses, need to be trained to identify pathophysiological changes, so that, together with the multiprofessional team, they can take adequate therapeutic measures to care for these patients⁽⁷⁾.

Even though patients with BD do not present any possibility of a cure, their care must be provided with quality, safety, and respect. The aim of these procedures is not only to enable organ and tissue donation and the treatment of multiple recipients, but mainly because the body carries various meanings to family members, professionals, and the recipients of organ and tissue donation⁽¹⁷⁻¹⁸⁾.

It is worth emphasizing that, over time, ICU professionals adopt a coping mechanism for the job and can frequently be unsensitized to the suffering of family members and the health/illness condition of patients. It is common to see health professionals providing care in a routine,

mechanical and technical way, giving priority to the biological dimension in detriment to the other dimensions of human beings⁽¹³⁾.

The present study did not explicitly identify mechanistic care centered on patient pathophysiology. However, it confirms the importance of nurses and other health professionals recognizing the value of comprehensive health care in this hospital environment and the biopsychosocial aspects of each individual as part of the process of humanizing health care in ICUs, with patients diagnosed with BD, and to improve the quality of care. It also corroborates that healthcare teams do not only work with the physical body, but also the other dimensions of individuals, families, and society⁽¹³⁾.

In this complex scenario, nurses play a significant role in providing care to BD patients. A study developed in Japan emphasized that nurse participation, due to their knowledge and comprehensive outlook of the population's health demands and their participation in BD processes, has contributed to advancing the number of organ and tissue donations for transplantation⁽¹⁴⁾.

In contrast, even though there has been significant scientific progress, increasingly greater availability of devices and qualified professionals to handle health and, more specifically, BD, it is still very common for health professionals to be ignorant about the process. However, organ donation is a thriving reality in Brazil and the world, and knowledge about the process directly influences the care provided by these professionals⁽⁶⁾.

A study developed in several Asian countries identified that the reluctance observed in the health system, due to religious, cultural and ethical issues, including among healthcare professionals, are reasons for stagnated organ and tissue donation rates⁽¹⁸⁾. A Spanish study emphasized that healthcare professionals, especially nurses, are knowledgeable about BD; however, there is mistrust regarding diagnostic precision and the effectiveness of BD protocols.

Thus, the knowledge of health professionals about BD diagnosis and other care procedures

involved in the process is still not enough. Continuing education is necessary to expand the quality of care provided in these cases, consequently resulting in increased supply of organs and tissues for transplantation in the world and in Brazil^(6,18-19).

Still regarding education, there is also the need to include the theme consistently throughout nursing education, thus enabling professionals to handle BD safely, competently and effectively. A study developed with undergraduate health students showed that they had little and inadequate knowledge about the theme and everything it entails, and about the care provided to possible donors. Associated with this situation are the weak undergraduate curricula, which do not usually include this theme. This is a great cause for concern, as these future professionals leave academia unprepared to handle this reality⁽²⁰⁻²¹⁾. Lack of information and knowledge about BD also contributes to family members maintaining hope in the patient's recovery at a moment of intense sadness and grief, especially due to ignorance about the pathophysiology of BD. Indeed, characteristics such as the patient's warm body and active heart make it difficult to understand BD⁽²²⁾.

With this possibility in mind, nurses should take on the role of educators with the goal of improving the relationship among patients, families and healthcare teams, in addition to contributing to the understanding of the process as a whole. Thus, it is necessary to foster interest in the acquisition of knowledge that leads health professionals and family members to acquire self-knowledge⁽²²⁻²³⁾. The work of nurses as educators must not be associated and limited to ICUs or other hospital settings, but expanded to include various public and social spaces, in order to increase the awareness of the population about the theme⁽²¹⁾.

Furthermore, being with the family of potential donors is also part of the duties of bedside and/or CIHDOTT nurses and other members of the healthcare team. However, this is a conflicting scenario experienced by these professionals, representing the hardest and most stressful moment of the entire process. Thus, nurses receive

training for this task, because family members are facing a difficult and painful moment, and it is crucial that they be supported by professionals that provide them comfort and reassurance and that help them better understand BD, increasing the chances of the family consenting to the organ donation process^(3,7,15).

National and international studies indicate that nurses should provide explanations using clear and consistent terminology, taking into account the sociocultural and religious reality of families, to ensure understanding, before discussing the organ and tissue donation process for transplantation. This precaution can prevent future misunderstandings by family members^(7,13,22-23).

The Federal Council of Nursing (COFEN) also determines that nurses are responsible for planning, executing, coordinating, supervising and evaluating nursing procedures carried out with possible organ and tissue donors. Beyond their duties, nurses and their respective teams are essential to this reality, because they monitor these patients 24 hours a day, improving the quality of care provided and expanding the potential of organs and tissues for the donation and transplant process^(5,10).

The care provided to patients with BD is multiprofessional, considering that nurses and the nursing team work with the other professionals, increasing the quality and effectiveness of care. After all, no one professional is individually capable of being responsible for the different dimensions that involve BD patient care^(5,8,11).

The CIHDOTT professionals involved in this process have duties such as the continuing education of the multiprofessional team about the different aspects involving organ and tissue transplantation, interpersonal communication skills, specific legislation, ethical aspects, and documents for organ and tissue donation, promoting the integration with units that have diagnostic resources, in addition to organizing the routines and protocols that enable the organ and tissue donation process⁽¹⁵⁾. The involvement of these professionals has allowed for the better

organization and identification of potential donors, a more suitable approach to family members and greater coordination between hospitals and notification, procurement and donation, increasing the quality and amount of transplantations^(5,15).

Limitations of the present study include the fact that only one setting was investigated, which does not allow for the generalization of its results. However, its importance resides in the possibility of underpinning the reflections and practices of nurses and other health professionals in similar scenarios.

Conclusion

The care provided to patients with brain death was signified by nurses as giving multiple recipients an opportunity for a new life. Through organ and tissue donation, such care can help save the lives of people whose only treatment option for living a quality and productive life is the end product of the entire process: transplantation. Organ and tissue donation only occurs through an agreement reached between family members and the multiprofessional team, especially the CIHDOTT, enabling the cure of various patients who are on the organ and tissue transplant waiting lists across the country.

Although the study was developed in a single setting and cannot be generalized, the authors hope that it can awaken in nurses who work with multiprofessional teams the need to adopt new stances in this context, especially that of health educators both for patients and especially for families and society, in order to increase the acceptance of organ and tissue donation for transplantation.

Further studies on BD are needed in other realities to contribute even more to the construction, discussion, and reflection about the stigma surrounding BD among nurses and other health professionals, with the goal of providing quality care to patients and families throughout the BD process, organ and tissue donation for transplantation and possible recipients.

Collaborations:

1. conception, design, analysis and interpretation of data: Murilo Pedroso Alves, Franciele da Silva Rodrigues, Giovana Dorneles Callegaro Higashi, Eliane Regina Pereira do Nascimento and Alacoque Lorenzini Erdmann;

2. writing of the article and relevant critical review of the intellectual content: Murilo Pedroso Alves, Franciele da Silva Rodrigues, Kamylla Santos da Cunha, Giovana Dorneles Callegaro Higashi, Eliane Regina Pereira do Nascimento and Alacoque Lorenzini Erdmann;

3. final approval of the version to be published: Murilo Pedroso Alves, Kamylla Santos da Cunha, Giovana Dorneles Callegaro Higashi, Eliane Regina Pereira do Nascimento and Alacoque Lorenzini Erdmann.

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