

# Nursing team and organ donation: an integrative literature review

Clesyane Alves Figueiredo<sup>1</sup>, Aline Maino Pergola-Marconato<sup>2</sup>, Maria Giovana Borges Saidel<sup>3</sup>

## Abstract

The nursing team takes the lead in decision making related to organ donation process and family care as both are part of its work. This study aimed at identifying nursing team's actions and activities directed to the families of potential organ donors in brain death from an integrative literature review. The final sample consisted of 10 articles whose analysis pointed to the central role played by nursing in creating bonds with the potential donor's family, especially considering the difficulty of family members in understanding the death process. The sample also indicated urgent need to implement training programs for nursing teams in order to help reduce their suffering while in contact with families experiencing this situation. As a conclusion, family care requires several complex activities, including rigorous preparation and humanization to deal with family members and professionals.

**Keywords:** Family. Nursing. Brain death. Transplants. Tissue donors.

## Resumo

### Equipe de enfermagem na doação de órgãos: revisão integrativa de literatura

A equipe de enfermagem integra o processo de doação de órgãos, sendo o cuidado aos familiares inerente a seu trabalho, uma vez que são protagonistas na tomada de decisão. Este artigo objetivou identificar ações e atividades da equipe de enfermagem dirigidas à família do potencial doador de órgãos em morte encefálica, a partir de revisão integrativa da literatura. A amostra final foi composta por 10 artigos, que apontaram o papel central da enfermagem em formar vínculos com a família do potencial doador, principalmente considerando a dificuldade dos familiares em compreender o processo de morte. A amostra também indicou a premente necessidade de implementar programas de treinamento e refletir sobre a questão para reduzir o sofrimento da equipe em contato com famílias nessa situação. Conclui-se que o cuidado com a família demanda diversas atividades complexas, sendo necessário preparo rigoroso e humanização para lidar com familiares e profissionais.

**Palavras-chave:** Família. Enfermagem. Morte encefálica. Transplantes. Doadores de tecidos.

## Resumen

### Equipo de enfermería en la donación de órganos: revisión integrativa

El equipo de enfermería está presente en el proceso de donación de órganos y el cuidado prestado a los familiares es inherente a su trabajo, ya que son protagonistas en la toma de decisiones. El objetivo de este artículo fue identificar las acciones y actividades del equipo de enfermería dirigidas a la familia del posible donante de órganos por muerte encefálica, a partir de una revisión bibliográfica integrativa. La muestra final consistió en 10 artículos, en los que se señalaba el papel central de la enfermería en la formación de vínculos con la familia del posible donante, teniendo en cuenta principalmente la dificultad de los miembros de la familia para comprender el proceso de muerte. La muestra también indicaba la necesidad urgente de poner en marcha programas de capacitación y de reflexionar sobre el tema para reducir el sufrimiento del equipo en contacto con las familias en esta situación. Se llegó a la conclusión de que el cuidado de la familia requiere varias actividades complejas, y que se necesita una preparación rigurosa y la humanización para tratar con los miembros de la familia y los profesionales.

**Palabras clave:** Familia. Enfermería. Muerte encefálica. Trasplantes. Donantes de tejidos.

**1. Graduate (specialist)** clealvesfigueiredo@gmail.com – Fundação Hermínio Ometto (FHO) **2. PhD** aline.marconato@fho.edu.br – FHO, Araras/SP **3. PhD** mgsaidel@unicamp.br – Universidade Estadual de Campinas (Unicamp), Campinas/SP, Brasil.

## Correspondence

Clesyane Alves Figueiredo – Av. Maximiliano Baruto, 500, Jardim Universitário CEP 13607-339. Araras/SP, Brasil.

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Organ transplantation is often the only therapeutic possibility for individuals with terminal functional failure<sup>1</sup>. In Brazil, Decree 9.175/2017<sup>2</sup> established that organs can be donated while people are alive or after a diagnosis of brain death, which is determined by the end of *brain functions, defined by the cessation of cortical and brainstem activities*<sup>3</sup>, according to Resolution 2,173/2017 of the Conselho Regional de Medicina (Brazilian Council of Medicine).

According to Associação Brasileira de Transplante de Órgãos (ABTO)<sup>4</sup> [Brazilian Organ Transplant Association], the number of potential donors differs from the number of transplants performed in the country. This reality is not restricted to Brazil: data from the Organ Procurement and Transplantation Network<sup>5</sup> reveal that in the United States more than 100 thousand patients were waiting for a transplant in 2018. Among the factors that limit the effectiveness of transplants in Brazil, brain death underreporting diagnoses at notification centers, the inefficient capture and distribution of organs, due to possible logistical problems, the occurrence of cardiac arrest before donation, medical contraindication and family refusal<sup>4</sup>.

ABTO<sup>4</sup> also reveals that, in the first quarter of 2018, 41% of the interviewed families differed from the potential donor's desire and did not authorize organ donation. This scenario justifies and supports discussions about best practices to reduce the non-realization of donations' rate, especially with regard to family refusal. The biggest ethical issue that permeates the potential donor's family approach comes from the lack of conceptual clarifications on brain death. In addition, there are other relevant ethical factors, such as respect for pre-existing beliefs and values, the difficult time faced by family members, the welcoming and availability of the interviewer and the shared search for the best alternative for the situation<sup>6</sup>.

The health team plays an important role in this interpersonal process and nursing is fundamental in assisting the potential donor. However, this care is not restricted to the patient, but extended to his/her family, which needs to be supported<sup>7</sup>. The nurse is a strategic figure in the course of organ donation, because during training he/she must develop skills and abilities that allow to ethically and properly assisting the patient's relatives. In addition to

therapeutic relationships, this professional is able to identify potential organ donors and put in practice care for their body maintenance<sup>8</sup>.

Usually, the family's bond with nursing is efficiently established. This occurs due to the coexistence and proximity established throughout the process, as the family uses the nursing team daily to clarify doubts and request guidance on the disease and the donation process<sup>9,10</sup>. Thus, this study aimed at identifying nursing team's actions and activities directed to the families of potential organ donors in brain death from an integrative literature review.

## Method

Integrative review is a research method that condenses published studies and provides general considerations about a certain field. It constitutes an extensive analysis of the literature, using pre-established criteria that broaden the debate on research methods and results, in addition to supporting possible reflections for future research<sup>11</sup>.

We conducted this research in six stages, as follows: 1) identification of theme and choice of hypothesis or research question; 2) determination of inclusion and exclusion criteria for studies/sampling or literature search; 3) definition of which information to extract from the selected papers and categorization of studies; 4) evaluation of the studies included in the integrative review; 5) interpretation of results; and 6) presentation of the review/knowledge synthesis<sup>10</sup>.

We elaborated the research question by applying the PICO strategy, whose acronym means patient, intervention, comparison and outcomes. This strategy highlights the central elements of the research and is also important as a support to the search in chosen databases<sup>12,13</sup>. Thus, in this research, we chose as "patient" the family of the potential organ donor in brain death; "intervention" was the care offered by the nursing team to this family; and "comparison" regarded the data obtained. Finally, "results" concerned the verification of actions and activities in the national literature about this type of care. Based on this, we elaborated the following question: What are the nursing actions and activities available in the national literature on nursing team care for families of potential organ donors in brain death?

We carried out a bibliographic survey in the following databases: Medical Literature Analysis and Retrieval System Online (Medline Complete); Scientific Electronic Library Online (SciELO) and Latin American and Caribbean Health Sciences Literature (LILACS). We collected and worked on the data between February and November 2018.

The sample included scientific articles covering the Brazilian reality published in English, Spanish or Portuguese between 2013 and 2017 and addressed aspects related to nurse's conduct, guidance and emotional support to the families of potential brain organ donors in Brazil. The time frame was based on data from the Brazilian Ministry of Health that showed a significant increase in the number of transplants within five years prior to the survey<sup>14</sup>.

We chose the following five descriptors: "family", "nursing", "brain death", "transplants" and "tissue donors". The search was made in all databases by using the Boolean operator "and" to specify the search with the following combination: "family and nursing and brain death and transplants and tissue donors". After reading the title, aim, summary and

some excerpts of the results and discussion, we selected articles that addressed the proposed theme, excluding those only about patient care.

The initial sample contained 65 articles. After excluding duplicate articles and reading them in full, 55 publications were removed, which resulted in a final sample of 10 articles. The articles were classified based on the level of evidence of Oxford<sup>15</sup>, considering, for each of the articles, the name of the authors, year of publication, journal title, article title, aim and level of evidence.

## Results

The results show that in the considered period, most articles of the sample were published between 2014 and 2016 (Chart 1). Among them, three (30%) indicate that organ donation and collection system present important administrative and logistical weaknesses. The lack of knowledge and the family's difficulty in accepting brain death are also regarded as challenges for the nursing team<sup>9,16,17</sup>.

Chart 1. Sample characteristics

n	Autores; year of publication	Journal	Article title	Aim	Level of evidence
1	Lima, Batista, Barbosa; 2013 <sup>18</sup>	<i>Revista Eletrônica de Enfermagem</i>	"Percepções da equipe de enfermagem no cuidado ao paciente em morte encefálica"	Understand the perceptions of the nursing team about its performance in caring for brain-dead patients	4
2	Cavalcante, Ramos, Araújo, Alves, Braga; 2014 <sup>10</sup>	<i>Acta Paulista de Enfermagem</i>	"Cuidados de enfermagem ao paciente em morte encefálica e potencial doador de órgãos"	Analyze nurses' opinion on nursing care for brain-dead patients and potential organ donors	4
3	Freire, Mendonça, Freitas, Melo, Costa, Torres; 2014 <sup>7</sup>	<i>Enfermería Global</i>	"Compreensão da equipe de enfermagem sobre a morte encefálica e a doação de órgãos"	Identify the nursing team's understanding of brain death and organ and tissue donation	4
4	Moraes, Santos, Merighi, Massarollo; 2014 <sup>19</sup>	<i>Revista Latino-Americana de Enfermagem</i>	"Vivência de enfermeiros no processo de doação de órgãos e tecidos para transplante"	Know the meaning of nurses' actions in the donation process to make organs and tissues feasible for transplant	4
5	Moraes, Neves, Santos, Merighi, Massarollo; 2015 <sup>20</sup>	<i>Revista da Escola de Enfermagem da USP</i>	"Experiências e expectativas de enfermeiros no cuidado ao doador de órgãos e à sua família"	Understand the experiences and expectations of nurses in intensive care units in caring for organ donors for transplants and their families	4
6	Fernandes, Bittencourt, Boin; 2015 <sup>21</sup>	<i>Revista Latino-Americana de Enfermagem</i>	"Vivenciando a doação de órgãos: sentimentos de familiares pós consentimento"	Identify experiences and feelings of donor family members in a transplant unit related to the organ donation process	4

continues...

Chart 1. Continuation

n	Autores; year of publication	Journal	Article title	Aim	Level of evidence
7	Silva Filho, Lopes, Bispo, Andrade; 2016 <sup>22</sup>	<i>Revista de Enfermagem UFPE On-Line</i>	“Enfermagem e a sensibilização de famílias na doação de órgãos e tecidos para transplante: revisão integrativa”	Identify the scientific evidence addressing nursing actions to increase families’ awareness of organ and tissue donation for transplantation	5
8	Costa, Costa, Aguiar; 2016 <sup>9</sup>	<i>Revista Bioética</i>	“A enfermagem e o paciente em morte encefálica na UTI”	Clarify the theoretical relevance in a detailed context regarding the practice of organ donation in society and know the role of the professional nurse in the capturing and donating process, highlighting the essential care to maintain the potential donor, assistance to the family and control of all vital functions until the time of donation	5
9	Junqueira, Cavalcanti, Santos, Silva, Silva; 2016 <sup>16</sup>	<i>Revista Saúde</i>	“Morte encefálica: o enfermeiro prestando assistência ao potencial doador de órgãos e tecidos”	Understand the importance of nurses in assisting potential donors of organs and tissues	5
10	Costa, Mourão Netto, Brito, Goyanna, Santos, Santos; 2017 <sup>17</sup>	<i>Revista Bioética</i>	“Fragilidades na atenção ao potencial doador de órgãos: percepção de enfermeiros”	To know the nurses’ perception of care fragilities for brain-dead patients	4

The nurse professional takes part in all stages of the organ procurement and donation process. In the sample, six articles (60%) demonstrate the importance of this professional and his/her primary role in guiding family members, patients and team<sup>7,9,10,18,19,21</sup>. And nursing care for potential donors in brain death also extended to the family was highlighted in eight articles (80%)<sup>7,9,10,16,17,20-22</sup>.

The adequacy of care provided by the nursing team was considered in four articles (40%). The clarification on all aspects about the organ donation process and the concept of brain death were highlighted from the first stage to the outcome. In such studies, nursing is shown as a fundamental human resource for more transparency and effective influence on how families should react to the possibility of organ donation<sup>7,18-20</sup>. However, three other articles (30%) indicated the difficulties faced by nursing professionals when extending care to the family, especially when related to emotional matters. The suffering and pain of the family when they perceive the death of the family member gives rise to feelings that are difficult for the professional to deal with<sup>10,17,19</sup>.

Finally, six articles (60%) emphasized that the role of nursing goes beyond the guidance

activities of the organ donation process, which is inherent to effective communication process. Those articles indicated that, despite the disturbance caused to professionals due to continuous contact with death of patients and the pain of their families, such prolonged and intense coexistence between the nursing team and family is paradoxically pointed out as responsible for both the humanization of relationships and the coping with death process by the patient’s relatives. Reception activities and therapeutic and empathic listening establish a relationship of trust with family members<sup>9,10,17,21,22</sup>.

## Discussion

Brazil performs a considerable number of transplants annually<sup>4</sup>. Despite this, adversities persist in all stages of organ procurement and donation<sup>18</sup>. We highlight in this process the care for the family of potential donors that count with strategic professionals in the nursing team to overcome difficulties at that moment. The response of these professionals to the challenge of effectively transmitting information and at the

same time supporting families in their suffering characterizes nursing as a continuously evolving and space conquering health area, thus offering new perspectives.

The process of diagnosis of brain death, procurement and donation of organs, tissues and transplants is interprofessional, and the nursing team plays a fundamental role in all stages regarding biopsychosocial care of potential donors<sup>8</sup>. Resolution 292/2004 from Conselho Federal de Enfermagem [Brazilian Nursing Council]<sup>23</sup> is the legal basis for this type of care, determining the nurse's responsibility to plan, execute, coordinate, supervise and evaluate the nursing procedures provided to patients in brain death, who are potential organ and tissue donors.

However, the nursing care offered to the potential organ donors in brain death does not end with the patient, but must extend to his/her family members<sup>7,9-11,16,17,21</sup>. The duties of the nursing team include the ethical, moral and legal clarification of all phases of the process of capturing and distributing the organs and tissues to be donated. Such guidance should be clear and objective, always respecting the opinions and desires of the family as well as the moment of loss and pain they are going through<sup>9</sup>.

It is advisable to allow family members to stay with the patient as long as possible, including during the brain death diagnosis process, which is carried out by the medical team. This guideline is fundamental, since the decision to donate organs depends on this process, and it is essential that the family understand the concept of finitude and death<sup>20</sup>.

Thus, competent communication plays a fundamental role in organ donation, as it provides family members with the necessary clarifications for them to position themselves on the possibility of donation. Therefore, the objectivity, clarity and simplicity in information transmission will certainly help the autonomous decision<sup>16,20</sup>.

However, some professionals show difficulties in facing situations of pain and loss of family members. In any case, the team must play its role of assisting and guiding in all phases of the donation<sup>10,18,23</sup>. In this sense, it is necessary to implement training programs for all health professionals who work in this activity, to build, expand and improve their skills and competencies in communicating bad news. Moreover, these programs are identified as important tools for the evolution of the entire process<sup>16,24</sup>.

The relationship of trust between the nursing staff and family members is essential. Such bond promotes comfort and emotional support, in addition to acting as a primary communication channel<sup>17</sup>. The selected studies of this review show that family members recognize such support in nursing and consider it substantial for a humanized approach<sup>19</sup>.

The humanization of assistance in organ donation is inherent the daily life of the nursing team. Therapeutic and extended listening is essential to the process and leads to empathic attitudes of care. Therefore, humanizing such activities means offering care to family members at the time of death, bringing genuine understanding to the experience. To achieve such results, it is necessary to develop a therapeutic relationship and stimulate the professionals' preparation, so that they can deal with the feelings, reactions and suffering intrinsic to this situation<sup>20</sup>.

### Final considerations

This study presents a limitation on its theoretical framework related to the role of nurses in the family care of potential donors in brain death. For this reason, we highlight the importance of more extensive review studies assisted by more robust methodologies on this theme.

We conclude that this care involves different activities of the nursing team and requires technical and scientific preparation, as well as competence and skill in therapeutic communication and attitudes, all this based on ethics and processes legality. Such attributes are essential to form bonds between the nursing team and family members, which can be decisive for families' autonomous and legitimate decision-making process. The humanized conduct of professionals in welcoming family members enables feelings and behaviors of security and trust in the entire process.

However, it is a constant challenge for nursing professionals to take care of human beings in all their vital cycles, as the nursing team is also composed of human beings who have daily feelings and losses, as well as their personal values and beliefs. Therefore, it is essential to look after these professionals and their needs in order to offer constant and systematic technical and emotional support. Such support directly contributes to improving care provided to family members.

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#### Participation of the authors

Clesyane Alves Figueiredo wrote the manuscript and, with Maria Giovana Borges Saidel, conceived the project and collected the data. With Aline Maino Pergola-Marconato, they conducted the critical review of the content. All authors designed the study, interpreted the data and approved the final version for publication.

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Clesyane Alves Figueiredo

 0000-0002-1206-2773

Aline Maino Pergola-Marconato

 0000-0001-5071-865X

Maria Giovana Borges Saidel

 0000-0002-3259-1760

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