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# BRAIN DEATH AND THE PROCESS OF DONATION OF ORGANS: A FAMILY CARE

## Morte encefálica e o processo de doação de órgãos: uma atenção ao familiar

## La muerte cerebral y el proceso de donación de órganos: un cuidado familiar

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## ABSTRACT

**Objective:** discuss about the family reaction in front of the communication process of brain death and possible organ donation. **Method:** integrative review of literature, with search of articles in databases: SciELO, BEDENF, LILACS, MEDLINE published between the years of 2008 to 2017. We selected for this research, 14 publicaçoes according to the criteria of inclusion and exclusion. **Results**: the main element for which the donation process is satisfactory is the family. And they have different reactions to receive the information of brain death and organ donation possible. Among these various factors are the place where the communication is performed and the lack of family about the opinion of the donor. **Conclusion:** to receive the diagnosis of brain death, the rooms feature manifestations such as sadness, crying and revolt. The lack of this subject, brings the family to a series of questions and a possible refusal in the donation.
**Descriptors:** Brain death; Family; Diagnosis; Organ donation.

### RESUMO

**Objetivo:** discutir sobre a reação familiar frente ao processo de comunicação de morte encefálica e a possível doação de órgãos. **Método:** revisão integrativa da literatura, com busca dos artigos nas bases de dados: SciELO, BEDENF, LILACS, MEDLINE publicados entre os anos de 2008 a 2017. Selecionou-se para essa pesquisa, 14 publicaçoes conforme os criterios de inclusão e exclusão. **Resultados:** o elemento principal para que o processo de doação seja satisfatório é a família. E que estes apresentam reações diversas ao receber a informação de morte encefálica e a possível doação de órgão. Dentre esses vários fatores estão a local onde a comunicação é realizada e o desconhecimento dos familiares sobre a opinião do doador. **Conclusão:** ao receberem o diagnóstico de morte encefálica, os familiares apresentam

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manifestações como tristeza, choro e revolta. O desconhecimento esse assunto, leva os familiares a uma série de questionamentos e uma possível recusa na doação.

**Descritores:** Morte encefálica; Família; Diagnóstico; Doação de órgãos.

### RESUMÉN

**Objetivo:** discutir acerca de la reacción de la familia frente al proceso de comunicación de muerte cerebral y posible la donación de órganos. **Método:** revisión de la literatura integradora, con búsqueda de artículos en bases de datos: BEDENF, SciELO, LILACS, MEDLINE, publicados entre los años de 2008 a 2017. Hemos seleccionado para esta investigación, 14 publicaçoes según los criterios de inclusión y exclusión. **Resultados:** el principal elemento para que el proceso de donación es satisfactoria es la familia. Y tienen diferentes reacciones para recibir la información de la muerte cerebral y la donación de órganos es posible. Entre estos diversos factores son el lugar donde se realiza la comunicación y de la falta de familia acerca de la opinión de los donantes. **Conclusión:** para recibir el diagnóstico de muerte cerebral, las habitaciones cuentan con manifestaciones como la tristeza, el llanto y la revuelta. La falta de este tema, trae a la familia a una serie de preguntas y un posible rechazo de la donación.

**Descriptores:** Muerte cerebral; Familia; Diagnóstico; Donación de órganos.

## INTRODUCTION

Brain Death (BD) is conceptualized as a complete and irreversible condition of all brain functions, keeping present heartbeats and breathing due to the advancement of technology and equipment. However, throughout mankind development, this concept has been modified, due to historical and cultural factors.[1]

In our reality, we still find it difficult to understand the concept of brain death due to the lack of knowledge, the lack of the team's preparation to perform the tests, the incorrect approach of families, failure to pass information about the patient's clinical condition, making difficult the notification of a potential donor and generating a family refusal before the donation.[2]

With regard to the relatives of the patient in BD situation, provide accurate information about the correct BD diagnosis and ensuring families the correct prognosis, differentiating BD from the coma state, may help them to recognize irreversible brain damage and remove the family's misperceptions about the possibility of a return to life.[3]

The family members' concern begins with the news that led the patient to the Intensive Care Unit (ICU). Providing clear and precise information, given the clinical condition aggravation and the prognosis worsening, guarantees a preparation of the family in the next stages of the process, facilitating the organs and tissues acceptance of donation.[1]

The family, a lot of the times, faced with the process of illness presents uncertainties related to the loss of control of the situation. A more accurate approach, with more information from the clinical case, can improve coping with the news and a better acceptance for the organs and tissues donation.[1]

Thus, in order to carry out this research, we start with the following problem: What are the feelings and reactions of family members in relation to the brain death communication process and potential organ donation of their loved one?

This research is justified by the contribution to a better understanding of how family members experience the diagnosis of brain death of a loved one. Through this knowledge, it is possible to plan a systematic and welcoming intervention to the family in this context, in a way that contributes to a better understanding and acceptance of this scenario, thus corroborating with a potential organs and tissues donation.

Considering this perspective, the present study aimed to discuss through the literature on the family reaction to the brain death communication process and potential organ donation.

## METHODS

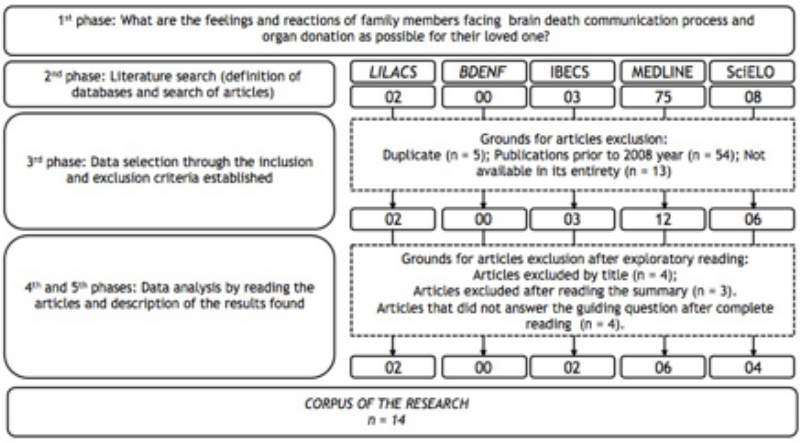
Herein, the integrative literature review was selected as a method, which enables the synthesis and analysis of the scientific knowledge already produced on the subject investigated. It is possible to elaborate an integrative review with different purposes, that is, directed to the definition of concepts, the review of theories or the methodological analysis of the included studies of a particle topic.[4] For the elaboration of this integrative review, [5] phases were followed:

- 1st phase: Elaboration of the guiding question and the research's objective;
- 2nd phase: Definition of databases and literature search;
- 3rd phase: Data selection through inclusion and exclusion criteria established;
- 4th phase: Data analysis by reading the articles;
- 5th phase: Description of the results found.

With the objective of guiding the integrative review, the following question was asked: What are the feelings and reactions of family members in relation to the brain death communication process and potential organ donation of their family entity? The search of the publications indexed in the following databases was carried out in the following sequence: Scientific Electronic Library Online (SciELO), *Base de Dados de Enfermagem (BDENF)* [Nursing Database] and *Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS)* [Latin American and Caribbean Literature in Health Sciences], Medical Literature Analysis and Retrieval System Online (MEDLINE). The terms "brain death, family, diagnosis, organ donation" were used as descriptors. It should be noted that the term "Brain Death", which is described in the DeCS/MeSH terminology as a state of irreversible prolonged cessation of all brain activity, including a decrease in lower brainstem function, complete absence of voluntary movements, responses to stimuli, reflexes of the brainstem and spontaneous breathing.

The defined inclusion criteria consisted of articles, theses, and dissertations that addressed the family of patients with brain death, published in Portuguese, English or Spanish, with the abstracts available in the selected databases, in the period from 2008 to 2017. Publications classified as comments, government information, biographies, annals of congresses were disregarded. The 5 steps covered in this literature review were outlined in a flowchart, as shown in **Figure 1** below.

**Figure 1 -** Flowchart of the 5 phases covered in this review. *Goiânia* city, *Goiás* State, Brazil, 2018.




A synoptic table was prepared, with information referring to the year of publication, the method used, level of scientific evidence and the main results/conclusions of the articles selected. With the purpose of including all the necessary information concerning the authors and the selected publications, it was necessary to search the researches in full. After reading the selected researches, the content analysis and description of the results found were performed.

## RESULTS AND DISCUSSION

A total of 88 publications were found, and an exploratory reading of them was done (TITLE, ABSTRACT), 74 articles have been excluded because they escape from the theme or do not answer to the proposed objective. For the present research, 14 publications were used, identified by the letter "A" and by Arabic numerals, which correspond to the reading order (A1 to A14) according to **Table 2** below. For the selected articles classification according to the level of evidence, the classification of Kyzas[5] was used as illustrated by **Table 1**.

**Table 1 -** Classification of Scientific Evidence according to the type of study. Adaptation of the classification proposed by KYZAS (2008).[5]

| Evidence Level (EL): | Points Type of study |
|---|---|
| 10 – Higher Evidence | Systematic reviews with meta-analysis of randomized clinical trials |
| 9 | Systematic reviews with meta-analysis |
| 8 | Randomized Clinical Trials |
| 7 | Clinical Practice Guidelines |
| 6 | Cohort and Case-Control Studies |
| 5 | Observational Studies (longitudinal or transverse) |
| 4 | Clinical Cases and Case Series |
| 3 | Basic Laboratory Research |
| 2 | Expert Opinions |
| 1 – Lower Evidence | Literature non-systematic reviews |

**Table 2 -** Summary of publications addressing the family and the brain death process. *Goiânia* city, *Goiás* State, Brazil, 2017.

| Article Year | Methods | EL | Main results/Conclusions |
|---|---|---|---|
| A1 2013.[1] | Literature review | 1 | Family members present peculiar experiences that may have repercussions on the mourning process, such as the concern about the patient's prognosis during hospitalization, misunderstanding of the possibility and diagnosis of the BD, and may present an experience of ambiguous loss and difficulty in perception of mourning reactions in the approach to organ donation, due to the restricted time for decision. Thus, it is concluded that it is indispensable the psychological support to the patient's relatives throughout the Brain Death process. |
| A2 2009.[2] | Qualitative phenomenology study | 5 | The propositions that emerged revealed that the reasons for family refusal to organs and tissues donate are related to belief, values, and inadequacies in the process of donation and transplantation. |
| A3 2016.[6] | Literature review | 1 | The intensivist team plays a very important role in maintaining the vital functions of the potential donor, and it is necessary to base all aspects of brain death, scientific and ethical knowledge since the viability of the organs or tissues to be donated depends directly on its adequate conservation. |
| A4 2010.[7] | Descriptive, exploratory study | 5 | The donation process is stressful for the family and nursing care becomes necessary at each stage of the donation, offering support to reduce the suffering of the family members. |
| A5 2017.[8] | Observational study | 5 | Families need to cooperate to make the donation happen. And they have evidence regarding refusal and failure in transplant permission. This could weaken confidence in the donation system. And the adoption of a hardline non-substitution system may have detrimental consequences for donation systems and donation rates. Therefore, the best option seems to be asking families and friends to respect donation intentions, by adopting more effective strategies before and after death, donation intentions, through the adoption of more effective strategies before and after death. |
| A6 2008.[9] | Qualitative cross-sectional study | 5 | One should think about the family decision process, contemplating possibilities of family interactions with other systems capable of offering the social support that the family needs. Definitively, this implies, we open hospital doors, but mainly, it implies to expand the focus of organ harvesting, and also, to take care of the family, during the experience of death and mourning. Instead of offering the possibility of donation and then abandoning the family, we can extract the best from the family by stimulating fundamental processes to encourage their growth in the face of chaos. Early intervention is a preventive measure and it is our duty as nurses. |
| A7 2013.[10] | Qualitative cross-sectional study | 5 | The causes of family refusal are related to non-comprehension of the diagnosis of brain death by relatives, aspects related to religion, unpreparedness of the professional who performed the interview. |
| A8 2013.[11] | Qualitative cross-sectional study | 5 | The causes of family refusal before a potential donor form the disagreement between family members; ignorance about the will of the potential donor; desire to keep the body intact; fear of delay in releasing the body; lack of understanding about the diagnosis of brain death and the religious question; discontent with the care of the hospital staff; respect for the opinion of the potential donor manifested in life and distrust and fear of organ trafficking. It is concluded that, for a greater family acceptance for the organs donation, it is necessary to elaborate informative programs, based on the reasons here highlighted, with a view to the adequate clarification of these subjects. |
| A9 2011.[12] | Opinion of experts | 2 | The main ethical issue is the lack of clarification during the process of obtaining consent from the family member. Other ethical aspects may influence the acceptance of family members in organs donation, such as respect for the moment the family member experiences, their beliefs and values, as well as the reception and availability by the interviewer and the assurance that the family member has chosen the most appropriate alternative for the situation. |
| A10 2013.[13] | Integrative literature review | 1 | The reasons for family refusal to non-organ donation are related to cultural and religious issues, disinformation or inadequate family approach. The approach of this family member is one of the most important stages in the organ donation process, and those involved must always be integrated, considering cultural, religious and affective issues. The nurse as a professional involved in the process of donation and organ harvesting should also participate in the family approach. And that the nurse's performance is not limited to the care of the potential donor subject, but also includes the family, as a fundamental segment in this gear. |
| A11 2009.[14] | Exploratory study of a qualitative approach | 5 | There is a need to demystify the donation process, to improve the information given to the family, in order to raise awareness among the population in general, to promote multi-professional interaction in the approach, making it deal with this situation with maximum information, less suffering and less possibility of regrets. |

| Article Year | Methods | EL | Main results/Conclusions |
|---|---|---|---|
| A12 2017.[15] | Review study | 1 | For the families of the potential organ donor, the period of the Intensive Care Unit (ICU) is often very brief, making it difficult to fully and completely understand the magnitude of the events that occur. Regardless of the length of patient admission, the clinical team's ability to provide a safe haven for relatives is critical. Families are especially susceptible when an injury or neurological disease occurs suddenly in their loved ones, which is usually associated with emotional exhaustion, which can be aggravated when the issue of organ donation appears. |
| A13 2014.[16] | Cross-sectional study | 5 | Since donors' own will is the most common reason why families choose to donate, it is necessary to remind the public of the importance of donating organs through education and public relations using mass communication approaches. In addition, because families felt suffering and guilt, besides losing their loved ones and pride towards them after organ donation, continued and systematic support is needed to promote their psychological stability. |
| A14 2015.[17] | Qualitative study | 5 | Discrepancies between the willingness to consent to donate and refuse to organ donate of a family member can be attributed to an unresolved dilemma: helping people or protecting the body of the deceased. Non-donor families often feel incompetent to decide. They refused consent for the donation, since their deceased had not given any directive. |

Among the selected articles, 9 papers (64.3%) are observational studies with level of evidence 5, another 4 articles (28.6%) are review studies, represented by the level of evidence 1 and 1 article (7.1%) is about specialists' opinions occupying the evidence level 2 on the Kyzas scale.[5] In general, all selected articles addressed the process of family feelings and reactions in relation to the brain death diagnosis and the decision on the organs and tissues donation of their loved ones. They present different types of feelings such as anguish, sadness, feeling of death, feeling of mourning or loss of a loved one, fear, distrust, insecurity, non-acceptance of diagnosis among others. For a better understanding of the readers, this study was divided into 2 categories: Approach of family members in the process of organ donation; implications for nursing care.

## Approach of family members towards the organ donation process

Law No. 9.434/97, known as the Transplantation Law, provides that the organs and tissues donation depending only on the authorization of the spouse or relative, at adult age, obeying the line of succession, straight or collateral, until second degree. The law also points out an item that emphasizes the importance on the family knowledge to know that the person wants to be an organ donor. In its second article, it defines that the manifestations of will related to the *post mortem* harvesting of tissues, organs and parts, included in the Civil Identity Card and the National Driver's Licenses, lose their validity from December 22nd, 2000.[18]

The donation of organs and tissues is seen by society as a solidarity action, where it can provide body parts to assist in the treatment of people, favoring a longer life expectancy. The nursing team plays an important role in this process, for example, in order to maintain the vital functions of the potential donor, scientific and technical knowledge related to brain death is required, and the viability of the organs and tissues to be donated depends exclusively on how they will be preserved.[6] Therefore, the main element in order for the donation process to be satisfactory is the family, in this sense it must receive assistance before and after the brain death diagnosis.[7] At this moment, some families are very distressed to learn about the death of their relatives and cannot contemplate the idea of donation, expressing their opposition so that the health team may find it difficult to resist - even if regulations and legislation say that the wishes of the patient should be respected.[8]

In the initial phase, referring to the clinical condition of the patient, the relatives present concern and fear of the prognosis, and the possibility of evolving to death, generating, and a denial of the clinical case. The next phase, diagnosis verification, most of the relatives have some difficulty in understanding the probability of brain death, at this moment hope is present among family members, expecting that the diagnosis may be negative. At the end of the tests to verify brain death and the diagnosis is positive, the family may not understand and accept it at first moment, being able to feel a double loss and disrupt the grieving process, making the organ donation approach unsatisfactory, it may also cause in relatives some difficulty in expressing their moment of mourning due to the decision to donate or not.[1]

In the majority of cases, the lack of understanding of the brain death possibility may be related to the lack of knowledge about the reason that led the patient to worsen the clinical condition, it is extremely important that the family gather information about clinical evolution.[1]

The whole experience is one of the factors that can stimulate or discourage the family from accepting the diagnosis and consenting to the organs and tissues donation. If you meet the humanistic goal of giving a new person a life, you can make the family consider the possibility of donation, as long as they know that the clinical condition is irreversible and that the individual is dead. Considering these facts, the decision to authorize the donation, touches the family's morale, by saving the lives of other people, minimizing the pain and giving relief in this process of mourning. This process is what helps the family, giving meaning to the life and death of the loved one.

It is evident that the family needs time to think about the possibility of a possible donation and to assimilate what is happening, the death of the loved one and the decision to donate or not.[10]

One of the reasons for the family refusal to organs and tissues donate is the lack of technical competence of the professionals who perform the interview. Another important factor is the places where these interviews are performed, usually, the environment is not appropriate due to lack of hospital facilities. Not to mention that the lack of courses, discussions of cases and exchanges of experiences between professionals almost does not exist.[9] Nevertheless, the factor most reported by relatives is the lack of knowledge of the donor's opinion, which leads one to understand that if the patient had expressed the desire to donate their organs, they would consent to the donation.[11]

Other factors related to family refusal are: religious beliefs where some expect a miracle to happen and the patient returns to the arms of the family members; the lack of understanding of the diagnosis, making the family think that it is only a state that the patient is in and that soon will improve; some family members have difficulty accepting to manipulate the patient's body; distrust in medical diagnosis for a possible black market for the sale of organs; the patient's opinion of not being a organs and tissues donor, and the fear of losing the loved one, lead the family to be impacted by the diagnosis.[2]

Adequate communication can be one of the fundamental points to be worked daily by health professionals for the effectiveness of the family approach, leading to an increasing donation. Capacitation and enlightenment of the potential donor's family must be performed every time, since there is the autonomy of the potential donor, and it is those family members who know the donor's desires.[12]

Capacitation programs should focus on the therapeutic relationship as well as the behavioral approach, so that the professionals have a better assimilation on life and death, learning to accept the values of the patients and family, through their own emotional structure, to provide assistance of quality and holistic.[12]

The family approach or the lack of attention to the family, influences in every human relationship and in any form of donation request, it is necessary to understand that the relatives have lost a family member and will not react in a habitual way.

After conducting evidentiary examinations, the family should be informed about the diagnosis and will undergo an interview to clarify the organs and tissues donation. The family's autonomy must be respected and all its members must expose their opinion regarding the donation, regardless of their family position, for a better acceptance of mourning.[10]

The interview does not have the principle to convince the family of donation, nor to induce that they agree, it is only for the purpose of explaining how the process is done. Authorizing the donation comforts and helps make sense in the death of the loved one, but not knowing who will receive may generate frustration for the family member, who coexists with the expectation of seeing their relative alive in another person. The decision to donate or not aims to alleviate the suffering of all, it is necessary, that everyone enters into a consensus, making the best choice, with the purpose of avoiding conflicts.[7]

Therefore, when the context promotes the acceptance of suffering, it welcomes doubts, provides time for the family to share ideas and feelings about the experienced moment, facilitates access to social support, provides the necessary information, the family can walk on a path of recovery in the decision process happens with less conflict. Hence, working with the family, respecting these conditions helps its members to construct meanings and a new reality to the experiences and interactions, being able to support each other, thus minimizing the suffering.[9]

## Implications for nursing care

The experience lived by the relatives is a fundamental point of suffering recognition and reception that must be approached by the nurse. Providing the necessary information about the patient's clinical condition in brain death and be transparent throughout the donation process, help the family to go through the recovery process more easily, with less internal conflicts, reducing stress, and favoring the taking of decision to donate.[7]

The failures during this reception and in the brain death communication process may be due to the lack of training, skill, and attention of the professionals responsible. These factors are indispensable in the daily routine practice of nursing care, which focuses on the integral care to relatives of a patient in brain death, based on the Nursing Diagnosis (ND), especially the "Compromised Family Coping".

And the nurse plays an essential role in supporting family in body release, which is a stressful process. Thus, it is important to emphasize that some people can evaluate this phase in different ways and present different reactions and repercussions, such as sadness, crying, non-acceptance, among other signs.[7]

Nursing must participate and interact in the family decision-making process, expanding the focus not only on the organs and tissues donation but also on caring for the family, understanding the moment of suffering. Provide continuing assistance to the family, independently if the response was positive or negative for the donation, it is a feature of an ethical and humane care by all professionals working in these areas.[14]

Given the communication situation of the patient evolution to brain death, the understanding process of the diagnosis meaning, and the different reactions of the family members involved in communication, it is necessary to qualify the nursing professionals, particularly the nurse, to elaborate the plan of care of both the patient and the family based on the main ND, a fact that can contribute significantly to the quality of care provided.

Given this context, some objectives such as better clarifying the situation of brain death and the possible process of organ donation, welcoming the post-enlightenment relatives and identifying the different impacts caused in the family

environment can be achieved through essential actions such as: training, institution of assistance protocols, definition and improvement of the roles of each one within the care team. This makes the parameters to be followed by nursing, should be based on the Nursing Care Systematization (NCS), which allows expressing the autonomy of the nurse through the ND during the care of the potential donor and their relatives, with this and other stages of NCS, elaborated and sequentially specified by a registered nurse, in order to ensure the best possible care.

## CONCLUSIONS

We have observed that family members present several manifestations when they received the brain death diagnosis, such as sadness, crying and non-acceptance. The lack of knowledge about the subject, the stress of allowing the donation and thinking that the loved one is no longer alive, leads the family to a series of questions, making the feeling experienced by them is of uncertainty, insecurity, and pain.

It is extremely important that health professionals be trained to care for the family in this time of mourning, providing assistance in adapting, accepting and coping with the loss. This can be done mainly through effective communication.

Considering that family members are responsible for authorizing or not of organ donation, and that the patient should have mentioned in life their desire, the literature points out that an interview with the family should be performed with the goal of facilitating the process of family's understanding after the death of the loved one in the context of organ donation.

From the bibliographical research, we have observed some limitations in relation to this theme, such as the nursing care itself to the family in this context of death and organ donation. We suggest conducting more research that covers these subjects, so that it collaborates with the scientific basis of nursing care.

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