

*FAMILY ATTITUDES IN THE ORGAN DONATION AND TRANSPLANTATION PROCESS:  
AN INTEGRATIVE REVIEW*

**ATTITUDES FAMILIARES NO PROCESSO DE DOAÇÃO E TRANSPLANTE DE  
ÓRGÃOS: REVISÃO INTEGRATIVA**

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**ABSTRACT**

**Objective:** to identify in the scientific literature factors related to family attitudes in the process of organ donation and transplantation. **Methods:** an integrative review carried out in July 2020, in five information resources, through combinations between the descriptors “organ transplant”, “tissue donors” and “tissue and organ procurement”, in their Portuguese and English versions. **Results:** fourteen articles made up the final sample, in which it was found that factors that hinder the transplantation process are mainly related to physical pain and feeling of fear, concern with the mutilation of the body, and also religious and cultural aspects, fear of corruption, ignorance about the process and distrust of the medical diagnosis of brain death. However, it stood out as factors that positively influence the process, education and awareness of the population, professional training, good dialogue and respect for families and well-structured institutions. **Conclusion:** the decision regarding organ donation is influenced by different factors that positively or negatively influence the entire process, which directly impacts the number of donors and the waiting list for transplants. **Keyword:** Organ Transplantation; Donors of Tissues; Procurement of Tissues and Organs.

**RESUMO**

**Objetivo:** identificar na literatura científica fatores relacionados às atitudes familiares no processo de doação e transplante de órgãos. **Métodos:** revisão integrativa realizada em julho de 2020, em cinco recursos informacionais, por meio de combinações entre os descritores “transplante de órgãos”, “doadores de tecidos” e “obtenção de tecidos e órgãos”, com versões em português e inglês. **Resultados:** catorze artigos compuseram amostra final, nos quais se verificou que os fatores que dificultam o processo de transplante estão relacionados, principalmente, à dor física e sentimento de medo, preocupação com a mutilação do corpo do mesmo, aspectos religiosos e culturais, receio de corrupção, desconhecimento sobre o processo e desconfiança do diagnóstico médico de morte encefálica. Contudo, destacaram-se como fatores que influenciam positivamente o processo educação e conscientização da população, capacitação profissional, bom diálogo e respeito com as famílias e instituições bem estruturada. **Conclusão:** a decisão quanto à doação de órgãos é tangenciada por distintos fatores que influenciam positivamente ou negativamente todo o processo, o que gera impacto direto no número de doadores e na fila de espera para transplantes. **Palavras-chave:** Transplante de Órgãos; Doadores de Tecidos; Obtenção de Tecidos e Órgãos.

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## INTRODUCTION

The organ donation and transplantation process takes place from a donor, living or dead, using surgical techniques that enable the replacement of compromised organs or tissues with healthy ones. Thus, when the donor of the organ to be transplanted is dead, prior authorization from family members is necessary for the procedure to occur<sup>(1)</sup>.

Although Brazil has one of the largest public transplant systems in the world, with 95% of surgeries being performed by the Unified Health System, the number of people waiting for a transplant is still significant. Considering that the effectiveness of the donation is influenced by the acceptance or refusal of the population through the process of organ donation and transplantation, professionals who should contribute to the acceptance process sometimes leave something to be desired when approaching potential donors or families<sup>(2)</sup>.

The nursing team becomes essential in this context, standing out for the interaction with the multiprofessional team and for its actions in the process, mainly for the ability to identify, validate and manage the care to the possible donor and the family. In addition, nurses have the ability to coordinate the logistics of organs, in the collection and distribution, also acting in administrative processes in relation to the results and the effectiveness of the donation process<sup>(3)</sup>.

There are many uncertainties about the reasons for acceptance or refusal for donation and, also, for organ transplantation by families. Thus, it is necessary to map the best evidence on the theme that supports actions of health professionals, including nurses, seeking to increase adherence to this process. Thus, it is believed that family attitudes are decisive for the refusal or acceptance in relation to organ donation, and that the nursing professional has a fundamental role in this process, therefore, the present study is relevant considering the impact, both positive and negative in the wait for transplant.

The objective of the research was to identify factors related to family attitudes towards the organ donation and transplantation process in the scientific literature.

## METHODS

Integrative review carried out according to the steps of the method<sup>(4)</sup>. For the development of the research question, the PCC strategy<sup>(5)</sup> P (Population) = family members; C (Concept) = family attitudes towards refusal or acceptance; C (Context) = organ donation and transplantation process. Thus, the research question was: “What has produced in the scientific literature about the factors that can influence family attitudes towards the organ donation and transplantation process?” The search for scientific production was carried out in July 2020 in the information resources: Latin American and Caribbean Literature in Health Sciences (LILACS), International

Literature in Health Sciences (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Nursing Database (BDENF) and Scientific Electronic Library Online (SciELO).

Descriptors previously selected in the Health Sciences Descriptors (DeCS/BIREME) and Medical Subject Headings (MeSH) were used, being, in Portuguese, “organ transplant”, “tissue donors” and “tissue and organ procurement”; and, in English, “organ transplantation” and “tissue and organ procurement” (MEDLINE and CINAHL), “tissue donors” (MEDLINE) and “transplant donors” (CINAHL).

Considering the specificity of each information resource, the search was carried out using descriptors in trio, using the Boolean operator “AND”. In the LILACS database, the search was conducted in Portuguese and the field used was “Subject descriptor”; in MEDLINE the search was in English and the field used was “SU Subjects”; in CINAHL the language used in the search was English and the field used was “SU Subject”; in BDENF the language used was Portuguese and the field used was the “descriptor de assunto”; and in SciELO the language used was Portuguese and the field used was “Assunto”.

For this study, the following inclusion criteria were used: publications from the last ten years (2010-2020), in the form of scientific articles, found in full online; in Portuguese, English and Spanish; which included factors

related to family attitudes towards the organ donation and transplantation process. As exclusion criteria, the following were considered: publications in duplicate in databases; articles for reflection and editorials; literature reviews and studies not related to the proposed theme. After applying the inclusion and exclusion criteria, the floating reading of the selected articles continued to verify adherence to the research theme.

To prepare the study selection flowchart, the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA)<sup>(6)</sup> strategy was used, freely translated into Portuguese. For the analysis of results an analytical matrix was elaborated that allowed the synthesis and grouping of the main results of the analyzed studies. The analytical matrix had the following data for interpretation and comparison: author, title, journal, year, language, and level of evidence, place where the study was carried out, type of study, main results and reference.

The following classification of the level of evidence was adopted to assess the selected articles: level I - systematic review or meta-analysis, relevant randomized controlled clinical trials or originated from clinical guidelines based on systematic reviews of randomized controlled clinical trials; level II - well-designed randomized controlled clinical trial; level III - well-designed clinical trials without randomization; level IV - well-designed cohort and case-control studies; level

V - systematic review of descriptive and qualitative studies; level VI - a single descriptive or qualitative study; level VII - opinion of authorities and/or report of expert committees<sup>(7)</sup>.

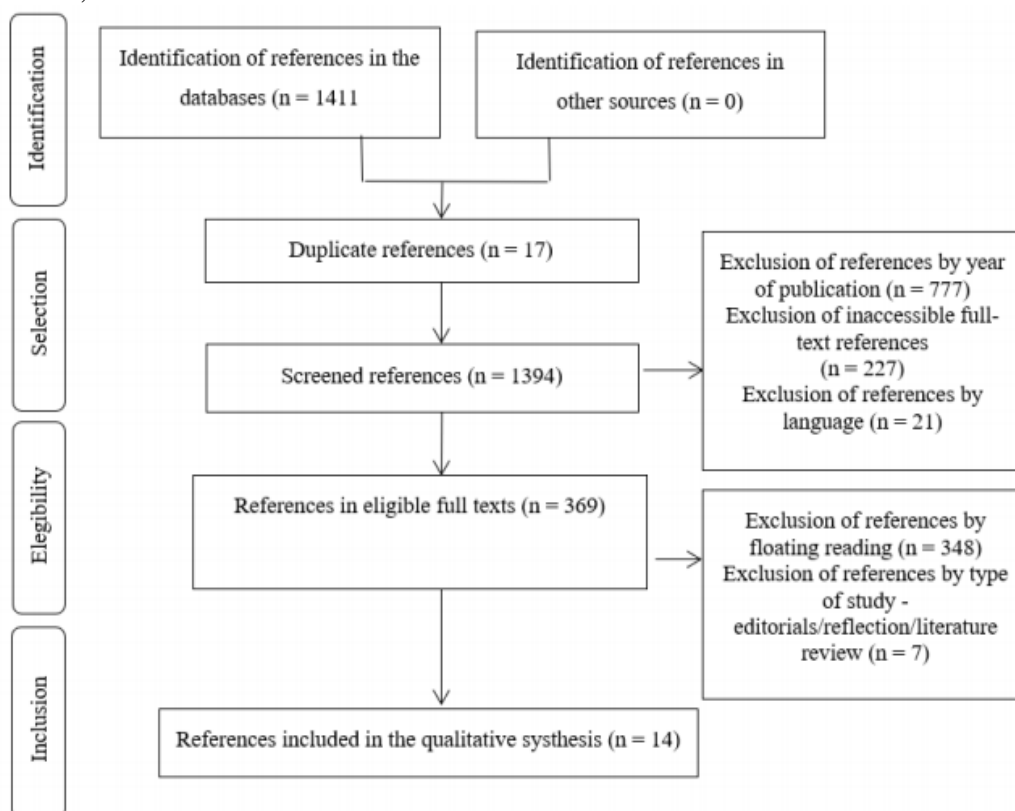
## RESULTS

The searches took place through the triple association of descriptors, which returned 1,411 publications in all information resources used, 27 in LILACS, 6 in BDENF and 27 in SciELO with the combination of descriptors “Organ Transplant AND Tissue Donors AND Organ Procurement and Fabrics”; 1,317 on MEDLINE combining descriptors “Organ Transplantation AND Tissue Donors AND Tissue and Organ Procurement” and; 34

at CINAHL using “Organ Transplantation AND Transplant Donors AND Tissue and Organ Procurement”.

In this universe, the inclusion and exclusion criteria were applied and the floating reading of articles was performed. Fourteen (14) articles referring to the theme of this study were selected for qualitative analysis, 1 in LILACS, 9 in MEDLINE, 1 in BDENF, 2 in Scielo and 1 in CINAHL, as shown in Figure 1. Articles that made up this review were inserted in the analysis matrix for data qualitative synthesis.

**Figure 1** - Flow chart of literature selection for the composition of the integrative review. Rio das Ostras, RJ, Brazil, 2019



Source: survey data

Of the total articles selected for analysis, 2 (14.3%) were published between 2017 and 2019, while the rest (85.7%) were published between the years 2011 and 2016. Nine (9) (64.3%) articles in English, 1 (7.1%) in Spanish and 4 (28.6%) in Portuguese were selected.

Regarding the type of study, 5 (35.8%) were of a qualitative approach and 9 (64.2%) were quantitative; of these, 2 (22.2%) were of an observational approach. Regarding the level of evidence of articles (Figure 2), from the classification previously described, 2 (14.2%)

level IV articles and 12 (85.8%) level VI articles were found.

Of articles analyzed 5 (36.1%) were carried out in Brazil. Of the others, 1 (7.1%) was performed in Australia, 1 (7.1%) in China, 1 (7.1%) in Spain, 1 (7.1%) in the Netherlands, 1 (7.1%) in Malaysia, 1 (7.1%) in Mexico, 1 (7.1%) in Peru, 1 (7.1%) in Qatar and 1 (7.1%) in Turkey.

**Figure 2** - Characterization of the articles selected for analysis, according to journal/year and level of evidence. Rio das Ostras, RJ, Brazil, 2020

Order	Journal/Year	Level of Evidence
A1 <sup>(8)</sup>	Clin Transplant/2011	VI
A2 <sup>(9)</sup>	Psychol Health Med 2012	VI
A3 <sup>(10)</sup>	Clin Transplant/2012	VI
A4 <sup>(11)</sup>	Saudi J Kidney Dis Transpl/2012	VI
A5 <sup>(12)</sup>	Einstein/2014	VI
A6 <sup>(13)</sup>	Clin Transplant/2015	IV
A7 <sup>(14)</sup>	J Relig Health/2015	VI
A8 <sup>(15)</sup>	Rev Bras Enferm/2015	IV
A9 <sup>(16)</sup>	Rev Esc Enferm USP/2015	VI
A10 <sup>(17)</sup>	Ann Transplant/2016	VI
A11 <sup>(18)</sup>	BMC Med Ethics/2016	VI
A12 <sup>(19)</sup>	Rev Peru Med Exp Salud Publica/2016	VI
A13 <sup>(20)</sup>	Clin Transplant/2017	VI
A14 <sup>(21)</sup>	Rev Enferm UFPE On line	VI

Source: The authors

The main factors related to family attitudes towards the denial in the organ donation and transplantation process (Figure 3), found in the selected articles, were summarized in the categories: pain and feelings, religion and culture, corruption, body mutilation, ignorance about the process and distrust. Of the total number of articles

analyzed, 4 (28.5%) point out pain and feeling as influencing the organ donation and transplantation process, while religion and culture were addressed in 9 (64.2%), corruption in 7 (50%), body mutilation in 6 (42.8%), lack of knowledge about the process in 7 (50%) and distrust in 6 (42.8%).

**Figure 3** - Characterization of selected articles for analysis according to order and main results. Rio das Ostras, RJ, Brazil, 2020

Order	Results	
	Main factors	Influence in the organ transplantation process
A1 <sup>(8)</sup>	Mutilation of the body; Religion and Culture.	Influence on family decision
A2 <sup>(9)</sup>	Mistrust; Mutilation of the body; Religion and culture; Corruption.	Influence on becoming a donor.; Influence on family decision
A3 <sup>(10)</sup>	Mistrust; Religion and culture.	Influence on becoming a donor..
A4 <sup>(11)</sup>	Mistrust; Religion and culture; Corruption.	Influence on family decision.
A5 <sup>(12)</sup>	Lack of knowledge about the process; Mutilation of the body; Religion and culture; Corruption.	Influence on family decision; Refusal of living donors.
A6 <sup>(13)</sup>	Lack of knowledge about the process; Religion and culture; Body mutilation.	Refusal to donate; Refusal of receivers.
A7 <sup>(14)</sup>	Lack of knowledge about the process; Religion and culture.	Refusal to donate.
A8 <sup>(15)</sup>	Mistrust; Pain and feelings.	Influence on family decision.
A9 <sup>(16)</sup>	Pain and feelings.	Refusal to donate.
A10 <sup>(17)</sup>	Mistrust; Mutilation of the body; Corruption.	Refusal to donate; Refusal of receivers.

A11 <sup>(18)</sup>	Mistrust; Lack of knowledge about the process.	Refusal to donate; Refusal of receivers.
A12 <sup>(19)</sup>	Lack of knowledge about the process; Pain and feelings; Religion and culture; Corruption.	Influence on family decision; Refusal of living donors; Refusal of recipients to accept the transplant; Increase in the queue.
A13 <sup>(20)</sup>	Pain and feelings; Lack of knowledge about the process; Corruption.	Refusal to donate; Decrease in donors; Waiting queue increase
A14 <sup>(21)</sup>	Lack of knowledge about the process; Religion and Culture.	Refusal to donate
A15 <sup>(21)</sup>	Lack of knowledge about the process; Corruption; Mutilation of the body; Religion and Culture.	Influence on family decision.

Source: The authors

Category “pain and feeling” is related in articles to the fear that family members have of possible physical pain that the living donor could feel during the process and the emotional pain of family members due to the loss of a family member, as well as the difficulty in accepting death of loved one. Still in this category, the most evident feeling is the fear related to associations of the dead donor with the organ recipient through the adoption of the donor's tastes, feelings or personality after the transplant. Still in the sphere of feelings, there is insecurity related to the unknown, both on the part of the living donor and the recipient's relatives and also of the dead donor, in addition to the fear of surgery for the transplant<sup>(15-16,19-20)</sup>.

About “religion and culture”, covered in more than half of the analyzed articles, although 3 of them point out that they are not

aware of any religion, they are absolutely against organ donation and transplantation, and even consider this an act of love and generosity, attitudes are influenced by the interpretation made by the followers of a certain religion to its teachings. The main influencing factor in this regard is the fear of not having the body intact for the postmortem<sup>(8-14,19,21)</sup>.

“Corruption”, a category very present in the studies analyzed, refers to the ideas of the existence of a conflict of interest on the part of the medical team that would benefit from the donation. Also mentioned is the trafficking and commercialization of organs in markets that violate laws, privileges during the process of donating and transplanting organs and the inequality in the allocation of organs collected, especially with regard to those who are in a favored socioeconomic position. And, finally,

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the fear that as a registered organ donor, the medical team will not try to save life in order to declare early death to collect organs<sup>(9,11-12,17,19-21)</sup>.

Body mutilation has also emerged as an influential category in family attitudes in the process of organ donation and transplantation, encompassing the desire to maintain bodily integrity in order to keep the body intact for life after death and/or entering the spiritual world. In addition, the fear of mutilation and disfigurement of the body of the deceased relative and the aesthetic effects for the funeral, the fear of manipulating the body of the loved one and the importance and need for a quick burial<sup>(8-9,12-13,17, 21)</sup>.

The lack of knowledge about the organ donation and transplantation process was present in studies referring to the denial of death due to the lack of understanding about the concept of brain death, in addition to the idea that there are age limits to be a donor or the belief that organs are not useful after death<sup>(12-14,18-21)</sup>.

Likewise, “mistrust” emerged in articles and encompass the family's incredulity about the medical diagnosis, the low credibility of the public health system, the fear of being mistakenly diagnosed with brain death when the organs are donated and mistrust regarding profits during the process since it is a procedure offered free of charge by the Unified Health System in Brazil<sup>(9-11,15,17,18)</sup>.

The main effects of these factors on family attitudes, referred to in articles, is the refusal in the process of organ donation and transplantation, both by potential donors and recipients, in addition to influencing the family's decision to donate. Therefore, the refusal of the organ transplantation process directly impacts the decrease in the number of donors, mentioned in 1 (6.25%)<sup>(20)</sup> articles analyzed, and in the increase in the waiting list for a transplant, mentioned in 2 (13.3%)<sup>(19-20)</sup> of the studies.

In 13 (92.8%) (8-18,20-21) selected articles were mentioned various forms and factors that can improve family members' adherence and positively influence attitudes towards the organ donation and transplantation process. Of these, 10 (71.4%)<sup>(8-9,12-15,17-18,20-21)</sup> point to education as the main positive strategy, 6 (42.8%)<sup>(9,12-14,17,20)</sup> the training of professionals, 10 (71.4%)<sup>(8-11,13,15-16,18,20-21)</sup> awareness of the population, 5 (35.7%)<sup>(9,11,13,15-16)</sup> good dialogue with the family and potential donors as a way to interrupt negative influences in the donation process. In addition, 3 (21.4%)<sup>(10-12)</sup> discuss the importance of a well-structured and well-informed institution on the subject, 1 (7.1%)<sup>(21)</sup> about respecting potential donors' wishes and 2 (14.2%)<sup>(10,21)</sup> about the need to disseminate adequate information about the theme.

It is noteworthy that out of the 14 selected articles, 5 (35.7%)<sup>(10,12-14,17)</sup> mention nursing professionals, 4 (80%)<sup>(10,12,14,17)</sup>,



describing the importance of the nursing professional's performance and including them as the most qualified health professional to act in the organ donation and transplantation process, 1 (20%)<sup>(13)</sup> addresses the nurses' strategies for a better performance in the process, 2 (40%)<sup>(13-14)</sup> identify the importance of the nursing dialogue with the family and potential donors and 2 (40%)<sup>(13,17)</sup> highlight the need for training the nursing team to work in the donation-transplant process.

## DISCUSSION

The present study showed factors related to family attitudes towards the organ donation and transplantation process, namely: pain and feelings; religion and culture; corruption; distrust; mutilation of the body; and ignorance about the process. These factors generate important repercussions throughout the donation process and, also, of organ transplantation.

The desire of the potential donor is also included as one of the factors for a possible acceptance or refusal for the donation of organs by the family. When the potential donor is favorable to donation, families tend to accept the process, even if they are upset. However, if the potential donor opposed donation in life, the family refuses it as a form of respect for the deceased<sup>(22)</sup>.

Corroborating these findings, a study conducted in São Paulo revealed that among the 1,772 potential donors, the main cause for

non-donation of organs was family refusal in 42.8%, among the main reasons mentioned are: he was not a living donor, time for delivery of the body, the family does not believe in brain death and religion/beliefs<sup>(23)</sup>.

In line with results of this integrative review, of the 350 medical records of potential donors in Pernambuco, 147 refused organ donation, citing the main reasons for maintaining the body intact in 36% of cases, followed by distrust of the donation process in 32.6% and a contrary living donor in 16.3% of the medical records<sup>(24)</sup>.

In this way, different factors can interfere with the success of this process, such as failure to notify a possible donor and failures in communication with the team responsible for the donation process, in addition to the causes of refusal of families that include religiosity, fear of mutilation and negative experience in another donation process, which creates difficulties in the removal of organs and their distribution<sup>(25)</sup>.

Pain and suffering are justified as a finding of this study in that it requires the family to position itself in a moment of extreme pain and anguish, due to the impact of the news of death, which can negatively influence the decision-making process. A survey carried out in the city of São Paulo, which assessed the psychological repercussions of organ recipients, identified several beliefs and fantasies, such as the possibility of transmitting personality

characteristics from the donor to the recipient after the transplant. In this way, fears and beliefs about the transplantation process are related to the lack of knowledge on the topic, since families present these narratives when questioned<sup>(26)</sup>.

In accordance with the findings of this article, a qualitative study that aimed to identify perceptions about life and death and its relationship with organ donation and transplantation, religiosity was observed as a determining factor in donation. There are, however, different ways of looking at death and the moment when it happens for each religion, being pointed out as a deciding factor for acceptance or refusal, considering that most religions regard death only as a passage, wishing body preservation to the postmortem. Since the body is also considered the symbol of life, the fear of mutilation manifests itself as a pretext for the family's refusal to donate organs<sup>(27)</sup>.

Still considering the influence of religions in the organ donation and transplantation process, it was observed that no religion is effectively against donation and transplantation showing itself in favor of the process, and considering it an act of solidarity. However, religiosity influences the decision on the donation related to the low degree of understanding of religions on the subject, so it is necessary that there is a minimum of knowledge about the theme, so that, when

addressing it, there are no doubts and, with this, controlling the spread of untruths<sup>(27)</sup>.

In Brazil, although no religion has expressed its opposition to organ donation, the stronger an individual's beliefs are, and even considering the particular interpretations that he makes of a certain doctrine, this can prove to be a negative aspect for the acceptance of the organ donation and transplantation process<sup>(22)</sup>.

Considering the socio-cultural context, it is noted that the different meanings established for the body by different cultures, can directly interfere in the acceptance or refusal by the organ donation and transplantation process. For each culture, the body has specific relationships, for example, the establishment of the heart as an organ popularly related to feeling and personality, creating fear that, somehow, these unique attributes of each individual may be transferred to another during a transplant. Thus, culture interferes with the acceptance of donation<sup>(28)</sup>.

As in the present study, distrust of assistance and fear of organ commercialization were influenced by the refusal for donation in 46.6% of the articles selected in a survey conducted in July 2019. Fear about anticipation or death induction, in the face of many discrediting the honesty of the donation process, is established from the belief in the existence of organ trafficking. These uncertainties are fostered by the erroneous approach of the health team, who, in many

cases, carry excessive information or do not clearly inform the patient's real state during the entire process<sup>(29)</sup>.

In addition, the population's misinformation related to the lack of knowledge about the concept of brain death and, therefore, the cause of death diagnosed by the multidisciplinary health team, generates more doubts and contributes to distrust regarding the honesty of the process. Therefore, the importance of integrating the family during the entire process of illness and death is observed, so that, subsequently, there is acceptance for organ donation<sup>(29)</sup>.

A study carried out in Rio Grande do Sul in 2017 pointed out that the denial of the diagnosis of brain death, related to a poor understanding of its meaning, due to the view of the heart as an organ of life control and, also, by the presence of heartbeat, respiratory movements and body temperature, can interfere in the decision of family members regarding donation<sup>(30)</sup>.

In all this process of mourning, conflicts and transformation, it is important the fundamental role of nurses, highlighted in some studies analyzed. In this way, validating nurses as the main players in the organ donation and transplantation process, it highlight the extent of their performance from the diagnosis of brain death, the family approach, patient care that ensures the viability of the organs and the care after transplantation to maintain the body to be buried<sup>(31)</sup>.

In the meantime, the role of nurses in the family approach is of paramount importance, with family refusal being pointed out as one of the main challenges for organ donation. Nurses must inform the family and resolve any doubts regarding the procedures involved, in addition to providing the necessary support to deal with the death of the deceased. All this action must take place in a humanized way, respecting decisions and opinions of family members, and any imposing, forced or coercive conduct is prohibited<sup>(31)</sup>.

In accordance with an experience report carried out in the state of Piauí, in which tasks of the multiprofessional team in the organ donation and transplantation process were described, nurses are perceived as the main players in the entire process. However, even if the family interview for the approach on organ donation is not done by the other professionals, it is extremely important that each one, in his respective functions, welcome and provide all support and assistance for the family, considering that the team's receptivity can be a powerful tool for stimulating and positively influencing the procurement of organs for transplantation<sup>(32)</sup>.

## CONCLUSION

The present integrative review showed that several factors can influence family attitudes in the organ donation and transplantation process. The family's receptivity can be influenced and impaired,

impacting the increase in the waiting list for a transplant. The most relevant findings relate to the origin of the factors and are related to pain and feelings, religion and culture, corruption, mutilation of the body, lack of knowledge about the process and distrust.

This study made it possible to highlight the ways to reduce the spread of erroneous information, contributing to make people aware of the organ donation and transplantation process and, with this, seek to raise awareness among the population about the theme, in particular, the relatives of possible donors. The importance of training and the approach of professionals charged with involving families in this very important topic are emphasized.

It is noteworthy that this research contributed to elucidate factors that interfere in the family decision to perform the transplant and, also, it allowed to emphasize the importance of nurses in this process. However, there are limitations based on the level of evidence of the articles analyzed and the scarcity of publications regarding the difficulties encountered in the donation and transplantation process, thus suggesting that future research addressing this aspect of the topic of transplantation should be carried out.

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