

## EXPERIÊNCIAS DE FAMILIARES DIANTE DA POSSIBILIDADE DE DOAR ÓRGÃOS E TECIDOS PARA TRANSPLANTES

### THE FAMILY EXPERIENCE IN LIGHT OF THE POSSIBILITY OF ORGAN AND TISSUE DONATION FOR TRANSPLANTATION

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**ABSTRACT** | This article aims to conduct a review of literature on texts and books that discuss the factors involved in the decision of donating organs and tissue for transplants. Thirty eight (38) articles were found on the subject, published between 2000-2015, and 12 articles published in printed books. Among those, eight articles were included and a book on the family experience in the donation process. During the search a concentration of scientific production of texts and research on the subject was found to be located in the state of São Paulo. The publication of this article is of great importance due to the limitations and paucity of research and academic publications on the subject within the state of Bahia, which presented in 2016 a rate of 62 % of family refusal for organ donation for transplants.

**Key words:** Organ donation. Brain death. Family. Transplantation.

**RESUMO** | Este artigo tem como objetivo realizar uma revisão de literatura de textos e livros que discutem os fatores que envolvem a decisão familiar sobre doação de órgãos e tecidos para transplantes. Foram encontrados 38 artigos relacionados ao tema, publicados nos anos 2000 a 2015 e 12 artigos publicados em livros impressos. Desses, foram considerados oito artigos e um livro que representam a experiência da família no processo de doação. Durante a pesquisa para a revisão, foi constatada a concentração da produção científica de textos e pesquisas sobre o tema no estado de São Paulo. A publicação deste artigo reveste-se de grande importância devido às limitações e à incipiência de pesquisas e publicações acadêmicas sobre o tema para o estado da Bahia, que apresentou, em 2016, uma taxa de 62% de negativa familiar para doação de órgãos e tecidos para transplantes.

**Palavras-Chave:** Doação de órgãos. Morte encefálica. Família. Transplantes.

## INTRODUCTION

For many patients, a transplant may represent the last possibility of life, however, in many countries, waiting times are a problem to that needs to be taken into account. In Brazil, the need to increase the number of organs donated is a societal challenge, leading to the need to understand the high level of family refusal to donate the organs and tissues of patients diagnosed with brain death.

According to a survey by the Brazilian Association of Organ Transplantation (Associação Brasileira de Transplantes de Órgãos: ABTO) published in 2015, despite a growth in organ donation and transplantation, the quantity of organs from deceased donors is insufficient to meet the country's need for transplantation. Studies from a number of sources reveal that family refusal is justified by the following factors: (1) difficulty understanding brain death, characterized as apnoeic coma, absence of supraspinal motor response and apnoea (Resolution 1480 – CFM/97) ; (2) inadequacies in the family interview; (3) cultural and religious beliefs; (4) lack of information in the general population about this issue; (5) lack of knowledge about the patient's desires when alive; (6) lack of confidence in the seriousness of the process; (7) concerns about bodily integrity and/or image; (8) the patient's refusal when alive; (9) lack of satisfaction with hospital care.

On being informed of brain death, families become aware of the death of their relative and are led to reflect on the finite nature of the human condition. A professional then conducts the interview about donation, bringing them into contact with the family at a time when usually only those very close to them do so. During the interview, the family is informed about the possibility of donating organs and tissue for transplantation. This is the most delicate part of the process.

According to the literature (Cajado, 2011) , the donation interview must take place in a specific space in which family members feel respected. In Spain, a country with a high level of family consent to donate, during the brain death protocol, the family is made to feel welcomed and assisted by

a team that is technically trained, including in how to communicate bad news and accept emotions and feelings in the face of the pain and loss of a family member. This has enabled the country to become a global reference centre for transplantation.

A study to assess the reasons for a family's refusal to donate organs and tissues, carried out by the Federal University of Sao Paulo (Universidade Federal de São Paulo: UNIFESP) and coordinated by the researcher Bartira De Aguiar Roza, mapped and examined the reasons for family refusal and came to the conclusion that the principal reason was that a large number of family members (21%) did not understand the concept of brain death. A further 19% attributed their decision to religious beliefs, while another 19% claimed it was because of the hospital team's lack of technical competence (FAPESB 237, Nov/2015 p. 34-37).

According to ABTO (2015) data, while the rate of family refusal to donate in Brazil doubled over seven years, rising sharply from 22% in 2008 to 44% in 2015, the situation is even more serious in the state of Bahia, where the rate for the same year was 70% (ABTO) . In 2016, according to data from the same source, the rate of family refusal to donate organs and tissues for transplantation in Bahia has remained high (62%) compared to the rest of the country (43%).

The importance of publishing this article resides in the limited and scarce research or academic publication on this subject at a time of debate about the high level of family refusal to donate organs and tissues for transplantation. According to the Health Department of the State of Bahia (Secretaria de Saúde do Estado da Bahia: SESAB), there are approximately 2,200 people on the state's transplantation list, placing it is amongst the Brazilian states that require public health policy attention and investment in order to accomplish transplants, as well as campaigns aimed at informing and explaining the importance of donation to the population.

## METHOD

Integrative reviews of the literature provide a systematic review of traditional narrative reviews and may include quantitative and qualitative studies, an analysis of theories and methods and the results of empirical research, thereby enabling a more comprehensive view of the phenomenon under study. Our selection of studies and articles related to the object of this review included the following stages: a general search of the SCIELO, MEDLINE, LILACS and BVS databases, in the Portuguese language, based on the following descriptors: transplantation; organ and tissue donation; brain death; family organ donation interview; family refusal to donate.

Within this universe we found 38 articles, published between 2000 and 2015, and 12 articles published in printed books. The inclusion criterion related to studies and articles that presented the family's experience and opinion about the donation process. The exclusion criterion referred to empirical works conducted with health professionals, students and the general population. For this integrative review of the literature, we examined eight studies, two theses and six articles representing the family experience of donation.

In our review, we sought to highlight: (1) the title and authors; (2) the objectives; (3) the research question; (4) a summary of the results, the state in which the study was undertaken, where it was published, the study method and the number of participants.

## REVIEW OF LITERATURE

To begin our review we present doctoral research by Sadala, published in the book "Doação de Órgãos: a experiência de enfermeiras, médicos e familiares de doadores" (Organ donation: the experience of nurses, doctors and the donor's family members). In this study, the authors sought to understand the perspective of the donor's family members in relation to their experience of donating organs upon brain death. It asked: what is decisive in determining the donation? How does it come about within the

family, what is the process of consent? What are the repercussions of this decision for family relationships? Who in the family makes the decision? How would the family evaluate the experience? The results also revealed aspects related to how the institution functioned - this was valued by the family when they thought that the donor had been well cared for. The author refers to several studies showing that families of organ donors requested support from the institution during the process. Far beyond simply informing them about the state of the donor or the process of organ donation, the results of this study suggest that it is essential for health professionals, particularly those closest to the care the donor received, to be available and open to perceiving the family members' needs, rather than merely informing them of the donor's condition.

The second study that serves as the basis for this review was Roza's doctoral thesis, "Efeitos do Processo de Doação de Órgãos e Tecidos em Familiares: intencionalidade de uma nova doação" (The Effects on Families of the Process of Donating Organs and Tissues: the intentionality behind a new donation), which sought to characterize both the socio-demographic and epidemiological profiles of deceased donors and the socio-demographic features of family members; and to assess and relate the effects of the process of organ and tissue donation on donor families. In conclusion, the author states that the intention to authorize a new donation is based on moral and cultural aspects that transcend the process itself; it considers that it is necessary to accompany families throughout the process, up to the delivery of the corpse, since this is characterized as an ethical situation for the defence of their rights. Finally, it asserts that families satisfied with the family interview are 9.53 times more likely to authorize another donation, emphasizing the need for the families of deceased donors to be incorporated into campaigns for the donation of organs and tissues for transplantation.

The third studied considered here is an article by Bouso, "O Processo de Decisão Familiar na Doação de Órgãos do Filho: uma teoria substantiva" (The Family's Decision-making Process regarding the Donation of a Child's Organs: a substantive theory), whose aim is to understand the family's decision-making process regarding the donation of a child's

organs and seeks to identify the meanings the family attributes to this experience. The results suggest that family decision-making is a process composed of the following phases: (I) experiencing the tragedy's impact; (II) working with the uncertainties of brain death; (III) handling the decision problem; (IV) reconstructing the history of the child's death. In her final considerations, the author states that there is value in considering the family's own context and understanding that their experience occurs within a matrix of interpersonal relationships that affect beliefs, emotions and behaviour and which call for a decision in the light of new, contemporary, cultural practices related to death, donation and organ transplantation. It also emphasizes the importance of sensitivity in the professional who attends the family. This study demonstrates that the donation decision is less conflicted when it is situated within a context that promotes and accepts suffering and doubts, and provides the information and social support required by the family.

The fourth study we selected was a work entitled "A Recusa Familiar para Órgãos e Tecidos para Transplante" (Family Refusal of Organs and Tissues for Transplantation) conducted by Moraes EL and Massarollo MCKB, which aimed to understand potential donor families' perceptions of the process to decide to refuse the donation of organs and tissues for transplantation. The authors also put forward considerations about the dilemmas related to understanding brain death, pointing out the difficulties of professionals who continue to resist disconnecting the respirator of a patient diagnosed with brain death, even following the refusal to donate. The authors' assertion encourages us to consider the varying medical attitudes about brain death, leading us to suppose that, as well as a technical understanding of the facts, there are other aspects, including some of a subjective nature, that may interfere in the attitudes and decision, from both a doctor's and a family member's point of view. The fifth article, entitled "A Experiência da Família frente à Abordagem para Doação de Órgãos na Morte Encefálica" (The Family Experience of the Organ Donation Approach at Brain Death) from the collective authorship of Dell Agnolo CM, Belentani LM, Zurita RCM, Coimbra JAH and Marcon SS, aims to understand and explore the experience of the potential donor family given the "approach" to

donate organs and the reasons that lead the family to authorize, or not, the donation. The authors conclude that the population's lack of knowledge about the meaning of donation leads to internal doubts and questions within the family which, in turn, lead them to opt for the certainty of not donating. These situations often occur because the doctor does not always have the time to explain and answer the family's questions related to brain death, which strengthens the need to improve the family donation interview and the corresponding and necessary trend for more humanized care.

The sixth study selected for this review, "A Receptividade da Notícia da Morte Encefálica nos Familiares de Doadores de Órgãos e Tecidos para Transplante" (Receptivity to News of Brain Death in the Families of Organ and Tissue Donors for Transplantation) was written by Cinque VM and Bianchi ERF. This study aimed to characterize receptivity to the news of brain death in families who participated in the donation process and to ascertain the level of association with variables of interest. The results of the authors' investigation allowed them to conclude that: 1. Most families receive the news of brain death in an agitated manner (62.5%). 2. There was a weak to moderate and significant association between the receptivity to the news of brain death and the variables: sex and age of family member, degree of family relationship and age of donor.

They also concluded that the possibility of receiving the news of brain death in a calm manner was less likely in female family members under 40 years old, as well as in families of donors under 40. First-degree relatives were 1.6 times more likely to receive the news of brain death calmly, compared to other family members, particularly when the communication was clear and made in understandable terms. One of the points highlighted in the text is that a lack of understanding about brain death hinders the donation decision.

The seventh article by Lira GG, Pontes CM, Schirmer J and Lima LS "Ponderações de Familiares sobre a Decisão de Recusar a Doação de Órgãos" (Family Considerations about the Decision to Refuse Organ Donation), sought to understand the social representations that guide the family's decision to refuse to donate organs for transplantation and

identified actions within the social environment that influenced this refusal. In the discussion, the authors reveal that the central nucleus of the social representations of organ donations for these subjects was based on three points: the context of care and the way they were received by the hospital; the culture of bodily integrity and beliefs about life and death; and issues linked to the group's level of knowledge. In the results, three themes emerge as the basis of the study: the model of care and the management of health services is decisive in donation refusal; the belief that the body is inviolable and the possibility of a return to life – the heart as the core of life and faith reinforcing hope.

The eighth study we selected, entitled “Avaliação das Causas de Recusa Familiar à Doação de Órgãos e Tecidos” (Assessment of the Causes for Family Refusal to Donate Organs and Tissues), by Pessoa JLE, Schirmer J and Roza BA, sought to assess levels of knowledge about brain death and their influence on the decision to donate, and determined that individuals do not understand the concept of brain death, and their confidence in both the brain death diagnosis and the doctor's capacity to make the correct diagnosis is low, which negatively influences the decision to donate. The aim of this study was to identify and analyse the causes of family refusal for the request to donate the organs and tissues of their deceased relatives, following the diagnosis of brain death in a service that acquires organs and tissues in the state of São Paulo.

In the discussion, the study suggests that the main

reasons to refuse to donate are: little knowledge of the subject among family members; lack of understanding about the diagnosis of brain death, which they posit is the principal cause of refusal; issues related to religious beliefs, described as a motive which is rarely discussed within academia; and a lack of technical competence in the professionals who conducted the interview, leading the authors to conclude that the main causes of family refusal are linked to family members' lack of understanding of the brain death diagnosis, aspects linked to religion, and lack of preparation on the part of the professionals who conduct the interview.

## DISCUSSION

The eight studies presented above provide analysis and interpretations about the determining factors related to family decisions to donate organs and tissues in Brazil. They are fundamentally important and support reflections and understanding of the causes of the high level of family refusal to donate in a number of states in the country, as well as revealing the need for greater involvement and the strengthening of public health policies, particularly those that involve activities to promote donation and organ and tissue transplants.

The table below presents, in order, summary descriptions of the publications that constitute this Literature Review.

**Table 1.** Summary descriptions of the publications selected for review

Order	Title	Authors	Place of publication	Method	No. of study participants / State
1	Donation of Organs: the experience of nurses, doctors and the donor's family members	SADALA MLA.	São Paulo: Editora UNESP, 2004.	Phenomenology	18 family members São Paulo
2	The Effects on Families of the Process of Donating Organs and Tissues: the intentionality behind a new donation	ROZA BA.	Thesis – UNIFESP / EPM/ PPGEE, 2005.	The study adopted a non-experimental, exploratory survey design, used to seek information about subjects, groups and/or institutions.	69 family members São Paulo
3	The Family's Decision-making Process regarding the Donation of a Child's Organs: a substantive theory	BOUSSO RS.	Journal - Texto & Contexto Enfermagem, Florianópolis, Jan-Mar. 2008.	Qualitative symbolic interactionism/Theory of Family Systems	13 family members São Paulo

**Table 1.** Summary descriptions of the publications selected for review  
(continuation)

Ordem	Título	Autores	Local de Publicação	Delineamento/Método	Nº de participantes do estudo
4	Family Refusal of Organs and Tissues for Transplantation, Reported by the Families of Potential Donors	MORAES EL, MASSAROLLO, MCKB.	Journal - ACTA Paul Enferm. São Paulo, 2009.	Qualitative phenomenological approach, situated phenomenon structure modality	8 family members São Paulo
5	The Family Experience of the Organ Donation Approach at Brain Death	DELLAGNOLLO CM, BELANTINI LM, ZURITA RCM, COIMBRA JAH, MARCON SS.	Journal - Revista Gaúcha de Enfermagem, Porto Alegre – RS, 2009.	Qualitative approach. Descriptive and exploratory study	8 family members Paraná
6	Receptivity to News of Brain Death in the Families of Organ and Tissue Donors for Transplantation	CINQUE VM, BIANCHI ERF.	Electronic Journal - Enfermagem Global. No. 16 Murcia, June 2009.	Quantitative method Descriptive, exploratory field study	16 family members São Paulo
7	Family Considerations about the Decision to Refuse Organ Donation	LIRA, GG and collaborators	Journal - ACTA Paulista de Enfermagem/ EPE/ UNIFESP, 2012.	Qualitative method using a descriptive and exploratory design. Theoretical basis: Theory of Social Representations	9 family members Pernambuco
8	Assessment of the Causes for Family Refusal to Donate Organs and Tissues	ROZA BA and collaborators	Journal - ACTA Paulista de. Enferm. vol. 26 no. 4 São Paulo, 2013.	Quantitative method. Cross-sectional study about the causes of family refusal to donate organs and tissues.	42 family members São Paulo

According to the SCIELO database index, the greatest number of scientific articles on the subject of organ and tissue donation in Brazil refers to the state of São Paulo. A significant portion of this production examines the situation within this state, whose prominence may be associated with its infrastructure for developing and performing transplants, a greater concentration of researchers and specialised human resources, and greater investment in its public and private health networks. In principle, these circumstances favour a more detailed understanding of the determining factors for family refusal to donate in this state. Of the

eight studies examined in this review, six presented the São Paulo context, while two examined refusal in the states of Pernambuco and Paraná, at specific moments in time, hindering further assumptions about the determining factors of family refusal to donate organs and tissues in these states. The incipient and/or inexistent nature of scientific and intellectual production on this theme in the state of Bahia, which has high indices of family refusal to donate organs and tissues for transplantation, demonstrates the importance of an understanding of and intervention in this context.

## FINAL CONSIDERATIONS

The production and publication of this review of literature, examining studies that present analyses and interpretations of the determining factors for family refusal to donate organs and tissues in Brazil, suggests a spatial concentration of the scientific production of texts and research in the state of São Paulo.

Due to the size and cultural diversity of the country, it is of fundamental importance for the Ministry of Health, through the National Transplant System (Sistema Nacional de Transplantes: SNT), to adopt incentive policies to support the states in developing instruments that enable investigation and intervention, aimed at reducing the real causes of the

low indices for the donation of organ and tissues for transplantation. We understand that the existence and expansion of education programmes regarding donation and organ and tissue transplantations, and scientific publications on this subject, will only happen as a result of scientific and academic investment, accompanied by public health policies.

### COMPETING INTERESTS

No financial, legal or political competing interests with third parties (government, commercial, private foundation, etc.) were disclosed for any aspect of the submitted work (including but not limited to grants, data monitoring board, study design, manuscript preparation, statistical analysis, etc.).

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