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## RESEARCH ARTICLE

### FAMILY-NEGATIVES IN THE PROCESS OF ORGAN AND TISSUE DONATION FOR TRANSPLANTATION NEGATIVAS FAMILIARES NO PROCESSO DE DOAÇÃO DE ÓRGÃOS E TECIDOS PARA TRANSPLANTE

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#### ABSTRACT

It is a documentary research of qualitative and quantitative approach, carried out through secondary data obtained through reports from relatives of patients with potential donor, female and male, patients diagnosed with brain death. That aims to know the reasons why the family not to authorize the donation of organs and tissues for transplantation. These records were made by a team of Organ and Tissue Procurement Organization (OPO Tapajós), a resident of the Lower Amazon Regional Hospital, in the city of Santarém, Pará. Data collection was conducted through forms with open and closed questions recorded on the instrument itself. The subjects of this study were all potential donors registered in the reporting forms with a diagnosis of brain death that are part of the records of that organization. The forms analyzed comprise the years January 2012 to March 2015. According to the organization, the records of notification of potential donors OPO Tapajós, the percentage of family refusals showed that in 2012 it obtained the highest number of negative, with 47% of potential donors, second 2014 with 42%, followed by 2015 which showed a 25% rate, and finally in 2013 with a lower rejection rate, only 20% of cases. We are listed six reasons for not organ donation, namely: 25% intact body, 25% religious conviction, dissatisfaction with hospital care 20%, family or donor contrary to the donation of 15%, lack 10% family consensus, 5% undecided family.

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#### INTRODUCTION

In Brazil, the family-negative is said to be one of the worst evaluation indicators of the process of donation and organ transplants in recent years. Because this factor is of paramount importance for the organ donation process, there is an impediment to the steps involved in the process being adequate to obtain a positive result, as a result of this factor there is still a very low number of organ transplants coming from donors with brain death (Revista Associação Brasileira de Transplante de Órgãos, 2012). The process of donating organs is the set of actions and procedures that competes in transforming a potential donor into an effective donor. The first requirement

for a possible donor to be identified is to be diagnosed with brain death, in which clinical contraindications that represent risks to future organ recipients have been ruled out (Secretaria de Estado da Saúde de São Paulo, 2002). The time for the process to occur is relative, can take hours or days which can cause stress and be traumatic to the family and, therefore, compromise unfavorably the number of donations, and therefore more possibility among the other reasons for familiar refusal (Santos *et al.*, 2005). The process of organ and tissue transplantation is considered a therapy in several chronic and incapacitating diseases, and also allows the rehabilitation and increase of the expectation of survival. In Brazil, the first cadaver donor transplant was a kidney transplant and occurred in 1964 in Rio de Janeiro. Since then, technological advances have become increasingly increasing and have boosted this

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development of immunosuppressive drugs, improvement of intensive care and use of more efficient preservation solutions. By contrast, progress in intensive care and mechanical ventilation medicine have increased the survival of critically ill patients with irreversible neurological problems in the ICU, through death to be linked to neurological criteria (Dalben *et al.*, 2010). The significant increase in the number of transplants occurred due to the scientific, technological, organizational and administrative advances, although it is insufficient, in relation to the enormous accumulated demand of organs. In Brazil, the rate obtained is 5.4 donors per million inhabitants per year. Studies indicate that there are a large number of potential donors, says that they are predisposed to donation: health professionals and the population in general, however, the reality shows a high number of refusals, which may be related to the donation process (Santos *et al.*, 2005). The donation process is generally defined as the set of actions and procedures that work together effectively to transform a potential donor into an effective donor (Secretaria de Estado da Saúde de São Paulo, 2002). Currently are regularly held by WHO worldwide multiple organ transplants and tissues such as heart, liver, lung, pancreas, kidney, corneas, skin, bone, veins, tendons, and bone marrow (Moraes, 2005). The disproportion between supply and demand for organs for transplantation is due not only to a lack of potential donors, but to several variables (Arcanjo *et al.*, 2013).

In a comparative study related to the epidemiological aspects of the candidates for organ donation in the states of Pará, Acre and São Paulo, it was observed that the number of potential donors pmp / year (per million people / year) in Pará was 15.4, In Acre 15 and in São Paulo 60.5. Among the causes of failure to achieve the unfamiliar acceptance in Pará represented 56% of the total, in Acre 43% and 39% in São Paulo (Conceição *et al.*, 2015). According to the Brazilian Association of Organ Transplants (ABTO, 2014), the family-negative rate is still high (46%), and a plausible target is to reduce by 2% per year until it reaches 30%. The rate of heart failure of 14.5% is difficult to analyze because it may be related to various conditions, such as difficulties in maintaining and / or delay in notification or in the diagnosis of brain death. The rate of medical contraindication of 14.5% is not very high and may be related to the sending of unused organs in some states to others with more liberal criteria, and a goal around 10% could be predicted for the next three years. In the State of Pará, the following data were used: number of notifications (n = 129), non donors (n = 111), effective donors (n = 18), donors whose organs were transplanted (n = 17), donors of multiple organs (N = 15), refusal number (n = 40), against medical indication (n = 23), cardiac arrest (n = 22), others (n = 26). Therefore, the refusal is the major cause for the high number of non-donors.

In general in the state of Pará in the last three years, there were no developments in reporting rates and effective donors, and in 2014, stayed in brand 17,0pmp and 2,4pmp respectively. The percentage of non-family authorization rose, from 31% in 2013 to 55% in 2014 (ABTO, 2014). Brazilian legislation has been presenting significant conceptual changes. The Brazil has published its first legislation for organ transplants, whose law 5,479 regulates the withdrawal and transplantation of tissues, organs and parts of cadavers for therapeutic and scientific purposes (Galvão *et al.*, 2007). In 1992, there was a need to clarify criteria for transplantation, and Law 8,489, dated November 18, was elaborated, which, in its article 3rd, caput and in items I and II, requires that transplants be performed: A)

the permission manifested in life by the 'disposer', by means of a private or public document, or, in the absence of such document; B) contrary manifestation of the spouse, ascendant or descendant in order to withdraw and transplant tissues, organs and parts of the human body, for therapeutic or scientific purposes (Mendes, 1996). In 1997, the Law 9,434 was approved, repealing the previous law. In article 4th it was described that the removal of tissues, organs and parts after death, could be effected, regardless of express consent of the family if, in life, the deceased did not express their objection. The paragraph 1st defined the expression of will in the opposite direction to the removal of tissues, organs and parts will be fully recognized are on the Civil Identity Card, issued by the identified bodies of the Union, the States and the Federal District, and the National Driver's License by inserting in these documents the expression 'non-donor of organs and tissues (Moraes *et al.*, 2006). Doubts about whether or not to authorize the donation were not met. In March 2001, Law No. 10,211 of March 23, was passed, where it says in Article 4th, single paragraph, "The removal of tissues, organs and parts of the body of persons deceased for transplantation or other therapeutic purpose will depend on the authorization of the spouse or Relative, of age, obeyed the line of succession, straight or collateral, to the second degree inclusive, signed in a document signed by two witnesses present at the verification of death" (ABTO, 2009). The Federal Medical Council, through resolution 1,480, of 1997, adopted criteria and principles for the diagnosis of brain death, according to the concept established by the World Scientific Community. The diagnosis of brain death was therefore based on data obtained through anamnesis, followed by physical examination and completed in laboratory tests (Silveira *et al.*, 2009).

Factors that limit organ donation are: lack of identification and notification of a potential donor; Inadequate care of the donor; Confirmatory subsidiary testing of brain death; Inadequate interview of family members; Relatives who do not authorize the donation in 30.0% to 40.0% of the time; Difficulties in contact with transplant teams; Difficulties in withdrawing organs; Distribution of organs donated (Clausell *et al.*, 2001). The donation is not only a sign of authorization agreeing to the withdrawal of organs, but the involvement of multiple feelings, such as: loss, pain and life expectancy to the other person, besides being considered a bureaucratic, time-consuming, distressing, tiring and very exhausting. It is understood that factors such as the will of the potential donor in favor of donation, have a prior knowledge about brain death and donation, receive all necessary explanations of organ harvesting team, emotional resources to deal with the time it is exposed exert strong influence to occur the giving of consent, and allow the family has less suffering in this painful process of loss and grief, reducing overall number of negative (Santoro *et al.*, 2013). The limited knowledge of people in general regarding the concept of brain death (BD), associated with the influence of a relative, presenting an external appearance of alive, with heart beating, and especially the body maintaining its heat, respiratory movements, Healthy color and functioning of its main systems, hinders an understanding and / or acceptance of the DB (Santoro *et al.*, 2005). Most people associate death with respiratory and cardiac arrest, still and cold body (Evans, 1995). It is important that the care given to the family is performed in a satisfactory way by the professionals of the Organ Procurement Organization, and responds to questions about brain death, doubts about the donation process and the release of the body are clarified,

offering the support and clarifications as to reduce the suffering and the donor's family's pain (Cinque and Bianchi, 2010). The guiding reasons regarding family decision to refuse organ donation have been supported in the representation of assistance to the family, the culture of body integrity maintenance after death, in addition to not understanding of brain death as actual death (Lira, Pontes, Schirmer and Lima, 2012). The Donation Program, Capture and Transplantation of Organs and Tissues, under the responsibility of the Department of Health Care (SAS) of the Ministry of Health aims to reduce waiting time in the queue of candidates for transplantation, through the use of optimization of organs and tissues, operational, human and assistance resources in the area of transplantation, with the preservation of ethics (TCU, 2006). In 1997, the National Transplant System (NTS) was created within the Ministry of Health. The General Coordination of the National Transplant System is the body responsible for managing the program. At the federal level, there is also the National Notification Center, Capture and Distribution of Organs (NNCCDO). There are 21 Centers for Notification, Capture and Distribution of Organs (CNCDO) in the states and one in the Federal District. The NTS is also integrated by 8 regional centers, which are located in the states of Minas Gerais and Paraná. In the State of São Paulo, it was decided to assign organs to entities linked to 10 public university hospitals called Organ Procurement Organization (OPO) (TCU, 2006).

Brazil has one of the largest public transplant programs in the world, with a policy based on Laws 9,434 / 1997 and 10,211 / 2001, with the following guidelines: "free donation, recipients beneficence, non-maleficence towards donors alive" (Moraes, 2005). The records of the Brazilian Association of Organ Transplants (ABTO) show that there was a 15% increase in donation and transplant rates in the country in 2008 (ABTO, 2009). There is a difference between organ transplantation and any other health issue, certainly due to specific characteristics in the donation process, not only dependence on the relationship between the health team and the patient is the most relevant, in order to follow that the process concludes Depends on a third element, the organ donor. Technological advances of no use for the procedure without the organ donor. It is necessary to have a good understanding of the public on the subject, it is also important that many sociocultural changes happen, because only then the acceptance level for organ donation undergoes positive change (Roza *et al.*, 2010). This study is relevant because its main objective is to highlight the main causes of refusals among the relatives in the process of donating organs and tissues of patients with a diagnosis of brain death.

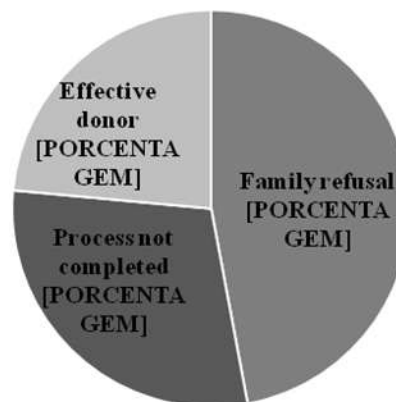
## METHODS

This is a documentary research with a qualitative and quantitative approach, conducted through secondary data obtained through reports from relatives of patients with potential donor (brain death diagnosis), female and male. These records were made by a team from OPO Tapajós. The subjects of this study were all potential donors enrolled in the notification forms with diagnosis of brain death that are part of the records of this organization. We analyzed 54 forms that comprise the years from January 2012 to March 2015. The data collection was performed at the Tapajós OPO, located at the Regional Hospital of Baixo Amazonas, in the city of

with open and closed questions recorded in the instrument itself. The data analyzed were tabulated in Excel spreadsheets and the results obtained through graphs, tables and descriptive statistics. The analysis of quantitative data was performed through the sum of the information tabulated and interpreted. The study was approved by the Ethics Committee of the Pará State University with opinion No. 1,005,033, CAAE No 42488314.2.0000.5188.

## RESULTS AND DISCUSSION

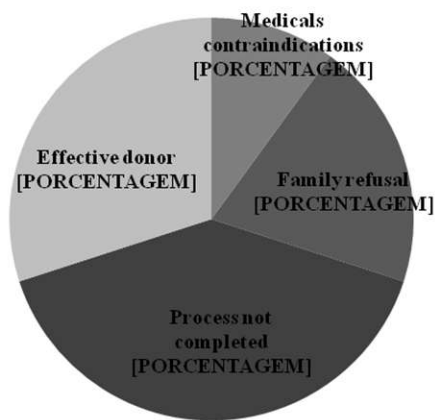
The results show that in the year 2012, the number of family refusals was higher than the other factors that made donation of organs unfeasible (Figure 1 and 6). In 2013 this reality changes, it was found that there was a decrease in family negatives, with only 20%, a number lower than the other factors (Figure 2). In 2014 the number of potential donors grows and, once again, family-negatives increase by 22% compared to the previous year (Figure 3 and 6). In all the analyzed years, the processes that were not completed were the second reason for not donating (Figure 1 to 4). In the year 2015 we present only the data from the first three months, where the number of refusals is half the number of unfinished cases, thus having a new problematic in sight (Figure 4). Regarding age, it is observed in this study that the highest refusal rate is found in patients over 40 years of age and under 60 years of age, totaling a 45% refusal of potential donors in this age group, as shown in figure 5. As to age, it is observed that the largest number of non authorization for donation was patients older than 72 years (Marques *et al.*, 2013). As for the age group of potential donors of families refused to donate organs and / or tissues, the research identified the oscillation between 13-78 years, with the highest incidence between 51-70 years, as also observed in a study conducted in 2010 (Dalben and Caregnato, 2010). When comparing the results of this study with the results of the researchers already mentioned, we can observe that the age group with the highest index of family negatives is over 40 years old (Figure 5).



Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

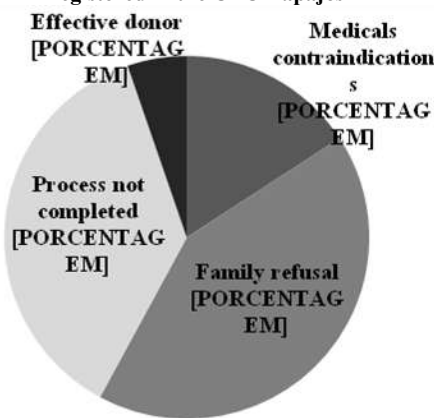
**Figure 1. Data referring to potential donors in the year 2012, registered in the OPO Tapajós**

The percentage of family refusals showed that in 2012, the highest number of refusals occurred, 47% of potential donors, 2014 with 42%, followed by 2015, with a rate of 25%, and 2013 Less refusal, only 20% of cases, as we can see in Figure 6. Bousso (2008) reports that family refusal is considered the greatest obstacle to donation.



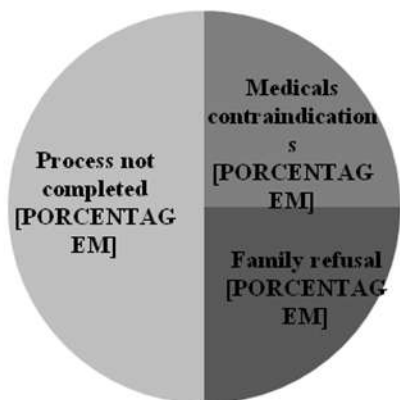
Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 2. Data referring to potential donors in the year 2013, registered in the OPO Tapajós



Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 3. Data referring to potential donors in the year 2014, registered in the OPO Tapajós

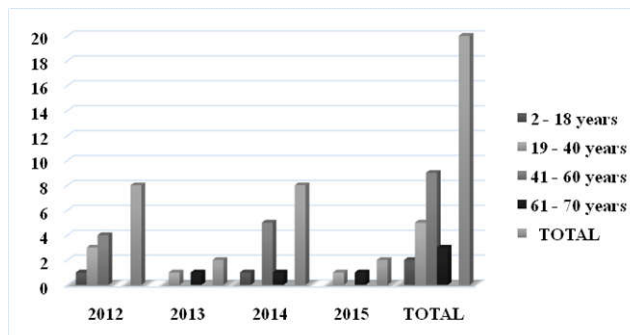


Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 4. Data referring to potential donors in the year 2014, registered in the OPO Tapajós

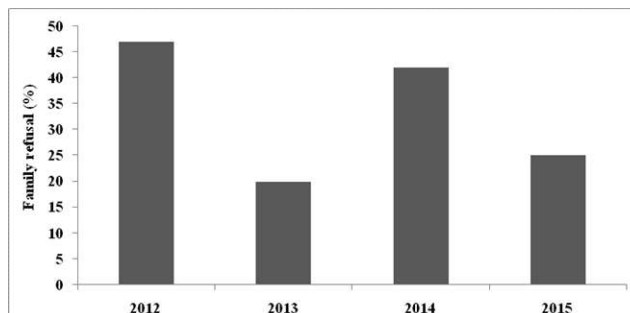
It justifies that, even with the existence of legislation, the issue of organ donation is still controversial. Garcia (2000) says that family-negative in their study was the second reason for not donating organs and this is often because the family is misinformed. According to data from the Brazilian Registry of Transplants, in 2007 the number of potential donors was 29.8

number of potential donors, the medical contraindication of 33.3% and the number of effective donors was 6.2 pmp / year. As Figure 7 shows, the most commonly used causes for non-donation were: religious conviction, and the completeness of the body. With their beliefs in mind, family members do not readily accept the diagnosis of brain death, believe that there may be an improvement, or even allow disintegration of the body. Dalben and Caregnato (2010) says that of the families addressed in their study, 15.7% refused the donation, being the most cited reason for the refusal the lack of knowledge of the potential donor's desire; The other reasons cited pointed to the donor's manifestation in life contrary to the donation, the family's desire to keep the body intact and by religious convictions.



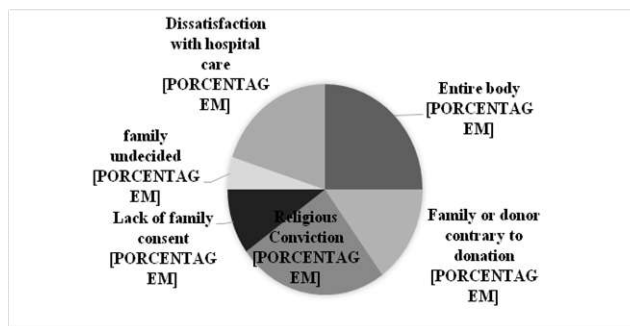
Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 5. Percentage referring to the age of non-donor patients per year, recorded at the Tapajós OPO, from January 2012 to March 2015



Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 6. Data referring to the family refusals registered and reported at the Tapajós OPO in the period from January 2012 to March 2015



Source: Records of notification forms of potential donor with brain death, from January 2012 to March 2015.

Figure 7. Data referring to the reasons for family denials to donation, registered at the Tapajós OPO, from January 2012 to

Moraes and Massarolo (2009) says "One of the reasons that families point to refuse the donation is related to religious belief. Cultural beliefs, rather than religious ones, are opposed to giving. The Roman Catholic, Buddhist, Hindu, Muslim and Protestant religions are supportive of the gift, classifying it as an act of generosity. Families manifest faith, believe that God will return the life of their loved one". It is observed that religious conviction, whole body, ignorance of the desire of the potential donor, are the motives most cited by relatives of potential donors in the comparative studies above, so there is a repetition of the same reasons listed, although there is a discrepancy in the years in which the studies were performed.

## Conclusion

When talking about donation of organs and tissues, it is noted that the great majority is still lax in relation to the theme, the lack of interest of the population, and the high number of negative media end up contributing to disbelief in the subject. Therefore, the search for information about the reasons for refusals and their perception regarding the importance of donating organs and tissues and knowledge regarding brain death becomes relevant for the effective increase of the authorizations for donations. The dissemination of results in statistical data is essential for the region to know and can compare the number of effective donors relative to the family negatives. During the research we can follow the routine of the OPO Tapajós team, it was possible to the already lived experiences, the difficulties, the challenges to perform some important tests for the opening of the protocol, lack of equipment, and the work they do to increase the number of donations, performing active search, campaigns and lectures. The main possible causes of the family refusal identified in this study through the records of the notifications of the potential donors of the OPO Tapajós, include six reasons for the non donation of organs and tissues, such as: Body integrity 25%, religious conviction 25%, dissatisfaction with care Hospital 20%, family or donor contrary to donation with 15%, lack of family consensus 10%, relatives undecided 5%. It is necessary, therefore, that there be an increase in qualified professionals to clarify the possible doubts of the relatives, and in general to work the conscientization in the hospitals, during the interviews as in the churches, independent of the religion. If the theme gains more media space in a positive way, certainly the number of family members of potential donors and the number of declared donors in life will gain a visible increase in the face of the negatives that still prevail today.

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