PROFILE AND REASONS FOR DENYING THE DONATION OF ORGANS AND TISSUES FOR TRANSPLANTS BY FAMILIARS

PERFIL E MOTIVOS DE NEGATIVAS DE FAMILIARES PARA DOAÇÃO DE ÓRGÃOS E TECIDOS PARA TRANSPLANTE

PERFIL Y MOTIVOS DE LAS NEGATIVAS DE LOS FAMILIARES PARA DONACIÓN DE ÓRGANOS Y TEJIDOS PARA TRASPLANTE

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Objective: describe the profile of family members and potential donors, and the negative motives for organ and tissue donation for transplants. Method: quantitative, cross-sectional study with data collection through the family interview form, carried out from 2008 to 2014, in Southern Brazil. Results: the predominant potential donor was male, between 41 and 60 years, married, donor of corneas, and the first degree family member. There was a family denial for organ donation in 74.9% of the total of 630 medical records. Among the 472 denials were: 20.8% due to lack of knowledge of the willingness of the potential donor, 17.6% due to the previous conviction of not being a donor, and 13.8% due to family disagreement. Conclusion: describing the profile of family members and potential donors and identifying the main reasons for non-donation can contribute to the planning and development of interventions that stimulate the donation of tissues and organs.


Objetivo: describir el perfil de familiares y de potenciales doadores y los motivos de negativas para doación de órganos e tecidos para transplantes. Método: estudio cuantitativo, transversal, con coleta de datos por medio del formulario de entrevista familiar, realizado de 2008 a 2014, en el Sur del Brasil. Resultados: el potencial doador predominante fue un varón, entre 41 y 60 años, casado, donador de córneas, y el familiar, de primer grado. Hay negativa familiar para la donación de órganos en el 74.9% de los 630 expedientes. Entre las 472 negativas hubo: el 20.8% por falta de conocimiento de la voluntad del doador potencial, el 17.6% por la anterior condena de no ser donante y el 13.8% por discordancia familiar. Conclusion: describir el perfil de familiares y potenciales donantes y identificar los motivos principales de no donación contribuye a la planificación y desarrollo de intervenciones que estimulen la donación de tejidos y órganos.

negativa familiar para doação de órgãos em 74,9% do total de 630 prontuários. Entre as 472 negativas: 20,8% por desconhecimento da vontade do potencial doador, 17,6% pela convicção prévia de não ser um doador e 13,8% por desacordo familiar. Conclusão: a descrição do perfil de familiares e de potenciais doadores e a identificação dos principais motivos da não doação podem contribuir para o planejamento e desenvolvimento de intervenções que estimulem a doação de tecidos e órgãos.


Objetivo: descrever o perfil de os familiares y de potenciales donadores y los motivos que los llevan a no donar órganos y tejidos para trasplantes. Método: estudio cuantitativo, transversal, cuya recolecta de datos se hizo a través de un formulario de entrevista familiar, realizado de 2008 a 2014, en el Sur de Brasil. Resultados: el potencial donador era, predominantemente, del sexo masculino, entre 41 y 60 años, casado, donador de córneas, así como el familiar de primer grado. Hubo una negativa familiar para la donación de órganos en un 74,9% del total de los 630 informes médicos. Entre las 472 negativas: el 20,8% lo hace por desconocimiento de la voluntad de ser un potencial donador, el 17,6% por la convicción previa de no ser un donador y, el 13,8% por desacuerdo familiar. Conclusión: la descripción del perfil de los familiares y de potenciales donadores, así como la identificación de los principales motivos para no donar, pueden contribuir para el planeamiento y el desarrollo de intervenciones que estimulen la donación de tejidos y órganos.


Introduction

Over the years, Brazil has presented innumerable advances in the process of organ and tissue donation and transplantation. The advances were both in the improvement of procedures and techniques as well as in the formulation of laws and public policies, which made possible the creation of the National Transplantation System (Sistema Único de Saúde – SUS)20. As a result of this program, from 2010 to 2017, Brazil has reduced the number of people waiting for organ transplantation, due to the increase in the rate of effective donors. In 2017, the rate increased by 14% to reach 16.6 per million population (pmp), and was due to a 3.8% increase in the reporting rate of potential donors (51.6 pmp) and 10.2% in the rate of donor effectiveness (32.4%). Among the states, Santa Catarina (40.8 pmp) with an increase of 10.9% and Paraná (38.0 pmp) with an increase of 26.2% were highlighted. Only Santa Catarina accounted for 50% of potential donors22.

Despite the advances in public policies and the growing number of effective donors and implementation of the transplant in Brazil, the supply still does not surpass the demand. In some states, this number is lower than expected. In December 2017, in the country, there were 32,402 people waiting for an organ and/or tissue. Among the 24 Brazilian states, São Paulo had the largest number of patients on the waiting list (15,021), followed by Minas Gerais, with 3,428, and Rio de Janeiro, with 1,918. As to Rio Grande do Sul, there are 1,224 patients on the waiting list22.

Faced with this scenario, there are innumerable factors that may contribute to the refusal in this process20, among them the refusal of the families of the potential donor. It was verified that some of the main factors for the refusal of the relatives in the donation of organs is the ignorance of the will of the family member44. Another factor also described in the literature was the lack of preparation of the health professional to approach the family at the moment of death and the interview, for not having enough information, leading relatives not to consent to organ donation78. The family interview is considered the most important stage of the process, and it is decisive in the decision making regarding the choice of relatives, or not, by the donation of organs and tissues57.
Although scarce, studies\(^9\)-\(^{14}\) indicate that family members’ refusal to donate organs and tissues is the main barrier to donation, pointing to reasons such as lack of dialogue in the family about the issue, lack of knowledge of the potential donor’s desire, lack of comprehension of the diagnosis of brain death, religiosity, long process time, decision of single family member, unprepared interviewer, and desire to maintain intact body, among others.

Therefore, the relevance of this study was based on the importance of understanding the reasons for the decision of family members refusing to donate organs and/or tissue and, thus, to contribute to the direction and planning of future interventions that may contribute to the increase in the number donors and transplants.

Faced with this problem, the objective of the present study was to describe the profile of family members and potential donors and the negative motifs for organ and tissue donation for transplants.

**Method**

This is a cross-sectional quantitative study, performed through retrospective collection of secondary data. The target registries were family interview forms contained in the charts of potential donors approached by the Intra-Hospital Organ and Transplant Tissue Donation Committee (Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos para Transplante – CIHDOTT) of a teaching hospital in a municipality in the Southern Region of Rio Grande do Sul, in which the relative denied the donation. The choice of this hospital for the study was due to the fact that it presented the largest number of donations in the South Region of the state since its implementation, which occurred in 2008, and is therefore the beginning of the selected period.

The results were obtained through the analysis of all the records of the potential donors registered in said CIHDOTT, from December 2008 to November 2014, which had a negative response in the family interview approach. During this period, 630 medical records of all the potential donors of that period were searched, but in a total of 472 medical records the family member denied the donation.

The instrument of data collection was a pre-coded questionnaire, based on a CIHDOTT family interview form with potential donors. The pilot study was carried out in the first half of January 2016, which allowed for the final testing of the questionnaire and the work logistics. Subsequently, three meetings were held to train collectors, nursing academics. At that time, the questionnaire and the instruction manual on the instrument’s completion were read and doubts were clarified in order to standardize data collection. Fields filled in with unreadable information or that referred to the question were considered to be ignored. Data collection began in the second half of January 2016 and was completed in March of the same year.

Data entry was performed with EpiData Software 3.1, with double typing and automatic checking of consistency and amplitude. The variables were analyzed in a descriptive and stratified manner using Stata Software 11.1. In this analysis the simple frequency and the percentage were calculated. Regarding the ethical aspects, the study complied with Resolution no. 466/2012, of the National Health Council. It was sent to the Research Ethics Committee of a Public University and was approved by Opinion no. 1,400,699, and was submitted to the Plataforma Brasil, receiving the Certificate of Presentation for Ethical Assessment (CAAE) no. 52679315.7.0000.5317.

**Results**

The study included 472 family interview forms contained in the records of potential donors with denial of donation from the family, among the 630 family interviews that occurred in the period from 2008 to 2014. The prevalence of family negative for organ donation was 74.9%. Graph 1 shows the number of family denials of organ and tissue donation of the potential donor, per year of death.
Graph 1 – Distribution of family denials of donation, per year of death of the potential donor. Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

Table 1 shows the sociodemographic data of potential donors and their relatives as well as the reasons for refusal to donate.

Table 1 – Distribution of sociodemographic data of potential donors and their relatives, and reasons for refusal to donate; Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex of potential donor*</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>272 (57,6)</td>
</tr>
<tr>
<td>Female</td>
<td>196 (41,5)</td>
</tr>
<tr>
<td>Age of potential donor (in years)*</td>
<td></td>
</tr>
<tr>
<td>0-20</td>
<td>22 (4,8)</td>
</tr>
<tr>
<td>21-40</td>
<td>60 (13,0)</td>
</tr>
<tr>
<td>41-60</td>
<td>199 (43,2)</td>
</tr>
<tr>
<td>61-80</td>
<td>179 (38,8)</td>
</tr>
<tr>
<td>&gt;80</td>
<td>1 (0,2)</td>
</tr>
<tr>
<td>Marital status of potential donor*</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>138 (29,2)</td>
</tr>
<tr>
<td>Not married</td>
<td>42 (8,9)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>18 (3,8)</td>
</tr>
<tr>
<td>Stable union</td>
<td>14 (3,0)</td>
</tr>
<tr>
<td>Municipality of potential donor*</td>
<td></td>
</tr>
<tr>
<td>Pelotas</td>
<td>262 (55,5)</td>
</tr>
<tr>
<td>Capão do Leão</td>
<td>13 (2,8)</td>
</tr>
<tr>
<td>Pinheiro Machado</td>
<td>11 (2,5)</td>
</tr>
<tr>
<td>Canguçu</td>
<td>10 (2,1)</td>
</tr>
<tr>
<td>Others</td>
<td>90 (19,1)</td>
</tr>
<tr>
<td>Type of death*</td>
<td></td>
</tr>
<tr>
<td>Cardiorespiratory arrest</td>
<td>402 (85,2)</td>
</tr>
<tr>
<td>Brain Death</td>
<td>68 (14,4)</td>
</tr>
</tbody>
</table>

Source: Created by the authors.

Note: n<472 by the lack of information.
Table 1 – Distribution of sociodemographic data of potential donors and their relatives, and reasons for refusal to donate; Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex of family member</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>246 (52,1)</td>
</tr>
<tr>
<td>Female</td>
<td>219 (46,4)</td>
</tr>
<tr>
<td><strong>Relationship of relative</strong></td>
<td></td>
</tr>
<tr>
<td>Fathers, mothers and children - 1º degree</td>
<td>218 (48,8)</td>
</tr>
<tr>
<td>Spouse, partner</td>
<td>94 (21,8)</td>
</tr>
<tr>
<td>Brothers, grandparents and grandchildren - 2º degree</td>
<td>88 (19,6)</td>
</tr>
<tr>
<td>Others</td>
<td>47 (10,5)</td>
</tr>
<tr>
<td><strong>Type of donation</strong></td>
<td></td>
</tr>
<tr>
<td>Corneas</td>
<td>403 (85,4)</td>
</tr>
<tr>
<td>Corneas and organs</td>
<td>47 (10,0)</td>
</tr>
<tr>
<td>Multiple organs (except corneas)</td>
<td>20 (4,2)</td>
</tr>
<tr>
<td><strong>Reasons for negative for donation</strong></td>
<td></td>
</tr>
<tr>
<td>Unawareness of the will of the potential donor</td>
<td>98 (20,8)</td>
</tr>
<tr>
<td>Previous conviction of denial</td>
<td>83 (17,6)</td>
</tr>
<tr>
<td>Family disagreement</td>
<td>65 (13,8)</td>
</tr>
<tr>
<td>Lack of emotional conditions</td>
<td>19 (4,0)</td>
</tr>
<tr>
<td>Doubts about the integrity of the body</td>
<td>16 (3,4)</td>
</tr>
<tr>
<td>Did not want to decide alone</td>
<td>10 (2,1)</td>
</tr>
<tr>
<td>Funeral delay</td>
<td>4 (0,9)</td>
</tr>
<tr>
<td>Religious causes</td>
<td>3 (0,6)</td>
</tr>
</tbody>
</table>

Source: Created by the authors.

* n<472 by omission of information.

The age of the potential donor was considered at the time of death. The other municipalities of the potential donor are from the South region and the same state. The other relatives referred to nephews, uncles, sons-in-law, friends, brothers-in-law, cousins.

Regarding the type of death by sex of the potential donor, in the period from January 2008 to December 2014, 237 (59%) men and 161 (40%) women died from cardiorespiratory arrest; 4 (1%) responses were blank and 35 (51.5%) women and 33 (48.5%) men had brain death.

The main reasons for refusal to donate are presented, according to the profile of the potential donor and the family member interviewed, in Table 2.

Table 2 – Distribution of the main reasons for denial of donation by sociodemographic variables. Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Previous Conviction of Non-Donation</th>
<th>Unawareness of the will of the potential donor</th>
<th>Family disagreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kinship</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Parents and sons</td>
<td>35 (43,2)</td>
<td>60 (61,9)</td>
<td>30 (48,4)</td>
</tr>
<tr>
<td>Spouse</td>
<td>19 (23,5)</td>
<td>18 (18,6)</td>
<td>9 (14,5)</td>
</tr>
<tr>
<td>Brothers, grandparents and grandchildren</td>
<td>17 (21)</td>
<td>11 (11,3)</td>
<td>18 (29)</td>
</tr>
<tr>
<td>Others</td>
<td>10 (12,3)</td>
<td>8 (8,2)</td>
<td>5 (8,1)</td>
</tr>
<tr>
<td>Sex of family member</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49 (59,8)</td>
<td>57 (58,2)</td>
<td>20 (30,8)</td>
</tr>
<tr>
<td>Female</td>
<td>33 (40,2)</td>
<td>41 (41,8)</td>
<td>45 (69,2)</td>
</tr>
</tbody>
</table>
Table 2 – Distribution of the main reasons for denial of donation by sociodemographic variables. Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Previous Conviction of Non-Donation n (%)</th>
<th>Unawareness of the will of the potential donor n (%)</th>
<th>Family disagreement n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-20</td>
<td>2 (2,5)</td>
<td>-</td>
<td>4 (6,5)</td>
</tr>
<tr>
<td>21-40</td>
<td>11 (13,8)</td>
<td>14 (14,9)</td>
<td>6 (9,7)</td>
</tr>
<tr>
<td>41-60</td>
<td>40 (50,0)</td>
<td>42 (44,7)</td>
<td>24 (38,7)</td>
</tr>
<tr>
<td>61-80</td>
<td>27 (35,8)</td>
<td>38 (40,4)</td>
<td>28 (45,2)</td>
</tr>
<tr>
<td>&gt;80</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Type of donation*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corneas</td>
<td>62 (75,6)</td>
<td>93 (94,9)</td>
<td>58 (89,2)</td>
</tr>
<tr>
<td>Corneas and organs</td>
<td>12 (14,6)</td>
<td>2 (2,0)</td>
<td>5 (7,7)</td>
</tr>
<tr>
<td>Multiple organs (except corneas)</td>
<td>8 (9,8)</td>
<td>3 (3,1)</td>
<td>2 (3,1)</td>
</tr>
</tbody>
</table>

Source: Created by the authors.

*n<472 by omission of information.

Note: Conventional signal used:
- numeric data equal to zero not resulting from rounding.

Table 3 shows the distribution of the blank information in the interview forms to the relatives of the potential donors of a CIHDOTT.

Table 3 – Distribution of blank information on potential donor forms. Pelotas, State of Rio Grande do Sul, Brazil – Jan 2008-Dez 2014 (N=472)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time of death</td>
<td>373 (79,0)</td>
</tr>
<tr>
<td>Reason for not donating*</td>
<td>126 (26,7)</td>
</tr>
<tr>
<td>Municipality of the interviewee</td>
<td>86 (18,2)</td>
</tr>
<tr>
<td>Signature of the person in charge of the service</td>
<td>46 (9,7)</td>
</tr>
<tr>
<td>Municipality of birth of the donor</td>
<td>27 (5,7)</td>
</tr>
<tr>
<td>Donor relative</td>
<td>25 (5,3)</td>
</tr>
<tr>
<td>Age of the potential donor</td>
<td>11 (2,3)</td>
</tr>
<tr>
<td>Marital status of the donor</td>
<td>260 (55,1)</td>
</tr>
<tr>
<td>Sex of the potential donor</td>
<td>4 (0,8)</td>
</tr>
<tr>
<td>Date of death</td>
<td>4 (0,8)</td>
</tr>
<tr>
<td>Type of death</td>
<td>2 (0,4)</td>
</tr>
<tr>
<td>Type of donation</td>
<td>2 (0,4)</td>
</tr>
</tbody>
</table>

Source: Created by the authors.

*Information not found on file and medical record.

Discussion

In the present study, the records of a CIHDOTT of a teaching hospital made it possible to identify 74.9% of the prevalence of family negative for organ donation, similar to a survey carried out in 2014, in Rio Grande do Norte, whose prevalence was 72.3% (65 potential donors)\(^3\). Over the years, it was expected to observe, in this study, a decrease in the amount of family denials for
organ donation, in view of the improvement of the approaches. During the year 2017, in Brazil, 10,629 cases of potential donors were registered, and a total of 7,214 non-donors. These include family refusal (2,740) as the main cause, as well as cardiac arrest (1,232) and medical contraindication (1,550). Understanding the relevance of the main reason for non-donation, the interview should be considered as crucial in this process, as it involves not only technical knowledge, but also the emotional preparation of the interviewer. In a study developed in Bahia, the nursing care of the potential organ donor refers to feelings and beliefs about death and dying in the team participating in the research. These feelings focus on denial, conflict and distancing, and may negatively impact the quality of this care.

Thus, it is fundamental that health professionals be provided with spaces for discussion, training and updating on the family approach to donation, as well as strategies to establish a link, and facilitate and develop effective communication in the process of donating organs and tissues for transplantation. In addition, it is necessary to develop activities that have the purpose of promoting the sharing of experiences, as well as of good practices of the nurses who work in this process with their peers.

In the present research, a sociodemographic profile of the potential donors of organs and tissues was delineated. The male sex (57.6%), 40-69 years old (75.8%), married (29.2%) was the predominant profile, similarly to other studies. The origin of the potential donors was higher in the research municipality (55.5%) and the others covered the region. Similar data were identified in another study, in which 57.14% were from the state of Piauí. The prevalent type of death was cardiorespiratory arrest (85.2%), with less than 15% identified by brain death. In the period between 2010 and 2017, it was observed, through the Brazilian Registry of Transplantation, that in the state of Rio Grande do Sul, 97 (12%) deaths occurred due to cardiac arrest and 57 (7%) due to brain death. In a survey in Santa Catarina with regard to family refusal, there was a predominance of 68% of males, with ages ranging from 20 to 30 years old and 52% of deaths caused by brain death. In view of this, it should be considered that the epidemiological profile of the potential donor has been modified over the years; traumatic deaths due to traffic accidents and violence are among the most prevalent. In addition, there is a donor with greater age and other chronic comorbidities.

The predominance of parents, spouses, children and siblings in the family interview was similar in another study in Sergipe. In an investigation in Piauí of 21 family members who refused to donate, the degree of kinship was 38.1% of parents and 23.8% of children. In Sergipe, in the family interview, the parents (35.3%) were the main ones involved in the refusal of the donation. In the present investigation, the lack of knowledge of the willingness of the potential donor (20.8%), previous conviction (17.6%) and family disagreements (13.8%) were the most frequent reasons for the negative response regarding the donation of organs and tissues.

In the literature it is mentioned that, between 2008 and 2012, the causes most cited in scientific publications for non-donation were, among others, the lack of knowledge of the potential donor's desire and family disagreement. In another study, it was identified that reasons such as ignorance of the deceased's will, respect for the desire of not being a donor and family disagreements are among the first four factors of refusal in the family approach, which together account for 59.57% of the total. The study that pointed out the need for more research on families' experiences of death and the decision-making process regarding donation is considered important.

In a study in Sergipe, the main reasons for family refusal were, among others: 36.2% without information, 26.7% against donation, 21.6% desire to maintain the body intact, 5.2% lack of knowledge of the donor's desire, 4.3% fear of delayed release of the body, 1.7% religious conviction. In another study, the family
refusal was due to: family divergence (28.58%), maintenance of intact body, potential donor was not a living donor, and lack of knowledge about the diagnosis of brain death (14.28% each)\(^{(13)}\).

Another investigation showed that 9.5% of the families interviewed had doubts about the integrity of the body, which is the main justification for denial\(^{(19)}\). Moreover, in the evaluation of the causes of family refusal, 9% of the sample had a previous conviction in terms of the integrity of the body, at 5.2%, and family disagreement, at 3.4%. In this context, it was evidenced that 63% of those interviewed had no knowledge of the donor will, 37% knew what the deceased wanted and were against their will. In the analysis of the degree of kinship of relatives with the potential donor, 64% were relatives up to second degree and 14% were spouses\(^{(5)}\).

In a hospital in Santa Catarina, 64.3% of the interviews had a family refusal to respond. Of these 48.4% of the families did not agree to the donation\(^{(20)}\). As to the profile of eligible donors in brain death, 52.4% were female\(^{(13)}\), as well as in the present study, where 17.9% were women. Of the relatives who refused to donate, 61.9% were women; 61.9% were first-degree relatives, 38.9% were fathers, 23.8% were sons and 14.3% were spouses and siblings\(^{(10)}\). As for the desire to keep the body intact, 100% of the relatives who refused the donation were the parents. When the reason given was not to be a living donor, 66.7% of the family members opposed to the donation were the children\(^{(14)}\).

According to Brazilian legislation on family consent, the “[...] authorization must be from the spouse, companion or blood relative, of legal age and legally capable, in the straight or collateral line, to the second degree, and it must be signed in a document also signed by two witnesses present at the death verification”\(^{(1)}\). In view of this, it is necessary to pay attention to who may be the relative who consents or refuses the donation, as well as the registration of this information in an appropriate way. In this study, situations related to family consent were contrary to the law.

In relation to the findings of the present investigation and other studies regarding the reasons for denial mentioned by relatives, the majority can be modified if actions of sensitization and education of the population are carried out. Examples are the countless and diverse media campaigns that point to the need for people to talk about the issue of family giving. Thus, it is essential that people understand that it is not enough to say “donor”; it is necessary that family members be informed about the desire, which will facilitate family decision making.

In a study carried out in six hospitals in Rio Grande do Norte, there was a lack of documentation and records as an important component of the organizational structure for organ and tissue donation\(^{(3)}\). It is understood that this process needs to be well conducted, at every stage, and adequately documented\(^{(21)}\). The inadequate filling of the records can hamper communication among multi-professionals, as well as the continuous care provided may undermine the patient’s full understanding and, therefore, negatively affect the security of the actions and their legal protection\(^{(22)}\). It is necessary to understand that it is the documents that report all activities with the potential donor and can show the transparency and credibility of the process, so that the family has confidence in the team.

In the present study, the information missing from interview records was related to the reason for non-donation (26.7%), interviewee community (18.2), interviewee signature (18.2%) and donor relative (5.3%). The marital status of potential donors was not included in their medical records. Such data can support the interviewer and the preparation of the team in the approach of the families. In another study carried out in Sergipe, 75% of the medical records presented a family interview, when it occurred, and 36.2% had no record of the non-donation reason\(^{(14)}\).

These data are critical to family safety and decision-making as well as to process management, as well as the ongoing training of professionals on the importance of complete and reliable records\(^{(10)}\). In this direction, the team is obliged to notify the occurrence of the death and to justify the authorization or denial of the donation of organs and tissues\(^{(22)}\). In order to deal
with these fragilities, the nurses’ fundamental role is described, as the phases of the organ and tissue donation and transplantation process take place in their work, and these phases involve aspects of care, management and education\(^{(24)}\). In the present study, the responses of other variables of the study, of great importance for the identification of the possible donor, were blank: time of death (79%), age of the potential donor (2.3%), date of death (8%), type of death (0.4%), type of donation (0.4%). In an investigation in Rio de Janeiro, it was mentioned that information such as this is essential in the family approach, since the professional needs to know details about the potential donor to perform the interview in a singular way, in each case, envisaging a possible authorization of the family for organ donation\(^{(7)}\).

In view of the above, it is also important to consider the records related to the donation and transplant process, identifying their fragilities, in order to provide sufficient and adequate information to the management and to the professionals involved. With this, it becomes possible to elaborate interventions, the improvement of public policies and the work process itself, which will allow the effective increase of donations and, consequently, of transplants.

The limit of this study is the impossibility of generalization of the findings, since the survey of refusals refers to the reality of a single moment in time, delimited between 2008 and 2014, whose cross-sectional design does not allow the establishment of causal relationships. In addition, because it was the collection of secondary data in medical records, some difficulties that are common in this type of collection also occurred, such as the lack of information in some fields, as well as the use of different forms for the registers over the years.

However, although it does not represent the reality of all the CIHDOTT in the region, this study allows supporting other Commissions in the search of the problems faced in a regional way, to better understand the non-donation of organs and tissues. Thus, other studies, with different methodological approaches, need to be carried out considering cultural, social and political aspects. This is a fundamental theme to be explored in order to direct actions aimed at making society aware of this practice.

**Conclusion**

The study made it possible to identify the socio-demographic profile of family and potential donors, the prevalence of family denial, as well as the main reasons for the non-donation of organs and tissues. The reason for the most frequent refusal was the lack of knowledge of the donor’s opinion by the family members responsible. This fact raises the discussion that if a person at some point in his life had informed his family about the desire to donate his organs, his family members would probably have respected his decision.

The findings of the present study can contribute to the targeting, planning and development of interventions oriented to the motives that can be modified, through access to the information and sensitization of the population in relation to the subject, thus increasing the number of effective donors and transplants, reducing the waiting list for an organ and/or tissue. It is emphasized that the performance of descriptive epidemiological studies has been important to characterize the reasons for the refusal to donate organs and tissues for transplantation. Thus, this type of approach can be one of the best strategies available to direct education actions to the population on the subject. To meet the demand to promote better understanding, solidarity and participation in the donation of organs and tissues, it is necessary to join forces between hospitals and their partners, such as university, community and society.

It is hoped that the results of this research will allow the development of other studies on this topic, as well as that the family will be involved in the process of donating organs and tissues for transplantation. However, these issues need an approach that goes beyond the biomedical aspects and includes the social and the cultural, since the participation of society, educational institutions, the media and public power is of paramount importance, since all must be in
convergence to obtain beneficial results for the dissemination of this theme.

Collaborations:

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References


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