



ORIGINALES

Clinical-epidemiological elements of family interviews for donation of organs and tissues

Elementos clínico-epidemiológicos de entrevistas familiares para doação de órgãos e tecidos
Elementos clínicos y epidemiológicos de entrevistas familiares para la donación de órganos y tejidos

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ABSTRACT

Objectives: To identify the clinical and epidemiological features of interviews with families of potential donors of organs and tissues.

Methods: Quantitative research, descriptive, exploratory and documental. The sample was composed of medical records of 93 patients, whose families have been addressed in the years 2012/2013. It conducted data analysis using the stational package "R".

Results: It was observed that 62.4% of approaches have been performed with families of patients who have become potential cardiorespiratory arrest donor. Parents were the most interviewed family members coming to meet 40% of approaches. The family consent to donation percentage was 51.6%. Eye/corneas globe was the most spoiled, coming to represent 87.5%. Knowing that the potential donor was contrary (in life) donation (46.7%) and ignored his desire in life (33.4%) were the main family groups for refusal.

Conclusion: Identify the clinical and epidemiological elements of family interviews for donation is very

important to evaluate the effectiveness of the activities performed in the donation process of the institutions

Keywords: Interview; Family; Obtaining tissues and organs; Transplant

RESUMO

Objetivos: Identificar os elementos clínico-epidemiológicos das entrevistas realizadas com familiares de potenciais doadores de órgãos e tecidos.

Métodos: Estudo quantitativo, descritivo, exploratório e documental. A amostragem foi composta por prontuários de 93 pacientes, cujas famílias foram abordadas nos anos de 2012/2013. Realizou-se análise dos dados por meio do pacote estatístico "R".

Resultados: Observou-se que 62,4% das abordagens foram realizadas com familiares de pacientes que se tornaram potenciais doadores pós-parada cardiorrespiratória. Os pais foram os familiares mais entrevistados, chegando a corresponder 40% das abordagens. O percentual de consentimento familiar para doação foi de 51,6%. Globo ocular/córneas foi o mais consentido, chegando a representar 87,5%. Saber que o potencial doador era contrário (em vida) a doação (46,7%) e desconhecer seu desejo em vida (33,4%) foram os principais motivos de recusa familiar.

Conclusão: Identificar os elementos clínico-epidemiológicos das entrevistas familiares para doação é de suma importância para avaliar a eficácia das atividades desempenhadas no processo de doação das instituições.

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Palabras clave: Entrevista; Família; Obtenção de tecidos e órgãos; Transplante

RESUMEN

Objetivos: Identificar los elementos clínicos y epidemiológicos de las entrevistas con las familias de potenciales donantes de órganos y tejidos.

Métodos: Estudio cuantitativo, descriptivo, exploratorio y documental. La muestra consta de 93 registros de pacientes, cuyas familias fueron abordadas en los años 2012/2013. Se realizó un análisis de los datos mediante el paquete estadístico "R".

Resultados: Se observó que el 62,4% de los enfoques se han realizado con familiares de los pacientes que se han convertido en potenciales donantes post-parada cardiorrespiratoria. Los padres fueron los miembros de la familia más entrevistados (40%). El porcentaje de donación de la familia fue del 51,6%. Globo del ojo/córneas fue el más consentido, llegando a representar 87,5%. Saber qué el donante potencial era contrario (en vida) a la donación (46,7%) y desconocer su deseo en vida (33,4%) fueron las principales razones de la negativa de la familia.

Conclusión: Identificar los elementos clínicos y epidemiológicos de entrevistas familiares para la donación es muy importante para evaluar la eficacia de las actividades realizadas en el proceso de donación de las instituciones.

Palabras clave: Entrevista; Família; Obtención de tejidos y órganos; Trasplante

INTRODUCTION

The Brazilian National Transplant System (SNT in Portuguese) is universally known as one of the most developed, and is also responsible for placing the country in a privileged position in the world ranking of organ donation and transplantation⁽¹⁻²⁾.

However, even occupying a prominent position in the international scenario, Brazil presents actual numbers of transplant that are proportionally smaller than the existing demand⁽²⁾. According to data from the Brazilian Association of Organ Transplants

(ABTO), in 2014 5,639 kidney transplants were performed, while the estimated need was 11,445. It was also estimated that 1,145 individuals required a heart in the above year, however, only 311 heart transplants occurred⁽²⁾.

In order for the supply and demand for transplants to be less disproportionate, more donations are required and this can be achieved by increasing the number of organ/tissue donors. Currently there are two possibilities for an individual to become a donor, according to the legislation in force in Brazil, being in life or *post mortem*, also said donor corpse⁽³⁾.

With regard to donation in life, this can be performed for spouse and/or for persons related up to fourth degree in the straight or collateral line and by assessment of non-loss to the donor. In the case of *post-mortem* donation, it may occur for post-cardiopulmonary arrest patients (post-CPA) or after confirmation of brain death (post-BD), always in the face of formal authorization from a related relative up to the second degree (straight or collateral line) or spouse with proven relationship⁽³⁻⁴⁾.

In the case of post-CPA patients, only tissue donation is performed, in view of the comprovation of irreversible CPA, which consists of the absence of effective cardiac activity after a minimum of thirty minutes of effective cardiopulmonary resuscitation maneuvers without the use of depressant drugs or hypothermia⁽⁵⁾.

Regarding donation from a post-BD patient, it should be emphasized that it can only be performed if the diagnosis follows the criteria established by Resolution No. 1,480/1997 of the Brazilian Council of Medicine (CFM), which states that it is imperative the accomplishment of two clinical evaluations, with interval of time between both evaluations defined according to the age group, as well as the execution of a complementary examination that also must be chosen by means of the age of the patient. It is also emphasized that at least one of the evaluations must be performed by a neurologist⁽⁶⁾.

During all suspicion and diagnostic confirmation of the BD, the members of the Intra-Hospital Organ Donation and Transplant Tissue Commission (CIHDOTT) should accompany the patient's relatives in order to clarify possible doubts regarding the diagnosis of BD and, after confirmation, and when there are no contraindications, the family interview is performed for donation of organs and tissues. In the case of post-CPA patients, CIHDOTT members perform the family interview whenever there is no contraindication to tissue donation⁽⁷⁾.

In the family interview the transition from the potential donor (PD) to the effective donor (ED) occurs. It is considered a crucial moment in any donation/transplantation process and therefore must be performed by a trained professional⁽⁸⁾ who has knowledge of the clinical condition of the PD, the diagnosis of BD, the donation and transplantation process as a whole, as well as the conditions to offer support to the relatives of the PD⁽⁸⁻⁹⁾.

So that the professional who conducts the family interview for donation is prepared for this, it is imperative that they have a thorough knowledge about the aspects that cover this moment, especially with regard to the epidemiological elements⁽¹⁰⁻¹¹⁾.

In view of the above, this article aimed to identify the clinical and epidemiological elements of the family interview for donation of organs and tissues for transplantation. It is believed that studies on this subject might contribute to the critical analysis and reflection on the conditioning and determining factors for the improvement in the rates of organ and tissue obtainment.

METHOD

This is a quantitative research, with a descriptive and exploratory approach, accomplished through documentary research. The study population consisted of patients that were PDs of organs and tissues who died during the years 2012 and 2013, whose family member was interviewed by a CIHDOTT member of a public university hospital in Paraná, Brazil.

Data collection was carried out according to the information contained in the Registry Books of Post-CPA and Post-BD Potential Donor Post-Notification, as well as in the checklists of post-CPA and post-BD donors and non-donors, these documents archived at the CIHDOTT of the studied institution.

All the (post-CPA and post-BD) PDs were included in this study, as long as the information contained in the records presented the following criteria: identification of the degree of kinship between the approached family member and the PD; interview outcome (acceptance or refusal to donate organs and tissues). It was established as exclusion criteria: absence of a clear and objective description of the interview outcome; in the case of refusal to donate, absence of data related to the reason; in the case of authorization for donation, absence of information on organs and tissues authorized for harvesting.

As a data collection instrument, a semi-structured script was elaborated, which was composed of five items: 1) Type of death of PD (CPA or BD); 2) Degree of kinship between the approached family member and the PD; 3) Interview outcome (family consent or refusal); 4) Reason for refusal and, 5) Organs and tissues authorized for harvesting (of those PDs whose family agreed to donate).

Data from the instrument were compiled into Microsoft Office Excel® version 2010 spreadsheets and then exported to the statistical package "R", through which simple statistical analysis was performed, and the application of the Chi-square test to verify the existence or not of association between: degree of kinship between the approached family member versus type of death of the PD; interview outcome versus degree of kinship of the approached family member, as well as analyzes of proportions assuming level of significance for p-value <0.05. The results were presented descriptively, as well as by means of figures and tables.

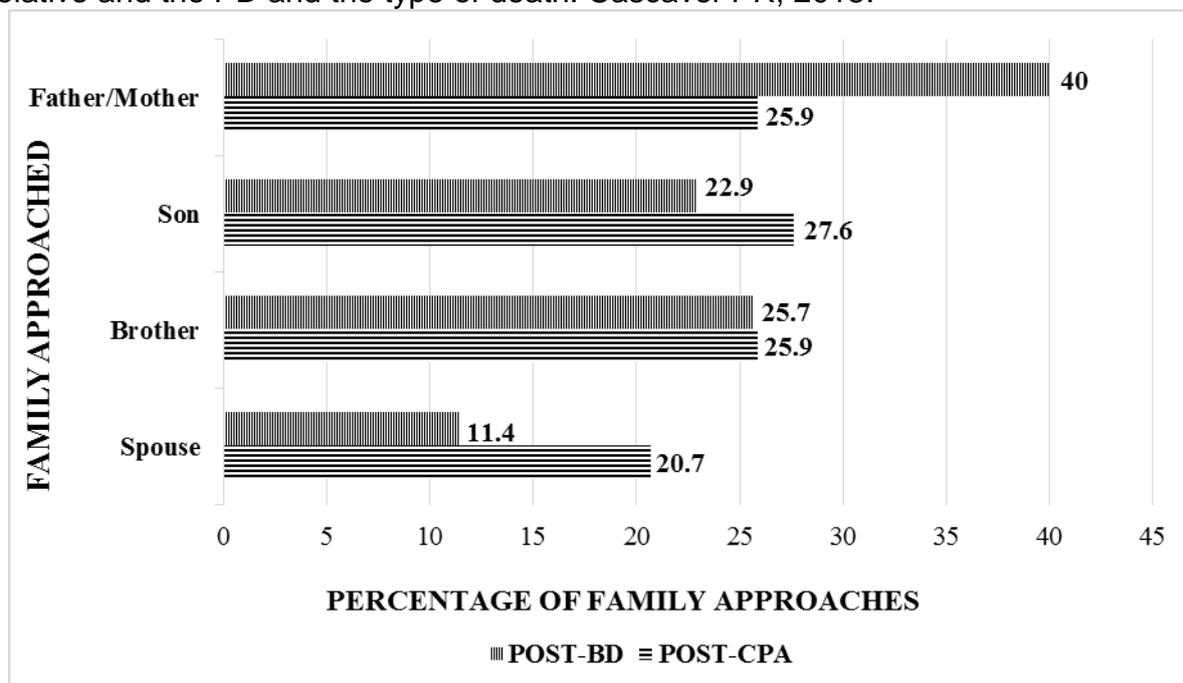
The collection of these data occurred during the months of October and November 2014, with the approval of the Research Ethics Committee (REC) of the Universidade Estadual do Oeste do Paraná (UNIOESTE), with favorable opinion No. 810,533, thus respecting all the ethical and legal precepts established by Resolution No. 466/2012 of the Brazilian Health Council (CNS) ⁽¹²⁾.

RESULTS

There were 97 family approaches for donation in the studied institution in the period of 2012 and 2013; however, the data of four (4.1%) approaches were not part of the study because the reason for the family refusal was not clearly defined in the documents analyzed. Of the 93 research records, 58 (62.4%) approaches were performed with relatives of post-CPA PDs and 35 (37.6%) with those of post-BD PDs.

Figure 01 shows the approaches according to the degree of kinship between the relative and the PD.

Figure 01. Percentage of approaches, according to the degree of kinship between the relative and the PD and the type of death. Cascavel-PR, 2015.



The application of Chi-square test revealed no statistically significant relationship between the degree of kinship between the relative and the PD and the type of death ($p = 0.444$).

Regarding the family decision to donate the organs and tissues of the loved one, it was found that in 48 (51.6%) approaches there was consent for organ and tissue collection, of which 28 (58.3%) were for post-CPA PD and 20 (41.7%) for post-BD PD. It was noted that there was no statistical difference ($p = 0.307$) between the interview outcome (decision to donate or not) and the degree of kinship that the family member presented in relation to the PD.

The distribution of the percentage of family members approached in the case of post-BD patients is quite broad, that is, it varies from 11.4% (spouse) to 40% (father/mother) (Table 01). In the case of distribution of the percentage of approached relatives of post-CPA patients, no such amplitude is observed, and the percentages are close.

The absolute (n) and relative (%) frequencies of the organs and tissues authorized for harvesting, in the interviews whose outcome was favorable to the donation, are listed in Table 01.

Table 01. Organ/tissue authorized for harvesting according to frequency of consent. Cascavel-PR, 2015.

Authorized Organ/tissue	Consent after CPA		Consent after BD	
	n	%	n	%
Kidneys	-	-	20	19.4
Liver	-	-	20	19.4
Pancreas	-	-	15	14.6
Lungs	-	-	06	05.8
Heart	-	-	14	13.6
Heart for valves	08	12.5	02	1.9
Eyeball/corneas	56	87.5	26	25.2
Total	64	100.0	103	100.0

Overall, of the total of 167 organs/tissues donated, 61.7% were from a post-BD PD, even with a lower percentage of consents for this type of PD (41.7%) (Table 01). It is observed that the donation of the eyeball/cornea represents almost half (82) of the organs and tissues donated in the studied period (Table 01).

Regarding the relative's refusal for donation, which was the outcome of 45 (48.4%) family interviews conducted in this study, Table 02 demonstrates the frequency distribution regarding reasons for refusal presented by relatives of the post-BD PD in relation to those presented by relatives of post-CPA PD.

Table 02. Reasons for refusal to donate organs/tissues according to type of death of the PD. Cascavel-PR, Brazil, 2015.

Reason for Refusal	Relative of post-CPA PD		Relative of post-BD PD	
	n	%	N	%
Not knowing the desire of the PD	10	33.3	01	06.7
PD contrary (in life) to donation	02	06.7	07	46.7
Fear of delay in the release of the body	06	20.0	01	06.7
Desire to keep the body intact	03	10.0	02	13.3
Religious Convictions	03	10.0	03	20.0
Other/undeclared	06	20.0	01	06.7
Total	30	100.0	15	100.0

It was observed that the reasons for refusal to donation were different according to the type of death, that is, for post-BD PDs, the most frequent reason for refusal was the PD's dissatisfaction with donation (46.7%). On the other hand, the most cited reason for refusal in the case of post-CPD PDs was the lack of knowledge of the PD's desire (33.3%) (Table 02).

DISCUSSION

The results of this research showed that, in 62.4% of the studied interviews, there was an approach to the relative of the post-CPA PD. It is inferred that this fact may be influenced by the fact that circulatory system disorders represent the main set of

causes of death in Brazil⁽¹³⁾ due to neurological causes and, therefore, the number of deaths by BD becomes significantly smaller and, consequently, the interviews for donation also occur in smaller numbers.

Regarding the degree of kinship between the approached individual and the PD, it was verified that for post-CPA PDs, most approaches were made with the children (27.6%); in the case of post-BD PDs, most approaches were made with the parents (40%), but there was no significant relationship between the degree of kinship of the interviewed relative and the PD and the outcome (acceptance/refusal). (Figure 01).

In a survey conducted at an Organ Procurement Organization (OPO) in the State of São Paulo, Brazil, researchers identified that in the interviews in which the decision was directly in charge of the parents, the negative outcome to the harvesting of organs and tissues was significantly higher in comparison to those in which the decision-maker was a second-degree relative⁽¹⁴⁾.

With regard to the wide variation in the frequency of approach observed in post-BD PDs (Figure 01), especially in relation to parents (40%) and spouse (11.4%), it may indicate that post-BD PDs are younger or do not have a solid/formal marital relationship, so that, legally, it is up to the parents to decide whether or not to donate organs and tissues.

Regarding the interview outcome (acceptance/refusal to donate), although the results indicated that there was no significant difference in relation to the degree of kinship between the approached individual and the PD ($p = 0.307$) and the outcome, the percentage of family consent for donation was of 52%, turning the PD into an ED.

In a study conducted by researchers from Rio Grande do Norte-RN (Brazil), it was found that the rate of ED was 27.7%⁽¹¹⁾. In another study, the percentage of ED among the PDs was 57.84%⁽¹⁵⁾. According to ABTO's Brazilian Registry of Transplants (BRT), from 2007 to 2014, the number of EDs in the country more than doubled, with regional differences being notable⁽²⁾.

It should be noted that Brazil has an extensive geographic area and that the quality indicators in the donation-transplant process are based exclusively and solely on the number of EDs⁽¹⁶⁾. It is also emphasized that the efficiency and effectiveness of services should be based on the triad "structure, process and results", since the adequacy or inadequacy of the structure and process directly reflect the results obtained by CIHDOTTs from different localities^(8,16).

Regarding the family refusal, the results indicated that in this study the rate was 48%, lower than in a study done in the city of Blumenau - SC, in which the family refusal corresponded to 86.05%⁽¹⁵⁾. However, it was slightly higher than the national prevalence (46%) in the year 2014.² In a survey conducted in a single French center, the family refusal rate between the years 2010 and 2011 was 30.8%⁽¹⁷⁾. In this context, it is important to emphasize that regardless of the rates achieved, the problem of family refusal is an international challenge that still needs to be overcome^(2,17-18).

As for the organs and tissues authorized for harvesting, the eyeball/corneas represented almost half of the donations of organs and tissues in the studied period (Table 01). In the case of post-BD PD, there was a greater percentage of consent for kidneys and liver, with 19.4% each, followed by eyeball/corneas with 25.2%.

Regarding the tissues authorized for harvesting of a post-CPA PD, the highest percentage of consent was for eyeball/cornea, with 87.5%.

The prevalence of authorization for harvesting organs and tissues as mentioned above was also observed in studies carried out by researchers from Santa Catarina (SC) and Ceará (CE)^(15,19).

It should be noted that the high rate of kidney/liver harvesting means high rates of transplantation of these organs. Data from the ABTO show that the above-mentioned organs totaled more than 50% of the total transplants performed in Brazil in 2014. In that same year, the country also obtained good numbers of corneal transplants; however, the year 2014 ended with more than 8,000 patients on the waiting list for this type of transplant⁽²⁾.

However, it is worth noting that sometimes family consent is not synonymous, imperatively, of harvesting. This occurs for several reasons, among which the morphological conditions in which the organ and the tissue are at the time of the surgical procedure for withdrawal, which determine the viability of harvesting⁽²⁰⁾.

Considering that the relationship of demand/need has a significant disparity, it is reaffirmed the relevance of the need to establish methods that increase the viability of organs and tissues. Thus, the professional qualification for better maintenance and clinical-care management of the PD in order to improve the number of eligible donors is characterized as a strategy, among others, which must be constantly and vehemently invested⁽¹⁸⁾.

Regarding the reasons for refusal, it is noted that they resemble those presented in the national and international literature^(8-11,17-19). In spite of this, the most prevalent reasons listed by relatives calls attention. As shown in Table 2, not knowing the desire (in life) of the PD was the main reason for refusal presented by relatives of patients who became post-CPA PDs (33.3%). The fact that the PD was contrary to donation when alive (46.7%) was the main reason presented by relatives of post-BD patients.

Therefore, it is inferred that educational intervention actions targeted to the general population to raise awareness about the importance of donating organs/tissues, as well as clarifications on the donation/transplantation process are crucial^(2,17-18).

Studies have shown that individuals who are more educated, enlightened and with a greater degree of understanding about the dynamics and policy of donating organs and tissues are easier to decide in a conscious way and, therefore, more likely to consent with the harvesting of organs and tissues of their bodies.⁽¹⁹⁻²²⁾

CONCLUSION

Of the 93 studied interviews, more than half occurred with relatives of post-CPA patients. As for the relatives approached for donation in post-PCA PDs, there was prevalence of the children and, in the case of post-BD PDs, there was prevalence of parents. The percentage of consent for donation was higher than refusal.

As for the most authorized organs and tissues, the eyeball/corneas (for post-CPA and for post-BD PDs), and kidney and liver (for post-BD PDs) were highlighted. The main reason for refusal to donate in post-CPA patients was the lack of knowledge of the

desire (in life) of the PD and, for post-BD PDs, it was the opposition of the PD (in life) to donate organs and tissues.

The obtained data allowed to draw a clinical and epidemiological panorama of the interviews carried out in the studied institution, a fact that corroborates the implementation of strategies of improvement of the professionals of the CIHDOTTs who perform family interviews for donation of organs and tissues, in order to improve the variables that can be changed.

Despite the prevalence of donation-favorable results (52% of the interviews) and although no relationship had been observed between the degree of kinship between the relative and the PD and the interview outcome, the CIHDOTTs should always seek to provide constant training of its professionals, with a view to improving, expanding knowledge and obtaining better results on the donation of organs and tissues.

Considering the purpose of the present study, it is recognized that the results obtained - from the applied method, as well as from the analyzed variables - present limitations on the understanding of the family interview step and its outcome within a broader and integrated context.

This research presented only a portion of the determining and conditioning components to the result of the approach carried out by CHIDOTT members. In order to promote better rates of organ and tissue donation, harvesting and transplantation, more studies are needed.

In view of the evident complexity of the process and the need for continuing education to all involved, future research -in addition to identifying the clinical and epidemiological elements of the family interview with- should seek to identify the epidemiological aspects related to the relatives of potential donors such as gender, age, occupation, degree of schooling and power of understanding about the donation-transplant process. Also, knowing the perception that family members have about the interview and its implications for decision-making are important factors that deserve in-depth studies.

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