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# Analysis of factors associated with family decision on corneal donation

## *Análise dos fatores associados à decisão familiar sobre a doação de córneas*

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## *Abstract*

***Objective:*** *analyzing the influence of schooling and kinship on families' decision to donate corneas for transplants.* ***Method:*** *quantitative, cross-sectional and retrospective study whose sample comprised 291 records of interviews conducted with family members of potential corneal donors from January 2015 to December 2017, who were treated in a public, general and large-sized hospital in Porto Alegre City, Rio Grande do Sul State, Brazil.* ***Results:*** *53.3% of the potential corneal donors were male at mean age of 57 years (57 ± 11); 55.7% were married and 29.6% of them died during the night shift, which was the shift when death took place more often. With respect to families' decision, 60.8% of interviewees decided for donation. There was association between donation and interview shift; dawn was the least favorable time (p = 0.04). The mean time between patients' death and the interview with family members was 1:39 (± 1:20) and it did not influence families' decision (p = 0.63). Among the interviewed family members, 58.8% were women and 53.3% were descendants of the potential donor. Descendants decide about the donation more often than ascendants, siblings or spouses. The age group of the interviewed family members (41 ± 13) was statistically different from that of potential donors. There was association between schooling and decision to donate (p = 0.03); family members with higher schooling were more often favorable towards donation.* ***Conclusions:*** *Family members' schooling, degree of kinship and interview shift had positive influence on individuals' decision to donate corneal tissue for transplants.*

**Keywords:** Cornea; Tissue and organ procurement; Tissue donors

## Resumo

**Objetivo:** analisar a influência da escolaridade e do grau de parentesco na decisão familiar pela doação de córneas para transplantes. **Método:** desenho quantitativo, transversal e retrospectivo com amostra composta por 291 fichas das entrevistas realizadas com familiares de potenciais doadores de córneas de janeiro de 2015 a dezembro de 2017 de um hospital público, geral e de grande porte localizado no município de Porto Alegre, Rio Grande do Sul, Brasil. **Resultados:** entre os potenciais doadores deste tecido, 53,3% são do sexo masculino com idade média de 57 anos (57±11); 55,7% são casados e o turno mais frequente da ocorrência do óbito é o noturno com 29,6% dos casos. Em relação à decisão familiar, 60,8% dos entrevistados decidiram favoravelmente à doação. Existe associação entre doação e turno da entrevista, sendo a madrugada o menos favorável (p=0,04). O tempo médio entre o óbito e a realização da entrevista é de 1:39 (±1:20) e não influenciou na decisão familiar (p=0,63). Dos familiares entrevistados, 58,8% são do sexo feminino e 53,3% são descendentes do potencial doador. O parentesco descendente decide sobre a doação com maior frequência do que ascendentes, laterais ou cônjuges. A faixa etária do familiar entrevistado (41±13) tem diferença estatística em relação a do potencial doador. Há diferença entre decisão de doação e nível de escolaridade (p=0,03) sendo que familiares com maior escolaridade decidem com maior frequência favoravelmente a doação. **Conclusões:** escolaridade do familiar, grau de parentesco e turno da entrevista influenciam na decisão positiva para a doação de córneas para transplantes.

**Descritores:** Córnea; Obtenção de tecidos e órgãos; Doadores de tecidos

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## Introduction

Cornea is a transparent tissue located in the anterior part of the eyeball; together with the sclera, it forms the fibrous and protective part of the eye. Changes in corneal shape and transparency can severely impair individuals' vision and may even cause its total loss. These changes can lead to several disorders and hinder patients' daily activities. [1] Corneal transplantation is a treatment option in these cases; cornea is the most transplanted tissue worldwide. [2]

The total number of 59,638 corneal transplants were performed in Brazil from January 2015 to December 2018. [3] Corneal transplant rate (68.2 pmp*) decreased by 4.3% in the first half of 2019, which ended up distancing the country from the expected rate to reach a "zero list" (90 pmp). [4]

A global study focused on measuring the supply and demand for this tissue in 148 countries has emphasized that the demand for corneal transplants has increased and that it cannot be properly met due to scarcity of corneal donors worldwide. [5] Several factors can contribute to lack of corneal donation such as family members' refusal to authorize the procedure. [6]

The mean rate of non-authorization by family members in Brazil reached 43% in 2018; it was only lower than 35% in Paraná (27%) and Santa Catarina states (33%) - [7] Rio Grande do Sul State has followed the national average. In total, 456 interviews were conducted with relatives of potential corneal donors in 2018 and family refusal was recorded in 195 cases (43%). [8]

Teams of experts from the Intra-Hospital Commissions of Organ and Tissue Donation for Transplants (CIHDOTT - Comissões Intra-Hospitalares de Doação de Órgãos e Tecidos para Transplantes) have their work structured and standardized in order to get favorable responses from relatives of potential corneal donors during the interviews. The authorization by relatives is considered the most important organ donation stage since it is the starting point enabling the whole donation process to progress and to be successfully concluded. [9]

Aspects associated with the families of potential corneal donors must be taken into consideration and investigated at this donation process stage, since they are determining factors for organ harvesters to reach favorable donation outcomes. The aim of the current study was to analyze the influence of education, sex, age, degree of kinship, time between patients' death and interview with family members, and interview shift on families' decision to donate corneal tissues for transplants.

## Methods

The study followed a cross-sectional, retrospective and quantitative design. [10] It is an original and applied research, which was carried out in the health field and involved one of the corneal donation stages for transplantation purposes, namely: the interview conducted with family members of potential donors.

The non-probabilistic sample comprised 291 records of interviews carried out with relatives of potential corneal donors who died in a public, general and large hospital in Porto Alegre City, Rio Grande do Sul State, Brazil, from January 2015 to December 2017. The study included all interviews carried out within the aforementioned period with relatives of patients diagnosed with brain death or who died due to cardiac arrest and who did not present contraindication for corneal donation.

The Family Interview Form (printed document to be mandatorily filled out at each family approach) was developed by the CIHDOTT of the investigated hospital. Interviews and registration in this form are only carried out by CIHDOTT members and follow specific service protocols – standardized approach to family members is adopted in all work shifts.

Data collection was carried out from January to May 2018, based on the specific form developed to group variables according to three information groups: the first group refers to potential corneal donors and comprises variables such as sex, age, marital status and time of death. The second group refers to the interviewed relative and encompasses variables such as sex, age, degree of kinship and schooling. The third group refers to the interview itself and presents variables such as time between patient death and interview with family members, time the interview was carried out, decision on whether to accept, or not, the corneal donation.

Variable 'degree of kinship' was in compliance with Decree n. 9175, from October 18th, 2017, which addresses the availability of organs, tissues, cells and body parts for transplantation and treatment purposes. The section addressing family consent - Article n. 20, paragraph 1 - establishes that the authorization can be given by patients' spouse or partner and by older and legally capable consanguineous relatives, in both lineal and collateral kinship, up to the second degree. Thus, data were grouped as follows: spouse (including partners who have proof of common-law marriage), ascendants (fathers, mothers and grandparents), descendants (sons, daughters and grandchildren) and lateral kinship (brother / sister).

Interview times were divided into Morning (from 7 am to 1pm), Evening (from 1 pm to 7 pm), Night (from 7 pm to 12 am) and Dawn (from 12 am to 7 am) in order to be as close as possible to hospital work shifts.

Data were inserted in comma-separated file (.csv) and retrospectively analyzed in free RStudio software Version 1.1.383; significance level of 0.05 was adopted for Chi-square and Student's t tests.

The project was submitted to the Human Research Ethics Committee, in compliance with Resolution n. 466, which was issued by the National Health Council of the Brazilian Ministry of Health - Brasília (DF) - in December 2012. The study was approved under CAAE ethical authorization number 79343217.4.0000.5530 and opinion number 2.394.361 from November 23rd, 2017.

## Results

The current study has analyzed 291 files of interviews conducted with family members of potential corneal donors; results are shown in three different tables. Table 1 provides information about the frequency of variables associated with potential corneal donors such as male (n = 155; 53.3%) and female sex (n= 136; 46.7%); mean age (57 years; SD = 11 years; coefficient of variation = 19.3%); marital status: married (n = 162; 55.7%), single (n = 68; 23.4%), widowed (n = 31; 10.7%) and divorced (n = 30; 10.3%); time of death: night (n= 86; 29.6%), morning (n = 82; 28.2%), evening (n = 75; 25.8%) and dawn (n = 48; 16.5%).

Table 2 shows data about interviewed family members: 120 (41.2%) men and 171 (58.8%) women (mean age = 41 years; standard deviation = 13 years; coefficient of variation = 31.4%); kinship: 75 spouses (25.8%), 155 (53.3%) descendants, 10 (5.4%) ascendants and 51 (17.5%) lateral kinship; schooling: 98 (49.2%) individuals had elementary school, 67 (33.7%) had high school and 34 (17.1%) had major degree; interview shift: 67 (23%) in the morning, 87 (29.9%) in the evening, 92 (31.6%) at night and

**Table 1**
**Frequency distribution of variables sex, age, marital status and time of death of potential corneal donors**

| Variables | n | % | PR | 95%CI | P value ($\chi^2$) |
|---|---|---|---|---|---|
| Sex | | | | | 0.24 |
| Male | 155 | 53.3 | 1 | | |
| Female | 136 | 46.7 | 0.88 | 0.83 – 0.93 | |
| Age (years) | | | | | 0.03 |
| < 57 | 119 | 40.9 | 1 | | |
| ≥ 57 | 172 | 59.1 | 0.69 | 0.67 – 0.71 | |
| Mean = 57 and SD = 11 | | | | | |
| CV = 19.3% | | | | | |
| Marital status | | | | | <0.001 |
| Married | 162 | 55.7 | 1 | | |
| Divorced | 30 | 10.3 | 0.18 | 0.12 – 0.24 | |
| Widowed | 31 | 10.7 | 0.19 | 0.13 – 0.25 | |
| Single | 68 | 23.4 | 0.42 | 0.34 – 0.50 | |
| Hospital shift when patients died | | | | | 0.01 |
| Morning | 82 | 28.2 | 1 | | |
| Evening | 75 | 25.8 | 0.91 | 0.85 – 0.97 | |
| Night | 86 | 29.6 | 1.05 | 1.00 – 1.10 | |
| Dawn | 48 | 16.5 | 0.58 | 0.47 – 0.69 | |

SD = Standard Deviation. CV = Coefficient of Variation. PR = Prevalence Ratio. 95% CI = 95% Confidence Interval. $\chi^2$ = Chi-square.

**Table 2**
**Frequency distribution of variables sex. age. kinship. schooling and shift when the interview was conducted with family members of potential corneal donors.**

| Variables | n | % | PR | 95% CI | P value ($\chi^2$) |
|---|---|---|---|---|---|
| Sexo | | | | | <0.001 |
| Male | 120 | 41.2 | 1 | | |
| Female | 171 | 58.8 | 1.43 | 1.24 – 1.63 | |
| Age (years)* | | | | | 0.29 |
| < 41 | 107 | 53.8 | 1 | | |
| ≥ 41 | 92 | 46.2 | 0.86 | 0.79 – 0.93 | |
| Mean = 41 and SD = 13 | | | | | |
| CV = 31.4% | | | | | |
| Kinship | | | | | <0.001 |
| Spouse | 75 | 25.8 | 1 | | |
| Descendant | 155 | 53.3 | 2.07 | 1.73 – 2.41 | |
| Ascendant | 10 | 5.4 | 0.13 | 0.05 – 0.21 | |
| Lateral kinship | 51 | 17.5 | 0.68 | 0.58 – 0.78 | |
| Schooling* | | | | | <0.001 |
| Elementary school | 98 | 49.2 | 1 | | |
| High school | 67 | 33.7 | 0.68 | 0.67 – 0.69 | |
| Major degree | 34 | 17.1 | 0.34 | 0.33 – 0.35 | |
| Interview shift | | | | | <0.001 |
| Morning | 67 | 23.0 | 1 | | |
| Evening | 87 | 29.9 | 1.30 | 1.28 – 1.32 | |
| Night | 92 | 31.6 | 1.37 | 1.35 – 1.39 | |
| Dawn | 45 | 15.5 | 0.67 | 0.66 – 0.68 | |

SD = Standard Deviation. CV = Coefficient of Variation. PR = Prevalence Ratio. 95% CI = 95% Confidence Interval.$\chi^2$ = Chi-square. *N=199

**Tabela 3**
**Distribuição das frequências de decisão da doação. segundo sexo. parentesco. escolaridade. idade do familiar. tempo entre o óbito e a entrevista e o turno da entrevista**

| Study factor | Donation decision | | | | | | | | P value |
|---|---|---|---|---|---|---|---|---|---|
| | Yes | | PR | 95%CI | No | | PR | 95%CI | ($\chi^2$) |
| | n | % | | | n | % | | | |
| Sex | | | | | | | | | 0.81 |
| Male | 72 | 60.0 | 1 | | 48 | 40.0 | 1 | | |
| Female | 105 | 61.4 | 0.98 | 0.81 – 1.18 | 66 | 38.6 | 1.04 | 086 – 1.25 | X |
| Family member's age* (years) | | | | | | | | | 0.17 |
| < 41 | 49 | 45.8 | 1 | | | 58 | 54.2 | 1 | |
| ≥ 41 | 51 | 55.4 | 0.83 | 0.63 – 1.09 | 41 | 44.6 | 1.22 | 0.92 – 1.60 | |
| Kinship | | | | | | | | | 0.05 |
| Spouse | 49 | 66.2 | 1 | | | 25 | 33.8 | 1 | |
| Descendant | 85 | 54.5 | 0.82 | 0.51 – 1.34 | 71 | 45.5 | 1.35 | 0.83 – 2.19 | |
| Ascendant | 7 | 70.0 | 1.06 | 0.65 – 1.72 | 3 | 30.0 | 0.89 | 0.55 – 1.44 | |
| Lateral kinship | 38 | 72.5 | 1.10 | 0.67 – 1.78 | 13 | 27.5 | 0.81 | 0.50 – 1.32 | |
| Schooling* | | | | | | | | | 0.03 |
| Elementary school | 47 | 47.9 | 1 | | | 51 | 52.1 | 1 | |
| High school | 34 | 50.7 | 1.06 | 0.73 – 1.54 | 33 | 49.3 | 0.95 | 0.65 – 1.37 | |
| Major degree | 25 | 73.5 | 1.53 | 1.06 – 2.23 | 9 | 26.5 | 0.51 | 0.35 – 0.74 | |
| Time elapsed between patient death and interview with family member (hour) | | | | | | | | | 0.63 |
| Up to 1 | 8 | 50.0 | 1 | | | 8 | 50.0 | 1 | |
| From 1 to 2 | 41 | 56.2 | 1.12 | 0.52 – 2.45 | 32 | 43.8 | 0.88 | 0.40 – 1.91 | |
| From 2 to 3 | 67 | 67.0 | 1.34 | 0.61 – 2.92 | 33 | 33.0 | 0.66 | 0.30 – 1.44 | |
| From 3 to 4 | 33 | 57.9 | 1.16 | 0.53 – 2.53 | 24 | 42.1 | 0.84 | 0.39 – 1.84 | |
| From 4 to 5 | 15 | 60.0 | 1.20 | 0.55 – 2.62 | 10 | 40.0 | 0.80 | 0.37 – 1.75 | |
| More than 5 | 11 | 55.0 | 1.10 | 0.50 – 2.40 | 9 | 45.0 | 0.90 | 0.41 – 1.96 | |
| Mean=1.39 and SD=1.20 CV=0.81 | | | | | | | | | |
| Interview shift | | | | | | | | | 0.04 |
| Morning | 50 | 74.6 | 1 | | | 17 | 25.4 | 1 | |
| Evening | 53 | 60.9 | 0.82 | 0.54 – 1.23 | 34 | 39.1 | 1.54 | 1.02 – 2.31 | |
| Night | 54 | 58.7 | 0.79 | 0.52 – 1.18 | 38 | 41.3 | 1.63 | 1.08 – 2.45 | |
| Dawn | 22 | 48.9 | 0.66 | 0.44 – 0.99 | 23 | 51.1 | 2.01 | 1.34 – 3.03 | |

SD = Standard Deviation. CV = Coefficient of Variation. PR = Prevalence Ratio. 95% CI = 95% Confidence Interval. $\chi^2$= Chi-square. *N=199.

45 (15.5%) at dawn.

Table 3 shows data about decisions deriving from interviews conducted with family members. Results were distributed in absolute numbers recorded for study factors, which were followed by decision rates.

Acceptance decisions comprised 177 (60.8%) of the total number of cases, as follows: 105 (61.4%) women and 72 (60%) men; 49 (62.2%) spouses, 85 (54.5%) descendants, 7 (70%) ascendants and 38 (72.5%) lateral kinship; 47 (47.9%) individuals had elementary school, 34 (50.7%) has high school and 25 (73.5%) had major degree; 51 (55.4%) individuals were older and 49 (45.8%) were younger than 41 years; 8 (50%) family members were interviewed within 1 hour after potential donors' death, 41 (56.2%) were interviewed between 1 and 2 hours after it, 67 (67%) between 2 and 3 hours, 33 (57.9% ) between 3 and 4 hours, 15 (60%) between 4 and 5 hours and 11 (55%) were interviewed more than 5 hours after potential donors' death; 50 (74.6%) individuals were interviewed in the morning shift, 53 (60.9%) in the afternoon, 54 (58.7%) at night and 22 (48.9%) at dawn.

Non-acceptance decisions comprised 114 (39.2%) of the total number of cases, as follows: 48 (40%) men and 66 (38.6%) women; 25 (33.8%) spouses, 71 (45.5%) descendants, 3 (30%) ascendants and 13 (27.5%) lateral kinship; 51 (52.1%) individuals had elementary school, 33 (49.3%) had high school and 9 (26.5%) has major degree; 58 (54.2%) individuals were older and 41 (44.6%) were younger than 41 years; 8 (50%) family members were interviewed within 1 hour after potential donors' death, 32 (43.8%) were interviewed between 1 and 2 hours after it, 33 (33%) between 2 and 3 hours, 24 (42.1%) between 3 and 4 hours, 10 (40%) between 4 and 5 hours and 9 (45%) were interviewed more than 5 hours after potential donors' death; 17 (25.4%) individuals were interviewed in the morning, 34 (39.1%) in the evening, 38 (41.3%) at night and 23 (51.1%) at dawn.

## Discussion

Organ donation is a decision to be exclusively made by family members of potential donors [11]. Family refusal is among the countless factors contributing to the non-effectiveness of corneal donation processes. [6] Family non-authorization rate among the 291 interview files analyzed in the present study reached 39.2%; this outcome was below the Brazilian mean recorded in 2018 (43%). [4]

Family members' refusal to donate corneas may be associated with lack of knowledge about the functioning of donation and transplantation processes. [12] It is essential giving family members the necessary information about the process in order to have their consent. [13] Most family members interviewed in the current study were women (58.8%). However, it was possible seeing that relatives' sex did not influence their donation decision, since the acceptance ratio was similar between men (60%) and women (61.4%); p = 0.81.

With respect to age, data from 2018 have shown that the largest number of organ donors in Brazil comprised patients in the age group 50-64 years. [7] The mean age of corneal donors (57 ± 11) and family members (41 ± 13) in the current study was subjected to Student's t test. Statistical difference (p < 0.001) has indicated that the youngest generation is often the one interviewed about donation, on average. Family members older than 41 years were more favorable towards donation than the younger ones.

Decision-making involving the family gives relevance to the degree of kinship of donors' relatives. Interview is the time when legal guardians are identified by interviewers who assess whether all family members are aware and informed about the process and allow them to express themselves in order to solve their main doubts. [14]

Based on the analysis carried out in the current study, 155 (53.3%) interviewees were descendants of potential donors, they were 2.07 times more likely (1.73–2.41; 95% CI) to be interviewed than their spouses. With respect to the decision to authorize the donation, 85 (54.5%) descendants, 38 (72.5%) side relatives, 7 (70%) ascendants and 49 (66.2%) spouses recorded statistically significant rates in comparison to the decision to not authorize it, p = 0.05.

The interview has been increasingly improved through the development of techniques, team training about the way they should talk to family members by using clear, transparent and honest language. [14] At this stage of the donation process, one must take into account the profile of the family member to be interviewed, as well as issues involving family ties and the way families discuss and share information among them. An American study about organ donation has shown that the number of harvested organs is influenced by family consents conditioned to certain organs due to emotional, cultural, religious or family conflicts. [15]

Relevant information about how cornea donation takes place is verbally presented to family members at interview time, which is a decisive step in their decision about whether, or not, to donate organs and/or tissues. [14] Rather than being the time to talk about the option for organ donation, the interview is understood as the ideal time for family members to be informed about the entire donation process. By assuming this educational nature, which is valuable in the donation process, the interview is an important means of educating, empowering and providing information to family members about their rights. [9]

According to the current study, schooling is a factor capable of interfering in donation processes, since there was statistically significant difference in the decision to authorize donation based on family members' schooling (p = 0.03): family members with major degree were 1.53 times more likely to authorize the donation (1.06–2.23; 95% CI), if one only takes into consideration valid data. Lack of information or inadequate information, in association with family members' low schooling level, can generate misinterpretations about how patients' body will be returned and about the equitable distribution of organs. [11] Several families appeared to have a hard time understanding the information provided to them, which are necessary for the decision-making process. [13]

Low schooling and lack of information can lead to misinterpretations about organ harvesting and transplantation processes. According to bioethical principles, individuals who are poorly informed about the topic in question are not able to consciously decide about whether, or not, they wish to donate the deceased one's organs. [16]

Brazil presents high illiteracy rate, as well as significant number of semi-literate individuals, a fact that compromises their autonomy, since lack of necessary and indispensable information limits individuals' free decision about their future. [16] Thus, interviewed family members' schooling can interfere in donation processes, since low schooling can reduce individuals' access to information in general and, most specifically, about transplantation processes. Likewise, higher schooling is a facilitating factor in decision-making processes.

This finding emphasizes that the development of transplant systems in a given country is not only determined by its economic development, but also by the association of organizational, economic, cultural and social factors. [14]

The concern about the time elapsed between donors' death and corneal removal is an important factor; however, the decision to donate this tissue does not depend on the time elapsed between patients' death and the interview with family members (p = 0.63), although such a time is an important factor to be taken into consideration to enable the conservation and maintenance of human tissues. The mean time between patients' death and donation decision in the current study was 1 hour and 39 minutes, standard deviation was 1 hour and 20 minutes and coefficient of variation was 81%, which indicated high internal variation.

There was association between decision to donate and interview shift; the morning and evening shifts were the most favorable for donation authorization (p = 0.04). Thus, understanding institutional data makes it easier suggesting new actions/approaches, such as expanding the team and adjusting schedules, which may help increasing the likelihood of obtaining better results. [17]

Since the interview must be adapted to the emotional state of the family [14], fields concerning schooling and age of family members were not completed in 92 (31.6%) forms. Of these, 74 (80%) individuals have authorized the donation and 18 (20%) did not. Data concerning this limitation were treated based on the data imputation technique [18]. Missing data were replaced by the most frequent one in categorical variable 'schooling' and by the mean value in the case of family members' age. After this method was applied, it was evident that variables such as schooling and age did not significantly affect family members' decisions. A correlation matrix [19] comprising all variables was built for factor analysis purposes. Family members' sex, schooling, degree of kinship and interview shift were the variables presenting the highest correlation coefficient. Comparisons between groups were based on the acceptance/non-acceptance decision ratio.

Thus, besides contributing to scientific improvements in the field of organ and tissue harvesting for transplantation purposes, the analysis of factors associated with family decision about corneal donation qualifies working processes involving family approach, not only with regard to the interview itself, but also to the organization, information management and improvements in the Family Interview Form.

## Conclusions

It was possible concluding that interview shift, family members' schooling and degree of kinship can influence individuals' decision to donate corneal tissue. Interviews conducted in the morning and evening shifts were more favorable to reach positive decisions about donation. Family members who had major degree were more likely to decide for donation. Descending and lateral kinship degrees were more favorable to make positive decisions about donation, whereas age and sex did not influence their decision. The time elapsed between patients' death and interview with family members did not influence their decision to donate.

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