

Specific Family Refusal to Donate Bones for Transplantation

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ABSTRACT

Introduction: Bone tissue is used in patients who need bone repair or reconstruction and in dental procedures. Objectives: To analyze the factors associated with and the trend of specific refusal of bone donation by an organ procurement organization in the state of São Paulo, Brazil. Methods: A cross-sectional study was conducted using data from 1,713 organ and tissue donation authorization forms from 2001 to 2020, provided by an organ procurement organization in the city of São Paulo. The study variables were year, age group, sex, cause of death, type of hospital, and donated and refused bones. The analysis was conducted using both descriptive and inferential statistics, employing chi-square tests, trend analysis, linear regression, and multiple logistic regression. Results: Bone donation was refused in 896 (52.30%) of effective donors, the majority of whom were male (513; 57.2%; $p = 0.009$) and aged 41 to 59 years (372; 41.5%; $p = 0.018$). From 2001 to 2009, there was a downward trend in bone donation refusals in the 0 to 11 and 12 to 19 age groups; however, there was an upward trend in refusals among those aged ≥ 60 years. In the period from 2010 to 2020, the trend of refusals remained decreasing in the age group from 0 to 11 years. From 2001 to 2020, the chance of people refusing bone donation was 24% lower in males ($p = 0.001$), 30% lower in the 20 to 40 age group ($p = 0.017$), 46% lower in the 41-59 age group ($p < 0.001$), and 51% lower in the ≥ 60 age group ($p < 0.001$). Conclusion: Over the last few years, there has been a decrease in the rate of refusal to donate bones. However, strategies targeting age groups involving young adults should be implemented, as they present higher refusal rates.

Descriptors: Tissue and Organ Procurement; Tissue Donors; Bone and Bones; Bone Banks; Nursing.

Recusa Familiar Específica de Doação de Ossos para Transplante

RESUMO

Introdução: Os tecidos ósseos são utilizados em pacientes que necessitam de reparações ou reconstruções ósseas e em procedimentos odontológicos. Objetivos: Analisar os fatores associados e a tendência da recusa específica de doação de ossos de uma Organização de Procura de Órgãos (OPO) no estado de São Paulo, Brasil. Métodos: Estudo transversal realizado com dados de 1.713 termos de autorização de doação de órgãos e tecidos no período de 2001 a 2020, fornecidos por uma OPO do município de São Paulo. As variáveis do estudo foram: ano, faixa etária, sexo, causa do óbito, tipo da instituição hospitalar e ossos doados e recusados. A análise ocorreu por meio de estatística descritiva e inferencial, aplicando-se teste qui-quadrado, análise de tendência, regressão linear e regressão logística múltipla. Resultados: A doação de ossos foi recusada em 896 (52,30%) dos doadores efetivos, sendo a maioria do sexo masculino (513; 57,2%; $p = 0,009$) e com faixa etária de 41 a 59 anos (372; 41,5%; $p = 0,018$). De 2001 a 2009, ocorreu uma tendência decrescente nas recusas de doação de ossos nas faixas etárias de 0 a 11 anos e 12 a 19 anos; no entanto, a tendência foi crescente para as recusas de 60 anos ou mais. No período de 2010 a 2020, a tendência de recusas se manteve decrescente na faixa etária de 0 a 11 anos. De 2001 a 2020, a chance de pessoas recusarem a doação de ossos foi 24% mais baixa no sexo masculino ($p = 0,001$), 30% na faixa etária de 20 a 40 anos ($p = 0,017$), 46% na faixa etária de 41 a 59 anos ($p < 0,001$) e 51% na faixa etária de 60 anos ou mais ($p < 0,001$). Conclusão: No decorrer dos últimos anos, houve uma diminuição na taxa de recusa de doação de ossos, mas estratégias direcionadas às faixas etárias que envolvem os adultos jovens devem ser realizadas, visto que apresentam taxas mais altas de recusa.

Descritores: Obtenção de Tecidos e Órgãos; Doadores de Tecidos; Osso e Ossos; Bancos de Ossos; Enfermagem.

INTRODUCTION

Bone tissue donation represents a highly relevant alternative for significantly improving the quality of life of individuals who have experienced bone loss due to congenital deformities, bone cancer, accidents, and other conditions. In the donation process of this tissue, unlike most solid organs, it is considered that a single donor may benefit numerous recipients, depending on the amount of tissue required and the site to be transplanted¹.

It is of utmost importance that individuals express during their lifetime to their family members their intention to donate bone tissue, since in Brazil these relatives are responsible for consenting to or refusing the donation during the family interview for organ and tissue transplantation². It should also be emphasized that, regardless of the family's decision, healthcare professionals are responsible for providing appropriate support, welcoming and respecting the relatives in their grieving process.

Brazilian developments and legislation allow tissue donation to be carried out from donors deceased due to cardiac arrest or brain death, whereas organ donation is permitted only in cases of brain death³. Thus, there is a greater likelihood of refusal in tissue donation compared to organ donation. It is observed that refusal rates for tissue donation, including bone tissue, remain high, even among families who consent to the donation of solid organs⁴. Many of the family members who refused the donation reported a complete lack of knowledge regarding bone tissue donation and transplantation¹.

The lack of information regarding bone tissue donation can be attributed to the scarcity of publications and studies specifically dedicated to this subject. In contrast, organ donation and transplantation have received greater attention in the scientific literature and in dissemination media⁵. As a consequence, there is a disruption in public knowledge, leading to family refusal of donation.

Between 2001 and 2016, there was a relative increase in bone tissue donation rates; however, in the following years, a renewed rise in refusal rates was observed¹.

Thus, the objective was to analyze the factors associated with and the trend of specific refusal of bone tissue donation within an Organ Procurement Organization (OPO) in the state of São Paulo, Brazil.

METHODS

This is a quantitative, cross-sectional, retrospective, and exploratory study addressing specific refusals related to bone tissue donation from brain-dead donors.

Context

In Brazil, the management of donations and transplants is carried out by the National Transplant System (Sistema Nacional de Transplantes – SNT), whose structure encompasses state-level coordinations that are further subdivided into regional structures known as Organ Procurement Organizations (OPOs)⁶. The study was conducted in one of the ten Organ Procurement Organizations (OPOs) that are part of the São Paulo State Transplant System. This OPO is responsible for coordinating the donation process in a region with 5,979,439 inhabitants, served by 96 public and private hospitals.

Data Collection

Organ and tissue donation consent forms signed by family members of deceased donors between 2001 and 2020 were analyzed, indicating which tissues were authorized or not for procurement. The variables considered in the study included year of donation (2001–2020), donor age group (0–11 years, 12–19 years, 20–40 years, 41–59 years, and 60 years or older), sex (male and female), diagnosis (cerebrovascular accident, traumatic brain injury, anoxic encephalopathy following cardiorespiratory arrest, external causes, and others), and institutional affiliation (public or private administration).

Statistical Methods

Data analysis was performed using Stata software, version 15.0, through descriptive and inferential approaches, including hypothesis testing and Prais–Winsten linear regression to calculate trends indicated by the parameter Annual Percent Change (APC). Trend determination was based on the following criteria: increasing trend – positive APC and $p < 0.05$; decreasing trend – negative APC and $p < 0.05$; stationary – $p > 0.05$. Throughout the analysis, $p < 0.05$ was considered statistically significant.

Ethical Aspects

The study was approved by the Research Ethics Committee under opinion No. 4,443,700/2021.

RESULTS

Of the 1,713 organ and tissue donation authorization forms, 896 (52.30%) corresponded to refusals of bone tissue donation. Among the most predominant variables associated with refusal were male sex (57.25%), donor age between 41 and

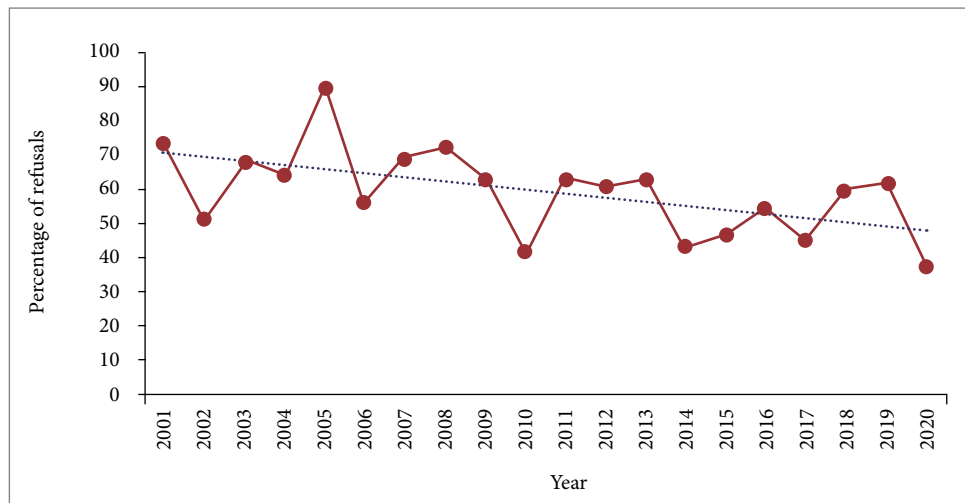
59 years (41.52%), cerebrovascular accident as the cause of brain death (52.34%), and public hospital administration (60.27%). The variables that most significantly influenced refusal were gender ($p = 0.009$) and age ($p = 0.018$) (Table 1).

Table 1. Characterization of bone tissue donations and refusals, considering the period from 2001 to 2020, São Paulo, 2025.

Variables	Refused n (%)	Donated n (%)	<i>p</i> value*
Sex			
Female	383 (42.75)	299 (36.60)	0.009
Male	513 (57.25)	518 (63.40)	
Age group (years)			
0 - 11	32 (3.57)	19 (2.33)	0.018
12 - 19	85 (9.49)	53 (6.49)	
20 - 40	272 (30.36)	225 (27.54)	
41 - 59	372 (41.52)	376 (46.02)	
60 or older	135 (15.07)	144 (17.63)	
Diagnosis			
Cerebrovascular accident (CVA)	469 (52.34)	396 (48.47)	0.316
Traumatic brain injury (TBI)	316 (35.27)	302 (36.96)	
Anoxia	58 (6.47)	61 (7.47)	
External causes	15 (1.67)	23 (2.82)	
Others	38 (4.24)	35 (4.28)	
Institutional affiliation			
Public administration	540 (60.27)	504 (61.69)	0.547
Private administration	356 (39.73)	313 (38.31)	

Source: Elaborated by the authors. * Chi-square test.

In the temporal evolution, a decrease in the percentage of refusals can be identified. However, it is important to highlight the extremes: the highest refusal rate occurred in 2005 (89.71%), while the lowest rates were observed in 2010 (41.32%) and 2020 (37.09%) (Fig. 1).



Source: Elaborated by the authors.

Figure 1. Temporal evolution of bone donation refusals from 2001 to 2020, São Paulo, 2025.

From 2001 to 2009, the age group of 12–19 years showed a significant decreasing trend (APC: -0.97, CI: -0.99 to -0.91, $p < 0.001$), in contrast to the age group of 60 years or older (APC: 185.20, CI 3.46–758.47, $p = 0.013$). The age group of 0–11 years presented a decreasing trend in refusals of bone donations in both analyzed periods: from 2001 to 2009 (APC: -0.87, CI -0.95 to -0.59, $p = 0.004$) and from 2010 to 2020 (APC: -0.60, CI -0.79 to -0.22, $p = 0.012$) (Table 2).

Table 2. Temporal trend of the percentage of bone donation refusals, according to characterization variables, in the periods 2001–2009 and 2010–2020, São Paulo, 2025.

Variables	2001 n (%)	2009 n (%)	APC* (IC95%)	Δ%	p-value	2010 n (%)	2020 n (%)	APC* (IC95%)	Δ%	p-value
Male sex	33 (75.00)	60 (55.05)	-0.96 (-0.99-31.35)	-26.60	0.290	39 (56.52)	31 (55.36)	-0.71 (-0.94-0.31)	-2.05	0.099
Public sector	23 (52.27)	49 (44.95)	9.96 (-0.90-128.72)	-14.00	0.275	39 (56.52)	35 (62.50)	5.60 (-0.77-203.17)	10.58	0.238
Age range (years)										
0 - 11	5 (11.36)	4 (3.67)	-0.87 (-0.95 a -0.59)	-67.69	0.004	2 (2.90)	0 (0.00)	-0.60 (-0.79-0.22)	-	0.012
12 - 19	9 (20.45)	6 (5.50)	-0.97 (-0.99-0.91)	-73.10	< 0.001	7 (10.14)	6 (10.71)	-0.25 (-0.92-6.58)	5.62	0.772
20 - 40	17 (38.64)	29 (26.61)	-0.91 (-0.99-6.42)	-31.13	0.230	23 (33.33)	18 (32.14)	0.41 (-0.36-2.23)	-3.57	0.355
41 - 59	11 (25.00)	52 (47.71)	25.92 (-0.99-758.56)	90.96	0.359	31 (44.93)	22 (39.29)	0.77 (-0.38-4.12)	-12.55	0.256
60 or older	2 (4.55)	18 (16.51)	185.20 (3.46-758.47)	262.85	0.013	6 (8.70)	10 (17.86)	1.51 (-0.80-31.35)	105.28	0.430
General population	44 (73.33)	109 (63.01)	3.57 (-0.97-75.57)	-14.07	0.499	69 (41.32)	56 (37.09)	-0.66 (-0.99-102.31)	-10.23	0.569

Source: Elaborated by the authors.

Associating refusals with sociodemographic characteristics, it was observed that, in the period from 2001 to 2009, the age group of 20–40 years showed a 64% lower chance of refusal for bone donation [odds ratio (OR): 0.36, confidence interval (CI) 0.14–0.91, $p = 0.032$], and considering the entire period (2001–2020), a 47% lower chance (OR: 0.53, CI 0.33–0.86, $p = 0.011$). The same pattern was observed for the age group of 41–59 years, with a 71% lower chance of refusal in the first period (OR: 0.29, CI 0.11–0.71, $p = 0.007$) and 57% in the total period (OR: 0.43, CI 0.26–0.69, $p = 0.001$). For individuals aged 60 years or older, the chances of refusal were 76% lower in the first period (OR: 0.24, CI 0.09–0.63, $p = 0.004$) and 62% lower (OR: 0.38, CI 0.23–0.64, $p < 0.001$) in the total period. The male sex presented a 23% lower chance of refusal in the first period (OR: 0.77, CI 0.63–0.93, $p = 0.009$) and 20% in the total period (OR: 0.80, CI 0.68–0.95, $p = 0.010$) (Table 3).

Table 3. Association between bone donation refusal and sociodemographic characteristics, considering crude OR, São Paulo, 2025.

Variables	2001 a 2009		2010 a 2020		2001 a 2020	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Sex						
Female	1	-	1	-	1	-
Male	0.96 (0.71-1.31)	0.829	0.77 (0.63-0.93)	0.009	0.80 (0.68-0.95)	0.010
Age range (years)						
0 - 11	1	-	1	-	1	-
12 - 19	0.41 (0.14-0.91)	0.090	0.95 (0.49-1.84)	0.885	0.67 (0.39-1.16)	0.161
20 - 40	0.36 (0.14-0.91)	0.032	0.71 (0.39-1.30)	0.274	0.53 (0.33-0.86)	0.011
41 - 59	0.29 (0.11-0.71)	0.007	0.58 (0.32-1.05)	0.075	0.43 (0.26-0.69)	0.001
60 or older	0.24 (0.09-0.63)	0.004	0.55 (0.30-1.02)	0.062	0.38 (0.23-0.64)	< 0.001
Diagnosis						
Stroke	0.79 (0.35-1.77)	0.579	1.09 (0.67-1.75)	0.722	1.08 (0.67-1.51)	0.968
Traumatic brain injury (TBI)	0.68 (0.29-1.61)	0.392	0.96 (0.59-1.56)	0.882	0.83 (0.55-1.26)	0.394
Anoxia	1.58 (0.52-4.75)	0.411	0.87 (0.48-1.56)	0.656	0.94 (0.57-1.55)	0.827
External causes	0.72 (0.30-1.68)	0.449	0.60 (0.27-1.33)	0.210	1.03 (0.63-1.69)	0.892
Others	1	-	1	-	1	-
Institutional affiliation						
Public administration	0.92 (0.68-1.26)	0.634	0.94 (0.77-1.14)	0.547	0.86 (0.73-1.01)	0.077
Private administration	1	-	1	-	1	-

Source: Elaborated by the authors.

In the analysis of the final adjusted model, male gender presented, in the second period (2010–2020), a 26% lower chance of refusal for bone donation (OR: 0.74, CI 0.60–0.90, $p = 0.003$) and, in the total period (2001–2020), 24% lower chance

(OR: 0.76, CI 0.64–0.90, $p = 0.001$). The age group of 20–40 years, during the total period (2001–2020), showed a 30% lower chance of refusal for bone donation (OR: 0.70, CI 0.53–0.93, $p = 0.017$). The age group of 41–59 years, in 2001–2009, presented a 31% lower chance of refusal for bone donation (OR: 0.69, CI 0.49–0.96, $p = 0.031$); in 2010–2020, the reduction was 28% (OR: 0.72, CI 0.59–0.89, $p = 0.003$), and in the total period (2001–2020), the data demonstrated a 46% lower chance of refusal for the same age group (OR: 0.54, CI 0.41–0.71, $p \leq 0.001$). Finally, individuals aged 60 years or older presented a 42% lower chance of refusal for bone donation in 2001–2009 (OR: 0.58, CI 0.36–0.93, $p = 0.025$); in 2010–2020, the data showed a 32% lower chance of refusal (OR: 0.68, CI 0.51–0.90, $p = 0.009$), and in the total period (2001–2020), a 51% lower chance of refusal was observed (OR: 0.49, CI 0.35–0.67, $p \leq 0.001$) (Table 4).

Table 4. Final reduced model of the association between bone donation refusal and sociodemographic and clinical characteristics, São Paulo, 2025.

Variables	2001 a 2009*		2010 a 2020†		2001 a 2020‡	
	OR (IC95%)	<i>p</i> -value	OR (IC95%)	<i>p</i> -value	OR (IC95%)	<i>p</i> -value
Sex						
Male	-	-	0.74 (0.60-0.90)	0.003	0.76 (0.64-0.90)	0.001
Age range (years)						
12 - 19	-	-	-	-	-	-
20 - 40	-	-	-	-	0.70 (0.53-0.93)	0.017
41 - 59	0.69 (0.49-0.96)	0.031	0.72 (0.59-0.89)	0.003	0.54 (0.41-0.71)	< 0.001
60 or older	0.58 (0.36-0.93)	0.025	0.68 (0.51-0.90)	0.009	0.49 (0.35-0.67)	< 0.001

Source: Elaborated by the authors. * $R^2 = 2.78\%$; $p = 0.007$; † $R^2 = 0.76\%$; $p < 0.001$; ‡ $R^2 = 1.10\%$; $p < 0.001$.

DISCUSSION

Based on the analysis of organ and tissue donation authorization forms from an OPO in the state of São Paulo regarding family-specific refusal of bone donation for transplantation, it was possible to observe that male gender and age group are factors associated with refusal.

The main reasons for the lack of family authorization for organ and tissue donation are: previous written or verbal expression by the potential donor, fear of mutilation or damage to bodily integrity, conflicts with healthcare professionals during hospitalization, or distrust in professionals or in the organ donation process, religious beliefs, and individual motivations⁷. However, when bone donation was specifically analyzed, refusals were related to lack of knowledge about which bones would be removed, about body reconstruction, and about the presentation of the body after procurement⁸.

A similar situation is observed regarding skin donation, a tissue still scarcely addressed in awareness campaigns. The notion of “animalization” was identified as one of the social representations attributed to skin donation, in which family members associate the removal procedure with the extraction of animal hide in slaughter contexts².

Moreover, the absence of effective communication by professionals with family members results in discomfort and dissatisfaction, which may negatively influence the decision-making process and contribute to family refusal of consent for organ and tissue donation⁹.

The importance of the technical and emotional preparation of the multidisciplinary team is related to the refusal rates for organ and tissue donation. In addition to providing support throughout the entire process and establishing the family–professional bond, it is necessary that the interviewer, in light of his or her own beliefs and knowledge, does not influence the family’s final decision regarding donation authorization¹⁰.

The results of this study revealed a trend toward a higher number of refusals among male individuals. However, recent studies conducted in different regions of Brazil show that male sex is, in fact, predominant at the moment of donation consent^{11,12}. In the national data, such as those described by the Brazilian Transplant Registry in 2024¹³, male cases also prevail. Therefore, further studies are needed to better understand the relationship between gender and bone-specific refusal.

The analysis of the data shows that the higher the donor’s age, the greater the likelihood of family refusal for bone donation. This finding contrasts with studies indicating an increase in the age of potential donors, related to population aging and the flexibilization of clinical criteria for expanded donors¹⁴.

The age criterion for bone donation, as established by the National Institute of Traumatology and Orthopedics (Instituto Nacional de Traumatologia e Ortopedia – INTO), is 10 to 70 years¹⁵. This delimitation may contribute to the dissemination of inaccurate information in society, leading to donation refusal, even in the absence of technical knowledge or official confirmation.

In 2005, there was a peak in the number of refusals, following a steady increase since 2002. The explanation for this phenomenon would be the abolition of presumed consent in 2001 and the lack of changes in public policies, with modifications only beginning in 2009^{6,16}.

The restructuring of the National Transplant System (*Sistema Nacional de Transplantes – SNT*) occurred only in 2009, with the regulation of several institutions, including the operation of Musculoskeletal Tissue Banks and the definition of responsibilities and operational workflows⁶. This new legislation explains the significant decline in that same year and in the following decade.

Moreover, another significant reduction in the number of refusals was observed in 2020, possibly influenced by the COVID-19 pandemic. This result may be explained by underreporting of data, and the various obstacles imposed by the health context contributed to the scenario observed, such as the suspension of surgical procedures, contraindications determined by health authorities, the reduction in the number of deaths due to brain death, the high occupancy of intensive care unit beds, and the difficulty in approaching families due to the risk of contamination¹⁷.

In addition, another factor that may have contributed to the decline in refusals was the organ and tissue donation authorized by the family of TV host Gugu Liberato at the end of 2019, which generated wide media coverage and national commotion⁴.

Although the models examined revealed significant factors, it is important to note that the variables analyzed are not sufficient for a definitive conclusion regarding the reasons behind specific refusals of bone donation. Nevertheless, this study highlights gaps in the understanding of these reasons in the identification of refusals and emphasizes the importance of investigating other specific characteristics that may influence the lack of consent for bone donation in individuals who died from brain death.

This study further suggests the need for additional research to fully understand the reasons behind refusals and to identify other variables that may be associated with the decision-making process. The results will contribute to the formulation of public policies and, most importantly, provide data to improve professional practice.

CONCLUSION

Specific refusal to donate bones was associated with male sex and age group. The study reveals a decline in refusal rates after 2009, possibly due to changes in the Brazilian transplant system. Despite the overall reduction, the year 2005 presented the highest percentage of refusals.

The age groups of 41 to 59 years and 60 years or older show higher refusal rates, suggesting the need for targeted strategies for them.

Effective communication between health professionals and families is crucial to increasing acceptance of bone donation. Improving this interaction may significantly contribute to increasing the number of donations and, consequently, to the performance of more successful transplants.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantial scientific and intellectual contributions to the study: Santos MJ, Pimentel RRS; **Conception and design:** Silva ICN, Hidalgo BRG, Pimentel RRS; **Analysis and data interpretation:** Pires APO, Gonçalves Neto C, Vieira GS, Oliveira GP, Silva ICN, Marchezzane PO, Nunes SR, Pimentel RRS; **Article writing:** Pires APO, Gonçalves Neto C, Vieira GS, Oliveira GP, Silva ICN, Marchezzane PO, Nunes SR, Pimentel RRS. **Critical revision:** Hidalgo BRG, Pimentel RRS; **Final approval:** Hidalgo BRG, Pimentel RRS.

DATA AVAILABILITY STATEMENT

All dataset were generated or analyzed in the current study.

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Not applicable.

DECLARATION OF USE OF ARTIFICIAL INTELLIGENCE TOOLS

The authors declare that no artificial intelligence tools were used in the preparation, writing, data analysis, or review of this manuscript.

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