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ORIGINAL PAPER

General Overview of Causes for Non-Effectiveness and Family Non-Consent in Organ Donation in the State of Rio Grande do Sul

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ABSTRACT

Introduction: This ecological study analyzed the causes of failed organ donation and family refusal in the state of Rio Grande do Sul (RS) from 2017 to 2024. **Objectives:** Using data from state transplant centers, the study aimed to identify weaknesses in the transplant system and suggest improvements. **Methods:** Statistical analysis compared donation completion rates in per million population (pmp/year) and family refusal between RS, the state of Santa Catarina (SC), and Brazil. **Results:** RS had significantly lower donation completion rates (20.3 ± 4.8) than SC (42.3 ± 2.7), though rates were similar to the national average (17 ± 1.6). Family refusal was also higher in RS (27.9% ± 2.7%) than in SC (22% ± 3.3%) (p = 0.003). In RS, the leading cause of donation failure was family refusal (27.93% ± 2.53%), followed by medical contraindications (17.64% ± 5.92%). The total causes of non-completion increased until 2021 (75.6%) and decreased until 2024 (67%). The main reasons for family refusal included the deceased not being a registered donor and family opposition. **Conclusion:** The study concludes that family refusal is a major barrier to effective organ donation in RS. It recommends professional training in delivering bad news and adopting strategies from the Spanish model to improve donation rates and system effectiveness.

Descriptors: Organ Transplantation; Breaking Bad News; Family Refusal; Brain Death; Donation Rates.

Panorama Geral das Causas de Não Eficácia e Não Consentimento Familiar da Doação de Órgãos no Estado do Rio Grande do Sul

RESUMO

Introdução: Este estudo ecológico analisou as causas de falha na doação de órgãos e recusa familiar no estado do Rio Grande do Sul (RS) de 2017 a 2023. **Objetivo:** Utilizando dados das centrais de transplantes do estado, o estudo teve como objetivo identificar fragilidades no sistema de transplantes e sugerir melhorias. **Métodos:** A análise estatística comparou as taxas de conclusão de doação [em per million population (pmp)/ano] e de recusa familiar entre RS, Santa Catarina (SC) e Brasil. **Resultados:** RS teve taxas de conclusão de doação significativamente menores (20,3 ± 4,8) do que SC (42,3 ± 2,7), embora as taxas tenham sido semelhantes à média nacional (17 ± 1,6). A recusa familiar também foi maior no RS (27,9% ± 2,7%) do que em SC (22% ± 3,3%) (p = 0,003). No RS, a principal causa de insucesso da doação foi a recusa familiar (27,93% ± 2,53%), seguida de contraindicações médicas (17,64% ± 5,92%). O total de causas de não efetivação aumentou até 2021 (75%) e reduziu até 2024 (67%). Os principais motivos para a recusa familiar incluíram o fato de o falecido não ser um doador registrado e a oposição da família. **Conclusão:** O estudo conclui que a recusa familiar é uma barreira importante para a doação efetiva de órgãos no RS. Recomenda-se o treinamento de profissionais para dar más notícias e a adoção de estratégias do modelo espanhol para melhorar as taxas de doação e a eficácia do sistema.

Descritores: Transplante de Órgãos, Dar Más Notícias, Recusa Familiar, Morte Encefálica, Taxas de Doação.

INTRODUCTION

Family understanding of brain death plays a key role in organ donation decisions, with personal beliefs, distrust, and cultural factors contributing to refusals.[1] While global leaders like Spain achieve high donation rates (48.9 donors/million in 2023), Brazil lags with 19.9/million, and a 47% family refusal rate in 2022 – possibly impacted by the pandemic.[2-4]

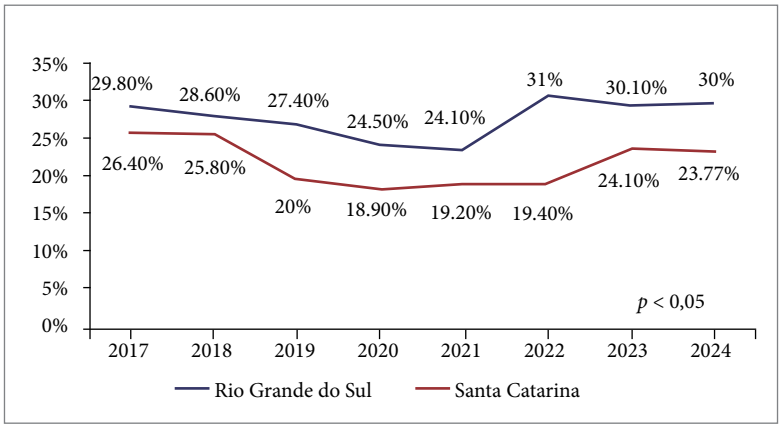
In 2023, only 29% of identified potential donors in Brazil became actual donors, revealing a significant loss throughout the organ donation process.[2] This study analyzes the high rates of family refusal and non-donation in the state of Rio Grande do Sul (RS), comparing them to national data and the state of Santa Catarina (SC), to identify possible barriers throughout the entire organ transplantation process

METHODS

This ecological study analyzed brain-dead potential donors reported in RS, SC, and Brazil using data from state health departments and ABTO. It examined transplant rates, family refusal rates, and refusal causes in RS. Statistical tests (Shapiro-Wilk, t-test, analysis of variance [ANOVA] with Tukey HSD) assessed differences, considering $p < 0.05$ significant. The data were public and anonymized, so no ethical approval was needed.

RESULTS

In the analysis of family refusal, the study showed a statistically significant difference when comparing the results from RS (28.19% ± 2.46%) with SC (22.20% ± 2.94%) ($p = 0.003$). For the sample, the total number of notifications of potential donors in RS (nrs = 4,696) and SC (nsc = 4,558) was considered. Fig. 1 shows the family refusal rate for potential organ donors for transplantation between RS and SC from 2017 to 2024. The statistical test is shown in Table 1.



Source: Elaborated by the authors.

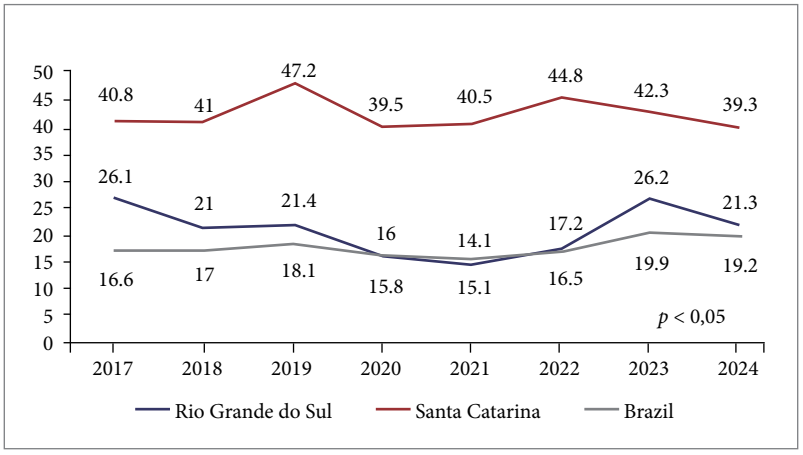
Figure 1. Comparative family refusal rate between states (nrs = 5,476, nsc = 5,311).

Table 1. Independent samples t-test for family refusal in RS and SC.

		Levene's test		t-Test for Equality of Means						
		Z	Sig	t	GL	Sig	Dif M	SE	95%CI of the difference	
									Inf	Sup
Family refusal	Equal variances assumed	1.5	0.2	-3.6	12	0.003	-5.95	1.62	-9	-2.41
	Equal variance not assumed			-3.6	11	0.003	-5.95	1.62	-9	-2.39

Source: Elaborated by the authors. The statistical test confirms that there is a statistically significant difference between the family refusal rates of the states. 95%CI = 95% confidence interval; Df = degrees of freedom; Dif M = mean difference; Inf = lower; SE = standard error; Sig = significance; Sup = upper; Z = Levene's test statistic value.

Fig. 2 presents a comparative analysis of organ transplant effectiveness in parts per million (pmp/year) between RS, SC, and Brazil from 2017 to 2023. After applying the post hoc test, significant differences were found between RS and SC ($p < 0.001$) and between SC and Brazil ($p < 0.001$). No significant difference was found between RS and Brazil ($p > 0.05$). The statistical tests are shown in Tables 2 and 3.



Source: Elaborated by the authors.

Figure 2. Effectiveness in parts pmp/year (RS x SC x Brazil).

Table 2. ANOVA test for comparison between Groups (RS, SC, and Brazil).

Dependent variable: effectiveness pmp/year					
	Sum of squares	**df**	**Mean square**	**Z**	**Sig.**
Between groups	2649.534	2	1324.767	121.01	0.000
Within groups	197.049	18	10.947		
Total	2846.583	20			

Source: Elaborated by the authors. The table shows that there is a significant difference between the studied groups (RS, SC, and Brazil).

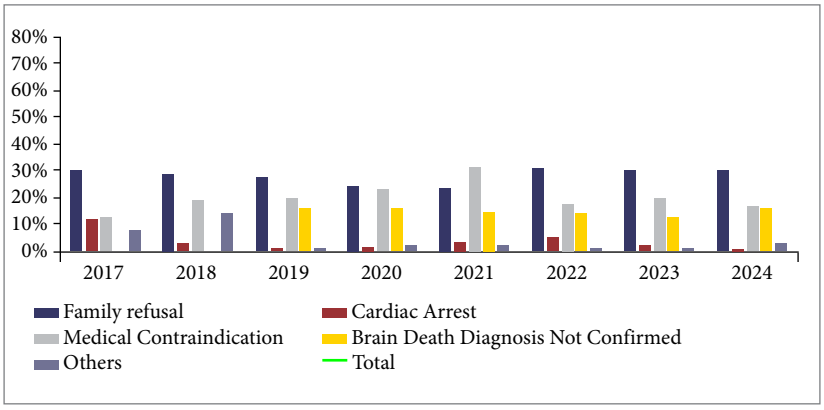
Table 3. Tukey HSD test for multiple comparisons of transplant effectiveness in RS, SC, and Brazil.

(I) State/Brazil	**(J) State/Brazil**	**Dif M (I-J)**	**Error**	**Sig.**	**95%CI**	
					Lower limit	**Upper limit**
RS	SC	-22.01	1.77	**0.00**	-26.53	-17.50
	Brazil	3.29	1.77	0.18	-1.23	7.80
SC	RS	22.01	1.77	0.00	17.50	26.53
	Brazil	25.30	1.77	**0.00**	20.79	29.81
Brazil	RS	-3.29	1.77	0.18	-7.80	1.23
	SC	-25.30	1.77	0.00	-29.81	-20.79

Source: Elaborated by the authors. I and J refer to the groups included in the comparison; the I-J column represents the difference between the mean of group I and that of group J. SC outperforms RS and Brazil in donation effectiveness. In RS, 67% of cases failed, mainly due to family refusal and medical issues. Peak failure occurred in 2021 (75.6%). Dependent variable: effectiveness pmp/year. Tukey HSD test.

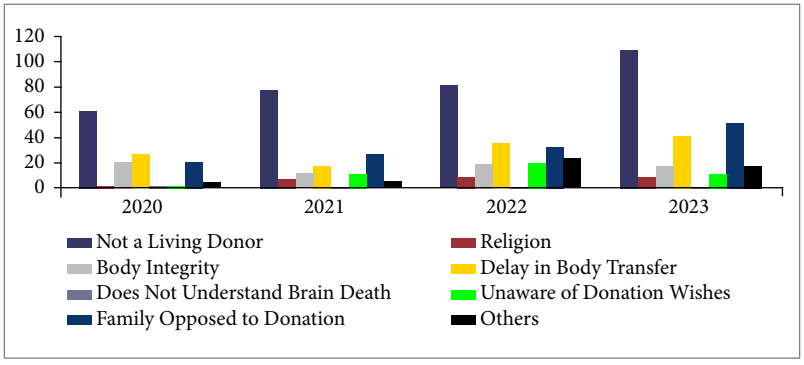
Fig. 3 shows the non-effective rates in RS. The total notifications from 2017 to 2024 constitute the sample (n = 5,749). It demonstrates that family refusal has higher rates than other causes, ranging from 28.19% ± 2.46%, while medical contraindication ranged from (20.08% ± 4.94%). The total non-effectiveness rate is 67% ± 3.66%, with a peak in 2021 at 75.6%, and decreased until 2024 (67%).

Fig. 4 illustrates the main reasons for family refusal in organ donation in RS. The most common reason is the individual not having expressed a wish to be an organ donor during their lifetime (mean 82.5 cases/year), followed by family opposition (mean 33 cases/year).



Source: Elaborated by the authors.

Figure 3. Non-effectiveness rate in organ donation in RS (n = 5,749).



Source: Elaborated by the authors.

Figure 4. Reasons for family refusal in organ donation (2020-2023) (n = 781).

Other relevant factors include delay in body transfer (30.25 cases/year), lack of knowledge regarding the donor's wishes (11.25 cases/year), and concerns about body integrity (17.25 cases/year). Reasons such as religion and misunderstanding of brain death are less frequent (fewer than six cases/year). The total annual family refusal rate was 195.25 cases.

DISCUSSION

The Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos para Transplante (CIHDOTT) organizes the protocol for brain death diagnosis and provides support to donor families. It operates from the identification of the potential donor through the delivery of the body to the family, coordinating with medical teams, verifying, and reporting brain death according to established guidelines.[4,5] It also trains professionals, updates records, collaborates with transplant teams, performs examinations, organizes the internal logistics of organ retrieval, supervises the process, and evaluates indicators.[5,6]

The better family refusal rates in SC (22.20% ± 2.94%) compared to RS (28.19% ± 2.46%) (p = 0.003) are related to the implementation, in SC, of the Spanish model of assistance in delivering bad news in critical situations, adapted in partnership with the Spanish Organización Nacional de Trasplantes (ONT). Results from this SC model showed that referrals for organ donation increased from 35.1 per million population (pmp) in 2007 to 74.0 pmp in 2017. Simultaneously, family refusal decreased from 39.8% to 27.8%. These data highlight a positive relationship between well-structured educational initiatives, especially intensive training in delivering bad news to families, and improvement in the identification of potential donors.[6,7]

The success of the Spanish transplantation model is based on strong and continuous governmental support, sustained by presumed consent legislation that increases organ availability. This model is reinforced by public trust, cultivated through transparency and effective communication. The system relies on trained professionals, particularly transplant coordinators, who receive ongoing education and training to manage the donation process. Additionally, it employs a comprehensive strategy that includes disease prevention and expanding the donor pool through the acceptance of extended criteria. The system's infrastructure is supported by a reimbursement mechanism that incentivizes hospital participation, as well as a centralized technology platform

that ensures efficient organ allocation. A culture of quality — maintained through audits, continuous improvement programs, and research supported by scientific societies — ensures safety, efficacy, and innovation within the system.[3,5,7-10]

In SC, strategies based on the Spanish model have improved the organ donation system. Professionals receive continuous education, brain death diagnoses undergo audits, and hospitals receive reimbursement. Effective communication and specialized training increase public acceptance and program success. The state adapted intensive care unit (ICU) beds, created quality programs, introduced intensivists and coordination teams in all hospitals, as well as programs for family interviews and donor identification. Coordinator remuneration incentivizes their work.[6] Teams ensure that communication about suspected death is conducted by the ICU medical staff. After confirmation, the physician informs the family, supported by others. Donation is not discussed during death confirmation; the interview is conducted by trained coordinators or, if unavailable, by specialized nurses.[5,8] These actions explain SC's better indices compared to RS, with donation effectiveness rates of 42.3 ± 2.7 pmp in SC and 20.3 ± 4.8 pmp in RS.

The main cause of non-effectiveness in transplantation in RS is the lack of family consent (28.19% ± 2.46%), possibly related to communication barriers in delivering bad news or insufficient professional training. Studies in Spain show that interview success depends on the interviewer's training and empathy. Focusing on family communication and a positive attitude reduces refusals, creating an environment that facilitates decision-making in critical moments.[10-12]

Receiving the news of a loved one's brain death and the invitation for donation significantly impacts family dynamics. Surrounded by the shock of the diagnosis, families face intense emotions such as denial. For many, accepting brain death is difficult, especially due to the external appearance of the patient, with a heartbeat and breathing.[13-15] Communication about death is delicate and performed by physicians in the presence of transplant coordination professionals. In one municipality in SC, this conversation is conducted by two physicians, resulting in high acceptance. Upon receiving a clear explanation about the diagnosis, some families reconsider their decisions and may view donation as an altruistic act.[6,16]

The absence of prior consent is an obstacle to organ donation, especially when the patient did not express their wish to donate before brain death, causing uncertainty in family authorization.[17] This results in family refusal, whose main cause in RS is the absence of prior consent for donation (82.5 ± 17.6 per year). In this context, the media must recognize its role and social responsibility regarding donation, promoting public awareness and dialogue among families. It is essential to provide complete information, emphasizing donor preservation and reducing barriers caused by a lack of knowledge.[18]

Maintaining organ viability is challenging, as few teams ensure deceased donor stability. Hemodynamic instability, with prolonged hypoperfusion, is a critical challenge, and ensuring hemodynamic stability is essential for organ viability. The rate of medical contraindications between 2017 and 2023 in RS was 19.8% ± 5.62%, compared to 16.6% ± 4.40% in SC,[19] both below the target of less than 26% set by the Quality Control Program of the ONT.[21] In a study conducted in SC, the adapted "VIP" approach, which includes ventilation, infusion, and evaluation of cardiac pump efficacy, is complemented by pharmacological interventions and specific considerations for shock management. Standardizing and simplifying care protocols can not only increase organ donation rates but also enhance the quality of care for neurological patients in ICU.[21]

CONCLUSION

Low donation rates in RS, driven by family refusal, highlight the need for better communication, professional training, and protocol standardization. Furthermore, adopting the Spanish model can improve outcomes. ICU standardization and public awareness are key to advancing donor management in the state.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Savaris DF, Lara DM, Arend RB, Valério NR, Kauer VLF; **Conception and design:** Arend RB, Valério NR, Kauer VLF; **Data analysis and interpretation:** Savaris DF, Lara DM, Arend RD; **Article writing:** Savaris DF, Lara DM, Arend RB, Valério NR; **Final approval:** Savaris DF.

DATA AVAILABILITY STATEMENT

Data will be provided upon request.

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