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Family Justifications for Not Authorizing Organ Donation: Documentary Study

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ABSTRACT

Objectives: To understand the reasons given by family members for not authorizing the donation of organs and tissues. **Methods:** This is a documentary study. The records of interviews with the families of potential donors, conducted in 2022 by the Organ and Tissue Procurement Organization in the state of Rio Grande do Sul, were analyzed. The study included records related to refusals for donation. Incomplete records or those lacking the family's justification were excluded. Data were collected in March and April 2024 and analyzed using simple descriptive statistics. The research project was approved by the Research Ethics Committee. **Results:** During 2022, the OPO conducted 121 interviews with family members of potential organ donors; of this total, there were 33 authorizations, 65 refusals, and 23 cases of medical contraindications for donation. Regarding family refusals, of the 65 records analyzed, 39 were excluded due to incomplete information or because they did not contain the justification for refusal. The final sample consisted of 26 interview records. The most common arguments for refusing donation were the patient was not a donor in life, the family was unaware of the deceased's wishes regarding donation, and the family expressed opposition to donation. **Conclusion:** The observed justifications included the deceased having declared themselves not to be a donor in life, lack of family consensus on donation, the family's desire to preserve the integrity of the body, the wait time for the return of the body, religious reasons, unawareness of the deceased's wishes regarding donation, and family opposition to donation. The results may be used by professionals in various healthcare services to develop strategies to mitigate family refusals.

Descriptors: Tissue and Organ Procurement; Tissue Donors; Transplantation; Family; Nursing.

Justificativas de Familiares para a Não Autorização de Doação de Órgãos: Estudo Documental

RESUMO

Objetivos: Conhecer as justificativas de familiares para a não autorização da doação de órgãos e tecidos. **Métodos:** Trata-se de um estudo documental. Analisaram-se os registros de entrevistas familiares de potenciais doadores, realizadas em 2022 por uma Organização de Procura de Órgãos e Tecidos (OPO) do estado do Rio Grande do Sul. Foram incluídos no estudo os registros referentes às negativas para a doação. Registros incompletos ou que careciam da justificativa dos familiares foram excluídos. Os dados foram coletados em março e abril de 2024 e analisados por meio de estatística descritiva simples. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa. **Resultados:** Durante 2022, a OPO pesquisada realizou

121 entrevistas com familiares de potenciais doadores de órgãos; desse total, houve 33 autorizações, 65 negativas e 23 casos de contraindicação médica para a doação. Quanto às negativas dos familiares, dos 65 registros analisados, 39 foram excluídos, pois estavam com informações incompletas ou não continham a justificativa para a não doação. A amostra final foi constituída por 26 registros de entrevistas. Os argumentos mais comuns para a negativa à doação foram paciente não era doador em vida, desconhecimento da família sobre o desejo do falecido quanto à doação e manifestação contrária da família. **Conclusão:** Entre as justificativas observadas estão a pessoa falecida ter se declarado não doadora em vida, a falta de consenso familiar acerca da doação, o desejo da família em preservar a integridade do corpo, o tempo de espera para a devolução do corpo, aspectos religiosos, o desconhecimento quanto ao desejo do falecido acerca da doação e a família ser contrária à doação. Os resultados poderão ser utilizados por profissionais em diferentes serviços de saúde para a criação de estratégias de mitigação das negativas dos familiares.

Descritores: Obtenção de Tecidos e Órgãos; Doadores de Tecidos; Transplante; Família; Enfermagem.

INTRODUCTION

Organ donation for transplantation is considered a charitable act in the moral and spiritual sphere. The process allows the removal of organs to reestablish hemodynamics and improve the recipient's quality of life. The implantation of the donated organ or tissue into the recipient is performed through a surgical procedure called transplantation. Transplantation, therefore, depends on donation, which only occurs with the express authorization of the family[1].

Transplantation is an effective treatment for people with organ failure and pathologies that affect tissues such as the cornea or skin, such as in individuals with extensive burns. Therefore, it can be said that transplantation enables survival and contributes to improving quality of life. However, the number of available donors is still insufficient compared to the number of people waiting for a transplant[2,3].

In 2023, there were 14,073 potential donors in Brazil, 838 of whom were located in Rio Grande do Sul (RS) state. These figures are below expectations, given that in December 2023, there were 59,958 active people on the waiting list throughout the country, while in RS, in the same period, there were 2,609 active patients on the waiting list to undergo the procedure[2,4].

In addition, in 2023, 8,063 interviews were conducted with family members in the national territory, 559 of which were carried out in RS. In the country, 3,425 interviews resulted in negative responses, while 252 families from Rio Grande do Sul refused authorization to extract the deceased's organs and/or tissues[2].

Several factors lead to organ donation not being successful, such as the cause that led to the diagnosis of brain death, hemodynamic instability, and clinical contraindications, among others. Family members' refusal results from multifactorial complex issues and may involve spiritual, economic, sociocultural, educational and/or political aspects[5,6].

Law No. 9,434/1997, the Transplant Law, regulates organ and tissue donation and transplantation. In Brazil, the National Transplant System (Sistema Nacional de Transplantes - SNT), linked to the Ministry of Health and connected to the State Health Departments, coordinates the donation and transplantation of organs and tissues in the country[1,7-9].

The SNT is responsible for creating standards and regulating actions related to organ donation and transplantation and controlling these activities. To this end, the system authorizes the action of the State Transplant Center (Central Estadual de Transplantes - CET), which manages, organizes and regulates the donation and transplant process in states and municipalities. Linked to the CET and operating both regionally and locally are the Organ and Tissue Procurement Organizations (OPO) and the Intra-Hospital Commissions for Organ and Tissue Donation for Transplants (Comissões Intra-Hospitalares de Doação de Órgãos e Tecidos para Transplantes - CIHDOTT)[7,10].

According to Ordinance No. 2,600/2009, OPOs are created by the CETs of each state, and their primary function is to organize the search for organ donation and transplantation in hospitals in their region, following geographic and population criteria. CIHDOTTs are committees in public, private and philanthropic hospitals and focus on establishing the organ donation care protocol in the institution, facilitating the diagnosis of brain death, conducting interviews with family members and supporting the family throughout the process, among other activities. This committee is mandatory in hospitals that fit one of the following profiles: CIHDOTT I, a hospital with up to 200 deaths per year and that has beds for ventilatory assistance, as well as intensive care, internal medicine and pediatric health professionals on its clinical staff; CIHDOTT II, a health institution with less than 1,000 deaths per year and that is a reference for trauma, neurology and/or neurosurgery, or a non-oncological health establishment with 200 to 1,000 deaths per year; and CIHDOTT III, a health institution with more than 1,000 deaths per year or that has at least one organ transplant program[10].

The donation process begins with the identification of the potential donor, continues with the completion of the brain death protocol and the interview with the family members, and culminates with the transplant when the family consents to the donation, which a living or deceased donor can perform. Living donations are made between individuals related to the fourth degree and their spouse; the donor must be of legal age and legally capable. Intervivos donation is also possible between unrelated individuals but with judicial authorization[1,7].

In the case of a deceased donor, whether due to brain or circulatory death, donation can only occur with the authorization of a family member. Only first—and second-degree relatives, such as parents, children, adult siblings, and spouses, can authorize donation. Only after the death diagnosis has been confirmed and the family is aware of this outcome can an interview with the family members of a potential donor be conducted.[1,11-14].

It is important to note that a healthcare professional trained for the role must interview family members. This process is complex since, upon the death of a loved one, the professional approaches the family members about the possibility of donating organs and tissues for transplant purposes. In addition, it is necessary to consider the fact that the family goes through different stages of mourning; therefore, it is up to the interviewer to identify what stage the family member is in and understand the particular needs of this individual, using active listening to facilitate the execution of the interview, given that this is a crucial moment for accepting the donation.[13,15-17].

Given this context, it is urgent to understand the reasons for not donating. Therefore, the following research question was raised: What are the reasons given by family members for refusing authorization for organ and tissue donation?

The objective of this study was to identify the reasons family members give for not authorizing organ and tissue donation based on records of interviews with potential donors' family members conducted by an OPO in the state of Rio Grande do Sul (RS).

METHODS

The present is a documentary study with a quantitative approach, carried out based on records of interviews with family members of potential donors conducted in 2022 by an OPO in RS. The period was chosen intentionally, as it was the first year after the coronavirus disease 2019 (COVID-19) pandemic when the number of donations increased again in the country. It is worth noting that the registration instrument used by the OPO where the study was conducted contains fields for the interviewer to fill in to collect information such as the potential donor's medical history, cause of death and the justification given by family members for not authorizing organ donation. Data collection was carried out in March and April 2024 by the principal researcher. For this, an instrument developed by two researchers of this study was used, with questions related to the age of the potential donor, the cause of death, the justification for not donating, the degree of kinship of the family member who participated in the interview, the age of the family member and the gender of the family member.

Documents referring to records of interviews in which family members refused to donate organs and tissues were considered inclusion criteria for the study. Incomplete records or those that lacked justification for not donating were excluded.

To facilitate the organization and analysis of the data, the documents that were part of the study were identified with the letter R for registration, followed by a number: R1, R2, R3, and so on. The data were analyzed using simple descriptive statistics.

The study was guided by Resolutions No. 466/2012 and 510/2016 of the National Health Council (*Conselho Nacional de Saúde - CNS*), as well as by the General Law on the Protection of Personal Data (Law No. 13,709/2018)[18-20]. The Universidade do Vale do Rio dos Sinos Research Ethics Committee approved the research project under CAAE nº 76019723.7.00005344. For the study design, the consolidated criteria for reporting qualitative research were followed through the Consolidated Criteria for Reporting Qualitative Research (COREQ)[21] checklist.

RESULTS

In 2022, the OPO survey conducted 121 interviews with family members of potential organ donors; there were 33 authorizations, 65 denials, and 23 cases of medical contraindication for donation. Regarding family members' denials, of the 65 records analyzed, 39 were excluded because they contained incomplete information or did not contain a justification for not donating. Therefore, the final sample consisted of 26 interview records.

Regarding the profile of potential donors, their ages ranged from 14 to 80 years, and 65% were between 40 and 69 years old. The most common cause of death was hemorrhagic cerebrovascular accident (HCVA). The details of this information are presented in Table 1.

In three situations (R2, R5, and R17), there was more than one justification for the family members' refusal. Therefore, the frequency indicates more than 26 responses, as shown in Table 2.

Table 1. Sample characterization.

Document Code	Age of potential donor (years)	Cause of death	Justifications for not donating
R1	80	TBI	Excessive waiting time for the return of the body
R2	30	Anoxic encephalopathy	Lack of knowledge of the deceased's wishes regarding donation. The family is against the donation.
R3	39	Brain tumor	Religious reasons
R4	43	HCVA	Lack of consensus among family members
R5	49	HCVA	Non-donor while alive. Lack of consensus among family members
R6	76	HCVA	Non-donor while alive
R7	45	HCVA	Non-donor while alive
R8	51	HCVA	Religious reasons
R9	63	HCVA	Non-donor while alive
R10	51	Anoxic encephalopathy	Non-donor while alive
R11	14	HCVA	Non-donor while alive
R12	64	HCVA	Excessive waiting time for the return of the body
R13	54	SAH	Lack of consensus among family members
R14	57	HCVA	Lack of consensus among family members
R15	60	HCVA	Non-donor while alive
R16	60	HCVA	Preference for keeping the deceased's body intact
R17	72	HCVA	Preference for keeping the deceased's body intact. Non-donor while alive.
R18	48	HCVA	Non-donor while alive
R19	86	CVA	Non-donor while alive
R20	55	CVA	Non-donor while alive
R21	73	SAH	Non-donor while alive
R22	66	HCVA	Preference for keeping the deceased's body intact
R23	40	Intracerebral hemorrhage	Lack of knowledge of the deceased's wishes regarding donation
R24	56	CVA	Non-donor while alive
R25	58	SAH	Excessive waiting time for the return of the body
R26	72	CVA	Non-donor while alive

Source: Elaborated by the authors. CVA = cerebrovascular accident; SAH = subarachnoid hemorrhage; TBI = traumatic brain injury.

Table 2. Justifications for family members' refusal to donate organs and tissues (n = 26).

Justifications for not donating*	Frequency (n)	Percentage (%)
Non-donor while alive	13	50.0
Lack of consensus among family members	4	15.4
Preservation of the integrity of the body	3	11.5
Waiting time for body return	3	11.5
Religion	2	7.7
Unexpressed desire	2	7.7
Family being against the donation	1	3.8
Total	28	107.6

Source: Elabotared by the authors. *The sum of the percentages exceeds 100% due to multiple responses.

DISCUSSION

The family often sees that the time required to release the body is prolonged. It is indicated in the literature as one of the reasons for refusing to accept the donation of the deceased's organs. It should be taken into account that when a loved one dies, the family wishes to continue with the farewell procedures and, in general, feels urgently needed. The literature also indicates that the following reasons for not donating include the desire not to violate the integrity of the body of the deceased family member, lack of knowledge or doubts about the diagnosis of brain death, lack of consensus among the family regarding donation and negative experiences with health services, which corroborates the results found in this study[14,22-24].

Regarding bodily integrity, Brazilian law states that the body must be reconstructed dignifiedly to recover its previous appearance as much as possible. For the family, the removal of organs from the deceased can be considered a form of mutilation of the body of their loved one since it interferes with its integrity. However, when donation occurs, techniques are performed for body reconstruction. For example, in bone donation, replacement prostheses are used in the donated areas to reconstruct the bone structure; in cornea donation, the eye socket is reconstructed with cotton or gauze, and the eyelids are glued or sutured, to preserve and maintain the appearance as similar as possible to what it was before the donation. Finally, in the donation of thoracic and abdominal organs, the tissues are sutured, and an occlusive dressing is applied to the incisions. These precautions are taken to comply with the law, mainly out of respect for the donor and their family[13,22,25].

Another factor that led to the negative results observed in this study and that corroborates the findings described in the literature is the time required between donation, extraction of organs and tissues and return of the body to the family[23]. In the region where the study was conducted, the estimated time for this process is usually 11 hours, with 4 hours for processing the serology after the interview with the family members, 6 hours for the surgery to remove the organs and tissues, and 1 hour for the reconstruction and return of the body to the family.

This complex procedure requires time for each step to be carried out with quality and safety. It is up to the health professionals involved in the donation process to recognize the urgency of the family in mourning the body of their deceased loved one and to inform the people involved about the steps, the necessary care, and the greatness of the act of donation[26].

One of the reasons cited in the literature to justify denying the donation process is the family's perception of the care, which is often considered unwelcoming and of low quality. It is worth highlighting the need for humanized, safe, quality care. Fortunately, institutions and health professionals have increasingly sought to improve the experience of patients and their companions in health care[14,23,27].

The lack of knowledge of family members regarding the diagnosis of brain death and the verification that the body of the deceased family member remains connected to equipment, which allows the heartbeat, respiratory movements and body warmth to be maintained, can generate confusion and make it difficult to understand the situation[14,28]. In this context, the team that will interview the family members must be ready to clarify doubts about the donation process and its legal procedures, as well as any other questions related to the stages of the donation and transplant process, aiming to contribute to increasing the likelihood of the family authorizing the donation.

As for religious issues, it is worth noting that no religion is against donation, as this is a selfless act in favor of life. However, this topic requires further study since it is one of the justifications mentioned by family members for not donating[9,29].

In addition to understanding the reasons for the family members' refusals, the factors that contributed to the donation being made were outlined, such as, for example, the preparation of the professionals who work in the donation and transplant process, especially those who work in the family approach, who need to have the profile to deal with difficult situations and know communication techniques to convey bad news and conduct the interview with the family members[17,28].

The professional must be sensitive enough to understand the family's needs, clarify doubts, and allow enough time for the family to discuss the decision harmoniously. In addition, the professional must be able to assist family members in conflict situations, highlighting the importance and greatness of the act of donating, making the benefits of donation clear to those on the waiting list for a transplant, and reminding them that, even in such a difficult situation, the family can give new meaning to death through donation. However, it is worth noting that the health professional must respect the decision made by the family, whatever it may be[14,28,30,31].

Another strategy that can contribute to organ donation is encouraging dialogue on the subject in society. This study showed that some refusals occurred because the family was unaware of their loved one's opinion on donation and, when in doubt, chose not to donate. This topic must be addressed in schools, universities, churches and families. Knowing the family member's opinion can facilitate decision-making in favor of donation[26,30].

Furthermore, it is suggested that positive campaigns and reports on the importance of donation and the positive impact of transplantation be increased for people who have this treatment as the only option to continue living or to have a better quality of life[23,26].

The initial project included collecting data on family members who participated in the interviews, but the records analyzed did not contain information on these family members. Therefore, such information was not included in this study. The absence of such data characterizes a gap in the records analyzed. It highlights the need for studies exploring the profile of family members who participate in organ and tissue donation interviews. In this context, it was observed that the records regarding the family member's justification for refusing the donation were brief, with few details and information, which can be understood as a limitation of the study. However, the results are relevant and can be used to list improvement strategies, such as qualifying the reception of families and encouraging, in health institutions, academia and the community, the discussion about the process of organ and tissue donation for transplantation.

CONCLUSÃO

The reasons given by family members for not authorizing organ and tissue donation for transplantation are multifactorial and may involve sociocultural, spiritual, and emotional issues, among others. The reasons found in this study include the individual declaring themself not a donor while alive, the lack of family consensus regarding donation, the family's desire to preserve the integrity of the body, the excessive waiting time for the body to be returned, religious issues, lack of knowledge of the deceased's wishes regarding donation, and the family being against donation.

Although this study did not find negative experiences experienced by family members during care in the health network or even a lack of knowledge about the donation and transplantation process, these are factors indicated in the literature as decisive for family members' refusal.

In this sense, several strategies can be used to increase organ and tissue donation and, thus, contribute to mitigating the suffering of those on the waiting list. Strategies include conducting educational activities in schools, universities, community centers and religious institutions, running campaigns and disseminating positive news about donation and transplantation.

In the social sphere, there is an urgent need to inform the population through educational campaigns to increase organ donations and combat misinformation. Furthermore, it is essential to encourage people to declare themselves as donors while they are still alive, which can help the family decide about donation.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Batista MEP, Treviso P, Telles CFS, Pierotto AAS, Barilli SLS, Rocha KR; **Conception and design:** Batista MEP, Treviso P; **Data analysis and interpretation:** Batista MEP, Treviso P, Telles CFS, Pierotto AAS, Barilli SLS, Rocha KR; **Article writing:** Batista MEP, Treviso P, Telles CFS, Peradotto BC; **Critical revision:** Batista MEP, Treviso P, Telles CFS, Pierotto AAS, Barilli SLS, Rocha KR, Rosa RR, Peradotto BC; **Final approval:** Batista MEP, Treviso P, Telles CFS, Pierotto AAS, Barilli SLS, Rocha KR, Rosa RR, Peradotto BC.

DATA AVAILABILITY STATEMENT

All datasets were generated or analyzed in the current study.

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