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FAMILY REFUSAL FOR ORGAN DONATION FROM A BIOETHICAL PERSPECTIVE: INTEGRATIVE REVIEW

*Negativa familiar para doação de órgãos sob a perspectiva da bioética: revisão integrativa**Negativa familiar para la donación de órganos desde la perspectiva bioética: revisión integrativa***Josenilton Matos Dias¹****Milene Dias Ferreira Magri²** **Cremilson de Paula Silva³** **Glilciane Morceli⁴** **Larissa Sales Martins Baquião⁵** **Marcela Souza Nóbrega⁶** 

RESUMO

Objetivo: analisar as evidências científicas acerca de questões bioéticas envolvidas na negativa familiar para doação de órgãos. **Método:** revisão integrativa realizada em março de 2024, utilizando os bancos BIREME, LILACS, PubMed/Medline e SciELO, com descritores do DeCS e MeSH. **Resultados:** foram selecionados 13 estudos que abordaram as razões éticas, morais e culturais associadas à recusa familiar. Os principais fatores identificados foram: desconhecimento da vontade do doador, influências religiosas, ausência de preparo da equipe de saúde e dilemas éticos e morais quanto ao processo de doação. **Conclusão:** a análise bioética da negativa familiar evidencia a complexidade da decisão e reforça a necessidade de considerar valores individuais e coletivos na prática clínica e na formulação de políticas públicas.

DESCRITORES: Doação de órgãos e tecidos; Bioética; Família.

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ABSTRACT

Objective: to analyze scientific evidence on bioethical issues involved in family refusal for organ donation. **Method:** integrative review conducted in March 2024 using BIREME, LILACS, PubMed/Medline, and SciELO databases, with descriptors from DeCS and MeSH. **Results:** thirteen studies addressing ethical, moral, and cultural reasons behind family refusal were selected. The main factors identified included: lack of knowledge about the potential donor's wishes, religious influences, unprepared healthcare teams, and ethical-moral concerns related to the donation process. **Conclusion:** the bioethical analysis of family refusal highlights the complexity of the decision and reinforces the need to consider individual and collective values in clinical practice and public health policymaking.

DESCRIPTORS: Organ and tissue donation; Bioethics; Family.

RESUMEN

Objetivo: analizar la evidencia científica sobre cuestiones bioéticas involucradas en la negativa familiar a la donación de órganos. **Método:** revisión integradora realizada en marzo de 2024, utilizando las bases de datos BIREME, LILACS, PubMed/Medline y SciELO, con descriptores del DeCS y MeSH. **Resultados:** se seleccionaron trece estudios que abordaron razones éticas, morales y culturales detrás de la negativa familiar. Los principales factores identificados fueron: desconocimiento de la voluntad del posible donante, influencias religiosas, falta de preparación del equipo de salud y preocupaciones éticas y morales sobre el proceso de donación. **Conclusión:** el análisis bioético de la negativa familiar evidencia la complejidad de la decisión y refuerza la necesidad de considerar los valores individuales y colectivos en la práctica clínica y en las políticas públicas de salud.

DESCRIPTORES: Donación de órganos y tejidos; Bioética; Familia.

INTRODUCTION

Organ and tissue donation is an act that involves the voluntary transfer of healthy organs from a donor, either living or after death, to a recipient in need of a transplant. This practice is often the last therapeutic alternative for patients with serious, acute or chronic illnesses, as well as for those with terminal insufficiencies of essential organs, who have no other treatment options available. Donation can improve the quality of life of recipients, as well as potentially reversing clinical conditions.¹

Organ and tissue donation can be carried out after confirmation of brain death or cardiorespiratory arrest.² Brain death is characterized by the complete and irreversible cessation of all brain functions, diagnosed in Brazil by means of two clinical examinations and a complementary examination carried out by different doctors, with a time interval that varies according to the patient's age.^{2,3} In brain death, organ and tissue donation is possible.³ Death due to cardiorespiratory arrest occurs due to the interruption of blood flow and oxygen to the brain and other organs.⁴ In Brazil, donation from patients in circulatory death is restricted to the following tissues: corneas, sclera, bone, tendon, osteochondral, skin and cardiovascular.⁵

Brazil is internationally recognized for its excellence in transplants and has the largest public system in the world.¹

Around 88% of the procedures carried out in the country are subsidized by the Unified Health System (SUS), making it the second largest country in terms of transplants, behind only the United States of America (USA).¹ Patients receive complete assistance free of charge, from preparatory exams to post-transplant follow-up and necessary medication.¹ Despite the increase in adherence to donation in recent years, the waiting list is still significant, resulting in more patients waiting for organs than available donors.⁶

Furthermore, several additional factors influence the performance of transplants in Brazil, including low donor notification rates, medical contraindications, family refusal, lack of prior consent from living donors, delays in diagnosing brain death, religious and cultural influences, and lack of information about organ donation.^{7,8}

In the Brazilian context, organ removal can only be carried out with family consent. Therefore, even if an individual has expressed their desire to be a donor during their lifetime, the donation depends on their family's authorization. In this sense, if the family does not grant permission for the donation, the organs will not be harvested, resulting in the loss of the opportunity to carry out transplants that could benefit patients on waiting lists, giving them life or improving their quality of life.¹

Family refusal to donate organs and tissues represents a complex challenge that affects the practice of transplantation.⁹

Reasons such as ignorance of the donor's wishes, disagreement between family members, religious issues and doubts about the integrity of the body all contribute to this refusal.⁹ The complexity of this scenario is not just limited to technical-scientific knowledge, but also includes subjective aspects, interpersonal relationships and ethical and bioethical considerations.^{9,10}

Ethical-conceptual aspects related to organ transplants are subject to controversy and influenced by different factors, such as individual opinions, religious, geographical, socio-cultural, economic and technical issues.¹⁰ In this context, both ethics and bioethics play fundamental roles in understanding the complexities involved in organ transplants.

Bioethics aims to protect human integrity and well-being, highlighting the importance of the intrinsic dignity of all human beings. In the Brazilian context, this area is based on principlist theory, encompassing the principles of autonomy, beneficence, non-maleficence and justice.¹¹ These principles guide decisions related to human behavior and underpin discussions about organ donation.

Given this context, it is important to understand and address the underlying reasons for family refusal in order to raise awareness about donation and improve communication and care practices. Health professionals play a vital role in this process, offering education, emotional support and guidance to families, contributing to the acceptance of organ and tissue donation, and consequently to an increase in transplant rates and the saving of lives. Thus, the aim of this study is to analyze the scientific literature on the bioethical issues involved in family refusal to donate organs.

METHOD

This is an integrative review (IR), which uses a methodological design that promotes the implementation of Evidence-Based Practices (EBP), guiding the work of health professionals.¹² This method comprises a comprehensive and careful analysis of scientific research, fostering in-depth discussions about the methods and results of previous studies. It also provides reflections that stimulate the construction of new studies. With this approach, it is possible to gain an

in-depth understanding of a specific phenomenon, based on previous research, with the aim of improving clinical practice and advancing the application of EBS.¹²

The construction of this study followed six stages: identification of the topic and research hypothesis; search for primary data in the scientific literature; determination of the information to be collected and categorization of the selected studies; evaluation of the studies included in the review; analysis of the results; and presentation of the review.¹²

Data was collected in March 2024, using the following sources of information: Latin American and Caribbean Center on Health Sciences Information (BIREME), Latin American and Caribbean Literature on Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (PubMed/Medline) and Brazil Scientific Electronic Library Online (SciELO), all linked to the Virtual Health Library (VHL). In addition, studies which were not found directly by the search strategy, but which were referenced in the selected articles and met the inclusion criteria, were also considered in this review.

The acronym PICO was used to formulate the research question: P (Problem/Population): Families of potential organ donors; I (Intervention): Analysis of the bioethical issues and influences involved in the family decision; C (Comparison): Families who accept versus families who refuse organ donation; O (Outcome): Understanding the ethical and cultural barriers that influence the decision and their implications for the availability of organs for transplantation. Thus, the guiding question is: What are the bioethical and cultural issues that influence the family decision to refuse organ donation, and how do these barriers impact on the availability of organs for transplantation?

The electronic search strategy was developed using the Health Sciences Descriptors (DeCS) and the terms available in the Medical Subject Headings (MeSH), namely: Transplantation; Organ Transplantation; Tissue Transplantation; Tissue Donors; Bioethics; Professional-Family Relations; Family; Caregivers and Family Relations.

These terms were crossed using the Boolean operators AND and OR, as follows:

DESCRIPTORS	CROSSING
<p>Transplante (Transplantation) (Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) (Transplantation OR Organ Transplantation OR Tissue Transplantation OR Tissue Donors)</p> <p>Família (Family) (Relações Profissional-Família OR Família OR Cuidadores OR Relações Familiares) (Professional-Family Relations OR Family OR Caregivers OR Family Relations)</p> <p>Bioética (Bioética) (Bioethics)</p>	<p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND Relações Profissional-Família</p> <p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND Família</p> <p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND Cuidadores</p> <p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND Relações Familiares</p> <p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND Bioética</p> <p>*(Transplante OR Transplante de órgãos OR Transplante de Tecidos OR Doadores de Tecidos) AND (Relações Profissional-Família OR Família OR Cuidadores OR Relações Familiares) AND (Bioética)</p>

Source: Authors (2024).

The inclusion criteria were: peer-reviewed journal articles published in the last decade (2014 to 2024), in any language, using quantitative, qualitative or mixed-methods research methodology and, in terms of target audience, studies involving health professionals and/or family members. Exclusion criteria: literature reviews, letters to the editor, theses and dissertations and duplicate or complementary studies.

To detect duplicate studies, the Rayyan QCRI® application was used to extract duplicate research and select the remaining studies by reading them in full, selecting the articles that answered the study question. It should be noted that the study selection process was carried out blindly by two independent researchers. All the articles selected underwent a joint evaluation by the researchers to ensure the consistency of the results.

An instrument was developed to extract the following information from the articles included in the IR: (1) study site,

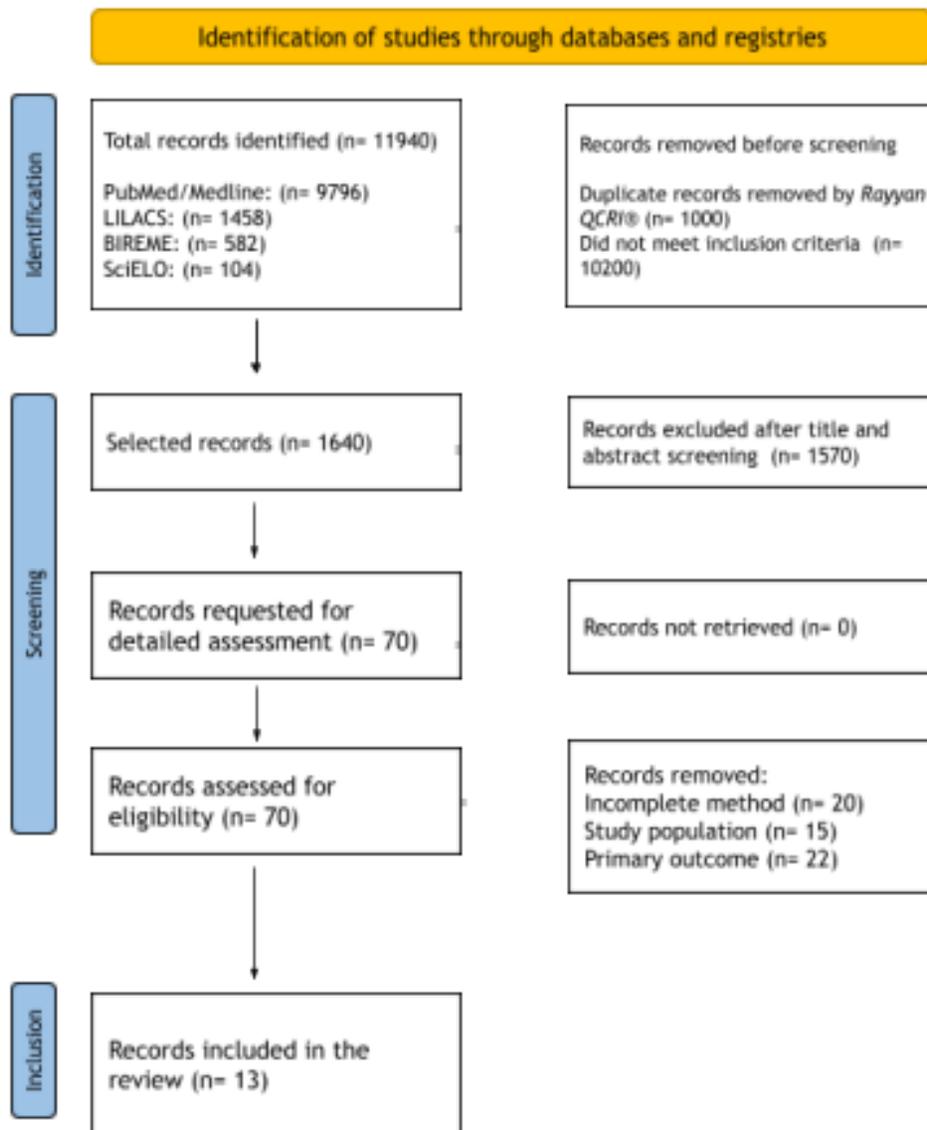
(2) year of publication, (3) study design, (4) sample, (5) results, (6) primary outcome and (7) secondary outcomes.

Outcomes related to the main reasons for family refusal were assessed, as well as other related outcomes, such as: lack of knowledge of the donor's wishes, religious issues, uncertainty about the process; disagreement between family members and emotional reasons. Outcomes relating to the health team's performance were also assessed (lack of adequate information; poor conduct of the family interview; lack of preparation on the part of the team).

RESULTS

After carrying out the integrative review on family refusal to donate organs from a bioethical perspective, a total of 13 studies were identified and analyzed which met the established inclusion criteria.

Flowchart of the selection of studies for the review. Muzambinho, MG, Brazil, 2024.



The results of this review were grouped into different themes and categories, allowing for a comprehensive analysis of the ethical reasons, influencing factors, psychosocial impacts and coping strategies related to family refusal to donate organs.

Characteristics of the studies

According to the estimated main outcome, all of the 13 articles selected described the perspective of family denial of organ donation (Tables 1 and 2).

The articles selected were carried out worldwide, in Australia, the Netherlands, Brazil, Iran, the USA, Turkey, Taiwan, Chile, the United Arab Emirates and Canada. Brazil was the country with the highest number of studies found, with three publications. Most of the studies had a qualitative methodological design, but cross-sectional, survey and prospective studies were also identified. The population studied varied between health professionals (mainly nurses and doctors), family members of donors and the general population.

Chart 1 - Characterization of the studies included in the analysis related to identification number (ID), title, authors and year of publication. 2024.

(ID) Title	Authors and Year of Publication	Study site
(1) Factors relating to consent for organ donation: prospective data on potential organ donors	MARCK et al; 2014	Melbourne, Australia
(2) Request for organ donation without donor registration: a qualitative study of the perspectives of bereaved relatives	DE GROOT et al; 2016	Nijmegen, Netherlands
(3) Family perspectives on organ and tissue donation for transplantation: a principlist analysis	DOS SANTOS, FEITO; 2017	São Paulo, Brazil
(4) Outcomes of organ donation in brain-dead patient's families: Ethical perspective	AHMADI; RAHIMI, KHALEG; 2017	Teerā, Iran.
(5) Deterrents to Organ Donation: A Multivariate Analysis of 766 Survey Respondents	SELLERS et al; 2018	Georgia, USA
(6) Abordagem familiar para a doação de órgãos: percepção dos enfermeiros	MARCONDES et al; 2019	Paraná, Brazil
(7) My loved one was not an organ donor: ethical dilemmas for family members of deceased potential donors when making the decision on donation	MORAES et al; 2019	São Paulo, Brazil
(8) Patient Knowledge, Attitudes, and Behaviors Associated with Organ Donation	UYAR et al; 2019	Konya, Turkey
(9) Understanding family dynamics in adult-to-adult living donor liver transplantation decision-making in Taiwan: Motivation, communication, and ambivalence	LIN et al; 2021	Taoyuan, Taiwan
(10) Características sociales y familiares asociadas a la decisión de ser donante de órganos y tejidos en población adulta, Coquimbo, Chile 2019	SALAS et al; 2021	Coquimbo, Chile
(11) How context affects people's willingness to register for the deceased organ donation programme	ALHAJRI, ALHEBSI, ALSUWA; 2021	Abu Dhabi, United Arab Emirates
(12) Concerns and Challenges of Living Donors When Making Decisions on Organ Donation: A Qualitative Study	BAHADO et al; 2022	Kerman, Iran
(13) Family and emergency physicians' knowledge and attitudes toward organ donation and deemed consent	URQUHA et al; 2024	Nova Scotia, Canada

Source: Authors (2024).

Chart 2 - Characterization of the studies included in the analysis related to identification number (ID), study design, sample and journal. 2024.

ID	Study design	Sample	Journal
1	Prospective study	123 potential organ donors	Internacional Medicine Journal
2	Qualitative study	14 family members of organ donors	BMC Medical Ethics
3	Exploratory, descriptive, qualitative	18 nurses	Nursing Ethics
4	Qualitative study	13 relatives of organ donors	Nursing Ethics
5	Survey	766 participants	Journal of the American College of Surgeons
6	Qualitative, explanatory and exploratory study	06 nurses	J Nurs UFPE online

ID	Study design	Sample	Journal
7	Qualitative study	8 individuals who refused organ donation	Transplantation Proceedings
8	Cross-sectional study	128 individuals from health centers and 111 dialysis patients	Annals of Transplantation
9	Qualitative study	36 participants (10 recipients, 13 donors, 13 caregivers)	American Journal of Transplantation
10	Analytical cross-sectional study	383 people	Revista Médica do Chile
11	Qualitative study	17 participants	BMC Public Health
12	Qualitative study	20 participants	Iranian Journal of Nursing and Midwifery Research
13	Survey	211 family doctors; 73 emergency doctors	Canadian Family Physician

Source: Authors (2024).

Results associated with the primary outcome: main reasons for family refusal

The main primary outcomes related to the bioethical issues involved in family refusal to donate organs encompass a series of ethical and moral aspects that influence family decision-making. This includes the autonomy of the patient and their wishes expressed in life, the principle of beneficence in relation to the potential benefit for organ recipients, non-maleficence

considering the psychosocial impacts on the donor's family, and justice in the equitable distribution of organs to those on the transplant waiting list.

In addition, cultural, religious and social issues also play a fundamental role in family denial, and it is essential to consider the diversity of values and beliefs when addressing this complex bioethical issue. The main results extracted from the articles analyzed are described in Table 2.

Table 2 - Identification of the main reasons for family negativity, 2024.

Study	Study population	Observed Outcomes
(1) Factors relating to consent for organ donation: prospective data on potential organ donors	Potential donors considered clinically suitable for organ donation	Factors related to consent included country of birth, cultural background in Australia, registration on the Australian Organ Donor Register, etc. Factors such as religion and knowledge of the deceased's wishes were identified as influencing consent for organ donation. Family factors such as fluency in English and knowledge of the deceased's wishes also influenced consent. Families of donors eligible for donation after circulatory death were less likely to consent than those of donors eligible for donation after brain death. Donors eligible for donation after brain death and with a shorter hospital stay were more likely to proceed with organ donation for transplantation.

Study	Study population	Observed Outcomes
(2) Request for organ donation without donor registration: a qualitative study of the perspectives of bereaved relatives	The study analyzed family members of eligible potential organ donors, not registered in the National Organ Donor Registry.	Family members of patients not registered as donors generally refuse consent, even if they are in favor of donation or know of the deceased's wishes. Half of the relatives who initially refused mentioned that it could have been a later option Emotional burden, unfamiliarity with talking about death, inadequate support and lengthy procedures contribute to refusal Health professionals can offer more emotional support, meet information needs and adapt the approach according to each situation
(3) Family perspectives on organ and tissue donation for transplantation: a principlist analysis	18 nurses who worked in municipal organ procurement organizations and conducted family interviews for organ donation	The context of family interviews for organ and tissue donation for transplantation involves ethical aspects, highlighting the principles of respect for autonomy, beneficence, non-maleficence and justice It has been observed that preparation for the interview, correct information provided to the family and facilitation of the donation decision are crucial to the process Ethics plays a key role in interacting with families during the delicate moment of organ donation, highlighting the importance of addressing these ethical principles when dealing with transplant issues
(4) Outcomes of organ donation in brain-dead patient's families: Ethical perspective	Relatives of brain-dead patients who have consented to organ donation	Challenges faced by families after the decision to donate organs include personal and interpersonal conflicts Positive outcomes reported by families are satisfaction, confidence in the decision and feelings of peace The discovery of transcendent outcomes was reported, such as spiritual, altruistic and cultural experiences Recommendation to provide emotional and informational support to deal with negative post-donation thoughts
(5) Deterrents to Organ Donation: A Multivariate Analysis of 766 Survey Respondents	General population of four healthcare providers' waiting rooms	The biggest independent concern associated with willingness to donate was the fear of receiving inadequate medical care if registered as a donor Having or not having a previous discussion about donation had a major impact on willingness to donate both one's own organs and those of a family member Race (for African-Americans) and age were also predictive, but to a lesser extent, of willingness to donate The biggest barrier to willingness to donate, both personally and from a family member, is a misperception that can be corrected
(6) Abordagem familiar para a doação de órgãos: percepção dos enfermeiros	Nurses working with families in healthcare institutions	The main difficulty faced by the nursing team is the lack of knowledge related to the organ donation process, especially about brain death Nurses working in the family approach should seek constant improvement Health institutions should invest in continuing and ongoing education for employees, as well as financial resources to increase awareness of organ donation
(7) My loved one was not an organ donor: ethical dilemmas for family members of deceased potential donors when making the decision on donation	Individuals who had experienced the loss of a family member and refused to donate their loved one's organs and tissues	Families refuse organ donation due to negative beliefs about donation Fear of the death of a loved one influences the decision to refuse Ethical dilemmas arise when deciding on organ donation. Refusal is often based on the loved one's prior wish not to be a donor The experiences of families reveal the importance of strategies to improve care for these relatives

Study	Study population	Observed Outcomes
(8) Patient Knowledge, Attitudes, and Behaviors Associated with Organ Donation	Individuals who attended Family Health Centers (FHC) and patients in hemodialysis units, all Muslims	Of the participants, 70.7% demonstrated knowledge of the concept of brain death Less than half of the participants (39.1% on FHSC and 36.9% on dialysis) expressed a willingness to donate their own organs There were significant differences between the groups, with dialysis patients less likely to donate to someone of another religion Although many participants had positive attitudes towards organ donation, this attitude did not necessarily translate into actual donation behavior
(9) Understanding family dynamics in adult-to-adult living donor liver transplantation decision-making in Taiwan: Motivation, communication, and ambivalence	36 participants from 13 families at Chang Gung Memorial Hospital in Taiwan	The study revealed that living donor liver transplantation is considered a “desperate remedy” and more urgent than living donor kidney transplantation. Participants expressed the importance of saving the recipient’s life as a significant motivating factor in the decision to donate an organ The choice of donor was influenced by considerations related to post-operative care and the financial costs associated with the transplant procedure. Donors showed ambivalence about the decision to donate an organ, influenced by cultural norms, gender roles and the division of labor in the family. The analysis highlighted the importance of donor autonomy and the emotional vulnerability associated with the decision to undergo a living donor liver transplant
(10) Características sociales y familiares asociadas a la decisión de ser donante de órganos y tejidos en población adulta, Coquimbo, Chile 2019	People living in the commune of Coquimbo, Chile, adults aged between 18 and 84 years old	It revealed a predominantly positive attitude of the population towards organ donation and transplantation, with 77.02% of participants stating that they were in favor of donation One of the main findings was the significant influence of family opinion on the decision to donate organs, highlighting that family rejection is the main cause of losing potential brain-dead donors The act of commenting and discussing the subject of organ donation within the family can favor the decision to donate, highlighting the importance of communication and awareness within the family to increase organ donation rates.
(11) How context affects people’s willingness to register for the deceased organ donation programme	People who have heard about the UAE’s deceased organ donation program, had experience with it or witnessed someone going through it or a similar program	The study identified fear as a significant factor influencing people’s willingness to donate organs. The importance of family, relational ties and the recipient’s identity were highlighted as influences on willingness to donate organs Religious beliefs and ethical values were fundamental in shaping participants’ opinions on organ donation and influenced their decisions Those with greater knowledge on the subject and positive or negative personal experiences related to organ donation tended to have different and more informed perspectives on the subject
(12) Concerns and Challenges of Living Donors When Making Decisions on Organ Donation: A Qualitative Study	Organ donors, family members, the organ recipient, a surgeon and a psychologist	The main theme identified was the conflict between doubt and certainty during the organ donation decision-making process Donors’ mental concerns that affect the donation decision, such as fear of future implications, doubts due to lack of knowledge, fear of surgery and anesthesia, among others Among the common concerns highlighted were post-donation recovery, family responsibilities arising from donation, and concern for the future health of both the recipient and the donor Perceived barriers and concerns in the community regarding organ donation were the importance of policies and awareness to improve living donor satisfaction

Study	Study population	Observed Outcomes
(13) Family and emergency physicians' knowledge and attitudes toward organ donation and deemed consent	Family doctors and emergency physicians practicing in the province of Nova Scotia	The majority of family and emergency physicians showed support for the presumed consent model in relation to organ donation Around 75% of family doctors indicated that they would only broach the subject of organ donation if the patient initiated the conversation The study identified knowledge gaps and obstacles in the implementation of presumed consent, highlighting the need to address these issues to promote better understanding and acceptance of the organ donation process

Source: Authors (2024).

DISCUSSION

The debate on organ donation from a bioethical perspective is essential to understanding the ethical dilemmas faced by health professionals and families, as well as the impact of cultural and religious beliefs on decision-making.¹⁵⁻²⁶ The intersection between ethical values, clinical practices and health policies plays an essential role in promoting an ethical and respectful approach to organ donation.¹³ Reflecting on the ethical implications of family refusal, discussing strategies to promote ethical and sensitive decisions and suggesting policies based on bioethical principles are fundamental steps towards improving the practice of organ donation in an ethical and compassionate manner.

One study addressed the issue of family refusal to donate organs and its significant impact on donation rates in various regions of the world.¹⁵ The analysis reveals that family refusal can reduce donations by up to 54% in Asia and 43% in the Americas, highlighting the seriousness of this problem. Countries such as Argentina, France and Colombia are implementing legislative reforms to combat this harmful practice, seeking to prevent family members from revoking donors' wishes and promoting donor autonomy.¹⁵

The discussion of medical ethics and bioethics is fundamental to understanding the ethical dilemmas involved in family refusal to donate organs.^{15,27} The article highlights the importance of balancing donor rights with the need to increase donation rates to meet the demand for transplants.¹⁵ The conclusion that the harm caused by family refusal is more serious than the potential harm of not allowing the veto underscores the urgency of reforms in the health system and legislation to ensure that donors' decisions are respected and implemented ethically, with the aim of saving lives and improving public health.¹⁵

A study carried out on organ donation in Brazil revealed that the majority of Brazilians are willing to donate organs after death, with around 67% of participants agreeing with this practice. However, a worrying fact is that only half of those interviewed had shared their decision to donate organs with a family member or close friend. This highlights the importance of communication and raising awareness about organ donation, especially in a context where donor registration is not mandatory in the country.¹⁶

In addition, the study identified disparities in willingness to donate organs between different regions of Brazil and age groups.¹⁶ The research pointed out that acceptance of organ donation was higher in metropolitan areas and among economically active people.¹⁴ These findings suggest the need to implement targeted educational and awareness strategies to increase acceptance of organ donation throughout the Brazilian population, aiming not only to increase the donation rate, but also to ensure that donors' decisions are communicated and respected.¹⁶

The role of health professionals must also be considered, as they face complex ethical dilemmas when dealing with organ donation, balancing respect for the autonomy of the deceased patient, beneficence for organ recipients, non-maleficence in relation to the emotional impact on families and justice in the equitable distribution of organs.¹⁵⁻¹⁷ Families, in turn, face dilemmas¹⁵ when deciding on donation, considering cultural, religious and emotional beliefs that can influence their decision.¹⁶⁻²³ These dilemmas highlight the need for a sensitive and ethical approach by health professionals to support families at this delicate time.^{15,17,18,24,25}

The influence of various factors on families' decisions regarding organ donation highlights the importance of prior knowledge of the deceased's wishes,^{16,26} understanding brain death tests,^{19,22,25,26} empathy¹⁵ and respect in the communication

process.^{15,25} Effective communication,^{18,22,23,27} professional care^{15,17,19,25,27} and taking time to absorb information^{23,27} are fundamental to helping families at this delicate time. Studies show that correct information^{15,18,22} and emotional support^{17,18,22} can help family members in the process of accepting organ donation.

From a bioethical point of view, the discussion of these findings highlights the importance of autonomy and beneficence in the context of organ donation.^{13,15} Respecting the prior wishes of the deceased^{16,26} and ensuring that families have clear information^{15,18,22} and adequate emotional support^{17,18,22} are essential ethical aspects. In addition, empathy and respect^{15,26} for families' feelings during the decision-making process are fundamental to promoting bioethical practice in the area of organ donation.^{15,19}

Cultural^{19,21,27} and religious^{16,18,22} beliefs also have a significant influence on organ donation decision-making, and can be both facilitating^{16,18,22} and limiting^{18,19,21,27}. Understanding and respecting these beliefs is essential for an ethical and respectful approach.^{16,18-21,27} The cultural and religious sensitivity of healthcare professionals can help establish effective communication with families, promoting an environment of trust and mutual respect during the decision-making process.^{15,21,23,24,26}

Religious views on organ donation highlight the importance of religious beliefs in transplant decision-making.^{16,18,22} Issues such as consent, brain death and respect for the body of the deceased are emphasized in some religions.^{19,22} Understanding these different religious views can contribute to reducing religious concerns about transplants and narrowing the gap between the need and availability of organs for donation.^{15,18-20} In terms of bioethics, consideration and respect for different religious perspectives are essential to ensure ethical and respectful decisions in the medical context, without putting undue pressure on patients.²¹

Ethical considerations in organ donation involve fundamental principles such as autonomy, beneficence, non-maleficence and justice.¹⁵ These principles guide clinical practices and health policies, ensuring that decisions are made ethically and respectfully.^{15,23} The practical implications of these ethical considerations are reflected in the quality of care provided to families and in the promotion of a culture of organ donation based on sound ethical values.^{15,19,20-24}

To promote an ethical and respectful approach to organ donation, it is essential to invest in continuing education for healthcare professionals, sensitizing them to the ethical issues involved.^{15,24,26} In addition, empathetic and culturally sensitive communication strategies can facilitate dialogue with families,

promoting informed and respectful decision-making.^{15,17,18,21,22} The creation of healthcare policies based on sound bioethical principles can guide clinical practices and ensure an ethical and compassionate environment for all those involved in the organ donation process.^{19,23,27,28}

The limitations of this review include the scarcity of studies in certain regions and the need for more qualitative research for a deeper understanding of the phenomenon.

CONCLUSION

The main reasons for family refusal include ethical, moral and emotional concerns, as well as cultural, religious and social issues that influence decision-making. The diversity of values and beliefs present in society plays a significant role in family refusal, highlighting the complexity and importance of addressing these issues sensitively and ethically in the context of organ donation.

Family refusal of organ donation is a complex and multifaceted phenomenon that involves an interaction of psychosocial, ethical and cultural factors. This integrative review provided a comprehensive analysis of the reasons behind family refusal, highlighting the importance of education, communication and respect for the beliefs and values of those involved.

The findings of this study contribute to the understanding of this phenomenon, providing valuable insights for health professionals and researchers interested in improving organ donation rates. It is recommended that future research further explores the cultural and religious influences on family refusal, as well as developing more effective intervention and support strategies for the families involved.

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