

Organ Donation: Knowledge and Factors Associated With Refusal Among First-Year Medical Students and Their Parents

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ABSTRACT

Objectives: To evaluate and compare the knowledge, perceptions, and attitudes of first-year medical students and their parents regarding organ donation. **Methods:** This was an observational, cross-sectional, and analytical study conducted with 89 students and 70 parents using electronic questionnaires (Google Forms), administered separately. The instruments addressed sociodemographic data, self-reported knowledge of Brazilian Law No. 9,434/1997, understanding and acceptance of brain death (BD), attitudes toward organ donation and transplantation, as well as factors associated with refusal to donate. Analyses included absolute and relative frequencies, 95% confidence intervals (95% CI), and comparison between proportions using Pearson's chi-square test ($p < 0.05$). **Results:** Approval of organ donation was high, reaching 100% among students and 95.7% among parents ($p = 0.049$). A significant dissociation between attitude and practice was observed, with low willingness to donate in cases of BD (11.2% vs. 15.7%; $p = 0.416$). Acceptance of BD was lower among students (10.1%) than among parents (92.9%; $p < 0.001$). Family communication was limited (49.4% vs. 45.7%). Most students (84.3%) and parents (97.1%) believed that the other group was favorable toward donation. Among students, the main factors were fear (57.3%) and lack of information (22.5%), whereas among parents, the primary factor was lack of prior reflection on the topic (77.1%). **Conclusion:** Despite the high level of acceptance, relevant gaps remain in knowledge, particularly in the understanding and acceptance of BD, in addition to limited family communication. Longitudinal educational strategies and the promotion of family dialogue are essential to reduce refusal rates for organ donation.

Descriptors: Brain Death; Education, Medical; Health Communication; Organ Transplantation.

Doação de Órgãos: Conhecimento e Fatores Associados à Recusa Entre Ingressantes do Curso de Medicina e Seus Pais

RESUMO

Objetivos: Avaliar e comparar o conhecimento, as percepções e as atitudes de ingressantes do curso de Medicina e de seus pais sobre a doação de órgãos. **Métodos:** Estudo observacional, transversal e analítico, realizado com 89 estudantes e 70 pais, por meio de questionários eletrônicos (Google Forms) aplicados separadamente. Eles abordavam dados sociodemográficos, conhecimento autorreferido da Lei n.º 9.434/1997, compreensão e aceitação da Morte Encefálica (ME), atitudes em relação à doação e ao recebimento de órgãos, bem como fatores associados à recusa da doação. As análises incluíram frequências absolutas e relativas, Intervalos de Confiança de 95% (IC95%) e comparação entre proporções pelo teste do qui-quadrado de Pearson ($p < 0,05$). **Resultados:** A aprovação à doação foi elevada, sendo de 100% entre os estudantes e 95,7% entre os pais ($p = 0,049$). Observou-se importante dissociação entre atitude e prática, com baixa disposição para doação em caso de ME (11,2% vs. 15,7%; $p = 0,416$). A aceitação da ME foi menor entre estudantes (10,1%) do que entre pais (92,9%; $p < 0,001$). A comunicação familiar foi limitada (49,4% vs. 45,7%). A maioria dos estudantes (84,3%) e dos pais (97,1%) acreditava que o outro grupo era favorável à doação. Entre os estudantes, destacaram-se o medo (57,3%) e a desinformação (22,5%); entre os pais, a ausência de reflexão prévia sobre o tema (77,1%). **Conclusão:** Apesar da elevada aceitação, persistem lacunas relevantes no conhecimento, na compreensão e na aceitação da ME, além de baixa comunicação familiar. Estratégias educativas longitudinais e o estímulo ao diálogo entre familiares são fundamentais para reduzir recusas à doação.

Descritores: Morte Encefálica; Educação Médica; Comunicação em Saúde; Transplante de Órgãos.

INTRODUCTION

Organ donation is a complex process involving legal, ethical, technical, and sociocultural aspects. In Brazil, transplantation is regulated by Law No. 9.434/1997, under which the actualization of post-mortem donation depends on family authorization, even when the potential donor had expressed a willingness to donate while alive¹. Although the country holds a prominent global position in terms of the absolute number of transplants performed, a gap persists between the supply of and demand for organs, with family refusal being one of the main obstacles to the system's effectiveness². On the international stage, the shortage of organs also remains one of the main limiting factors for transplantation³, reinforcing the relevance of studies on factors influencing the decision to donate⁴.

Medical training plays a fundamental role in reducing family refusal, both through technical proficiency and the development of communication skills, as well as through a proper understanding of brain death, a concept often associated with uncertainty among both professionals and the general public. Studies show that knowledge regarding organ donation and brain death remains insufficient, even among healthcare students⁴⁻⁶. Although greater exposure to the topic tends to be associated with more favorable attitudes^{7,8}, significant gaps persist, particularly regarding the understanding of brain death, knowledge of the legislation, and confidence in the donation process⁹⁻¹².

In addition to cognitive aspects, emotional, cultural, and relational factors, such as fear, misinformation, and distrust of the system, exert significant influence on the decision to donate¹³. The difficulty of addressing the topic within the family setting also stands out as a significant factor. Open family communication is recognized as an essential measure for reducing refusals¹⁴, while academic training in health represents an important opportunity to foster knowledge and influence individual and family decisions¹⁵.

Given this, it is relevant to investigate the knowledge, attitudes, and perceptions of incoming medical students and their parents regarding organ donation, considering that under Brazilian law, the final decision rests with the family¹.

Thus, this study aimed to analyze and compare the knowledge, attitudes, and perceptions of first-year medical students and their parents regarding organ donation—including legal aspects, understanding and acceptance of brain death, willingness to donate and receive organs, and the main factors associated with refusal to donate.

METHODS

This was an observational, cross-sectional, analytical study conducted with first-year medical students from a private higher education institution in Fortaleza, Northeastern Brazil, and their parents.

Data collection

Data collection took place during the first week of the second semester of 2025, using two distinct, self-administered electronic questionnaires created by the authors via Google Forms specifically for this study; these were completed independently by each group. Students answered the questionnaire in the classroom, while parents received the link through their children. Students were asked not to share their opinions on the topic with their parents before completing the questionnaires to minimize potential response bias. As the instruments were developed specifically for this study, the questionnaires had not been previously validated or pilot-tested.

The instruments included questions regarding sociodemographic data, self-reported knowledge of Law No. 9.434/1997, understanding and acceptance of brain death, attitudes toward organ donation and receipt for transplantation, and reasons associated with refusal.

Statistical analysis

The data were analyzed using descriptive statistics, including absolute and relative frequencies and 95% confidence intervals (95% CI). Comparisons between groups were performed using Pearson's chi-square test, with a significance level of 5% ($p < 0.05$).

Ethics Committee

The study was conducted in accordance with the guidelines of Resolution No. 466/12 and its supplementary resolutions, including National Health Council (CNS) Resolution No. 510/2016. The project was approved by the Research Ethics Committee of the University of Fortaleza (opinion No. 4.888.179), and free and informed consent was obtained from all participants.

RESULTS

A total of 159 individuals participated in the study: 89 first-year medical students and 70 of their parents. Among the students, females predominated (65.2%), with a mean age of 19.3 years (range: 17–20 years). Among the parents, the mean age was 53 years (range: 42–62 years), with a predominance of fathers (60%) over mothers (40%).

Overall approval of organ donation was high in both groups: 100% among students (95% CI: 95.9–100) and 95.7% among parents (95% CI: 88.3–98.6; $p = 0.049$). However, this acceptance did not translate into actual behaviour, as only 11.2% of students stated they would be donors in the event of brain death, while the figure for parents was 15.7% ($p = 0.416$).

Communication within the family regarding organ donation was limited and similar across groups, reported by 49.4% of students and 45.7% of parents. Nevertheless, the perception of acceptance by the other group was high, with 84.3% of students believing their families were in favour of donation, and 97.1% of parents believing their children shared this view.

Regarding their perceived knowledge of the subject, both students and parents exhibited significant gaps. Among students, 58.4% rated their knowledge as fair, whereas parents predominantly rated theirs as good (47.1%) or fair (37.1%). Both groups demonstrated greater familiarity with the kidneys, heart, and liver, while the intestines, skin, and bones were recognized less frequently.

Understanding of brain death revealed significant discrepancies. Only 25.8% of students (95% CI: 17.8–36.0) and 7.1% of parents (95% CI: 3.0–16.0; $p < 0.001$) knew that organ donation is contingent upon a diagnosis of brain death. Conversely, the majority reported knowing what brain death is (93.3% of students and 100% of parents; $p = 0.052$). However, acceptance of this concept as a definition of death differed between the groups, standing at only 10.1% among students (95% CI: 5.0–18.9) and 92.9% among parents (95% CI: 84.1–97.1; $p < 0.001$).

Factors associated with the non-acceptance of donation also differed between the groups. Among students, fear (57.3%) and misinformation (22.5%) were the most prominent factors, whereas among parents, the lack of prior reflection on the subject predominated (77.1%), followed by fear (11.4%) and mistrust of the process (8.6%).

High acceptance of receiving a transplant was also observed in both groups, with 100% of students and 97.1% of parents stating they would accept a kidney from a brain-dead donor. In contrast, the willingness to donate in the event of brain death was low in both groups (11.2% vs. 15.7%; $p = 0.416$).

Finally, there was absolute consensus regarding the need to address the topic more extensively in medical education, with 100% of participants from both groups expressing interest in including organ donation in the curriculum.

DISCUSSION

The results reveal a high level of theoretical acceptance of organ donation among students and their parents, accompanied by a significant disconnect between attitude and practice. This disconnect was particularly pronounced among the students. Although all declared themselves in favour of donation, only a small proportion (11.2%) stated—in a hypothetical scenario—that they would donate their organs in the event of brain death. This figure is substantially lower than that reported in national and international literature on medical students; most such studies include students at various stages of their undergraduate training, in whom willingness to donate typically exceeds 90%^{4,6,8,16}.

This finding aligns with evidence pointing to gaps between desire, attitude, and action, wherein abstract acceptance of donation does not guarantee a concrete willingness to donate or to authorize donation in a real-life situation¹². In this context, the lower willingness observed may be related to the fact that the participants were first-semester students, given that knowledge of the subject tends to develop throughout medical training and is associated with a greater willingness to donate^{17,18}. However, gaps persist even in later stages of training^{4,8}. Furthermore, the participants in this study had not yet received formal instruction on organ donation, transplantation, or brain death during their undergraduate studies, which may have contributed to this finding.

Another central aspect was the limitation of family communication. Less than half of the students and parents had talked about organ donation, despite both believing, in a high proportion, that the other group was in favour of donation. This finding is consistent with the literature, in which a significant number of students in favour of donating still do not communicate this decision to their family, as well as with studies that point to family dialogue as a critical step in making the donation effective^{4,15}, especially in contexts in which the final decision rests with family members, as in the case of Brazilian legislation¹. Ignorance of the potential donor's wishes is one of the main reasons for family refusal, making it difficult to convert the potential donor into an actual donor^{2,19}. Thus, the results of the present study indicate that the problem is not restricted to theoretical support for donation, but includes the absence of dialogue and explicit agreement within the family, an essential aspect for the potential donor's wishes to be known and respected¹³.

Barriers to the actualization of donation also differed between the groups, highlighting the need to understand their causes in both academic and family settings, given that the lack of discussion while alive constitutes a critical obstacle to donation². Among students, fear and misinformation stood out; among parents, a lack of prior reflection on the subject predominated, followed by fear and mistrust regarding the process. Fear and misinformation emerge as recurring factors behind the refusal to donate, alongside mistrust of the process, religiosity, and a lack of knowledge^{4,8,13,20}.

In the present study, religion played a relatively minor role, suggesting that, in this specific context, cognitive and emotional barriers may be more significant than strictly religious ones. The fear identified in this study may reflect sociocultural barriers and stigmas described in the literature, such as concerns regarding the preservation of bodily integrity after organ removal, the apprehension that retrieval might occur before death is confirmed, and a lack of familiarity with the rigorous protocols for diagnosing brain death^{8,11,20,21}. Furthermore, studies show that difficulty accepting a diagnosis of brain death, the importance placed on bodily integrity, and certain cultural or religious beliefs can negatively influence the decision to donate organs^{11,20-24}. Thus, understanding these barriers can help reduce family refusal, which is the primary reason why organ donation does not proceed in Brazil². Ideally, everyone should reflect on this topic and share their decision with family members²⁴.

Also noteworthy is the fact that the willingness to receive an organ was nearly universal, whereas the willingness to donate remained low. This asymmetry has been described in the literature. It underscores a significant ethical aspect of the organ donation debate, highlighting a disconnect between holding a favourable view and taking concrete action, as well as the tendency of non-donors to accept transplantation if the need arises^{8,17}. In the present study, this paradox was observed among both students and parents, indicating that valuing transplantation as a therapeutic option is not always accompanied by a corresponding willingness to donate organs.

Understanding brain death was undoubtedly the most critical aspect of the study. Although most students claimed to be familiar with the concept, its acceptance as a definition of death was extremely low. In contrast, the majority of parents recognized brain death as a valid definition of death. This finding aligns with the literature, which identifies brain death as a key area of conceptual uncertainty—even among healthcare students—characterized by varying levels of acceptance and understanding^{4,8,9,25}.

The results of the present study reinforce the existence of significant gaps, particularly among incoming students. This scenario suggests that the early stage of medical training may represent a particularly vulnerable period regarding the understanding of the subject²⁵. At the time of data collection, the students had not yet received formal instruction on brain death, organ donation, or transplantation during their undergraduate studies. This factor likely contributed to the low level of acceptance observed. Understanding and accepting the diagnosis of brain death is a process of technical and ethical maturation that evolves throughout medical training, highlighting the central role of undergraduate education in developing these competencies. In this context, first-semester students, being at the beginning of this process, tend to exhibit uncertainties and perceptions more closely aligned with those of the general population²⁵.

Data regarding self-reported knowledge of Brazilian legislation on organ donation also warrant attention. Students reported greater knowledge of Law No. 9.434/1997 than parents did, yet agreement with the legislation was higher among parents. This difference aligns with Brazilian discussions regarding autonomy and family decision-making, although it did not reach statistical significance in the present study. National surveys involving students and physicians have previously demonstrated discomfort with the legal model that leaves the final decision in the hands of the family, even when the individual has expressed a wish to donate while alive^{1,4,16,18}. In this regard, the results of the present study suggest that parents and students may interpret the balance between individual autonomy and family decision-making differently.

From an educational perspective, the findings reinforce the need to integrate the topic of organ donation into the medical curriculum in a longitudinal, structured, and contextualized manner, starting in the early stages and continuing throughout the entire undergraduate program. The low willingness to donate, coupled with gaps in the understanding and acceptance of brain death, suggests that late or superficial exposure to the subject may hinder the development of consistent attitudes. This interpretation aligns with studies indicating persistent educational shortcomings and highlighting the importance of progressive exposure to the topic throughout medical training^{5,7,9}. Furthermore, evidence indicates that educational strategies associated with the development of communication skills can positively impact attitudes toward donation, especially when combined with actions aimed at the community and the family environment^{4,15}.

In the present study, the participants' unanimous interest in discussing the topic during the course reinforces not only the feasibility but also the urgency of this approach. Accordingly, the results point to direct implications for transplant practice—particularly regarding the approach to families—suggesting that enhancing medical training can contribute to more effective communication with patients and their families and, potentially, to a reduction in family refusal rates, thereby strengthening the organ donation system.

Study limitations

This study presents certain limitations that should be considered when interpreting the results. As this was a cross-sectional study, it is not possible to establish causal relationships between the variables analyzed. Furthermore, the sample consisted of incoming students from a single private higher education institution and their respective parents, which may limit the generalizability of the findings to students from other institutions, regions, or sociocultural contexts. The use of self-reported questionnaires may also be subject to response biases, including social desirability and overestimation of knowledge.

It is worth noting that the instruments used were developed by the authors specifically for this study, without prior formal validation or pilot testing, which may have influenced the precision of the measurements obtained. Additionally, the analysis relied on self-reported perceptions, which may not accurately reflect the participants' actual behaviour in real-world organ donation decision-making situations. It should also be noted that the responses were obtained in a hypothetical context and may not faithfully replicate decisions made in actual situations. Finally, although the questionnaires were administered independently, the possibility of indirect influence between students and their parents cannot be entirely ruled out.

CONCLUSION

High theoretical acceptance of organ donation was observed among students and parents; however, significant gaps persist regarding technical knowledge and, above all, the understanding and acceptance of the concept of brain death, particularly among students. Furthermore, a notable disconnect between attitude and practice was evident, characterized by a low willingness to donate in real-life situations. Family communication proved limited and influenced by potentially distorted perceptions, while distinct barriers were identified across the groups, with direct implications for the actualization of organ donation.

These findings underscore the need for the structured, longitudinal, and early integration of this topic into medical curricula, combined with the development of communication skills and community education initiatives that encourage family dialogue and clarify the legal and medical aspects of organ donation. These findings have implications for the formulation of public policies aimed at strengthening education on organ donation and increasing donation rates.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Silva SFR, Silva SL; **Conception and design:** Silva SFR; **Data analysis and interpretation:** Silva SFR, Silva SL, Macêdo LCCL, Maia JM, Gonçalves PG, Lousada MCSO, Montenegro ALR, Pinheiro MMLB, Oliveira IS; **Article writing:** Silvia SFR, Silva SL, Macêdo LCCL, Maia JM, Gonçalves PG, Lousada MCSO, Montenegro ALR, Pinheiro MMLB, Oliveira IS; **Critical revision:** Silva SL; **Final approval:** Silva SFR.

DATA AVAILABILITY STATEMENT

Data will be available upon request.

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DECLARATION OF USE OF ARTIFICIAL INTELLIGENCE TOOLS

The authors used artificial intelligence tools to assist in organizing and analyzing the data, as well as in the linguistic review of the manuscript. All methodological decisions, interpretations of the results, and the final version of the text are the sole responsibility of the authors.

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