

To donate or not to donate: meanings of family refusal to the refusal to donate organs and tissues

Doar ou não doar: significados da negação familiar para a doação de órgãos e tecidos
Donar o no donar: significados de la decisión familiar de no donar órganos y tejidos

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Abstract

Objective: To understand the meanings attributed by family members about the refusal to donate organs and tissues. **Methods:** A descriptive and exploratory study with a qualitative approach. A semi-structured questionnaire was used for data collection and thematic content analysis was employed for the treatment of the data obtained. The sample comprised by 10 participants was defined by means of the theoretical saturation criterion. **Results:** There was a tendency for family members to consent to the donation when well-oriented about brain death and the humanistic purpose of the donor, but the main obstacles to refuse donation are as follows: lack of knowledge about organ donation, fear of body mutilation for not knowing how the procedure for removing organs and tissues is performed, bureaucracy with the delay in releasing the body for burial and disagreement between family members. **Conclusion:** The meanings of family refusal permeate fear, a feeling of emptiness and lack of information about the processes involved in organ and tissue donation, as well as cultural and religious aspects, although despair, pain and lack of empathy of the health teams can also corroborate refusal.

Descriptors: Tissue and Organ Procurement; Transplant; Family relationships.

Whats is already known on this?

Organ donation imposes important discussions for health in the family context and is permeated by taboos fed by lack of knowledge about the procurement and donation process.

What this study adds?

It discusses the meanings attributed by family members that refused to donate organs and tissues, enabling to expand knowledge about the topic and possible changes in the scenario under study.



How to cite this article: Fontenele RM, Costa NR, Moraes LMN, Silveira WJA, Almeida HFR. To donate or not to donate: meanings of family refusal to the refusal to donate organs and tissues. Rev. enferm. UFPI. [internet] 2023 [Cited: ano mês abreviado dia];12:e3613. doi: 10.26694/reufpi.v12i1.3613

Resumo

Objetivo: Compreender os significados atribuídos por familiares sobre a negação para a doação de órgãos e tecidos. **Métodos:** Estudo descritivo, exploratório, com abordagem qualitativa. Utilizou-se um questionário semiestruturado para a coleta de dados e a análise temática de conteúdo para o tratamento dos dados obtidos. A amostragem de 10 participantes foi definida pelo critério de saturação teórica. **Resultados:** Percebeu-se a tendência de os familiares consentirem a doação quando bem orientados sobre a morte encefálica e de a finalidade humanística do doador, mas os principais obstáculos para a negação da doação são a falta de conhecimento sobre a doação de órgãos, o medo da mutilação do corpo por não saber como é realizado o procedimento de retirada de órgãos e tecidos, a burocracia com a demora na liberação do corpo para sepultamento e a discordância entre os familiares. **Conclusão:** Os significados da negação familiar permeiam o medo, o sentimento de vazio, a falta de informação sobre os processos que envolvem a doação e captação de órgãos e tecidos, bem como aspectos culturais e religiosos, embora o desespero, a dor e a falta de empatia das equipes de saúde também possam corroborar a recusa.

Descritores: Obtenção de Tecidos e Órgãos; Transplante; Relações Familiares.

Resumen

Objetivo: Comprender los significados que atribuyen los familiares sobre la decisión de no donar órganos y tejidos. **Métodos:** Estudio descriptivo y exploratorio, de enfoque cualitativo. Se utilizó un cuestionario semiestructurado para recolectar los datos y análisis temático de contenido para el tratamiento de los datos obtenidos. El muestreo de 10 participantes se definió por medio del criterio de saturación teórica. **Resultados:** Se percibió cierta tendencia en los familiares a consentir la donación cuando fueron bien orientados con respecto a la muerte encefálica y al propósito humanístico del donante; sin embargo, los principales obstáculos para no donar órganos y tejidos son la falta de conocimiento sobre la donación de órganos, el miedo a la mutilación del cuerpo por no saber cómo se realiza el procedimiento de ablación, la burocracia en la demora para entregar el cuerpo para el entierro y los desacuerdos entre los familiares. **Conclusión:** Los significados de la decisión familiar en contra de la donación pasan por el miedo, una sensación de vacío y la falta de información sobre los procesos implicados en la ablación y donación de órganos y tejidos, al igual que aspectos culturales y religiosos, aunque la desesperación, el dolor y la falta de empatía por parte de los equipos de salud también pueden reforzar la negativa.

Descriptor: Obtención de Tejidos y Órgãos; Trasplante; Relaciones Familiares.

INTRODUCTION

Some diseases can only be cured through organ transplantation; however, there is significant divergence between the number of donations and the number of patients on the waiting lists.⁽¹⁾ Transplants consist in replacing diseased organs or tissues by healthy ones. These organs or tissues can be from a living or cadaveric donor.⁽²⁾

In accordance with the laws that regulate organ transplantation in Brazil, family members up to the fourth kinship degree have the power to authorize or refuse organ and tissue donation from potential deceased donors.⁽³⁾

Considering that the donation can be from a living donor, part of the liver, lung, spine or one of the kidneys can be donated. In turn, heart, corneas, tendons, blood vessels, kidneys are liver are the most requested from cadaveric donors, although other organs and tissues can also be donated. For living donors, it is necessary to prove kinship between donor and recipient. When there is no kinship, donation is also possible via a legal order and proof that the living donor will not have their health impaired.⁽⁴⁾

Cadaveric donors are the ones who suffered brain damage and had Brain Death (BD) confirmed, receiving care from then on to maintain vitality of the organs through medications and devices. It is only after BD has been verified and communicated to the family that the organ and tissue donation interview can be initiated.⁽⁵⁾

With resolution 2173/2017, brain death is no longer diagnosed only by neurologists and has become competence of physicians with specific training in accordance with the established protocol. This measure provided more security to the team and enabled rapid mediation with the family.^(5,6)

Countless people can be benefited, as it is possible to procure several organs for transplantation from the same donor. Among the most frequent surgeries are heart, lungs, liver, pancreas, intestine, kidneys, corneas, blood vessels, skin, bones and tendons.⁽⁷⁾

However, the number of donors has gradually decreased and family refusal is one of the main limitations in the donation process. Half of the families do not accept donating organs and tissues of their deceased loved ones.⁽⁸⁾ Thus, family refusal contributes to scarcity of donors in meeting the growing demand for recipients on the waiting lists.⁽⁹⁾

The reason for this study is based on the importance of organ and tissue donation to ensure survival chances for patients with good life prognoses. Therefore, it becomes necessary to conduct this research with the objective of understanding the meanings attributed by family members to the refusal to donate organs

and tissues, as well as allowing a space for discussion on the topic with a view to changing perspectives together with family power regarding authorization of the donation to meet the donors' will.

METHODS

This was a descriptive and exploratory research study, of an analytical nature and with a qualitative approach. It was conducted at a high-complexity reference hospital located in the municipality from São Luís, state of Maranhão.

Data collection was initiated through a documentary survey of potential donors admitted to the hospital, through 14 medical charts that had a record of refusal to donate organs and tissues reported by the patient's responsible family member between January and December 2019, having included relatives over 18 years old, regardless of the consanguinity degree, and living in the city of São Luís. In turn, the medical charts excluded from the study were those with incomplete addresses or missing data that precluded contact with the family member to proceed with the subsequent research stages, as well as family members who presented depressive states during data collection, which could be aggravated by continuing to participate in the study, guaranteeing them the assistance of the Psychology Service of the hospital itself, as provided for in the Free and Informed Consent Form.

The interviews were conducted in a place chosen by the study participants, with prevalence of their own homes and predefined times according to their availability. For data collection in this stage, an electronic device was used to record the researchers' and interviewees' testimonies. A semi-structured questionnaire accompanied by the guiding script, containing a total of 10 questions, sought to record aspects related to age group, gender, marital status, degree of kinship, children, schooling and family income, in addition to other important factors for achieving the objectives of this study.

In order to ensure the participants' anonymity, the letter "F" for "Family member" was assigned, along with Arabic numbers to differentiate them. This study was submitted to *Plataforma Brasil* under CAAE No. 08481719.6.0000.5084 and was approved by the Research Ethics Committee under opinion No. 3,207,743 on March 19th, 2019.

The data were analyzed based on thematic content analysis⁽¹⁰⁾. Data treatment in the qualitative research study was performed through three stages. The first stage consisted in the pre-analysis, which dealt with choosing the documents to be analyzed based on the documentary survey and with the invitation to take part in the study with pre-scheduling of the interviews. The interviews lasted a mean of 45 minutes and were subsequently transcribed to analyze the empirical material.

Transcription of the collected data was initiated from a floating reading process and allowed choosing the testimonies that would be used based on meeting the study objectives proposed. Subsequently, the material was explored and coded, characterizing the unprocessed data into nuclei of meanings, based the theoretical saturation framework for understanding the text, allowing the construction of categories to be discussed after grouping the nuclei of meanings by affinity.

RESULTS

Sampling was based on 10 family members and defined through the application of the theoretical data saturation method,⁽¹¹⁾ which interrupts inclusion of new participants when detecting repetitions in the nuclei of meanings. In this way, it was noticed that repetitions began to appear in the 6th interview; however, to verify theoretical saturation of the qualitative data,⁽¹²⁾ it was decided to continue the research until the 10th interview, as shown in Chart 1.

Chart 1. Verification of theoretical data saturation through the occurrence distribution of new statements in the interviewees' testimonies. São Luís, Maranhão, Brazil, 2020.

Nuclei of meanings	F1	F2	F3	F4	F5	F6	F7	F8	F9	F10	Total repetitions
Disagreement between Family members	x		x	x	x	x	x	x		x	08
Guilt transfer	x										01
Pain	x						x			x	03
Knowledge through the media	x				x			x	x		04
Fear of mutilation	x		x			x		x			04
Humanized care	x	x	x	x			x	x	x		07
Understanding Brain Death	x		x								02
Experience in other donations	x		x			x					03
Lack of discussion about the topic	x	x	x	x	x	x	x	x		x	09

Bureaucracy	x		x		x	x				x	05
Religiousness	x	x	x			x			x	x	06
Saving lives	x	x	x	x		x	x	x		x	08
Prolonging life	x	x	x	x						x	05
Quality of Life	x	x			x			x			04
Hope	x		x	x			x				04
Regret about not donating	x	x	x	x		x	x	x		x	08
Despair		x			x	x				x	04
Familiarity		x									01
Miracle		x							x		02
Uncertainty about being a donor	x	x		x	x						04
Family support		x			x						02
Schooling level			x			x		x			03
Time for farewells			x		x					x	03
Anguish			x							x	02
Certainty about being a donor			x						x		02
Empathy			x	x						x	03
Discontent with the team					x	x					02
New statements	17	04	05	0	1	0	0	0	0	0	27

Source: Adapted from Nascimento *et al.* (2018) and from Fontanela, Ricas and Turato (2008).

1) Characterization of the research participants

In the group there was predominance of women, single, aged over 46 years old and with a mean of two children. Regarding schooling and income, they had Complete high School and monthly family incomes between R\$ 1,200.00 and R\$ 1,500.00. In relation to kinship, there was prevalence of first-degree, namely daughters or wives.

2) The meanings of family refusal to donate organs and tissues

Through nuclei of meanings that were translated by lack of discussion on the topic and schooling level, the meanings attributed for family refusal were religiousness, uncertainty or certainty about the patient's will, bureaucracy and disagreement between family members, which also appeared as guilt transfer.

Bureaucracy for not knowing how the procedure takes place and how long it would take to release the body translated the fear of not having time for farewells, as the procedure might delay care for the wake and burial.

Fear of body mutilation when understanding that removing an organ or tissue would leave the deceased patient with a deformed appearance, lack of understanding about the brain death diagnosis that was intertwined with the expectation of a sudden, religious improvement, like a miracle, and despair, understood as not having spaces between mourning and the family group for this type of discussion due to the painful moment when the brain death news is received.

Above all, despair of being in a lonely context was perceived, upon the death news, or receiving a violated and mutilated body, unworthy of a vigil, as reported in the following statements:

"[...] we were already suffering a lot with his hospitalization [...] we believed that he could get better and that's one of the reasons that wouldn't lead us to think about this issue" (F7)

"The main reason that led me not to donate was first my lack of knowledge about the procedures [...] and then [...] I believed that this would violate my father's body [...]" (F8)

Speaking about organ donation requires talking about death, and it is perhaps due to this that the subject matter is not discussed. Imagining a loved one in a hospital situation is not easy; thus, talking about death and removing an organ becomes unimaginable. In this context, disagreement between family members appears as an *impasse* between those who know the brain death protocol and the importance of the act and those who see themselves for the first time in this situation, claiming for the entire body:

"[...] when I got the news, I thought we'd donate, but I was alone in the city, I called my sister [patient's mother in the inland] and she replied desperately 'Please, for all that is sacred, bring my daughter back in one piece, the way she left here [...]" (F3)

Being desperate was highlighted as one of the possible obstacles for family members to authorize the donation. Despair was understood as a moment of loneliness, without any aid from other family members or emotional support, which precluded immediate reasoning of the family members who reported not being able to think about the issue at the time of the approach and ended up saying no during the interview with the team from the procurement sector:

"[...] we can't think about that [accepting the donation and helping other people] I think that, at the moment you have that thing so crazy, you don't even think about it" (F5)

Those responsible for the patients also showed concern about the bureaucracy involved in the burial procedures, mainly those who live in the inland and depend on travel schedules, for example:

"[...] we thought it'd take a long time to release the body if we accepted removal of the organs. If it were quick... we'd donate" (F10)

It is known that some religions forbid organ and tissue donation procedures; however, even having expressed the desire in life, the family's refusal was perceived:

"[...] I'd donate, but when a person dies in their religion [interviewee's mother], no type of removal of organs or any part of the body is authorized" (F9)

3) Retaliation or resignification?

To assemble this category, nuclei were used that translated the meanings for not donating as discontent with the health team characterized by misunderstandings and dissatisfaction with the medical team and lack of humanized care, in which the family member did not feel supported by any feeling of empathy on the part of the health team in such context.

It should be noted that the decisive factor for family refusal was not always the emotional stress experienced during hospitalization, however brief it may be, as the patient's companion needs to adapt to a new routine of visits, trading the bed and warmth of their own home for a plastic chair, or an armchair for uncomfortable times, made available to sleep in that strange environment, permeated with noise and intense sleep interruptions.

However, lack of empathy and dehumanization in the care provided by the multiprofessional team was present in the respondents' testimonies as an aspect exerting a negative influence:

"The doctor who operated on him [interviewee's brother] was very harsh on my mother [...] it was as if he was blaming her [...] saying 'How come he had an aneurysm that size and no one noticed?', so I refused to donate due to this form of treatment, disrespecting our pain" (F5)

4) The impacts of refusal and change in attitude

After understanding the meanings of the refusals that produce an increase in the transplant waiting lists and a reduction in the number of donors, topics such as the legislation and procedure, as well as ethical and aesthetic aspects, were addressed with the participating family members in order to demystify organ procurement as disfigurement of a dead body.

This category emerged from nuclei of meanings such as Saving lives, Quality of Life and Prolonging life, which were translated into the hope of giving a better life to someone who waits anxiously in the transplant waiting list. Nuclei such as Regret for not donating were also pointed out, allowing to discuss the theme because there was experience with the collection team previously.

It was possible to identify the change in the family members' discourse and the dissatisfaction with the negative response in relation to permission to donate organs and tissues at that first moment, suggesting acceptance in a later experience, as it is difficult to decide on something about which people have little or no information. Thus, not understanding the donation processes especially impairs its effective implementation:

“After some clarifications, I believe so, that I'd choose to donate the organs because, in a way, it'd be an extension of what my father was and I believe helping people is something he'd like to do, you know, so I guess I'd think differently now” (F8)

The study participants showed gratitude for the diverse information received and willing to later on share what they had learned with friends and family members.

DISCUSSION

Lack of understanding about the brain death diagnosis has been described in studies that deal with organ and tissue donation, making it difficult to accept the donation procedure.⁽¹³⁾

The act of deciding whether or not to donate organs from the family members' perspective, in which the main reason for not donating is lack of knowledge about the patient's willingness to be a donor, also highlights the patient's decision as the main obstacle to organ donation refusal.^(7,14)

However, when there are no documents supporting the patient's will, non-consensus among the family members is one of the main obstacles to the effective donation of human organs and tissues.⁽¹⁵⁾

It is important to highlight that the decision to donate or not used to be recorded in the Brazilian National Identification Card, which allowed the procurement service to respect the patient's will after death. During development of this study, a Law Bill was passed in which the decision to donate organs and tissues or not might be returned to the Identification cards, removing the current decision by the family members and, thus, reducing bureaucracy for donations.

The bureaucracy to release the body is related to lack of humanized care due to the routine agitation of the shifts. It turns out that this bureaucracy, associated with the fact of having to decide on organ donation, can generate a significant deal of stress that affects the family members' lives, such as despair.⁽¹⁶⁾

The death of a loved one is almost always a traumatic and delicate moment for the family, when feelings such as pain, fear, anger, anguish and despair are involved. The mixed feelings can cause the family to move away from the situation, a distance that needs to be addressed almost immediately to accept organ and tissue or not.⁽¹⁷⁾

In Brazil, individuals with strong religious beliefs tend to have less favorable attitudes towards organ donation, being more likely to oppose it.⁽⁷⁾ In this study, the family members who identified themselves as Catholics revealed that their beliefs exerted no influence on their decision.

Families with some dissatisfaction with the medical team tend to choose not to donate, especially when care is not based on care humanization for the patient and their family.⁽¹⁸⁾

Assistance provided outside the standards expected by the families, added to any of the aforementioned factors, leads people to only want what is necessary from the hospital, making it impossible to even think about the possibility of authorizing organ and tissue donation.

Humanizing the donation process is important to establish a helping relationship with the family members of the potential donor, as it is considered that this action eases interaction with them, aiming to reduce family discomfort and to offer resources so that they can face the loss of their relative.^(19,20)

The current research has as limitations the size of its sample and the restriction to a single health service, whose results may differ from other populations.

Discussing the organ and tissue donation scenario is fundamental to disseminate knowledge among the general population, mainly because it enables decision-making given the dilemmas that arise in the face of potential donors.

CONCLUSION

The main obstacle to organ donation is lack of information about the procedures for the family. Lack of information in all stages of this process culminates in low donation effective rates and in increased family refusal, as it holds the decision-making power over the deceased person's body. Therefore, making the population aware of the desire to be a donor or not for the family can reduce the family discourse that strengthens refusal.

It is fundamental to promote a peaceful and welcoming environment for the family members, prioritizing interviews with more than one relative. This becomes essential for both to feel the support of the family. However, despite being part of the natural life cycle, there is still resistance to talking about death when realizing that brain death is still poorly understood by the population, which can make it difficult for the family to accept death.

It was concluded that the meanings of family refusal permeate fear, a feeling of emptiness and lack of information about the processes involved in organ and tissue procurement and donation, as well as cultural and religious aspects; although despair, pain and lack of empathy on the part of the health teams can also corroborate refusal.

Consequently, it is suggested to expand clarification spaces on organ and tissue donation through lectures, seminars, distribution of information, social networks, in schools, associations and colleges, among other environments accessible to the general population, aiming to solve doubts and highlight the relevance of this process for public health in order to characterize new perspectives on donation.

CONTRIBUTIONS

Contributed to the conception or design of the study/research: Fontenele RM, Costa NR. Contributed to data collection: Costa NR. Contributed to the analysis and/or interpretation of data: Fontenele RM, Costa NR, Almeida, HFR. Contributed to article writing or critical review: Fontenele RM, Costa NR. Final approval of the version to be published: Silveira WJA, Moraes LMN, Almeida, HFR.

ACKNOWLEDGMENT

To the In-Hospital Commission for Organ and Tissue Donation (*Comissão Intra-Hospitalar para Doação de Órgãos e Tecidos para Transplantes*, CIHDOIT) of the Dr. Carlos Macieira High-Complexity State Hospital from São Luís – Maranhão, for welcoming us and granting us the possibility to conduct this study.

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Conflicts of interest: No
Submission: 2022/28/11
Revised: 2023/27/01
Accepted: 2023/29/03
Publication: 2023/18/05

Editor in Chief or Scientific: José Wicto Pereira Borges
Associate Editor: Francisca Tereza de Galiza

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