Brazilian Journal of TRANSPLANTATION

https://doi.org/10.53855/bjt.v28i1.681_ENG

ORIGINAL PAPER

Phenomenological Analysis of Psychological Subjective Experiences that Motivated Refusal of Organ Donation in Brazil

Anderson Galante[1,2,*], Leila Bernarda Donato Göttems[3], Tommy Akira Goto[4]

1.Central de Transplantes do Distrito Federal – Brasília (DF) – Brazil.

2.Escola de Saúde Pública do Distrito Federal – Brasília (DF) – Brazil.

3.Universidade do Distrito Federal – Escola Superior de Ciências da Saúde – Programa de Pós-Graduação em Ciências para a Saúde – Brasília (DF) – Brazil.

4.Universidade Federal de Uberlândia – Faculdade de Psicologia – Programa de Pós-Graduação em Psicologia – Uberlândia (MG) – Brazil.

*Corresponding author: anderson.galante@fepecs.edu.br

Seccion editor: Ilka de Fátima Santana F. Boin

Received: Mar. 26, 2025 | Approved: June 6, 2025

ABSTRACT

Objectives: To understand the psychological subjective experiences that motivated the refusal of organ donation for transplants. **Methods:** Qualitative, exploratory study, developed in light of the psychological-phenomenological method, with 56 family members who did not authorize organ donation in different geographic regions of Brazil, whose states presented the highest absolute number of refusals. **Results:** Distrust in the transplant system was the invariant meaning identified, and the variant meanings were prolongation of family suffering, insecurity in decision-making, threat, regret, injustice, disrespect, and psychological helplessness. The meanings were structured by the participants' perception, based on the relationship with the healthcare teams, the absence of services, the lack of maintenance of brain death diagnostic equipment, the Brazilian political image, and the lack of knowledge of the rules of the public policy on donation and transplantation. The meanings experienced were analyzed, and the psychological subjective experiences were identified: perceptive intentionality, psychic causality and motivation, impulse for protection, and affective-cognitive experience, which culminate in the refusal to donate. The analysis identified the psychological experience as affective-cognitive. **Conclusion:** The meanings reveal that the distrust factor was present, to a greater or lesser extent, in all family members. There are three psychological variables: I) family members have a negative perception; II) there are affective and cognitive motivations; and III) a need for protection. The lack of knowledge of the population studied regarding the operation of the transplant system seems to be an element that has negatively impacted the donation subsystem, and the elements indicated can guide public policy managers in the development of actions that inform and enlighten society on an ongoing basis, and not just through annual campaigns.

Descriptors: Request for Consent for Organ Donation; Health Management; Health Policy; Psychology; Phenomenology.

Análise Fenomenológica de Vivências Psicológicas que Motivaram a não Doação de Órgãos no Brasil

RESUMO

Objetivo: Compreender as vivências psicológicas que motivaram a não autorização da doação de órgãos para transplantes. **Métodos:** Estudo qualitativo, exploratório, desenvolvido à luz do método psicológico-fenomenológico, com 56 familiares que não autorizaram a doação de órgãos em diferentes regiões geográficas do Brasil, cujos estados apresentaram maior número absoluto de recusas. **Resultados:** Desconfiança no sistema de transplante (ST) foi o significado invariante identificado, e os variantes foram prolongamento do sofrimento familiar, insegurança na tomada de decisão, ameaça, pesar, injustiça, desrespeito e desamparo psicológico. Os significados foram estruturados pela percepção dos participantes, a partir da relação com as equipes assistenciais, da ausência de serviços, da carência de manutenção de equipamentos de diagnóstico de morte encefálica, da imagem política brasileira e do desconhecimento das normas da política pública de doação e transplante. Os significados vividos foram analisados e foram identificadas as vivências psicológicas: intencionalidade perceptiva, causalidade psíquica e motivação, impulso de proteção e vivência

afetivo-cognitiva que culminam na recusa à doação. A análise identificou que a experiência foi vivida como afetivo-cognitiva. **Conclusão:** Os significados revelam que o fator desconfiança esteve presente, em maior ou menor intensidade, em todos os familiares. Há três variáveis psicológicas: I) os familiares têm percepção negativa; II) há motivações afetivas e cognitivas; e III) necessidade de proteção. O desconhecimento da população estudada sobre a operacionalização do ST parece um elemento que tem impactado negativamente o subsistema de doação, e os elementos apontados podem nortear os gestores da política pública no desenvolvimento de ações que informem e esclareçam a sociedade de modo contínuo, e não apenas por campanha anual.

Descritores: Solicitação de Consentimento para Doação de Órgãos; Gestão em Saúde; Política de Saúde; Psicologia; Fenomenologia.

INTRODUCTION

Transplantation as a therapeutic option is widely adopted worldwide, and the disparity between the demand and supply of organs and tissues is a global issue, highlighting that numerous factors positively and/or negatively impact this complex system[1,2]. Approximately 150,000 transplants are performed annually; however, the supply of organs meets less than 10% of the global need[3].

The Brazilian public policy on organ and tissue donation and transplantation, since its implementation, has undergone a constant process of refinement, given the complexity of the transplant system (TS), comprising its three subsystems: donation, procurement, and transplant. Social participation is essential, especially in the donation subsystem, since donation in Brazil is consented and there is no transplant without donation[4].

Public policies, as products of organized society, are a set of strategic actions planned by governments, social sectors, and/or citizens, implemented and evaluated by the three constituted national powers, to prevent and/or solve problems, representing the interests of society, as well as benefiting and protecting it[5-7]. As complex systems, they are influenced by social capital, but it is also through these that a country's network of norms and patterns of trust can be built and rebuilt[8].

Social capital refers to the structure and organization of society, as well as the relational connections that are based on horizontalization, trust, and reciprocity. It is believed to be capable of enhancing physical and human capital[9,10].

Social connection, based on trust and reciprocity, is capable of mobilizing citizens for actions of collective interest, for the conscious use of resources, and for producing and using material and human resources[8].

In terms of the donation subsystem, the average refusal to donate organs in Brazil over the last decade has fluctuated above 40%[11,12], while the ideal by European standards is below 10%[13].

In 2023, the national average of non-authorized donations was 42%, with the worst result at 78% in a state in the Central-West region and 27% in a state in the South region, which obtained the best result[12].

Family members of potential organ donors experience unstable situations with health problems during hospitalization, such as the process of diagnosing brain death and receiving news of brain death from the health team when they are interviewed by the organ procurement network team about the possibility of donation[14].

Failure to authorize the donation was listed as the primary obstacle in the donation process[15]. To analyze the impact of public policy, it is essential to consider long-term data since, in the last 10 years, studies have shown that, among the explicit reasons given by family members in different Brazilian regions and different study periods, are the deceased declared during his lifetime that he would not be a donor; lack of knowledge of the deceased's wishes regarding donation; family's desire to keep the body intact; waiting time to receive the body; lack of knowledge about the diagnosis of brain death; dissatisfaction with the team's communication with family members; lack of clarity in information; donation interviews with excessive technicalities and lack of empathy; anger with the hospital team; religion; and negative experiences[14-17], without presenting or analyzing the psychological behaviors and subjective experiences associated with the refusal to donate.

Brazil has a legal and regulatory framework that establishes safety standards for donation and transplantation, and there are recommendations for good care and management practices[18,19]. Despite this, the high percentage of refusal to donate in Brazil has generated discussions about the trade of organs and tissues to make it possible to increase the availability of transplants[20].

The explicit reasons for refusal have already been widely explored, but the percentage remains high. We are compelled to ask: what is there in the experience and psychological experiences of family members that have motivated them not to authorize the donation of organs and tissues from their brain-dead relatives?

To contribute to filling this knowledge gap, the objective of this study was to understand the psychological experiences that motivated the non-authorization of organ donation for transplants based on the description of family experiences during the hospitalization of the potential donor, the identification of the essential meanings and variations of the experiences, and the description of the psychological experiences.

METHODS

Exploratory, qualitative study[21], phenomenological-empirical, which appreciates human manifestations as they occur and without theoretical interference, based on phenomenological reflection, constituted by the epoché and eidetic reduction[22-25], with analysis of experiences: a) obtain the reports of the experience; b) transcribe the reports; c) present the synthesis of the experience from the researcher's perspective; d) identify the invariant and variant units of meaning; e) identify the psychic experiences; and f) describe the psychic experiences[25,26].

The phenomenon studied was the psychological experience of participants facing the death of their family members and their expertise when interviewed about the possibility of donating organs for transplants, given the decision to refuse.

The selection of the co-participating State Transplant Centers (Centrais Estaduais de Transplantes-CET) was by convenience sampling, using the criterion of the highest absolute number of refusals to donate that occurred from January to June 2022, as this was the year in which the research project was prepared, with 20% of the total number of refusals selected from each state and 100% from the Federal District (DF), as this is where the leading researcher works. Due to the non-agreement of a CET from the Southeast Region, Rio de Janeiro (RJ) was included, with the second-highest absolute number of refusals. The co-participants were from Amazonas (AM), Bahia (BA), Goiás (GO), Rio de Janeiro (RJ), Rio Grande do Sul (RS), and the Federal District (DF)[27].

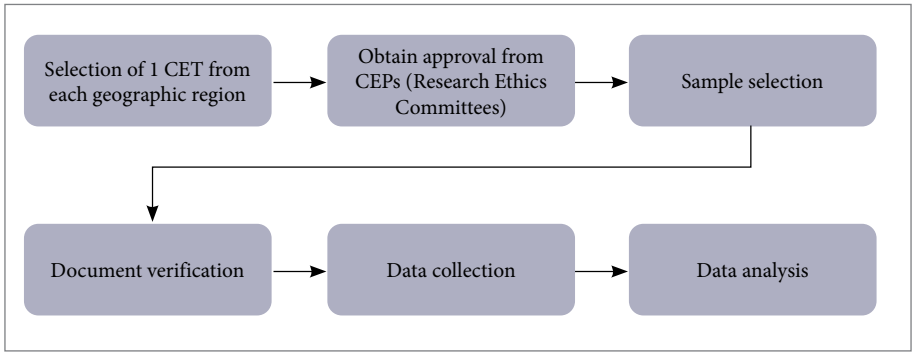
The sample was a simple random probability, assigning a number to each kit of documents from non-donors. The study cases were selected by lottery through the Sorteador website, with seven from AM, 32 from BA, 34 from DF, and 20 from GO, totaling 93 possible participants. Respected The number of refusals from January to June 2022, and selected the cases of refusals from January to June 2023 for in-depth analysis.

The inclusion criterion was that the family member responsible for the refusal, whose name was registered in the CETs document kit, as required by the law[28].

The invitation to potential participants was made by telephone. There was no willingness to conduct an in-person interview, and those who accepted the telephone interview reported difficulty in receiving the Free and Informed Consent Form (FICF) virtually, signing it, and returning it. The FICF was sent via WhatsApp, and a screenshot of the conversation was taken. Some people did not answer the phone calls; in these cases, an invitation message and the FICF were sent via WhatsApp, requesting a response.

Data collection took place from December 2023 to October 2024. At the CETs, the collection was characterized by access to document kits for verifying documentary compliance. Each of the 93 kits was coded and registered in an Excel spreadsheet by state, with the following data: name of the person who did not authorize the donation, degree of kinship, date of death, reason for refusal to donate, and telephone number of the family member. The interview was conducted by the researcher, lasting 10 to 50 minutes, using a smartphone, recorded with the Call Recorder application, with the guiding question, "How was the experience of the death of your family member and the non-donation of organs and tissues for you?" and complementary questions: "Were any other factors present during your experience related to the non-donation of organs?" and "Would you like to report anything about your experience that you have not yet mentioned?".

Fig. 1 presents the methodological steps.



Source: Elaborated by the authors.

Figure 1. Stages of methodological procedures.

There was no data collection in RS, out of respect for the psycho-emotional condition of the people of Rio Grande do Sul, who were facing the consequences of the climate tragedy, nor in RJ due to budgetary limitations for the project.

The interviews were recorded and checked. The experience reports were identified by a code consisting of the letter "P" (for the participant), followed by the acronym of the Federative Unit and the corresponding registration number on the sampling

spreadsheet. The stages of the phenomenological method were operationalized with the use of free imaginary variation from the researcher's perspective[22-26].

The epoché was characterized by the researcher's suspension of knowledge about the TS, regardless of the content and context reported, upon hearing the participants' reports. The researcher did not provide technical information, guidance, clarification, or contestation. Finally, the psychological-phenomenological reduction was undertaken to achieve the synthesis of psychological meanings.

The study was approved by the CEPs of the Health Sciences Teaching and Research Foundation of the Federal District, under Opinion No. 5,982,078, with scope for AM and RJ, since the CETs are not linked to a CEP, by the Health Department of the State of Bahia, under Opinion No. 6,192,213, by the School of Public Health of the Health Department of Rio Grande do Sul, under Opinion No. 6,137,192, and by the State Health Department of Goiás, under Opinion No. 6,050,896.

This study discusses public policy on donation and transplants without specifying a particular sector or department.

RESULTS AND DISCUSSION

Of the 93 possible participants, 29 (31.2%) did not have their phone numbers registered in their medical records. Their numbers were unavailable, and they did not have a WhatsApp profile. Of the 64 people with active numbers, four were from AM, 19 from BA, 31 from DF, and 10 from GO. Of these, eight (12.5%) did not agree to participate in the research.

The final sample consisted of 56 participants, who contributed in two ways: seven (12.5%) were interviewed, and their content was recorded; 49 (87.5%) presented behaviors and justifications for not being recorded, which were essential components for the phenomenological analysis.

The summary of the experiences is presented below.

PDF 02 – They said she wanted to end the matter that day and stop suffering; the situation still affects them emotionally; they considered the subject of organ donation to be dangerous and are afraid to talk about it.

PDF07 – They considered the donation to be extremely important and revealed that they were in favor of it; they presented a religious justification for helping other people with what they have received freely from God; they reported that they did not know much about the subject and that she was concerned about the possibility of the organs being removed without their authorization; their distrust was based on the fact that Faustão (a famous TV host) had been transplanted in a short time because he had money and was well-known; this fact made them believe that it was possible to skip the line. They added that when the team requested between 3 and 5 days to deliver the body for burial, they considered only the desire to end the suffering of the family and that time did not make sense; they reported that they felt a lack of professional psychological support and that the lack of information may have interfered with their decision.

PDF 10 – They reported that they were in favor of donation, that they had already authorized the donation of organs from one of their brothers, but that, in the case in question, they did not authorize it out of anger because their family members died in the queue waiting for organs and no one donated to them; the Faustão episode proved that it is possible to obtain benefits when a person has money.

PDF 14 – They said that the little they knew about the donations were from one or two television advertisements and that the image of Brazilian politics makes them suspicious of everything. The brain death diagnostic equipment was broken, and they believed that their family member was being kept alive on the equipment only because they were interested in the organs, without thinking about their family's suffering. They do not trust the system because there is no transparency, and the fact that the donor family cannot meet the recipient family does not allow for social control. They mentioned that politicians do everything in their interest and believe that this can also happen to benefit acquaintances who need transplants. When the team requested 3 days to deliver the body, they considered that, in addition to being disrespectful to the family, it could not be honest to ask for so much time and that the requested interval should be to choose who would benefit. They reported that, as they had never discussed the matter with their father, they decided to end the situation and stop suffering. Afterward, they realized the importance of donation and felt regret for not having spoken to their father. They considered that there is little information and that the government does not invest in clarification. They talked to their family and informed them that, from then on, they were donors.

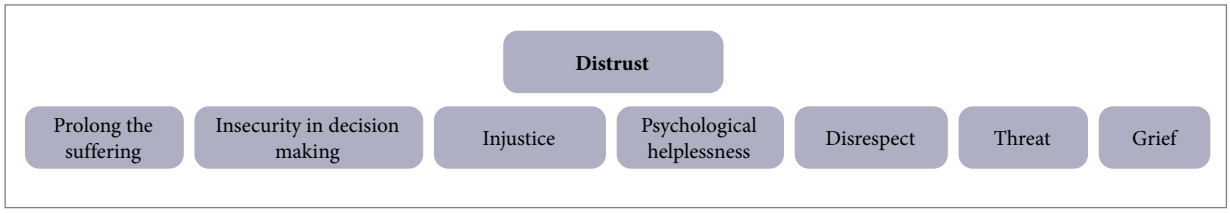
PDF 20 –They reported the period of intense family suffering during hospitalization, despite the healthcare team's complete transparency regarding the prognosis; they did not believe in the diagnosis of brain death because, in their view, only God can decide and, if their family member was breathing, they could not be dead; they believed that the doctors were keeping their family member alive to keep the organs viable for removal and that did not think about the family's anguish. They recognize the importance of donations and know that people need them, but do not trust the TS because there is a lack of social control, as it is impossible to confirm whether only the authorized amount was removed, and because they believe it is possible to skip the line.

If the donor family could know who received the organs, it would be a way for the system to be more transparent and reliable. They felt pressured by having to decide whether to donate in a short period and felt threatened when informed that if they did not authorize the donation, the machines would be turned off. The team requested between 3 and 5 days to return the body, which they considered to be too long and, therefore, disrespectful and inhumane; as they did not trust the system, they did not think it more viable to end everyone's suffering.

PBA 01 – They reported that they did not feel comfortable or safe talking about the subject, not because of grief but for another reason. They asked to close the conversation.

PBA 22 – It was reported that the experience was dramatic, that the psychologist and the doctor explained the evolution of the condition, and that this conduct made the family prepare for death. It was reported that they were in favor of donation, knowing that the line is long, but that given the family's shock, most decided not to authorize the donation because they believe that there is organ trafficking in Brazil, not of hearts, but of kidneys, and cited the African continent as an example. They mentioned the fear that their family member's organs would be lost and that they do not trust the system's work because Brazilian politicians only help those who are interested in them and mention that because they are poor and live in the interior of the state, they feel abandoned by the political class.

The invariant meaning was considered essential because it was present for all participants, and the variant meanings, which represented the experiences that emerged from the reports of some participants, were identified. (Fig. 2).



Source: Elaborated by the authors.

Figure 2. Schematization of invariant and variant meanings.

The invariant meaning was "distrust" in the TS, whose representative quotes were:

> *This is a dangerous subject… it's scary to talk about it* (PDF 02);
>
> *I was suspicious and afraid because I confess that the situation with Faustão at the beginning made me doubt about jumping the queue because he had money* (PDF 07);
>
> *Just because you're poor you die in line. Then a Faustão comes along and gets everything because he has money. That's why I didn't donate* (PDF 10);
>
> *I believe that there are a lot of people who are cut in line, because that's Brazil, right? There are numerous issues in our country. Politicians do whatever they want, and of course, a relative or friend of theirs would cut in line, imagine otherwise!* (PDF 14);
>
> "*For many days, they kept him on life support just to keep him and think about the organs… I honestly don't trust them; I don't know, right? Because, there, they're the ones who do everything; they do everything inside, and we only see the body, the body at the IML (Forensic Institute). So, if they removed it or not, how am I supposed to know?… but to what extent can we be sure that these organs are actually going to a person who really needs them? If they had transparency… if only the family that is donating had access to who is receiving them* (PDF 20);
>
> "*I don't feel comfortable and safe talking about it, not because of grief, but for another reason* (PBA 01);
>
> "*I don't trust it very much because we don't know how it works… family members didn't want to [donate] for fear of loss… fear of organ trafficking* (PBA 22).

Trust is based on dimensions such as integrity, which represents honesty and reliability; competence, a synonym for both technical and interpersonal skills; consistency, which encompasses factors such as security, predictability, and judgment; and loyalty. The act of trusting allows us to assume a state of vulnerability based on positive beliefs about the intentions, behaviors, and ethical movements of another person. The social context influences individual behaviors, which in turn affect acts of citizenship[29,30]. For social psychology and sociology, trust is the act of a person expecting an institution or social organization to behave within expected civil parameters in terms of honest intention, loyalty, sincerity, and efficiency in its function[31].

In the absence of a relationship of trust, the person tends to remain alert and exercise control over the situation. This absence is what happened with family members who refused organ donation because they did not perceive the dimensions of integrity,

competence, consistency, and loyalty in the TS institution, among the professional agents, or the political agents. They remained in control, exercising their autonomy in decision-making.

Individual perception supports trust because to trust something or someone, one must meet the criteria established by the systems of beliefs, values , and knowledge.

The varying meanings are presented below.

“Prolonging family suffering” alluded to the acute emotional crisis experienced by family members, whose statements were:

> *After the body was removed from there and taken to the organ collection center, the time I could wait to be buried was between 5 and 7 days… I was already suffering for 7 days there, right? Waiting for that protocol… That time is not viable, and my family decided not to donate* (PDF 7);
>
> *They asked for 3 days to deliver my father's body to us, so I said, "It's going to take too long; I want to get this over with... we've been suffering for 2 weeks now", and that's when I said I didn't authorize it* (PDF 14);
>
> *The length of time he was going to be there, and the suffering we suffered, you know? Because I had already been going back and forth for 4 days… and another 3 to 5 days is a long time to remove the organs; it has to be done with less suffering for the family* (PDF 20).

The time requested by the teams for the recruitment process to take place triggered negative perceptions. The team's chronological space differs from the qualitative time that the family needs[14]. Death can be interpreted as something good or bad. Still, in Western culture, it is a cause of emotional suffering with a negative meaning[32], and acute emotional crises interfere with the personal decision to interrupt the triggering stimulus.

"Insecurity in decision-making” was related to the lack of knowledge about TS:

> *I knew very little about donation, only what we saw on TV… My family also knows very little about it… what they think is just the same as what I heard from very superficial information… It is very complicated to see a relative of ours there with a warm body, heart beating and we understand that he is no longer alive, that he has already suffered brain death, and that he is no longer able to live… I just wish it could be more enlightening for us, the population, right?… So many people who could perhaps be donors, and who, sometimes, due to lack of clarification, lack of education, lack of teaching, do not donate* (PDF 7);
>
> *I talked to my older brother, who lives in another country, and he said, "Yes, it's okay." The other one who lives here said "no"' I couldn't talk to my mother, and that's when I told him I wouldn't do it… because all I knew was from the occasional commercial on TV, as the government doesn't invest in it... there's little information on the subject, and the few advertisements are just asking for donations, but none of them explain how it all works (PDF 14);*
>
> *I doubted the diagnosis of brain death…* (PDF 20).

Security is built through established relationships, and insecurity, as an emotional state, can be characterized by a lack of self-confidence and one's abilities, in addition to being associated with uncertainty, instability, anxiety, and nervousness; it typically connotes a perception of risk and external threats.

Insecurity was linked to a lack of knowledge about the donation, collection, and transplant processes. Notably, one of the participants emphasized that there is a lack of information disseminated on the subject. When this occurs, it is typically done by asking the population to donate without providing explanations about the system. Thus, the difficulties of the family in understanding what the organ procurement network team is informing them about can be accentuated, which is why the team needs to provide space for dialogue and not turn the moment into a monologue in which only the team speaks.

“Injustice” emerged in the context of the perception of rights violations:

> *I think it is unfair and dishonest to society that we cannot know who received the organs because it would be a way for society to control* (PDF 14).

Social psychology defines justice as the concept of equity and proportionality in relationships. Therefore, it should not be ignored that when interaction with other people generates a perception of imbalance, the perception of injustice emerges, accompanied by the associated feeling of anger. The experience of injustice affects not only the individual but also the social group with which they interact[33].

During the interview, PDF 10's tone of voice represented their anger and how much he believed the TS had wronged them because some of their family members had died while waiting for a transplant. Based on their perception of injustice, they, who had already authorized organ donation, changed their attitude and may be influencing other people with their negative experience in the donation and transplant process.

“Psychological helplessness” was related to the lack of psychological support during hospitalization and at the time of the interview:

> *A painful process, because in this case, we spent almost 5 days waiting, right? We wish we had more access to psychological help during this wait* (PDF 07);
>
> *I got the news right away. It was a shock… I think it's a total lack of respect for the family, you know? Because when we bring a patient to the hospital, we immediately say that there's no way out, there's nothing we can do, it's up to God, we say it right away… and they don't give us any support* (PDF 20).

Helplessness denotes a lack of assistance and support and, in the social context, is associated with situations in which a human being feels powerless in the face of a particular problem. Social relationships influence feelings of helplessness; when experienced, it causes anguish, often triggered by a dangerous situation due to the loss of something important[34].

"Disrespect" referred to the time when donation teams requested to carry out organ collection and hand over the body to the family:

> *Three and five days to return the body is a long time and, therefore, disrespectful and inhuman* (PDF 20).

Respect is about care, attention to the rights of others, and dignity, and is fundamental for building social ties and harmonious coexistence as well as solidifying mutual respect[35]. Feeling disrespected arises when a person perceives that their boundaries and rights have been violated.

"Grief" showed the family members' lack of courage to talk about donation during life:

> *Because if my father had said, when I die you donate my organs, his wishes would also have prevailed* (PDF 14);
>
> *There isn't much talk about this type of situation involving death, organ donation… only those who are in the situation know the feeling at the time of death, it's excruciating, having to decide without knowing the other person's wishes* (PDF 20).

Grief is an emotional state that manifests sadness, pain, remorse, or regret. The Western cultural context has a negative perception of the phenomenon of death since, as it is a subject that triggers emotional reactions, it is postponed or not addressed.

"Threat" was represented by the statements:

> *I don't feel comfortable and safe talking about it, not because of grief, but for another reason* (PBA 01), and
>
> [...] *then, suddenly, they come and say, I have to turn off the machine… they do things under pressure if you don't donate we have to turn off the machines* (PDF 20).

This finding represented a critical insight, as the topic of organ donation is closely tied to sensitivity and solidarity rather than danger. What stereotype does the TS carry that makes people afraid to talk about organ donation and/or authorize it?

In all the psychological meanings identified, explicit reasons for refusal were present, which have been compiled by several researchers over the last decade[14-17]. However, this research reveals a new component: how the family members who gave explicit reasons experienced the process of hospitalization and refused to donate.

Five participants stated that they recognized the importance of donation, but despite this, the meaning of distrust overrode the optimistic view.

Every act represents an intention; therefore, overt physical or psychological behavior is subject to analysis and interpretation. In this sense, the content presented by the 49 participants who were not recorded was still analyzed.

The behaviors and justifications presented were as follows:

> *I will read the document [FICF], and I will be in touch* (PBA 13),

which did not happen, and there was also no response to the researcher's subsequent contact; the interview was scheduled, but they did not answer the phone or respond to the message after the attempt (PGO 2, PGO 17, PBA 13, PDF 01, PDF 16); others interacted with the researcher by telephone, but ended the call when informed about the research topic (PBA 5, PGO 18, PBA 23); there were also those who did not respond to the WhatsApp message containing the documents and explanations about the research, even though they had visualized them (PAM 2, PAM 5, PBA 12, PBA 32, PDF 11, PDF 34, PGO 5, PGO 8).

As explored in the meaning of "Prolonging family suffering", both the phenomenon of death and emotional pain and insecurity are aversive events. In this sense, the psychological resistance to participating in the interview may be related to individual self-protection mechanisms anchored in the experiences obtained with the death of their family members.

Psychological resistance is an individual protection mechanism that emerges in situations of change as a response to potent threats aiming to avoid harm[36]. This understanding of resistance aligns with intentionality as the capacity of the human mind to relate to the world through the meaning of things and awareness of its experiences[22,37].

However, in addition to emotional pain, some people mentioned insecurity and fear of talking about the subject and refused to record the interview, even though they were informed about the safety of the research procedures. The intention to participate initially indicated positive signs, but insecurity ultimately prevailed.

In this context, how have family members perceived TS? What is the motivation for their distrust? How was the experience lived?

Perceptual intentionality

In the phenomenological approach to perception, the body serves as a perceptive subject involved in the constitution of meaning, through which the individual relates to the world and constitutes themselves as a being. Perception, being the human capacity to interpret and organize stimuli and attribute meaning, is not limited to the passive reception of sensory data, as it is an active phenomenon based in the body, the essential mediator of the person's interaction with the world[38].

The perceptive process involves both the body and consciousness, as the body not only perceives but also gives meaning to what is perceived. Perception is inseparable from bodily existence, being lived, subjective, and directed towards what is being perceived – perceptive intentionality. It is not neutral since it carries within itself a dimension of desire, an impulse that, when recognized, generates an intention and a motivation to act. Both perception and motivation are situated in a socio-historical context. The way each person perceives the world and what motivates them to act is shaped by interactions. Perception is not a solitary, individualistic activity; it emerges from shared experiences[38].

Considering the perceptive intentionality, how have the family members participating in this research perceived the TS?

If, on the one hand, there is recognition that organ donation is essential, on the other hand, there is a negative meaning attributed to the system, based on beliefs and opinions that the TS does not have consistent rules, that there are privileges for recipients who are better off financially, that political agents can interfere with benefiting people of interest, and that it is possible to traffic organs and tissues in Brazil. It is also noted that there is a lack of knowledge among citizens regarding their rights in the donation and transplant process.

It is noted that the TS has been perceived negatively. When perceiving, in its context, that the TS poses some risk to physical integrity, the psycho-emotional structure, or morality, the human tendency is to activate the mechanisms of protection of oneself and others.

Psychic causality and motivation

No less critical for the results of this research is the understanding of the motivational relationships that operate within the psyche, how they underpin knowledge, and how motivation acts on human consciousness, directing it toward the execution of psychic, physical, bodily, and behavioral acts.

Perception and motivation are interconnected, and the latter presents both psychic and physical causalities, as both the physical and spiritual dimensions influence the former. The psyche has specific characteristics in each individual that can be sensitive or spiritual. By spiritual, we understand the transcendent personal dimension inherent to Humanity, which enables us to know ourselves, fulfill ourselves, and go beyond ourselves to overcome the limits of corporality, empathizing, reasoning, deciding, and acting[39]. Psychic causality is qualitative; it is not measurable, and it is influenced by the environment and the context in which it is experienced[38-40].

The psychophysical subject does not have the power to decide whether or not to react, as impulses represent psychic events without the will being activated. The psyche represents the passive sphere; its law is causality. In the spirit, there is the active sphere governed by motivation. In this context, the individual can perceive psychic operations and act in a way that is distinct from involuntary suggestion.

Motivation is not external but rather the force that emerges from the individual's relationship with the world, stemming from their perception of the environment. It does not arise from an isolated rational plan but from the primary interaction between the body and the world. By perceiving the environment, the subject is impelled to act, move, and respond to this environment[38].

In this context, it is possible to infer that, based on the negative perception they reported about TS, which generates distrust, the family members were motivated to react, not authorizing organ donation as a particular response to the environment that they perceive as threatening and that makes them vulnerable.

In the reports, motivations of an affective dimension associated with belief and value systems were identified, and, in the cognitive dimension, those related to lack of knowledge. Both characteristics describe the psychic dimension and appear to be sustained by the lack of information on the subject.

Protection impulse and affective-cognitive experience

Trusting connotes depending on another person and accepting being vulnerable to them. Trust can be both an emotional attitude and a reflexive attitude[41]. The attitude of trust is influenced by the individual's socio-historical context, beliefs, and values, but it is also constructed in the present. It implies an attitude of interdependence, as a person can trust a specific institution by trusting a person who works at the institution in the same way as they trust other people. The same occurs with distrust[41,42].

While the act of remembering evokes experience and experience from memory, perception captures objects and interactions as data from immediate experience[23,38].

It is possible to infer that the participants distrust public managers, political agents, and health professionals with whom they had contact, all of whom, to a greater or lesser extent, were agents of the TS. Because they distrusted the executors of public policy, the distrust was generalized for the TS institution, implying negative consequences for its reputation and image. It is inferred that the participants identified that the act of donating organs can cause harm to themselves or others.

The psychophysical impulse of protection is a movement related to the need for security and stability, therefore constituting a defense mechanism. In the hierarchy of basic human needs, after the physiological needs, comes the need for safety43. Failure to meet this need, such as distrust, can generate uncertainties typical of crises and activate the impulse to seek protection.

Affective acts, essential constituents of subjective experience, and the attribution of meaning to the lived world, are related to the valuation, emotions, and feelings that give meaning to acting in the world. Affection is essential in motivation and decision-making because when experiencing something, the emotions, values, and beliefs of society are also captured, which are fundamental for the formation of social life and a sense of belonging[23].

When they perceived risks to themselves and their families in the experience, the participants experienced the psychophysical impulse to protect themselves and others, characterizing the affective experience, directed towards something objective but imbued with the value-based social baggage and the cognitive experience, by acting concretely and not authorizing organ donation as a form of protection and ceasing to have contact with the aversive phenomenon: the experience of the death of their family members.

CONCLUSION

The essential meaning "distrust in the TS" and the variant meanings lead to the understanding that distrust permeates them to a greater or lesser extent, which is why the psychological-phenomenological analysis was developed on the invariant meaning.

After identifying the meanings present in the experiences, the developed analysis revealed three psychological variables: (I) family members have a negative perception; (II) there are both affective and cognitive motivations; and (III) a need for protection exists. The analysis revealed that the psychological experience occurred in conjunction with the affective-cognitive experience.

This study highlights the contribution of psychology to management, given the understanding that subjective factors impact objective results and that the management of complex systems, such as transplantation, demands multidisciplinary efforts and interactions since only in this way will the social capital on public policy for organ and tissue donation for transplantation be improved in individual and collective contexts, capable of generating greater engagement and increasing authorization for donation.

The lack of knowledge of the population studied about the operationalization of the TS appears to be an element that has negatively impacted the donation subsystem, and the elements highlighted can be used as subsidies for public policy managers to develop actions that inform and clarify society on an ongoing basis and not just through an annual campaign.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Galante A, Göttems LBD, Goto TA; **Conception and design:** Galante A; **Data analysis and interpretation:** Galante A, Göttems LBD, Goto TA; **Article writing:** Galante A; Galante A, Göttems LBD, Goto TA; **Final approval:** Galante A, Göttems LBD.

DATA AVAILABILITY STATEMENT

All dataset were generated or analyzed in the current study.

FUNDING

Not applicable.

ACKNOWLEDGEMENT

To CETs AM, BA, GO, DF, RJ, RS; Secretaria de Estado de Saúde do Distrito Federal and Câmara Legislativa do Distrito Federal – Deputado Distrital Jorge Vianna and Gabriella Ribeiro Christmann, diretora da CET-DF.

REFERENCES

1. Organização Pan-Americana da Saúde [Internet]. Estratégia e plano de ação sobre doação e acesso equitativo a transplante de órgãos, tecidos e células 2019-2030. 57º Conselho Diretivo: Documentos de Trabalho CD57/2019. https://iris.paho.org/handle/10665.2/59704
2. Torres LC, Ferreira Filho FJ, Cruz JRD, Pinheiro PL de O, Figueiredo FJG. Transplantes de órgãos: abordagens éticas e soluções legais. Rev Bioét, 2024; 32: e3703PT. https://doi.org/10.1590/1983-803420243703PT
3. World Health Organization. Human organ and tissue transplantation: Seventy-Fifth World Health Assembly. Switzerland: WHO; 2022 [access on 25 Feb. 2025]. Available at: https://apps.who.int/gb/ebwha/pdf_files/WHA75/A75_41-en.pdf
4. Galante A. Teoria de sistemas e o Sistema Nacional de Transplante. Curso lato sensu gestão do Sistema Brasileiro de Transplante de Órgãos e Tecidos. Escola de Saúde Pública do Distrito Federal; 18 Feb 2025.
5. Göttems LDB, Mollo MLR. Neoliberalismo na América Latina: efeitos nas reformas dos sistemas de saúde. Rev Saude Publica, 2020; 54(74). https://doi.org/10.11606/s1518-8787.2020054001806
6. Furtado BA, Sakowski PAM, Tóvolli MH. Abordagem de sistemas complexos para políticas públicas. In: Furtado BA, Sakowski PAM, Tóvolli MH. Modelagem de sistemas complexos para políticas públicas. Brasília: IPEA; 2015. p. 21-41.
7. Rand W. Sistemas complexos: conceitos, literatura, possibilidades e limitações. In: Furtado BA, Sakowski PAM, Tóvoli MH. Modelagem de sistemas complexos para políticas públicas. Brasília: IPEA; 2015. p. 43-64.
8. Coleman JS. Social capital in the creation of human capital. Am J Sociol, 1988; 94: 95-120. https://doi.org/10.1086/228943
9. Putnam R. Bowling alone: the collapse and revival of American community. New York: Simon & Schuster; 2000.
10. Bourdieu P. The forms of capital. In: Richardson JG. Handbook of theory and research for sociology of education. New York: Greenwood; 1985. p. 241-58.
11. Associação Brasileira de Transplantes de Órgãos. Dimensionamento dos transplantes no Brasil e em cada estado: 2006-2013. Registro Brasileiro de Transplantes. 2013 [access on 22 Feb. 2025]; 29(4). Available at: https://site.abto.org.br/wp-content/uploads/2020/06/rbt2013-parcial1.pdf
12. Associação Brasileira de Transplantes de Órgãos. Dimensionamento dos transplantes no Brasil e em cada estado: 2016-2023. Registro Brasileiro de Transplantes. 2023 [access on 22 Feb. 2025]; 30(4). Available at: https://site.abto.org.br/wp-content/uploads/2024/04/rbt2023-restrito.pdf
13. Knihs NS, Roza BA, Schirmer J, Ferraz AS. Aplicação de instrumentos de qualidade em doação de órgãos e transplantes da Espanha validados em hospitais pilotos em Santa Catarina. J Bras Nefrol 2015; 37(3): 323-32. https://doi.org/10.5935/0101-2800.20150052
14. Knihs NS, Leitzke T, Roza BA, Schirmer J, Domingues TAM. Compreensão da vivência da família frente à hospitalização, morte encefálica e entrevista para doação de órgãos. Cienc Cuid Saude 2015; 14(4): 1520-7. [access on 22 Feb. 2025]; Available at https://pdfs.semanticscholar.org/998a/5e8856dd1d92af86f667aa968ee506b2dcb1.pdf
15. Oliveira AFCG, Cardoso RAB, Freitas KC, Lotte EJ, Lucas BL. Lacunas e fatores impeditivos da doação de órgãos no Brasil: revisão de literatura. Braz J Tranpl, 2023; 26: 2723. https://doi.org/10.53855/bjt.v26i1.520_PORT
16. Batista MEP, Telles CFS, Pierotto AAS, Barilli SLS, Rocha KR, Rosa RR, Peradotto BC. Justificativas de familiares para a não autorização de doação de órgãos: estudo documental. Braz J Transplant, 2024; 27: 4524. https://doi.org/10.53855/bjt.v27i1.627_PORT
17. Amazonas MAM, dos Santos JS, Araujo JC, Souza ATA da C, Coelho MB, dos Santos JPS, de Souza EJF, Silva WGC, Castilho NMO, Figueiredo SN. Doação de órgãos: dilemas dos familiares na doação de órgãos. Revista Eletrônica Acervo Saúde 2021;13(1): e5871. https://doi.org/10.25248/reas.e5871.2021
18. Brasil. Presidência da República. Secretaria-Geral. Subchefia para Assuntos Jurídicos. Decreto 9.175, de 17 de outubro de 2017. Regulamenta a Lei nº 9.434, de 4 de fevereiro de 1997, para tratar da disposição de órgãos, tecidos, células e partes do corpo humano para fins de transplante e tratamento. Diário Oficial da União, 2017. [access on 23 Feb. 2025] Available at: https://www.planalto.gov.br/ccivil_03/_Ato2015-2018/2017/Decreto/D9175.htm
19. Roza BA, Schirmer J. Boas práticas e apoio decisório para o processo de doação e transplantes de órgãos, tecidos e células humanos. [access on 23 Feb. 2025]. Brasília: ANVISA; 2023. [access on 22 Feb. 2025]; Available at: https://bibliotecadigital.anvisa.gov.br/jspui/bitstream/anvisa/8090/3/Livro_vigilancia.pdf
20. Botelho AGA. A descriminalização do comércio de órgãos no Brasil frente ao princípio da dignidade humana. Uberlândia. TCC – Universidade Federal de Uberlândia; 2021. https://repositorio.ufu.br/handle/123456789/33266

21. Creswell JW. Investigação qualitativa e projetos de pesquisa: escolhendo entre cinco abordagens. 3ª ed. Porto Alegre: Penso; 2014.

22. Husserl E. Psicologia fenomenológica e fenomenologia transcendental: textos selecionados (1927-1935). Petrópolis: Vozes; 2022. Coleção Pensamento humano.

23. Husserl E. Ideias para uma fenomenologia pura e para uma filosofia fenomenológica. São Paulo: Ideias e Letras; 2012.

24. Giorgi A, Souza D. Método fenomenológico de investigação em psicologia. Lisboa: Fim de Século, Editora Sociedade Unipessoal; 2010.

25. Goto TA. Pesquisa em enfoque fenomenológico: a psicologia fenomenológica como ciência psicológica e método de investigação. In: Barroso SM. Pesquisa em psicologia e humanidades: métodos e contextos contemporâneos. Petrópolis: Editora Vozes; 2022.

26. Feijoo AMLC, Goto TA. É possível a fenomenologia de Husserl como método de pesquisa em Psicologia? Psic Teor Pesq, 2016; 32(4): 1-9. https://doi.org/10.1590/0102.3772e3241

27. Associação Brasileira de Transplantes de Órgãos. Dimensionamento dos transplantes no Brasil e em cada estado: 2015-2022. Registro Brasileiro de Transplantes. 2022 [access on 22 Feb. 2025]; 29(4): 1-100. Available at: https://site.abto.org.br/wp-content/uploads/2023/03/rbt2022-naoassociado.pdf

28. Brasil. Presidência da República. Casa Civil. Subchefia para Assuntos Jurídicos. Lei 10.2011, de 23 de março de 2001. Altera dispositivos da Lei no 9.434, de 4 de fevereiro de 1997, que "dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante e tratamento. Diário Oficial da União, 2001. [access on 23 Feb. 2025] Available at: https://www.planalto.gov.br/ccivil_03/leis/leis_2001/l10211.htm#:~:text=LEI%20No%2010.211%2C%20DE%2023%20DE%20MAR%C3%87O%20DE%202001.&text=Altera%20dispositivos%20da%20Lei%20n,fins%20de%20transplante%20e%20tratamento%22

29. Andrade T, Estivalete VFB, Malheiros MB , Rossato VP. Confiança interpessoal e confiança organizacional como antecedentes dos comportamentos de cidadania organizacional. REAd Rev Eletrôn Adm, 2021; 27:3. https://doi.org/10.1590/1413-2311.332.106296

30. Aronson E, Wilson TD, Akert RM. Conformidade: influenciar o comportamento. In: Aronson E, Wilson TD, Akert RM. Psicologia social. 8ª ed. Rio de Janeiro: LTC; 2018. p. 152-79.

31. Lanz LQ, Tomei PA. Confiança nas organizações. Rio de Janeiro: Elsevier; 2014.

32. Batista WS. Morte, eutanásia e cuidados paliativos. In: Reis MSP. Cronicidade e terminalidade na saúde pública. Rio de Janeiro: Conquista; 2022. p. 123-31.

33. Assmar EML. A experiência de injustiça na vida diária: uma análise preliminar em três grupos sociais. Psicol Reflex Crit, 1997; 10(2): 335-50. https://doi.org/10.1590/S0102-79721997000200011

34. Campos EBV, Silva AN. O desamparo como categoria afetiva fundamental do mal-estar na atualidade: um ensaio psicanalítico. Rev Psicol, 2020; 19(1): 67-87. [access on 22 Feb. 2025]; Available at https://www.revpsico-unesp.org/index.php/revista/article/view/317

35. Alencar HM, Taille Y. Humilhação: o desrespeito no rebaixamento moral. Arq Bras Psicol. 2007 [access on 4 Jan. 2025]; 59(2): 217-31. Available at: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1809-52672007000200011&lng=pt&nrm=iso

36. Brehm JW. A theory of psychological reactance. New York: Academic Press; 1966.

37. Rodrigues Filho MF. A conexão entre a intencionalidade e a consciência: um estudo filosófico. Fractal Rev Psicol, 2024; 36: e5810. Available at https://doi.org/10.22409/1984-0292/2024/v36/5810

38. Merleau-Ponty M. Fenomenologia da percepção. 5ª ed. São Paulo: WMF Editora; 2018.

39. Stein E. Contribuciones a la fundamentación de la psicologia y de las ciencias del espírit. In: Urkiza J, Sancho FJ, organizadores. Obras completas. Vol. II: Escritos filosóficos (Etapa fenomenológica: 1915-1920). Burgos: Monte Carmelo; 2005. p. 950.

40. Mendes LO. Um estudo sobre causalidade psíquica e motivação em Edith Stein como compreensão da liberdade humana na busca do sentido da vida. Rédula. 2024 [access on 26 Feb. 2025]; 9(9): 64-83. Available at: https://redae.uc.cl/index.php/STE/article/view/83168

41. Ávila EM. Confianza reflexiva: la reflexión sobre la confianza ante conocimientos y acciones Sociales. Investigaciones Fenomenológicas. 2023 [access on 26 Feb. 2025]; 20: 141-57. Available at: https://dialnet.unirioja.es/servlet/articulo?codigo=9246230

42. Steinbock AJ. Emociones morales: el clamor de la evidencia desde el corazón. Cap. 6. Barcelona: Herder Editorial; 2022. p. 283-319.

43. Feist J, Feist GJ, Roberts TA. Maslow: teoria holístico-dinâmica. In: Feist J, Feist GJ, Roberts TA. Teorias da personalidade. 8ª ed. Porto Alegre: AMGH; 2015. p. 167-90.