








## THE FAMILY MEANING ON ORGAN DONATION: AN ANALYSIS BASED ON THE SYMBOLIC INTERACTIONISM

A FAMÍLIA SIGNIFICANDO A DOAÇÃO DE ÓRGÃOS: UMA ANÁLISE À LUZ DO INTERACIONISMO SIMBÓLICO

EL SIGNIFICADO FAMILIAR DE LA DONACIÓN DE ÓRGANOS: UN ANÁLISIS A LA LUZ DEL INTERACCIONISMO OSIMBÓLICOSISTEMÁTICA

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### ABSTRACT

**Objective:** to understand the meaning that the family gives to the experience of having consented to organ donation. **Method:** qualitative study, based on the theoretical framework of Symbolic Interactionism and the methodology of Grounded Theory. It was carried out with 14 family members who consented to the donation of multiple organs. Data collection took place between July and November 2019, through intensive interviews recorded and transcribed in full, in addition to a research diary. To form the sample groups, the criteria proposed by the Grounded Theory were followed. These groups were organized by the MAXQDA software, and, for their analysis, the first two stages of coding were used: open and focused. **Results:** an analytical process explaining the experience of the family that consented to the donation of a family member's organs through loss and grief emerged, resulting in the concept that guides a model of care: "Minimizing suffering by exercising solidarity", supported by three categories: experiencing the impact of the diagnosis of brain death; motivating oneself to donate organs; and Meaning organ donation. **Conclusion:** the meanings that families gave to the experience of consenting to organ donation were understood, with the diagnosis of brain death and the time to complete the protocol associated with feelings of anguish, distress, and hope that death would not occur; to the body as an inviolable temple and to solidarity as a way of alleviating suffering and facing grief.

**Keywords:** Transplant; Obtaining Tissues and Organs; Family Relationships; Decision-Making; Life-Changing Events.

### RESUMO

**Objetivo:** compreender o significado que a família atribui à experiência de ter consentido a doação de órgãos. **Método:** estudo qualitativo, baseado no referencial teórico do Interacionismo Simbólico e na metodologia da Teoria Fundamentada nos Dados. Realizado com 14 familiares que consentiram a doação de múltiplos órgãos. A coleta dos dados ocorreu entre julho e novembro de 2019, por meio de entrevistas intensivas gravadas e transcritas na íntegra, além de um diário de pesquisa. Para a formação dos grupos amostrais, foram seguidos os critérios propostos pela Teoria Fundamentada nos Dados. Esses grupos foram organizados pelo software MAXQDA e, para sua análise, foram utilizadas as duas primeiras etapas de codificação: aberta e focalizada. **Resultados:** resultou-se em um processo analítico explicativo da experiência da família que consentiu a doação de órgãos de um familiar mediante a perda e o luto, do qual emergiu o conceito que orienta um modelo de cuidado: "Minimizando o sofrimento exercendo a solidariedade", sustentado por três categorias: vivenciando o impacto do diagnóstico de morte encefálica; motivando-se à doação de órgãos; e Significando a doação de órgãos. **Conclusão:** compreendeu-se os significados que as famílias atribuíram à experiência de consentir a doação de órgãos, sendo o diagnóstico de morte encefálica e o tempo para a conclusão do protocolo associados aos sentimentos de angústia, aflição e esperança de que a morte não se concretizasse; ao corpo como um templo inviolável e à solidariedade como forma de amenizar o sofrimento e enfrentar o luto.

**Palavras-chave:** Transplante; Obtenção de Tecidos e Órgãos; Relações Familiares; Tomada de Decisões; Acontecimentos que Mudam a Vida.

### RESUMEN

**Objetivo:** comprender el significado que la familia otorga a la experiencia de haber dado su consentimiento para la donación de órganos. **Método:** estudio cualitativo basado en el marco teórico del Interaccionismo Simbólico y en la metodología de la Teoría Fundamentada en los Datos. Se llevó a cabo con 14 familiares que dieron su consentimiento para la donación de múltiples órganos. La recolección de datos se realizó entre julio y noviembre de 2019, mediante entrevistas intensivas grabadas y transcritas íntegramente, así como un diario de investigación. Para la formación de los grupos de muestra, se siguieron los criterios propuestos por la Teoría Fundamentada en los Datos. Estos grupos fueron organizados mediante el software MAXQDA y para su análisis se utilizaron las dos primeras etapas de codificación: abierta y focalizada. **Resultados:** se obtuvo un proceso analítico explicativo de la experiencia de la familia que otorgó su consentimiento para la donación de órganos de un familiar tras la pérdida y el duelo, del cual emergió el concepto que guía un modelo de cuidado: "Minimizando el sufrimiento ejerciendo la solidaridad", sustentado por tres categorías: experimentar el impacto del diagnóstico de muerte cerebral; motivarse para la donación de órganos; y darle significado a la donación de órganos. **Conclusión:** se comprendieron los significados que

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las familias otorgaron a la experiencia de dar su consentimiento para la donación de órganos, siendo el diagnóstico de muerte cerebral y el tiempo necesario para completar el protocolo asociados a sentimientos de angustia, aflicción y esperanza de que la muerte no se materializara; al cuerpo como un templo inviolable y a la solidaridad como una forma de mitigar el sufrimiento y enfrentar el duelo.

*Palabras clave:* Trasplante; Obtención de Tejidos y Órganos; Relaciones Familiares; Toma de Decisiones; Acontecimientos que Cambian la Vida.

## INTRODUCTION

Organ and tissue donation is a noble act that offers a fresh start and the possibility of new perspectives for those waiting in line for a transplant. Despite the considerable increase in the number of organ donations in several countries, including Brazil, the disproportion between demand and supply still represents a major challenge to overcome. In addition to the lack of sufficient supply, there are other issues described in the literature that make it difficult to create a more favorable scenario such as the lack of infrastructure, the absence of qualified teams, and, mainly, issues related to the families of potential donors<sup>(1-2)</sup>.

Among the issues related to families, we can observe distrust in the diagnosis of brain death, dissatisfaction with the care offered by the team of health professionals, family disagreements, and ignorance of the wishes of the probable donor, among others<sup>(1-3)</sup>. Therefore, interviewing families who have had a family member declared brain dead, to obtain consent for the donation of organs and tissues, is one of the most difficult stages in the entire process of diagnosis, procurement, and organ transplantation. This is a delicate and stressful situation, both for the health professionals involved in the process and for the family, who, in addition to the pain of loss, face doubts, and anguish when asked about the possibility of donating at such a painful time<sup>(4-5)</sup>.

In this context, organ donation means recognizing the death of a family member at a time when the family may not yet be ready to accept it. Recognizing this death means accepting the individual's death, further increasing the pain of grief in which the family is already immersed, in addition to awakening fear and guilt, if their judgment is wrong, and they may even feel responsible for the death of their family member. In the consent process, being aware of the validity of the brain death diagnosis is a key element for the family to consider donation. Although this concept is understandable to family members, it requires time and support to make sense of their reality. Failure to make these resources available can hinder to assimilation of the situation and compromise the relationship with the health team involved in this organ procurement

process<sup>(6)</sup>. Therefore, the organ donation process is complex and requires commitment from the health professionals involved to convert potential donors into actual donors. Therefore, how health professionals who work in intensive care services, in the Intra-Hospital Commission for Donation of Organs and Tissues for Transplantation (CIHDOTT-*Comissão Intra Hospitalar de Doação de Órgãos e Tecidos para Transplante*) or Organ Procurement Organization (OPO-*Organização de Procura de Órgãos*) approach and elucidate the diagnosis of brain death, support and help family members to manage discussions and decision-making, can impact both consent and the experience of grief<sup>(7)</sup>. A study conducted in France identified that families of potential donors experience intense emotional overload and do not feel supported during the process<sup>(8)</sup>. Knowing and valuing the experiences of those involved and their grief trajectories after donation can help health professionals find innovative strategies that help them balance respect, the patient's desires, and the feelings of the bereaved family, maximizing the success of the acquisition of organs and favoring a better quality of life for the population waiting for a transplant<sup>(7)</sup>.

Thus, families are experts in their experiences and we should consider them as guidelines for the development of strategies that enable the improvement of the entire process of organ donation and transplantation, resulting in more friendly assistance to those involved<sup>(8)</sup>. Although several studies address family interviews in the process of organ and tissue donation, it is necessary to develop a concept that supports a model of care based on robust references that guide professional practice, especially nursing care. Nursing is a theoretical-practical science that guides a more appropriate approach at this difficult time for the family, generating more positive results in the number of organ donations. In this context, the research question was: What is the meaning of organ donation for families who consented to the donation? The aim was to understand the meaning that the family attributed to the experience of having consented to organ donation.

## METHOD

This is a qualitative study that used Symbolic Interactionism (SI)<sup>(9)</sup> as a theoretical reference and the Grounded Theory (GT) as a methodological reference, based on Charmaz's constructivist perspective<sup>(10)</sup>. This research followed the guideline proposed by COREQ – Consolidated Criteria for Reporting Qualitative Research<sup>(11)</sup>.

Conducted in a city in southern Brazil, with 14 family members who consented to organ donation, identified from an OPO database of 2018. The inclusion criteria consisted of being a family member of multiple organ donors, regardless of the cause that triggered brain death, family members and donors aged 18 years or over, the diagnosis and interview process took place in notifying hospitals in the index municipality and took place between January and December 2018, have contact updated phone number. We excluded family members of patients whose brain death protocols were conducted exclusively for diagnostic purposes (statistical) and family members who refused to donate organs. Also, we excluded family members who could not be located due to outdated registration data. The sample losses consisted of four parents who consented to the donation of their children's organs and were invited to participate; however, they refused due to the suffering represented by having to talk about the grief and loss of their children. This fact was one of the limitations of the proposed study.

Data collection took place from July to November 2019, through a survey of potential participants in the OPO database. It was carried out through an intensive interview, which consists of a topic-oriented conversation, allowing an examination more detailed description of a given experience and how the participant interprets it, even if the researcher helps the participant to articulate their intentions and meanings. Furthermore, we had the support of the research diary, in which notes were made immediately after contact with the participants and through records of reflections, doubts, and/or insights from the researchers, which helped in the development of hypotheses for the conducting of theoretical sampling<sup>(6)</sup>.

To form the sample groups, the criteria proposed by TFD were followed. Three sample groups were created, and the number of families was determined based on the analysis of their statements. In this way, it started with the most representative group and changed according to new stimuli and the formulation of hypotheses. As data analysis continued, new data was sought so that the categories could be better developed and densified.

The first group was made up of four participants who authorized the donation of their parents' organs. This group was formed to understand how they experienced the authorization of the organ and tissue donation, as well as the impact of this decision on their lives. The interviews began with the following question: What was the experience of consenting to a family member's organ donation like? We used a script with supporting questions and a research diary. As we collected and analyzed data,

participants raised new questions about changing family roles, pain, grief, and intense longing.

From the first group, the following question arose: is the experience of consenting to organ donation from fathers similar to children who consent to their mothers? Based on this, we created a second group with five participants who consented to the donation of their mothers' organs. Following this premise and emerging new meanings, another question arose: does the organ donation process experienced by spouses have different interpretations than their children? Therefore, the third group was created by five participants who authorized the donation of organs from their spouses, to verify whether the meanings and symbols were the same as those attributed by children who authorized the donation of organs from their fathers and mothers. Considering the emergence of new issues, we selected the fourth group composed of parents who consented to the donation of their children's organs. However, everyone refused to participate in the study, claiming they were unable to talk about the subject.

The interviews were carried out in the location desired by the participants, 11 at the interviewees' homes and three at the workplace, in a private room, without impacting their professional activities. They were recorded on an audio device, with an average duration of 32 minutes, and were individual. In only two cases, the conversations took place in the presence of other family members, according to the participant's wishes. After each interview, a complete transcription was made for data analysis, which occurred simultaneously.

Families were approached within a minimum period of six months and a maximum of one year after organ donation, to facilitate the location of participants, respecting the first months of mourning. The research team was made up of two nurses, with the responsible researcher having experience in the area. They had the support of a reference psychologist, in case the participants needed assistance after the interviews. However, no participant required further support or intervention.

To support the organization of data in this research, we used the software MAXQDA The Art of Data Analysis version 2018. For data analysis, the first two stages of coding were used: open (line by line) and focused. Open coding began with microanalysis, as the first step in the unfolding. This involved opening the data using the "line by line analysis" technique, which allowed the participants' implicit and explicit ideas and concerns to be captured, as well as identifying gaps that became starting points for future interviews. From this initial analysis, provisional codes were created, which were later

grouped and/or replaced to improve data understanding. Throughout the collection process, in parallel to the microanalysis, a total of 609 provisional codes were identified, which were later regrouped into 139 initial codes. After establishing the analytical objectives in open coding, we proceeded to focus on coding, where a large amount of data was synthesized to demonstrate the most relevant codes, whether due to frequency or importance, for elucidating the phenomenon. Then, there was a comparison between these codes, giving life to the categories and subcategories until the central category emerged, to substantiate the concept that comprises and represents a model of care. It is worth mentioning that the change from open to focused coding does not occur linearly due to the circular data model and the possibility of searching and elucidating data that were previously implicit<sup>(10)</sup>.

To validate this concept and verify its reliability, three participants, one representative of each sample group, received an email containing the diagram representing the constructed model and a summary of the investigation, including the objectives, a brief explanation of the analysis strategies, and the categories and subcategories that emerged. In this email, the validator was asked to describe the model presented in the diagram, their understanding of the figure, whether they viewed themselves as part of the theory, and whether it proved to be relevant to the situation they were experiencing. Understanding and theoretical generalization were considered as adjustment criteria<sup>(12)</sup>.

This study was approved by the Permanent Ethics Committee on Research with Human Beings (COPEP). All participants signed the Informed Consent Form in two copies of equal content, following Resolutions 466/2012 and 510/2016 of the National Health Council. To protect their identity, participants were identified with the letter F (family member), followed by a number corresponding to their entry into the research and the degree of kinship with the person who died (Ex.: F1, Daughter - Mother).

## RESULTS

At the end of the collection stage concomitant with data analysis, we found that, from an epidemiological aspect, the sample had 14 family members who consented to organ donation. Among them, nine were children and five spouses, aged between 22 and 59 years. As for organ donors, six were male and eight were female, with an average age of 61 years. The main causes of death were ischemic stroke and hemorrhagic stroke.

Also, three categories were formed which, through an analytical process, resulted in the experience of the family that consented to the donation of a family member's organs, considering loss and mourning. The categories identified were: "experiencing the impact of the diagnosis of brain death", "motivating oneself to donate organs" and "meaning organ donation". Based on data analysis, these categories are presented below. From these categories, the concept that guides a care model was obtained: "Minimizing suffering, exercising solidarity".

### Experiencing the impact of a brain death diagnosis

The process begins with the announcement of the injury suffered by the individual. The family is emotionally shaken and going through a moment of anguish. The prognosis causes confusion and family members search for meanings and answers to the current condition, fearing the possibility of their family member's death.

*I thought the worst was over, but the doctors had warned that after the surgery it would be even worse, and that it could get complicated. On Thursday, he died (F1, Son - FATHER)*

The experience continues with the evolution of the individual's clinical status, leading the family to deal with the news of the possibility of brain death. At this point, the waiting time for the protocol to be carried out can intensify the family's suffering. During this period, feelings such as pain, disbelief, uncertainty, and fear are experienced until the outcome is confirmed..

*This protocol takes a long time. It seems like it was three days, but I still have the feeling that it was a year, that I was in this situation because you go to the hospital in the morning, you go at night. I stayed with him like that for three days. (F2, Daughter - FATHER)*

After the protocol confirms brain death, uncertainty brings pain and suffering, which can result in ecstasy and fear of losing their references.

*The pain is immense, it will be a year ago, but it seems like it was yesterday. Everything I do remembers her (mother), special dates are boring. Her house was a desert, everyone abandoned it, and no one was able to stay there, because she was a happy, playful person, suddenly you enter the house and there is no spark, that smile to brighten up the house. (F6, Daughter- MOTHER)*

*The problem with all this is the lack, the emptiness. Until this matures in you because the person ceases to exist, my father and*

*my mother are alive in me, I remember them, I have a photo, I remember every detail, everything..., but they no longer exist, I can't hug them, it will be the first Father's Day without him. (F2, Daughter - FATHER)*

In this way, family members strive to experience grief as the only alternative to the suffering presented. It was noticed that mourning can still cause a feeling of increased responsibility and role reversal within the family nucleus, which occurs immediately after death or after a certain period.

*I tell people that I'm experiencing grief this year, the moment of not getting out of bed, of crying, of feeling the loss of myself. Knowing that she really won't be with me anymore won't help me in the same way as before. Financially, if I need something, I no longer have it: Mother helped me! And I also don't find it easy to say to others: Help me! I believe I am experiencing grief now. (F5, Daughter - MOTHER)*

### Motivating to donate organs

With the announcement of brain death, participants developed strategies to minimize uncertainty, improve understanding and accept the situation.

*I was desperate, but it wasn't the hospital's fault, because due to the fall, they didn't have much to do, what you expect is that the care is quick, which apparently wouldn't be much to do. She (her mother) went to the ICU, and they (the team) said they would wait to see if she could have surgery the next day. The next day came, and they said that she (mother) got worse. (F8, Daughter - MOTHER)*

We observed that the participants, upon understanding the gravity of the situation and the remote possibility of the family member's survival in a vegetative state, began to reflect on their loved one's wishes in that situation. This began the process of accepting grief.

*I kept thinking that she (mother) would survive, we thought if she (mother) survived, she would have consequences for the rest of her life and if she had consequences, she wouldn't be able to bear living in bed like that, but, on the other hand, we wanted her to survive. (F7, Son - MOTHER)*

Recognizing death is a determining factor for the family to reflect on organ donation and to consent to it. Another important aspect that positively influenced donation consent was knowing the family member's wishes. This understanding led participants to lean towards organ

donation, as they knew how to discern their family member's desires. However, in situations where the will was unknown, the family sought references in acts and actions carried out during the family member's life, justifying their decision, and honoring the story of the one who passed away.

*My father had already said he wanted to (donate). My parents already wanted to donate, she (my mother) was always a supportive person, whatever she could do for others she did, without even thinking. She (mother) thought it was very beautiful when it was on television. One day they said that whoever went first would donate, so I told him (nurse): we donate. (F8, Daughter - MOTHER)*

Even though they are prone to donation, everything that involves this complex phenomenon can raise doubts, arising exclusively from the act of consenting to it. This fact can be seen in the reports that indicated anguish regarding the violation of the body after death when they reflected on the event.

*After you look at the person at the wake, you say: "This is missing, that is missing. They took this away, they took that away" It goes through our heads, there's no point in saying no because it goes away. We asked if he would feel pain. (F13, Wife)*

*At the time I thought: but are you going to leave my mother with nothing? (F9, Daughter - MOTHER)*

### Meaning of organ donation

Death changes the family structure, and its members strive to reorganize themselves, attributing some meaning to the experience and to the life that must continue. This is a time when they look for new perspectives, considering donation as a support measure.

*I remember a day that comforted me a lot when the nurse called me and told me which of his organs (husband) had been donated. (F14, Wife)*

The families' desire to donate their loved one's organs was firm. Regardless of the reason that motivated them, the participants' need to know whether the donation occurred was observed. This occurs because families have expectations regarding the recipient and the transplant, wanting their actions to become concrete.

*I didn't go after it, because they say you can't give this information, but it's my wish, I would like to know. Let's suppose, I don't know, you donated a kidney, knowing what the person experienced, was living, received the kidney in the donation, and what their life is like today. (F10- Husband)*

*I'm hoping someone wants to know who donated because they wanted to help. I hope to get to know her, exchange information, what it was like for her to receive it. What it was like for us to donate. Find out if they liked what we did for them. (F6, Daughter-MOTHER)*

The main factors that drive the feelings of relief and comfort experienced by families when donating their loved one's organs are solidarity and empathy which help to give meaning to the process, as expressed in the reports:

*I think always helping others, I think he (father) would be happy, to be doing good for someone. (F3, Daughter - FATHER)*

*My father didn't die to help these people, it was a consequence. We have to think that my father died, but even though he went he managed to help someone. Because we know that doing good to others, in any way, is good, it is good for ourselves. Even if it is a moment of pain, perhaps it can bring joy to another family, or to another person who is in need at that moment too. (F4, Daughter - FATHER)*

Thus, participants viewed the donation and transplantation process as a new opportunity for life, both for the recipient and for the one who passed away. When reflecting on their consent, they saw it as a noble act, especially for guaranteeing a more dignified fate for their family member's body, instead of decomposition.

*Eu I feel like somewhere he (husband) is alive, his heart valves are in someone, he helped someone, I'm happy to know he's there, that there's a little piece of him. (F13, Wife)*

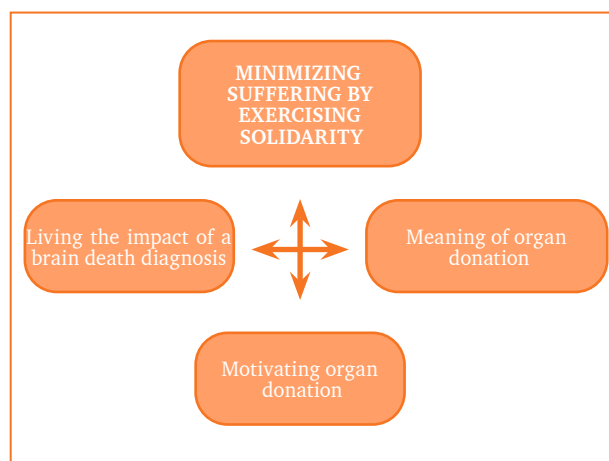
*What will an organ be doing there (underground)? I could be saving another life! Being buried and decomposing and that's it! (F11- husband)*

*The soul goes somewhere else, the body doesn't! I kept thinking that the body would decompose, and it wouldn't help anyone. (F12- Husband)*

From the articulation between the constructed categories and the theoretical connections made, a

representative diagram of this concept was constructed that can guide care, based on the experience of the family that consented to the donation of organs and tissues from a family member, even in the face of loss and of mourning. Figure 1 is made up of three circles that represent the phases of the organ and tissue donation process, symbolizing the meaning attributed by families who experienced this process, to minimize suffering.

Figure 1. Diagram representing the concept that guides a care model and its categories. Maringá, Paraná, Brazil, 2020.



## DISCUSSION

From the constructed concept, it is possible to understand the meanings attributed to the experiences of families who authorized organ donation. From this perspective, the family experiences a moment full of pain and suffering, which affects their beliefs, emotions, and behaviors. Furthermore, they need to deal with decision-making<sup>(2)</sup>. Death is felt by the family as a foreign element that takes life, leaving them with a significant need for rational explanations, which leaves family members uncertain about what the future holds for them. In this way, death is a delicate subject that is rarely reflected upon, having a clear attitude of denial<sup>(14)</sup>.

To deal with the situation of mourning, the family creates protective mechanisms to minimize their suffering. They also draw on feelings of altruism based on solidarity and evoke the deceased family member's wishes to consider organ donation. This behavior can be compared to the results of studies carried out in Spain and France, in which it was observed that families feel more confident when making decisions when they know the donor's wishes regarding organ donation. Furthermore, the belief that the family member's life can continue in

some way brings a sense of inner peace and helps to minimize suffering<sup>(7,13,15)</sup>.

In the context of the diagnosis of brain death, followed by mourning and the possibility of organ donation, the family goes through certain phases. Initially, they need to deal with the poor prognosis of their family member's illness, which causes uncertainty and insecurity due to the possibility of losing someone so important in their lives. This feeling persists until the diagnosis of death is confirmed, a phase that was considered the most intense and painful by the participants, since uncertainty about the possibility of death gives way to confirmation, increased by the pain of loss. According to a study carried out in 2011, people are not used to dealing with losses, but human reality is marked by continuous oscillations between gains and losses, with loss being painful<sup>(14)</sup>. This pain causes discomfort and turns grief into a symbol of suffering, loss, and fear of the impact it can have on their lives. These results corroborate a survey carried out in Bahia in 2016, in which this stage of suffering also arises due to the fear of breaking up the family unit<sup>(15)</sup>. In this context, the family faces the difficult decision about the possibility of organ donation, and considering this alternative necessarily implies recognizing the irreversibility of the situation. Therefore, whether to authorize organ donation is a decision guided by the moral aspect, aiming to save other lives and minimize suffering while exercising solidarity, in addition to attributing meaning to the life and death of a family member. It is important to emphasize that acceptance or denial is a response to how human beings interpret the world around them<sup>(7,13,15)</sup>.

From this perspective, the family builds a path to be followed, giving new meaning to certain aspects already experienced or not. This process can be perceived by the way family members see the time needed to complete the diagnosis of brain death<sup>(9)</sup>. The same is experienced based on these premises, transforming one day (average time to complete the diagnosis) into a distressing eternity. The family mentions that the period of waiting for the diagnosis, with uncertainty and fear, is as distressing as the loss of their family member<sup>(16)</sup>. Therefore, understanding and accepting the veracity of brain death and its implications as a social issue proves to be fundamental for the family to be able to go through the mourning period in a less tumultuous way<sup>(8,17,18)</sup>. It is known that interactions between family members and the team involved in the organ donation process can make a difference in the way pain is heightened or alleviated. The literature highlights the importance of health professionals working in Intensive Care Units, CIHDOOT, and OPO paying attention to

the moment of the interview to open the organ donation process, providing clear and reliable information about the entire process, adapting to the level of understanding of the family and offering time to reflect on the decision, avoiding a hasty choice<sup>(13,16)</sup>.

A study carried out in 2022 highlights the importance of the bond established between health professionals and the donor family, since, from the perspective of family members, the attention received during the process influences the acceptance of organ donation<sup>(16)</sup>.

The nurse plays an important role in this process, accompanying the family from the opening of the protocol until the completion of the donation process and delivery of the body to the family. However, this professional must be properly prepared and open to communication with family members and members of the healthcare team, especially during the interview with the family, to clarify doubts related to the diagnosis of brain death, organ and tissue donation and transplantation, acting with respect, ethics, sensitivity, empathy, and solidarity<sup>(16,17,19)</sup>.

Therefore, as the family becomes aware of the situation, they begin a process of redefining their perspectives on what is right, organ donation takes on countless meanings, as a source of comfort, relief, and the opportunity to do good to the other. These feelings have great social importance since society develops through interaction between its members. Symbolic Interactionism describes human beings as unpredictable and active in the world, but it is important to consider that their actions aim to choose the best option for themselves, to minimize their suffering<sup>(9)</sup>. Within the scenario of instability caused by death and using interaction with oneself to interpret the world and make decisions (human action), the family analyzes the situation and based on this, decides on the possibility of organ donation and its consequences. This is in line with the literature that suggests that by serving others in situations of extreme suffering, one can help to face a post-traumatic event<sup>(9)</sup>.

The literature also shows that one of the most significant implications of consent to donation is the fact that the family may be responding to a desire expressed by the donor during his lifetime, enabling them to experience the social object of generosity and altruism. Furthermore, they feel more secure with the decision made, thanks to the confidence that there will be no family disagreement on the matter. It is also important to consider the importance of the relationship of trust that the family establishes with the professional who accompanies them during the process. Negative interactions, such as indifference or lack of interest by the team, are one of the biggest

factors of wear in this grieving process. In this way, the authorization of donation is also driven by a moral aspect that determines the action of saving other people's lives to minimize suffering through solidarity, transforming this action into a symbol of benevolence permeated by empathy. It is exactly this definition that motivates the family to consent to organ donation, while it is also used as a strategy to give meaning to the life and death of their family member.

Although consent to donation consoles and helps families make sense of the death, they experience frustration at not being able to meet the recipient. The family creates expectations about the entire transplant process and starts to live with its consequences. This symbolic interaction between family and society becomes permanent for the families that authorize the donation. They interpret this social action, react, and demonstrate their frustration and expectations.

Brazilian legislation guarantees the anonymity of organ donors and recipients, following Decree 9,175 of October 18, 2017. However, a survey carried out in Goiás and the Federal District identified that most transplanted people did not express a desire to know the identity of the donor to preserve their autonomy and confidentiality<sup>(24)</sup>.

Faced with the conviction of donation, the families, when reflecting on the process, were afraid about the violation of their family member's body. Studies indicate that this belief constitutes one of the main reasons for family refusal to donate organs<sup>(3)</sup>. From the theoretical reference adopted, we understood that the body was given the symbol of a temple, which must be preserved, as in the past it enabled the construction of the subject's history. By violating it, his history is transgressed and the family unit is unbalanced<sup>(9)</sup>.

Thus, the construction of the concept that guides the care model "minimizing suffering, exercising solidarity" represents the meaning that the bereaved family attributes to organ donation. Its movement is not linear, the experience occurs as a continuous flow of action generated by the interactions present in the process of each member and all systems. Different systems are formed and restructured during the lived experience. As it is dynamic, the categories of each phase may not be exhausted and may be present in more than one phase. Although the entire process of donation and transplantation significantly interferes with the self, triggering symbols associated with feelings, time, and the body as a temple, it is solidarity that drives them and helps them face grief<sup>(9)</sup>.

Therefore, the family's experience involves the desire to provide the best for their family member and the family

unit, both before and after their death, reinforcing the dynamic nature of the family experience in the process of consent to organ donation. This represents the process experienced by the family in search of a path that minimizes sadness and seeks relief. These findings can contribute to and solidify the work of professionals who work in this area, especially nurses, as they participate in the entire process, from the diagnosis of brain death to the donation of organs and delivery of the body to the family. In this way, directing professionals' actions based on the experiences lived by these families can make the process less physically and emotionally burdensome for everyone involved, supporting their decisions, and ensuring holistic, empathetic, and humanized care.

Regarding the limitation of the interpretations of this study, the composition of the sample groups is mentioned, consisting of only three types of ties. We believe that the participation of parents who consented to the donation of their children's organs and tissues could strengthen the construction of the concept that guides a model of care, to guide health professionals who work in family interviews towards a more appropriate, sensitive and welcoming approach, which positively impacts the number of organ and tissue donations in Brazil. Furthermore, other types of kinship, such as siblings, did not have enough individuals registered in the OPO available for this study to compose a sample group.

## FINAL CONSIDERATIONS

It is possible to understand the meanings that families attributed to the experience of consenting to the donation of organs and tissues, with the diagnosis of brain death and the time required to complete the protocol being attributed to feelings of anguish, distress, and hope that death will not occur; to the body as a temple that should not be violated and to solidarity as a way of alleviating suffering and facing grief.

From this perspective, based on the concept that guides a model of care, emerging from the experiences of families who consented to the donation of organs and tissues from their family members, the importance of health professionals working in Intensive Care Units, CIHDOTT, and OPO is highlighted, especially those who conduct family interviews, approach brain death and organ donation from the perspective of understanding the family. We suggest that by helping family members to accept the suffering of loss, accepting existing doubts about organ donation and transplantation, providing time for the family to



share ideas and feelings, and facilitating access to social support, one can favor a trajectory of recovery from grief with less conflict and suffering, in addition to having a positive impact on consent to organ and tissue donations.

Approaching the family and respecting these conditions can help individuals construct meanings for the family member's death and deal with the new reality of grief. Therefore, it is important to consider carrying out family interviews to obtain consent for organ donation and considering opportunities for family interaction with other systems that can offer the necessary social support. This implies expanding the focus beyond organ harvesting, and to caring for the family during the experience of death and mourning. It is possible to extract the best from the family by stimulating essential processes that promote its growth during chaos. Early intervention is a preventative measure and, as nurses involved in the organ donation and transplant process, it is important to consider families' perspectives so that they feel welcomed. Furthermore, based on the participants' reports, we suggest the discussion on organ donation be reintroduced to the agenda and debated between the parties involved and those responsible for formulating public policies to think about the dissemination of information through consent

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