





Non-donor families' experiences in cases of brain death

A experiência de famílias não doadoras frente à morte encefálica

La experiencia de familias no donantes ante la muerte encefálica

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ABSTRACT

Objective: to understand the lived experience of adult families in cases of brain death and the option not to donate organs. **Method:** this qualitative study based on Symbolic Interactionism was conducted at a public hospital in Rio Grande do Sul state, with six families who had a potential organ donor family member diagnosed with brain death and who refused to donate. Data were obtained through narrative interviews between May and November 2016, after ethics committee approval, and analyzed with emphasis on content. **Results:** this was an unexpected and unknown situation of uncertainties, pain, and suffering from illness, brain death, and the decision whether to donate organs or not. **Conclusion:** in an interactional context of uncertainties, specifically the collapse of family life following an unimaginable event, brain death and organ donation were perceived to intensify the loss, which corroborated the decision to not donate.

Descriptors: Acute Disease; Brain Death; Tissue and Organ Procurement; Family; Nursing.

RESUMO

Objetivo: compreender a experiência vivenciada de famílias de adultos frente à morte encefálica e a opção pela não doação de órgãos. **Método:** estudo qualitativo fundamentado no Interacionismo Simbólico, realizado em um hospital público, no estado do Rio Grande do Sul, com seis famílias, que tiveram um familiar potencial doador de órgãos diagnosticado com morte encefálica e negaram a doação. Os dados foram obtidos por meio de entrevista narrativa no período de maio a novembro de 2016, após aprovação do Comitê de Ética da instituição, e analisados com ênfase no conteúdo. **Resultados:** refere-se a uma situação inesperada e desconhecida, de incertezas, dor e sofrimento ante o adoecimento, a morte encefálica e a decisão pela doação de órgãos ou não. **Conclusão:** Em um contexto interacional de incertezas, definido como o desmoronar da vida familiar por um evento inimaginável, a morte encefálica e a doação de órgãos é percebida como a intensificação da perda, o que corrobora na decisão pela não doação.

Descritores: Doença Aguda; Morte Encefálica; Obtenção de Tecidos e Órgãos; Família; Enfermagem.

RESUMEN

Objetivo: comprender la experiencia vivida de las familias adultas en casos de muerte cerebral y la opción de no donar órganos. **Método:** este estudio cualitativo basado en Interaccionismo Simbólico se realizó en un hospital público del estado de Rio Grande do Sul, con seis familias que tenían un familiar donante potencial de órganos diagnosticado con muerte cerebral y que se negaron a donar. Los datos se obtuvieron a través de entrevistas narrativas entre mayo y noviembre de 2016, luego de la aprobación del comité de ética, y se analizaron con énfasis en el contenido. **Resultados:** se trata de una situación inesperada y desconocida de incertidumbre, dolor y sufrimiento por enfermedad, muerte cerebral y la decisión de donar órganos o no. **Conclusión:** en un contexto interaccional de incertidumbres, específicamente el colapso de la vida familiar tras un evento inimaginable, se percibió que la muerte encefálica y la donación de órganos intensificaban la pérdida, lo que corroboró la decisión de no donar.

Descriptores: Enfermedad Aguda; Muerte Encefálica; Obtención de Tejidos y Órganos; Familia; Enfermería.

INTRODUCTION

Organ transplantation may be the last alternative for life continuity. However, for the families of potential donors, this is a process that makes them face the finitude of life, which is revealed in the concept of brain death (BD)¹. The BD diagnosis, defined as the complete and irreversible loss of all brain functions, is the condition for organ donation as its occurrence defines the person's death².

Given the Confirmation of BD, the Intra-hospital Commissions of Organ and Tissue Donation for Transplantation (*Comissões Intra-hospitalares de Doação de Órgãos e Tecidos para Transplante*, CIHDOT) are responsible for teaching and making families aware of the possibility of organ and tissue donation³. It is this commission's responsibility to conduct an interview that consists of a meeting with the family, in which the organ and tissue donation process is explained, providing information so that they can make a decision¹.

The family reaction when facing the communication of BD and possible organ donation has been the object of various studies. An integrative review of the literature⁴ reports that family members show sorrow, crying, and fury when

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receiving the BD diagnosis. The lack of knowledge about the subject matter leads them to question a possible refusal to donate. A gap related to the Nursing assistance directed to families that are experiencing the BD of a family member was also identified⁴.

The family needs to understand what BD actually is to make a decision about donation. However, this moment is characterized as the most difficult of the process, as the responsibility for this decision is experienced in circumstances involving pain, anguish, loss, and the interruption of a life^{1,3}. It is possible to infer that the interpretation of the interactions present in the experience is perceived more emotionally than rationally, which will influence the decision to donate organs or not.

Regarding organ donation, data of the Brazilian Association of Organ Transplantation from January to March 2020 point out that, of the 2,730 notified potential donors, 1,612 families were asked about their intention to donate organs or not; 577 refused to donate and 965 were effective donors, which corresponds to the reduction in the rate of family non-consenting (36%), for the first time below 40% in Brazil⁵.

Although there is some progress, a number of studies approach reasons related to non-donation and family refusal⁶⁻¹². Justifications include previous conviction of non-donation, unawareness of the potential donor's will, preservation of body integrity after death, and family disagreement^{6-7,9-10}. Additionally, apprehension regarding the time for body release, the fact of not accepting BD as the end of life, religious beliefs, and situations in which the family does not inform their reasons for non-donation^{8,11}. These reasons can still be corroborated by subjectivities present in the interaction with the team that conducts interviews for procurement¹².

In this context, the need is perceived to expand the understanding related to the experience of the families with a relative diagnosed with BD and that have opted for not donating organs. These studies are relevant so that, when interacting with the families, nurses and procurement teams are capable of paying attention to the feelings and meanings present in the family context as dimensions that need to be assessed to direct and support the professional practice.

This study has the following research question: What is the experience of adults' families when facing brain death and the option of not donating organs? The objective of these studies was to understand the experience of adults' families when facing brain death and the option of not donating organs.

THEORETICAL FRAMEWORK

Symbolic Interactionism (SI) is a theoretical framework that seeks to understand human behavior and action, based on meanings that human beings attribute to their experiences, built from the experienced interactions in which the individuals define situations, elements and behaviors, interpret others and act¹³.

This framework has the three following premises: human beings act in relation to the facts according to what they mean for them; the meaning of the facts arises from the social interaction established with others; and meanings are manipulated and changed as a consequence of interpretive processes made effective by the person when handling with the facts¹³. Therefore, it is understood that human action results from the interpretation of what people perceive within the contexts in which they are inserted, in relation to the others and to themselves, being determinant for their behavior. The concepts that shape SI are as follows: symbol, self, assuming role of the other, human action, social interaction, and society¹³.

The study adopted SI as its theoretical framework for understanding that the experience of families when facing the BD of a family member and organ donation is within a context of social interactions whose family action is a result of the symbolic meaning attributed to the experience¹³.

METHOD

A qualitative study based on SI¹³ and conducted with families who had an adult family member with BD diagnosis and potential organ donor, hospitalized in an Intensive Care Unit (ICU) of a public hospital of Rio Grande do Sul, and who refused to donate. For inclusion, the BD cases identified by an active search in the ICU in 2016 and the cases reported in the CIHDOT documents before 2016 were considered. The families excluded were those that consented to organ donation and those that did not know the BD clinical condition of their family member, according to the reports by the professionals involved in the assistance.

Of the 17 families that met the inclusion criteria, seven were excluded for impossibility of access due to the absence of an address or telephone number in the medical records. Of the ten families contacted through telephone, six accepted to participate in the study, and four refused. Accessibility defined the number of participants.

Data collection was carried out from May to November 2016 in houses or workplaces, as preferred by the participants. In order to obtain information, an open interview lasting a mean of 35 minutes was conducted, always by the same researcher, in the form of an individual narrative, audio-recorded, and guided by the following initial question: "Can you tell how the experience of your family in relation to the brain death of your family member was? Tell me about the decision to not donate organs."

The audios were transcribed and later deleted. The material produced was submitted to narrative analysis with an organization of categories with an emphasis on content, including the following stages: selection of the subtext, definition of the content categories, classification of the material into categories, and preparation of conclusions based on the results¹⁴. The interpretation the results was based on SI.

The study was approved by the Research Ethics Committee, under opinion No. 1,513,581. In order to ensure the participants' anonymity, the narratives were coded with the letter F (Families) followed by numbers from 1 to 5, and, for the interviewees, the letter E ("Entrevistados" in Portuguese), followed by numbers from 1 to 3 for the families with more than one participant.

RESULTS AND DISCUSSION

The analysis *corpus* was composed of data obtained with six families. Of these, three had experienced the BD process with refusal to donate organs more than one year ago, and three, less than one year ago. In four families, two family members participated in the interviews, in one, three participated and, in the other, one family member participated, totaling to 11 people interviewed individually.

Females prevailed (seven) in the six families. In relation to the patients with BD, four were men and two were women, aged 18 to 43 years old. The family relationships were as follows: two spouses, two mothers, one daughter, two siblings, and four siblings-in-law, aged 19 to 61 years old. Regarding the cause of BD, there were four traumatic brain injuries and two hemorrhagic strokes. The mean hospitalization time in the ICU was seven days. In the analysis process, two categories were organized, as presented below.

An unexpected and unknown situation: Uncertainties towards the disease and brain death

The interactional context and the developments with which the families needed to deal with given the acute disease, explicit an unexpected and unknown situation permeated by uncertainties, leaving family members disoriented and insecure. As they cannot understand what is happening, they feel no control over the situation and oscillate between feelings of anguish, sorrow, and hope.

Something I never imagined in my life. I never thought that we were going to go through that. I was paralyzed, shocked. I never saw anything like that, I can't even find words to explain. We had some hope that.... (F5-E1)

Me, always believing that he'd get better, that they were going to operate, but nothing. (F3-E1)

Perplexity points out that, initially, the family does not attribute meaning to the fact experienced and, for this reason, cannot understand what is happening or act before an unknown object, as social interaction becomes symbolic when it has meaning both for the sender and the receiver of the action¹³. The family feels paralyzed, requiring time to elaborate the meanings related to the new facts experienced.

Additionally, when they know about the hospitalization of the family member, the family does not evaluate the situation as worrying, since previous events are considered in this evaluation. However, when arriving at the hospital, they face the severity of the clinical condition and react emotionally to the BD announcement, expressing themselves through crying, despair, and fury.

We though he had fallen off the motorcycle and got an arm hurt. When I got there, I looked through the glass of the emergency room, my brother was there, desperate. We didn't have any idea about the severity. Then the doctor said that it was extremely severe and that the tendency was evolving to brain death. (F2-E1)

My son called me saying that the youngest had been shot. I panicked. I cried, I was really furious. It wasn't easy to receive such news and know that he had very few chances to survive. (F3-E1)

By visualizing the emergency scenario and the family member's physical conditions, interacting with the professionals, other people, and themselves, each family member starts processing the diverse information, sharing impressions and perceptions, and identifying the symbols present in the facts experienced. Symbols are social objects used by human beings for representation and communication, through meanings that they believe in and make sense to them¹³.

Social interaction becomes symbolic when it has meaning both for the sender and the receiver of the action. It is during this symbolic interaction process that families start understanding the fact experienced and defining BD. A study highlights that, for the families, the situation of an unexpected and acute disease contributes to the difficulty in accepting the BD condition, making the decision about donation even more complex⁸.

Another study related to the family decision about organ donation evidences that the experience of the families begins at the moment they start to experience the impact of the tragedy¹⁵, which is defined as a nightmare, followed by uncertainties and concern about prognosis and the future. With the perplexity of the acute disease, the despair that comes from bad news, the hospitalization of the family member, and the risk of death, the families experience a disorganization process that makes it difficult to understand what is happening,¹⁵ and, initially, they do not consider death as a possibility¹⁶, pointing out this interpretation as a determinant for the actions adopted by the families.

In an internal process of interaction with themselves (self)¹³, the family members, both individually and as a family unit, access resources that help them understand the facts. Therefore, they seek elements present in previous illness experiences to establish a connection and anticipate the possible evolution of the family member. The comparison is a result, above all, of the reference to chronic diseases, in which families can follow the trajectory, but that confers an expectation different from the evolution of the acute clinical condition and, possibly, death as an unexpected outcome.

If it was something she already had, some cancer, or another disease, we'd have been prepared, but it was out of the blue, she stayed a short time at the hospital. We hoped she'd get better, that she'd stay more time hospitalized, but it didn't happen. (F4-E1)

It was also very fast, it happened in such a short time. Our life was over, it destroyed us, it destroyed everybody. Our life fell apart. (F3-E2)

Given the short period of time between the accident, the hospitalization, and the BD diagnosis, the families report having difficulty assimilating what was happening and getting reorganized. It is possible to deduce that the interactional process established in this context presented symbolic elements to which families could not attribute any meaning at the experience moment, emphasizing the difficulty to act intentionally¹³.

When facing an unexpected event that threatens life and a feeling of uncertainty, in which loss can be materialized with the BD announcement, the pain and powerlessness present in the family context stand out, which precludes attributing meaning to what they are experiencing.

From uncertainty to the decision to donate the organs

When the families are informed about BD, they face another fact, also unexpected and unknown: deciding about the possibility of organ donation. Permeated by uncertainties, fear and suspicion, they decide for non-donation. In this process, they consider that the information about the BD diagnosis seems to go against evidence indicating the presence of heartbeat and breathing, even if controlled by devices. In interpreting the interaction established, they asserted feeling "under pressure" by the health care team and suspicious about the veracity of the BD diagnosis. Considering the possibility of their family member still being alive, they do not authorize organ removal, thinking about the survival possibility.

We keep wondering if there wasn't really anything to be done. When they talk about organ donation, aren't they hurrying things? Aren't they putting pressure on us, hurrying to say that the person is really dead just to remove the organs? (F2-E1)

A number of research studies point out that families feel under pressure to make a quick decision, and the time interval between the BD announcement and the information about organ donation is important so that they can organize their thoughts and define a decision¹⁵⁻¹⁶. However, this time is not respected by the professionals¹⁶. Human actions, as a result of the interpretation of the interactions experienced, demand time to reflect about symbolic elements present in the context, especially the information received, the circumstances of the loss, death and organ donation, as the action/decision will depend on the meaning attributed by them¹³.

As justification for the decision of not donating the organs, the families mention lack of communication and unawareness about the family member's opinion on the subject matter, fury when facing the situation, the unexpected death of the family member, and the existence of previous thoughts about not willing to donate.

He never talked about that. We're positive about that! (F2-E3)

They had already done the whole donation process and, at the last minute, he said no, I'm not donating the organs anymore! Why did God take him from me? I'm not donating anymore. I got furious at that time. (F3-E1)

Right away I thought about not donating, because he didn't ask in life, if he had asked in life I would've donated. (F6-E2)

The results corroborate a research study that presents diverse evidence about how difficult it is for the families to understand what the BD protocol represents and accept that it expresses death¹⁶. Although the interactional process established in the hospital environment contributes for families understanding what is happening and, given the facts, noticing the worsening or non-improvement of their family member, obstacles in communication, as well as pain and

suffering, can hinder the assimilation of reality, leading family members to develop physical and emotional changes¹⁶, which can hinder the decision-making process.

It is possible to identify that beliefs that the body would be mutilated and unrecognizable if they consent to donation contributed to the decision.

My heart almost came out from my mouth! I was thinking: my God, he'd be all ripped, punctured, with pieces removed, taking things from inside him (referring to the organs). He wouldn't be him anymore! (F5-E1)

Decision-making is part of a difficult moment for the family but mainly for the person who needs to be communicate the decision, a responsibility that often falls on the relative that is present at the hospital and that, in the implementation of an almost solitary process, seeks to gather the information that helps them to think about what other family members and the potential donor would do in such a situation.

It was horrible! I was there, alone, to make that decision. As I knew that his father was not going to donate, then I made a decision and said no. (F1-E1)

The emotional difficulty present at this moment make the family members feel incapable of making a definitive decision¹⁵⁻¹⁷. On the other hand, the study shows that the decision becomes easier for the family when they had discussed about organ donation with the family member who suffered BD¹⁸. Additionally, there is the fact that, in the context of the interview conducted by the health care professionals, requesting donation can constitute an obstacle, as the communication inability of both physicians and nurses can have a negative impact on the families¹⁹. The mediator role of the interviewer, based on an ethical and reliable interaction, directed to the care and attention to the families' needs, contributes to the decision-making process¹⁹⁻²⁰.

Some of the families interviewed experienced the BD diagnosis and the decision not to donate one year or longer ago, and perceived that the time elapsed favors reflections on the experience, promoting reinterpretations and the understanding that, currently, they could act differently.

If it was today I'd accept, but as it was back then. What happened was a surprise, which angered me, at the time I accepted and later I turned back. I'd act differently if it was today. (F3-E1)

The information provided by the health care team about BD is not always objective and capable of elucidating the families' doubts during the conversation¹⁰. The BD diagnosis is defined in the Brazilian legislation², but the concept, as in other contexts, seems to be unknown to most people, which contributes to uncertainties regarding the confirmation of the person's death²¹. Understanding that a family member with heartbeats, respiratory movements, and normal body temperature is dead is a difficult experience for the family, and explaining it is an arduous task for the professionals³. Many families are still in a state of shock due to the BD announcement when they are surprised by the possibility of organ donation¹⁶⁻¹⁷.

When remembering the course of the facts related to the experience and the family member who died, and reflecting about how they decided not to donate, one of the participants remembers that her son had shown a desire to be an organ donor.

But, at that time, how could I remember? Now that I'm talking, I remembered that one day he spoke about organ donation and said: if there's anything they can use from me, let them use it! Only that I never again remembered that. I only remember now. (F5-E1)

The decision of not donating organs is circumscribed to the time interim and the interactional context of pain and suffering experienced by the family. When facing the uncertainties of what may happen to their family member, the unexpected situation, the lack of knowledge about BD, and the urgency in making a decision, the families see their lives falling apart. With no time to recover elements of family life and the opinions of other family members that contribute to the elaboration of meanings, the reflexive process is triggered by an experience of uncertainties. Therefore, the meaning attributed to BD and organ donation is related to the intensification of the loss, strengthening the decision to not donate.

Study limitations

Having as research locus a public service that is a reference in BD diagnosis and organ donation is a study limitation, as it contributed to the reduced number of families interviewed that opted for not donating and restricts the possibility of generalizing the results. In addition to that, the need to access the medical records, which had incomplete information about the location of potential participants, limited the sample.

CONCLUSION

The results allow understanding that the experience of the family with a relative with BD resulted from an unexpected event, interrupts the normal course of life, disorganize their *status quo*, and makes them interact with symbolic elements of an unknown context, pain, suffering, and death, requiring that, in a short period of time, they have

enough information to make decisions about the possibility of organ donation. The uncertainties and the suspicion of understanding and interpreting the facts and information received permeates the family's interactions with the health care team and the subsequent events, making them vulnerable, insecure, and weakened. In addition to that, the perspective that organ donation can become a factor for more suffering, family opposition and disagreement, contributes to the decision of non-donation.

The families' experience enables to expand knowledge on the theme of BD and organ donation, emphasizing that the interpersonal relationships established in this environment, when sensitive to recognizing and embracing pain, suffering and uncertainty, in a respectful manner to the singularities of each family, and available to inform and answer questions, are resources that can help them to decode the unknown elements, (re)organize thoughts, and decide about donating or not.

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