

ORGAN AND TISSUE DONATION: PERCEPTION OF FAMILY MEMBERS WHO CHOSE NOT TO GIVE DONATION

DOAÇÃO DE ÓRGÃOS E TECIDOS: PERCEPÇÃO DE FAMILIARES QUE OPTARAM PELA NÃO DOAÇÃO

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RESUMO

Objetivo: Conhecer a percepção de familiares de potenciais doadores de órgãos e tecidos que optaram pela não doação. Método: Pesquisa de natureza descritivo-exploratória, de abordagem qualitativa, guiada por um roteiro de entrevista semiestruturada e que utilizou a análise de conteúdo proposta por Bardin. Foram entrevistados oito participantes que recusaram a doação de órgãos e tecidos, após o diagnóstico de morte encefálica de um familiar. Resultados: Emergiram sete categorias: assistência ao paciente e seus familiares; desconhecimento sobre o processo de doação de órgãos; dificuldades em compreender a morte encefálica; respeitar o desejo do paciente manifestado em vida; demora na liberação do corpo; medo da mutilação do corpo; e manifestação contrária por parte de um membro familiar. Considerações finais: Assim, sugere-se a implantação de novas estratégias e ações que fortaleçam as políticas públicas voltadas para conscientização popular, a fim de evitar os elevados índices de recusas familiares no momento da decisão de doar.

PALAVRAS-CHAVE: Obtenção de Tecidos e Órgãos; Família; Percepção; Recusa de participação; Enfermagem.

ABSTRACT

Objective: Recognizing the perception of family members of potential organ and tissue donors who chose not to donate. Method: This is a survey of a descriptive-exploratory nature, with a qualitative approach, guided by a semi-structured interview script and which used the content analysis proposed by Bardin. Eight participants were interviewed who refused to donate organs and tissues, after the diagnosis of brain death of a family member. Results: Seven categories emerged: assistance to patients and their families; ignorance about the organ donation process; difficulties in understanding brain death; respect the patient's desire manifested in life; delay in the release of the body; fear of mutilation of the body; and opposing manifestation by a family member. Final notes: Thus, it is suggested the implementation of new strategies and actions that strengthen public policies aimed at popular awareness, to avoid the high rates of family refusals at the time of the decision to donate.

KEYWORDS: Tissue and Organ Search; Family; Perception; Refusal to Participate; Nursing.

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INTRODUCTION

The technological evolution related to procedures involving organ and tissue transplants presented a notorious development, with important repercussions on the survival of thousands of people, as a form of treatment performed for patients with organ failure and for those affected by terminal chronic diseases.^{1,2}

In Brazil, in recent years, the number of organ transplants has increased significantly. In 2011 there were 4,158 transplants, and in the same year, considering the different types of transplanted organs, Brazil reached the mark of 23,397 transplants. The proportion, which in 2011 was 10 donors per million inhabitants, in 2015 reached the target of 15 donors per million inhabitants.³

On the other hand, in the state of Piauí, where the type of transplantation performed is that of cornea and kidney, of which they increased until 2013, showed a fall in 2014, in each estimated to be performed 565 transplants, only 230 were effective, presenting a level well below expected.⁴

Although organ transplants are an effective treatment for some irreversible chronic diseases, the demand for recipients for the number of donors is still high, making it difficult for organ banks to provide all who need it, resulting in long waiting lines. Even with the growing trend of transplants across

the country, the Brazilian reality is still unfavorable.⁵

In this context, the removal of organs designated for transplantation is undoubtedly preceded by the diagnosis of Brain Death (BD), defined through the criteria of Resolution nº 2,173/17 of the Federal Council of Medicine (FCM). Therefore, Brazilian legislation uses the donation of consented organs, where it will be exclusively up to family members to decide to donate or not the organs and tissues of the deceased and potential donor.^{6,3}

However, given the diagnosis of BD, the experience of a shock situation, the despair of the unexpected hospitalization of the family member, the distrust with the request for organ donation, the denial of BD, the suffering, the weariness of the loss of the loved one and the family conflicts for decision-making are among the multiple causes that result in the refusal to donate.³

In this sense, family refusal has represented a major obstacle to performing transplants, as well as the failure to identify and notify potential donors and a high rate of clinical contraindications for donation, as some studies have shown. In 2012, 28.8% of family members refused when calculated in relation to potential donors, corresponding to 2,315 families who chose not to donate organs and tissues, when the denominator becomes the number of family interviews

conducted, the rate of family refusal rises to 41%.^{7,8}

During 2013, 8,871 cases of potential donors were registered in Brazil, but only 2,526 became effective donors, corresponding to only 28.5% of the total. Among the main causes of non-implementation of the donation is family refusal (2,622).⁹ Between 2015 and 2017, refusals showed rates of 44% of non-realization of donation of potential donors.

Thus, there is a need to identify the reasons and factors that lead family members, potential organ and tissue donors, to opt-out of donation, to contribute to the improvement of this process. Therefore, the present research sought to know the perception of family members of potential organ and tissue donors who chose not to give.

METHOD

This is a descriptive-exploratory research, with a qualitative approach, which occurred during October 2018 and had eight participants, registered in the database of the Organization of Organ and Tissue Search (OOT) of a public hospital in the municipality of Teresina- Piauí.

In the data collection, a semi-structured interview script containing questions formulated by the researchers was used, divided into: at the first moment, the sociodemographic characterization of the participants was sought, such as gender, age, income, marital status and religion; and in the

second moment formed by questions related to knowledge about the donation process, assistance given by health professionals and the reasons that led them not to donate the organs and tissues of the family member who received the diagnosis of brain death.

For the selection of participants, the following eligibility criteria were met family members who chose not to give organs and tissues, aged 18 or older and who lived in the city of Teresina- PI. Being excluded: family members who did not have an effective participation in the decision-making of organs and tissues of the deceased person.

The empirical material obtained was by recording the participants' statements for subsequent transcription in full. That said, the content analysis proposed by Bardin¹⁰ was applied, with application of the word association test and soon after, organization of the analyses with decoding of the data into categories.

It is emphasized that following all the components and ethical norms contained in Resolution n° 466/2012 of the National Health Council (NHC)¹¹, this study was submitted for consideration and subsequently approved by the Research Ethics Committee of the Getulio Vargas Hospital (CEP/HGV), with the CAAE: 96479218.2.0000.5613, under the number of opinions: 2.95.515, on 10/03/2018. The participants were explained all the objectives, risks and benefits of the study, as well as asked to read and sign the

Free and Informed Consent Form (FICF), before the interviews. To ensure anonymity, participants and their statements were identified and named by codes from E1 to E8.

RESULTS AND DISCUSSION

Regarding the characterization of the participants, the research was conducted with 08 relatives of patients who would be

potential donors, between the years 2016 and 2017. Among the participants, there was a predominance of females 5 (62.5%), aged between 18 and 30 years 5 (62.5%), complete high school 3 (37.5%), family income of up to 1,500.00 5 (62.5%), married marital status 6 (75.0%), Catholic religion 6 (75.0%) and who lived with 4 to 5 family members 6 (75.0%), as can be seen in Table 1.

Table 1 - Sociodemographic characterization of study participants. Teresina, Piaui, Brazil, 2018. (n=08).

	N (%)
Gender	
female	5 (62.5%)
male	3 (37.5%)
Age group	
18 to 30	5 (62.5%)
31 to 40	3 (37.5%)
Schooling	
Incomplete elementary school	2 (25%)
Complete high school	3 (37.5%)
Incomplete higher education	1 (12.5%)
Complete elementary school	1 (12.5%)
Complete higher education	1 (12.5%)
Household income	
Up to R\$ 954,00	1 (12.5%)
Up to R\$ 1,500.00	5 (62.5%)
Over R\$ 2,000	2 (25.0%)
Members of the Family	
1-3 people	2 (25.0%)
4-5 people	6 (75.0%)
Marital status	
Single	2 (25.0%)
Married	6 (75.0%)
Religion	
Catholic	6 (75.0%)
Evangelic	2 (25.0%)

Source: search data.

Regarding the information collected and analyzed, from the participants' statements, seven categories emerged, namely: care to the patient and his/her family members; ignorance about the organ donation process; difficulties in understanding brain death; respect the patient's desire manifested in life; delay in releasing the body; fear of mutilation of the body; and contrary manifestation by a family member.

Patient care and to their families

At the beginning of the procedures to confirm brain death, the nursing professional should inform the multidisciplinary team about the need to communicate and clarify to the family of the possible donor all the procedures that should be performed. This support and professional care is of paramount importance, because, in most cases, what makes it difficult for family members to accept this condition is the fact that they only have contact with the diagnosis of BD, after completion.¹² It is noted that this reality is present in everyday life, as shown in the E4 report:

at first we didn't have so much follow-up, after the death yes, we had all follow-up with the psychologist and everything... and said that her chances were so percent, that she couldn't... we had follow-up right after the diagnosis, and the

doctor came and said that her chances were such... and if she continued in the devices it would be that vegetative state, which was almost impossible, that in medicine had no chance ... after death yes, came the doctors talking, the psychologist who started to follow more we and everything (E4)

It is extremely important to maintain the social relations between nurses and other professionals, making interpersonal communication decisive in this context, as it is established among individuals that complete themselves, influencing their actions mutually.¹³ Problems such as lack of communication between professionals and unsatisfactory interpersonal relationship are established in health care, such as the e3 report, such as the explains the report of E3, such as the e3 report explains:

we do not feel welcomed, unfortunately health is a dehumanized area, there is no humanization, it is what we value most... Unfortunately, we do not have many interpersonal relationships, the staff has no humanization, thick nurses, ignorant ... it is an area that is becoming a butcher himself, and when we ask says he does not know, only the doctor" (E3)

Research¹⁴ states that nurses report objectivity, clarity and simplicity in the information transmitted as important in

helping the family members of the eligible donor in decision-making with autonomy. In the testimony of participant E6, it was noticed the lack of information during the care provided by the professionals to the patient, which consequently generates a greater impact on the family with the communication of a possible irreversible state.

We were not aware of the procedures they did, before the doctors said that he only had kidney problems, and then already said that he was suspected of brain death" (E6)

For the articulators of the donation, humanizing means providing support and support to the relative of the potential donor, so that they can stimulate means of coping and acceptance of the diagnosis of brain death. It is necessary that these subjects have empathy to treat these family members adequately, understanding the situation, feelings and behaviors identified.^{15,16}

The professional should offer emotional support to the family member, given the uncertainties in which he/she is, prioritizing not only the obtaining of organs, but a humanized care for both the family and the patient. Therefore, family members need professional involvement during the hospitalization period.¹⁷

The report of participant E5 confirms that when professionals provide humanization and empathy for the patient in an integral way with information about the patient's condition,

family members assimilate the situation more easily, softening the impact of a new diagnosis:

"[...] there was always a person there talking, paying attention, explaining to us how his procedure was ... As he was in the ICU, it is a restricted area, but in visiting hours, they were always telling us how he was continuing the medications, whether he reacted or not, they always talked to us ... The service was good they were always there guiding us what was going on ... After some tests, the doctor he told me that the injury he suffered was large, that they would try to get around with medications, but that it was difficult for him to survive, he was sincere you know... he spoke with good and everything... but practically he prepared me to be able to follow me and as the days went by I saw what was happening ... and I was comforting myself to be able to comfort my mother and sister... By the tests we were almost sure that he would give brain death.... and we were accepting what was happening [...]" -E5

In this circumstance, to be successful in the organ donation process, there must be good assistance from professionals to the potential donor, as well as the support of the entire multidisciplinary team.¹⁸

Ignorance about the organ donation process

After confirming the diagnosis of BD, the family is told about death and diagnosis, and the death certificate is the duty of the physician, obligation of the institution and family law. Then, the family is referred to the place where the family interview will be held, which aims to provide all the information and support necessary for the family's decision-making regarding the donation.¹⁹ However, this is often the first time that family members have contact with this subject and it can be verified in the speech of E6 when asked about knowing the process of organ and tissue donation.

Knowledge of donation to us did not have, we had no knowledge. My family didn't understand much, until I did when the doctor explained it, I tried to explain everything to them and even the hospital staff, but they were kind of like this...(E6)

In the case I had no knowledge about organ donation, but I had heard several people commenting on these issues... but I didn't know how it worked or what situation I could donate. (E8)

The understanding of BD is considered as a factor that influences whether to authorize donation, because, generally, families who do not have previous knowledge

about this subject have greater resistance in the conception of the idea of the cessation of brain functions in the apparently living being.²⁰

Difficulties in understanding brain death

It is observed that the general population has difficulty in understanding BD, besides the intrinsic nature of bad news, it can still include other difficulties, such as: the concept of BD is not always transmitted with the use of terms accessible to family members; the antagonistic perception that, although without brain activity (dead), the patient seems to breathe normally, having blushed skin, heartbeat, and being asleep can confuse family members; and beliefs (religious or not) that still feed the patient's hopes/expectations of improvement, may influence family members to refuse the donation of the patient's organs.²⁰ And these difficulties were verified in the reports of E6 and E8:

It was strange to know that the person died, but we feel the heart beating... (E6)

My greatest difficulty was to understand how a person is dead and the heart beating normally and the temperature too, and to tell you the truth to this day I have my doubts. But the doctors told me that they did all the tests and that I had nothing else to do, that it was Brain Death, that her

heart worked even because of the devices and that when they turned off, everything would stop... (E8)

It is still complex for society to understand the definition of brain death, due to lack of knowledge, the lack of preparation of teams to perform evidential exams, the incorrect approach of families, failures to pass information on the clinical status of the patient, hindering the notification of a potential donor and generating a family refusal before the donation. Thus, providing accurate information about the correct diagnosis of BD and ensuring the correct prognosis for families, differentiating BD from the coma state, can help them recognize irreversible brain damage and remove the family's wrong perceptions of the possibility of returning to life, positively influencing organ donation.²⁵

Respect the patient's desire manifested in life

Respecting the desire of the deceased patient manifested still in life was one of the reasons that led them to opt out. For the family, the patient's desire not to be an organ donor is an attitude considered still important, even if for many people this request is no longer considerable after death, and often until an act of selfishness refuses the donation³. This was confirmed in several reports, where the family members chose not to give because they respected a decision that had already been made by the patient. It was

noticed, then, that the autonomy of the decision remains intact, and performing the patient's will means a lot to them, as observed in the e5 report:

He always said that if something ever happened to him and his organs would keep working these things, he would not accept organ donation, so much so that in his identity he has no 'donor' because he never accepted. Then it was his own decision, then my mother followed what he wanted, my mother didn't want me to give it at all... Then it was her opinion, her choice. (E5)

It is important to know the opinion of the deceased family member, still in life, to make the decision in the request for organ donation.¹⁵ The families mentioned that refusing the donation means respecting the patient's desire. This fact is clearly observed in the reports of participants E4 and E2, who state that this attitude would alleviate the pain they felt by making a request that had been requested by their loved one:

A matter of personal choice, my mother had already decided and had already communicated to the family, and we respect the decision... (E4)

We wanted to do this will by her choice.. (E2)

However, when the family is aware of the potential donor's desire, the decision to refuse the donation is a sure situation to

occur, as the family member is confident in the decision made, although other family members consider it a questionable attitude. In addition, people lose the power to decide after brain death and the right thing for the family to do is to respect what the dead person believed in life.¹⁵

Delay in releasing the body

Another factor that is complicating the donation process is the delay in removing organs, since it causes suffering to the family, making the situation distressing and increasing the feeling of helplessness through the act of waiting⁽²¹⁾. This condition is still seen as an obstacle, because as the family member E1 mentions, it was one of the great reasons that led him not to give organs:

We would even donate the organs, only we realized that it would take a long time to release the body, that it would have a whole process and it would be more painful for my mother who was suffering a lot, and we also of course, so we decided not to donate... (E1)

A study reveals that the delay in the donation process appears with 2.7% of the reasons for family refusal. The feelings of family members while waiting for the release of the body for the preparation of the wake is characterized as an exhausting moment, families experience feelings of anxiety and nervousness due to the delay of the entire

bureaucratic process, which ends up directly influencing the non-donation.²² This was observed in the following statements:

Then there was also the delay of the release of the body and this all martyred us a little, I just did not like that part there because there they were already mistreating us, practically because we did not accept the donation, then we waited until when the body was released ... (E5)

Then we decided not to donate... as soon as we saw it would take a long time" (E7)

These reports are confirmed in another study conducted in the state of Rondônia, Brazil, in which 7.9% of the medical records investigated by potential donors demonstrated that the family members chose not to give, due to the prolongation of the suffering and emotional stress represented for the family, referring to the delay in the process of organ removal and release of the body, being a relevant factor in cases of refusal.⁷

Fear of body mutilation

In this subcategory, it was observed that the perception and the need to watch over the body in its total integrity is one of the causes that influences the refusal to donate. In this sense, a cross-sectional study conducted in a municipality of Pernambuco, Brazil, with

524 medical records, identified that the main cause of family refusal refers to the maintenance of the healthy body (36.0%). Family members believe that the body is something untouchable, deeming important the cult of the present body, and thus it must remain. By manipulating this body to remove the organs, they interpret it as lack of care and respect for the deceased, and because they do not see the body as something material, they end up resisting the donation believing that acceptance would cause more pain and suffering to family members.²²

In the E6 report, it is evident that the family member believes and fears in the deformation of his or her body, and does not understand that the scar remains as a surgical incision:

The reason that led us not to donate my mother's organs, was because my father did not accept, he wanted her whole body, and I also think he thought my mother would be full of marks and her body would be deformed, then I as a daughter had the will to even donate ... but as I said I had to do his will that did not accept for fear of leaving the body deformed... (E8)

Other studies indicate that the family fears the violation of the body, due to the perception that the family member has suffered a lot and that such fear suffers the influence of the fragmentation of knowledge.

The way the individual relates to body image can serve as a factor of facilitation or resistance to donation. It is advocated that the fear of body mutilation, added to the idea that donation can anticipate the death of the potential donor, is an important factor of influence on families.^{23,24}

Contrary manifestation by a family member

Another reason identified was the manifestation contrary to the donation by one of the family members. A study⁷ reveals that of 106 records analyzed, 15.9% refused to donate for family disagreement. Although most of the entities wanted to make the donation, the relatives followed the opinion of the other family member who refused to donate the organs of the deceased relative. This finding is evidenced in the following statement:

my brother who lives in another city did not agree, and the girl said she had to have the consent of the whole family for the donation. We had even talked about donating the corneas, but we had never concluded... (E5)

When there is disagreement among the entities, family members favorable to the donation prefer not to donate for fear of repression by other family members. The family member in favor of the donation, in

view of the contrary manifestation of another family member, ends up respecting the decision made, to avoid conflicts; thus, the opinion of the family member contrary to the donation prevails.²⁴

There are several factors related to the process and decision-making by family members regarding non-donation. Reasons such as respect for the patient's desire manifested in life, delay in the release of the body, contrary manifestation of a family member and fear of mutilation to the body were identified as being present. Thus, it becomes evident the need to carry out actions and strategies aimed at the information process, which seek to achieve the awareness of the population about the importance of organ and tissue donation and how this process works, but with a view to respecting the singularity and aspects of everyone that influence not to give.

FINAL NOTES

The research made it possible to understand the real perceptions that lead family members to decide not to give organs, finding that insecurity, fear, lack of knowledge about the process and doubt, are still part of a scenario that goes back to the success of the effective donation. Not to mention, the lack of subsidies from some institutions and their health professionals has

made this process slow and even more difficult.

In this sense, it emphasizes the need to work more on the training and improvement of health professionals, as well as to seek the implementation of strategies and elaboration of public policies that aim not only to make the population aware of the importance of the act of donation, but to clarify their doubts about this process, to improve and avoid the high numbers of family refusals at the time of the decision.

Becoming a donor is a noble attitude of such solidarity, empathy and love for others. However, there are interlaces that need to be worked, so that the ability to reverse and transform this problem into a solution is opportunities, because it is known that organ and tissue donation is the hope of continuing to live thousands of people who need this treatment option. Thus, it is considered of great importance not only for the scientific community and the health system (public and private), but for the population in general, to deepen and know the perceptions, visions and all aspects and factors that influence these individuals for non-donation.

Moreover, it is worth mentioning that some questions made it difficult to carry out this study, such as the lack of information in the medical records, which helped in the identification and contact with the relatives of potential donors, and the feeling of the family members, manifested during the interviews,

regarding the memory of the hospitalization period and death of their loved ones.

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