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PERCEPTION OF FAMILY MEMBERS ON THE DONATION OF ORGANS AND TISSUES

PERCEPÇÃO DE FAMILIARES SOBRE A DOAÇÃO DE ÓRGÃOS E TECIDOS

PERCEPCIÓN DE FAMILIARES SOBRE LA DONACIÓN DE ÓRGANOS Y TEJIDOS

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ABSTRACT

Objective: to understand the perceptions of family members regarding the donation of organs and tissues. **Method:** This is a qualitative, exploratory and descriptive study. The sample was composed by seven family companions from patients admitted to the hospital chosen for the research. As a data collection instrument, a semi-structured script containing idealized questions was used to express the opinions of the respondents without necessarily agreeing to the theme. The data were submitted to the Bardin Content Analysis. **Results:** the participants had little knowledge about the donation; however, empirical definitions emerged about them. There are several factors that interfere in the donation process such as respect for the will of the potential donor, issues of solidarity and perpetuation of life, as well as ignorance about the entire donation process in Brazil. **Conclusion:** there was little knowledge and understanding about organ donation, and this result is a reflection of several factors, such as the low discussion about the subject in the social environment. **Descriptors:** Organ Donation; Tissue Donation; Transplant; Public Opinion; Death; Organ.

RESUMO

Objetivo: objetivou-se compreender as percepções de familiares a respeito da doação de órgãos e tecidos. **Método:** trata-se de um estudo qualitativo, exploratório e descritivo. Compôs-se a amostra por sete acompanhantes familiares de pacientes internados no hospital escolhido para a pesquisa. Utilizou-se, como instrumento de coleta de dados, um roteiro semiestruturado contendo perguntas idealizadas para expressar as opiniões dos pesquisados sem, necessariamente, concordar com a temática. Submeteram-se os dados à Análise de Conteúdo de Bardin. **Resultados:** verificou-se que os participantes possuíam pouco conhecimento sobre a doação, todavia emergiram definições empíricas a seu respeito. Depreendeu-se que existem diversos fatores que interferem no processo de doação, entre eles o respeito à vontade do potencial doador, questões de solidariedade e perpetuação da vida, além do desconhecimento sobre todo o processo de doação no Brasil. **Conclusão:** constatou-se o pouco conhecimento e entendimento sobre a doação de órgãos, sendo esse resultado um reflexo de vários fatores, como a baixa discussão sobre o tema no meio social. **Descritores:** Doação de Órgãos; Doação de Tecidos; Transplante; Opinião Pública; Morte; Órgão.

RESUMEN

Objetivo: comprender las percepciones de familiares sobre de la donación de órganos y tejidos. **Método:** se trata de un estudio cualitativo, exploratorio y descriptivo. La muestra fue de siete acompañantes familiares de pacientes internados en el hospital escogido para la investigación. Se utilizó una guía semi-estructurada como instrumento de recolección de datos conteniendo preguntas idealizadas para expresar las opiniones de los investigadores sin necesariamente estar de acuerdo con el tema. Los datos se sometieron al Análisis de Contenido de Bardin. **Resultados:** se verificó que los participantes poseían poco conocimiento sobre la donación; sin embargo, surgieron definiciones empíricas. Existen diversos factores que interfieren en el proceso de donación, entre ellos, el respeto a la voluntad del potencial donador, preguntas de solidaridad y perpetuación de la vida, además del desconocimiento sobre todo el proceso de donación en Brasil. **Conclusión:** se constató poco conocimiento y entendimiento sobre la donación de órganos y que ese resultado es un reflejo de varios factores, como la baja discusión sobre el tema en el medio social. **Descritores:** Donación de Órganos; Donación de Tejidos; Trasplante; Opinión Pública; La Muerte; Órgano.

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INTRODUCTION

The first kidney transplant in Brazil was performed in 1965 and the first heart transplant was performed in the country in 1968 but without any legal support for donation or organ collection and definition of encephalic death. The transplants were suspended in the country for approximately 15 years, as a result of the failures due to rejections.¹

With the significant increase of this type of procedure, the regulation of this activity is necessary, which is marked by the diagnosis of encephalic death (ED). In 1997, the Federal Council of Medicine (FCM) defined the concept of brain death through Resolution 1,480, as an irreversible stop of the function of the brain (brainstem or brain stem). In this resolution, the criteria for the diagnosis of ED were established, characterized by clinical and complementary examinations during variable time intervals appropriate for certain age groups. The observations before the beginning of the confirmatory tests are: the identification and hospital record of the patient; the establishment of the coma cause; check if the patient has hypothermia; verification if the patient is under the effect of depressant drugs of the central nervous system and evaluation if the patient does not have arterial hypotension.²

After the observation of these prerequisites, the patient is submitted to two neurological examinations aimed at assessing brainstem function. These tests must be performed by two doctors who are not members of the collection and transplantation team. The time interval between the exams based on the patient's age is defined.²

When the ED picture is detected, the patient care team communicates the family about the diagnosis and then it performs the notification of the potential donor to the Notification, Collection, and Distribution Center of Organs (NCDCO). The NCDCO make notifications to the Organ Procurement Organization (OPO), which will evaluate the clinical conditions of the potential donor and the feasibility of conducting a family interview, acting in a process with a set of actions that can transform a potential donor into an effective donor. This process involves several steps that range from the identification of the potential donor to the release of the body into the family.³

The entire donation process is managed by the National Transplant System (NTS), at the national level, and by the State Transplant Centers, which regulate the waiting list for

the organs in each State. According to the Brazilian Association of Organ Transplants (ABTO), about 33,199 patients were waiting in the waiting list for organ or tissue transplantation up to June 2016. More specifically in the State of Pernambuco, 815 patients waited in line. Between January and June 2016, 249 potential donors were notified, but only 72 became effective donors.⁴

There are several reasons that stop the donation such as family disagreement; the lack of knowledge about the will of the potential donor; the desire to keep the body intact; the lack of understanding about the diagnosis of ED; religious issues; dissatisfaction with hospital care; the delay in the release of the body; mistrust and fear of organ trafficking.⁵

The basis of Law 10.211 of 2001 defined that authorization for the removal of organs and tissues for transplantation is decided by family members.⁶ When the family members do not have a good understanding of the process of donation of organs and tissues and of the benefits that this act can provide, they become apprehensive and present doubts, since it is a matter on which they have no clarification.⁷

In this sense, considering the various factors that positively and negatively influence family authorization for donation, the interest in conducting a research based on the following guiding question emerged: "How do patient relatives perceive the organ donation process of their family members and what situations would influence a possible future donation authorization?"

Knowing the population's perception about organ donation can support the development of strategies to approach family members with the purpose of guiding the awareness raising works about the issue, as well as contributing to the scientific production on the theme.

OBJECTIVE

- To understand the perceptions of family members about organ and tissue donation.

METHOD

This is a qualitative, exploratory and descriptive study, developed with seven hospitalized patients, from June to October 2016. The following inclusion criteria were being over 18 years old, being a relative of a hospitalized patient a hospital, in the medical, surgical and orthopedic sectors. The relatives of patients hospitalized in the emergency room and intensive care unit

and/or in brain death were excluded from the studies. These criteria were adopted considering that the approach of this issue with relatives of serious patients could cause discomfort and insecurity by the interviewees, besides changing the dynamics of the relationship of the relatives with the hospital staff.

The interview technique was used for data collection, using a semi-structured script, which contained auxiliary questions, allowing the respondents to express their opinions without necessarily agreeing to the topic and without limit the question.⁸

After recording the interviews, they were transcribed into a text editor and submitted to Bardin's Content Analysis. This method transforms the material in a systematic way, converting it and grouping it into smaller units, called categories. Categorization is defined as an operation to classify constitutive elements by differentiation and subsequent regrouping, according to previously established criteria.⁹ In this research, the steps in the method were considered: pre-analysis; exploitation of the material and treatment of results obtained and interpretation. After analyzing the data, the following categories and subcategories were listed: knowledge about the donation process; factors that influence the decision process; respect to the opinion of the potential donor; solidarity and the perpetuation of life; ignorance of the donation process and other influencing factors.

As a study scenario, a university hospital located in the city of Petrolina (PE) was selected. The research was approved by the Ethics and Research Ethics Committee (CEDEP/UNIVASF), and it is registered in the Certificate of Presentation for Ethical Appreciation number 53583616.4.0000.5196. In accordance with the legislation of Resolution 466/2012 of the National Health Council, the participants took note and signed the Informed Consent Form. The study individuals were identified with fictitious names, represented by plants and flowers characteristic of the caatinga biome to guarantee their anonymity.

RESULTS

The participants were between 19 and 44 years old, all of them were female. After analyzing the family bond between the participants and the hospitalized relative, two of them were granddaughters, three were sisters, one was a daughter and one was a daughter-in-law. The level of schooling had

two who did not finish high school, four who had completed high school and only one who had a complete upper level. Regarding the marital status, three participants affirmed to be married and four declared to be single. Among the interviewees, the Catholic religion was prevalent, and only two participants claimed to be evangelical. The monthly family income ranged from R\$ 300.00 to two minimum wages. Through the results obtained from the data analysis, it was possible to elaborate six thematic categories and subcategories that deal with the perception of the relatives about the donation of organs and tissues: 1) Knowledge about the donation process; 2) Factors that influence the decision process; 3) Respect the opinion of the potential donor; 4) Solidarity and the perpetuation of life; 5) Ignorance of the donation process; 6) Other influencing factors.

DISCUSSION

◆ Knowledge about the donation process

During this study, the need to understand the participants' understanding of organ donation was noted. Thus, during the appreciation of the speeches, the little or no knowledge about the participant was identified, as illustrated below.

Because people imagine: what is an organ donation? They think it's something from another world. I also think so, because I know very little. So I can not even talk so much. (MALVA)

At the moment... very, no. Some things only, [...] I know very little. (MELOSA)

What I know, I do not know much. I know you're like when somebody dies. (MARIANA)

Organ donation is a controversial issue becoming the interest and having discussions in various social segments. The lack of knowledge, sensational news about organ trafficking, the absence of permanent programs aimed at raising public awareness and encouraging organ collection contribute to feed doubts and promote myths and prejudices.⁷ Many people are verbalizing their intention to become organ donors, but they are unaware of existing resolutions, legislation and other aspects that involve this issue.

Although they reveal limited knowledge, the statements of some individuals demonstrate empirical definitions regarding brain death and family authorization, as can be seen below.

What I know about organ donation is just that, to donate, we have to have the authorization of the relatives, if the person wants. [...] because, sometimes, people do not even die of an illness, they die of an

accident and such. Our organs are working right, the heart has stopped, but the other organs are working. (ROSA)

I die, I can donate my organs if I want; if the family and me authorize [...] we can donate the organs. (PALMA)

The concept of brain death is one of the most complex and controversial subjects, but this is not a problem only in Brazil. Studies conducted in the United States have been reported that in general, people do not have enough accurate information to decide about the donation of family members.¹⁰

Through Law 10.211, the current legislation establishes the obligation to consult the family for the authorization of donation and removal of organs. About 60% of the general population says they do not know the current legislation on organ donation in Brazil, collaborating for the refusal of consent.¹¹

Also, in the midst of the discourses, knowledge about the in living donation is identified.

Depending on the donation, as the liver, [...] there is no problem at all. You can stay alive and give the liver. (MELOSA)

Living donors are those who donate a double organ such as the kidney, a part of the liver, or the lung, or a tissue, such as the bone marrow, so it can be transplanted to someone in their family or a friend. Law 9.434/97 and Regulatory Decree 2.268/97 are allowed, to the juridically capable, the free disposal of parts of the body, as long as its vital functions are not compromised.¹²

The lack of awareness seems to be the most important factor for low donation rates. It is suggested that educating people using graphic and digital media and conducting awareness programs can help improve donation rates. Also, ignorance, in general, implies situations of doubts and internal questions of family members when they are approached.¹³

There is a need to demystify and clarify what the organ donation process is, and to improve the information provided to family members and the population in general, to promote awareness, for the affirmative responses to the donation.¹⁴

The dissemination is considered fundamental so the population can create an opinion on the subject, and the media have a relevant role in this process of formation of conscience. As a strategy, the theme should be addressed in schools, so people grow up getting information about the whole process because there is a lack of knowledge about the topic.¹⁵

◆ Factors influencing the decision process

The objective of this category was to identify how the decision-making process would be favorable or unfavorable to organ donation in case the respondents had to give a position on the topic about a family member, besides to listing the main factors which influence the decision-making process of family members.

In the subcategories, respect is expressed for the opinion of the potential donor, when it was manifested in life, questions of solidarity, the perpetuation of life after death and ignorance as important influencing factors.

◆ Respect for the potential donor's opinion

In the most emphatic statements, the desire for the donation and appreciation of the favorable manifestation of the possible donor while living were evidenced, as observed in the outstanding speeches.

Firstly, if the person were in favor, of course, I would not oppose. But first, I respect her will. (MANDACARU)

I think that even after death, we have to take into account the opinion of the person because it is his organ, it is up to him to decide whether he will want to donate or not. (ROSA)

Studies pointed out that, among the families addressed, 15.7% refused to donate, and the most cited reason for refusal is the lack of knowledge of the potential donor's desire; the other reasons cited pointed to the donor's manifestation in life contrary to the donation, the family's desire to maintain the integrity of the body and religious convictions. From these elements and from the statements presented, the point of greatest relevance in the decision-making process is respect for the will of the potential donor.¹⁶

The understanding of the influence of uncertainty in the family decision process is of paramount importance. The discovery of the influence of uncertainty on the definition of reality and, consequently, on the family decision, has implications, mainly, in the family decision process. The most important difference between the families that authorize and those that do not authorize the donation of organs is linked to the family's perception when they were approached.¹⁷

The lack of knowledge about the donor's desires about organ donation is one of the main reasons stated by non-donor families.¹⁸ The ignorance of the will of the potential donor was the most influential factor during

the course of the study, according to the following statements.

Thus, if he said no, I would take it into account because it's his opinion, it's his; but it would not be cool, because it will take everything to him [...] but I will respect because it is his opinion! But I'll respect it because it's his will, do you understand?! (MUZAMBÉ)

I was going to take that into account because each one has his will. I was going to try to donate, but in that case, I try to make it before dying, if he wanted to make the donation. But if he did not want to, I would have to respect his will. (PALMA)

The most expressive refusal reason was the lack of knowledge of the potential donor's opinion, corroborating the above discourse. It is noticed that when the desire of the potential donor is known by the family, the decision to refuse the donation is a situation that does not cause doubt since the family member feels secure in the decision taken, even if for other family members, the attitude may be cause for questioning.¹⁹

Considering the donation depends exclusively on family authorization, even with acceptable rates of refusal, it is important to broaden the debate on the topic, to carry out campaigns to stimulate and raise awareness among the population and to encourage people to express their desire and discuss the decision made in the family. Given the social importance of donating organs and tissues, it is believed that these strategies can contribute positively to the decision-making process, with the consequent increase in the number of donations, giving rise to an increase in the number of transplants.¹⁶

♦ Solidarity and the perpetuation of life

The reasons for donating or not are complex and, although important altruism does not seem to be sufficient to motivate the donation of organs.¹⁵ Most of the respondents brought the desire to donate as the greatest will expressed. The feelings involved between the family member interviewed and the patient are also listed as motivations for making the favorable decision; feelings like love and solidarity are the most identified, according to the speeches below.

Because, sometimes, like, like, people need it. And if I can donate, for something, to help them, because it's no good for us, it costs nothing to give, right? (PALMA)

Because, let's say, he died, he will take everything to him, and that could be helping other people there. (MUZAMBÉ)

Despite the demonstration of solidarity and the desire to see the other good and save lives, the non-acceptance of death leads

feelings of hopelessness and helplessness, reflecting the fear of facing one's own finitude.¹⁰

Therefore, it is concluded that the decision to donate is a complex process and that family dynamics and expectations related to the roles of the individuals have an important place in this procedure, requiring a differentiated and specific approach, not only for family members of patients but also for the general population.²⁰

It is suggested that the desire to perpetuate life can be a strong ally for the authorization of transplantation, especially in cases where family members whose loved one died in their youth feel impelled to donate organs and act as if the relative were still alive, feeling maintained by the symbolism of the organ¹⁰. This fact was verified in the following reports.

My brother died. Then, they wanted me to donate his organs. I wanted! But my sister did not want to. Then, I wanted to. I signed. My family was against it because they didn't want me to sign. Because I wanted so, since he had no life, he could; like that, to have another life with his life. (MARIANA)

Her will to continue (live), in a way, present among us, giving a little bit of it to someone else. (MANDACARU)

Almost all the interviewees mentioned the continuation of life after death through donation. The families' perception of organ donation through love and affection is demonstrated, idealizing the attachment to the loved one, based on the feeling of solidarity, realizing that generosity and kindness will make the family member stay alive through the receiver.²¹

♦ Ignorance of the donation process

When imagining that death has different meanings for different people, the moral difficulties in relation to the decision-making about the donation are considered, and its impact on the daily life of the families that decide, favorably or unfavorably, for the donation of the organs of their loved ones are questioned²². In this way, it was sought to know the factors that can influence, positively and negatively, the response regarding organ donation.

Because it is a very controversial topic and death is characterized by an inherent fear, people choose to avoid such matters with their relatives, causing them to be unaware of patients' opinions on the topic. However, this reason for refusal can have at least four distinct meanings: 1) the person was actually opposed to the donation, but without

seriously reflecting on the topic and without waiting for the relatives to seriously take this desire; 2) the person was against the donation at a time when he had little information on the topic; 3) the person was wrongly motivated by concerns such as mutilation and disfigurement of his body; 4) the person did not actually manifest about the donation, but the family claims the opposite, in an attempt to close the conversation about the donation.²³

One of the unfavorable reasons given for the donation was the lack of information on the whole process, as highlighted below.

I think the no donation is more the lack of information even because, in fact, a donation is a good thing you do.
(MANDACARU)

Then, we hardly know much about organ donation. (ROSA)

To donate? The will of the patient. And not to give, the fear, of not knowing... I do not know. It's a seven-headed creature. (MALVA)

The lack of information hinders decision-making and not understanding the donation process is responsible for refusal.¹⁵

The manifestation of the desire to donate becomes inconceivable since the family member has no knowledge about the process of donating. This is a problem that could be avoided if the health teams informed the population about all the different possibilities of donation and about the therapeutic purpose of the process, recognizing the complexity of the barriers and the facilitators of organ and tissue donation, and how this may contribute to avoiding blind spots in ongoing efforts to help more people survive because of the greater availability of organs for transplantation.²⁴

◆ Other influencing factors

The discordance between members of the same family by some interviewees is pointed out as an important factor of influence, as can be seen in the next speech.

Because there is the family conflict. Because, not always, someone solves it, you have to listen to everyone's opinion.
(MANDACARU)

In most cases, when there is disagreement about donating, one of the relatives responsible for authorizing the donation clearly assumes responsibility for the decision; in this context, some of them assume non-participation in the decision-making process. It is evidenced that the donor-friendly family prefers not to donate for fear of repression by other family members. It is revealed that the family member favorable to the donation, in the face of the opposite manifestation of

another member of the family, ends up respecting the decision taken, in the attempt to avoid conflicts; thus, the opinion of the family member who opposes the donation prevails.¹⁵

During the interviews, the religion was mentioned by one participant only once.

[...] religion, too. In fact, I met a family in the Family (EC), which is a religion that is against blood transfusion and which, because of this, it worsened the health of a family member because of the transfusion.
(MANDACARU)

No religion is absolutely contrary to the donation, fact that bases the mention of the religion in a single time during all the interviews. A minimum level of understanding of cultural and religious diversity is essential for the health team since this is a necessary condition for addressing the issue at different levels of health care.²⁵

A reference to the mutilation of the body and the fear that the donation could anticipate the death of the potential donor in the course of the study has been identified, as shown below.

I have already been told that if the person is already dead, near death, he asks the family to leave, right? In that case, the family donates. Then, automatically, she's going to die. She's going to make the donation, he might even die... if he said no, I do not feel well, I do not want to give, I do not want to cut me, then I would not.
(MELOSA)

The fear of mutilation is influenced by the fragmentation of knowledge. Surveys show that the way in which the individual relates to the body image can be a factor of facilitation or resistance to the donation. It is argued that the fear of corporal mutilation together with the idea that donation can anticipate the death of the potential donor is an important factor influencing the families.¹⁰

CONCLUSION

In the speeches evaluated, the lack of knowledge or understanding about organ donation was observed, and this is a reflection of several factors, such as the low discussion about the topic in the social environment and also the lack of information conveyed by the media. Despite this, all participants were in favor of the donation, provided that the potential donor had mentioned their desire in life.

The factors that may influence the donation process were the lack of knowledge of the will of the potential donor; the divergence between the opinions of family

members; the deficit of understanding and knowledge on the topic; altruism; the solidarity and the desire that a piece of your loved one continue to live, when transplanted in another person.

There were difficulties in obtaining participants for the research because when the participants became aware of the content of the study, they were tense, and sometimes refused the participation due to the fact that it is a theme that often makes the people uncomfortable, because it is still a topic surrounded by myths, fears, and apprehension.

Also, the family member has a significant importance in the care of diseases in general, being responsible for several decisions that are inherent in the health-disease process. It is of great value to unveil the perceptions, the knowledge and the factors that influence the donation.

It is necessary to approach this reality to be able to help other people through the processes of organ and tissue donation; in this way, this research benefits not only people who can be clarified of this reality but also, the scientific community, by promoting a new view to these factors, subsidizing new research.

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