



## Reasons for the family members' refusal to donate organ and tissue for transplant\*

*Recusa de doação de órgãos e tecidos para transplante relatados por familiares de potenciais doadores*

*Negación de donación de órganos y tejidos para transplante relatados por familiares de potenciales donadores*

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### ABSTRACT

**Objective:** To understand the perception of family members of potential donors in regard to their reasons for refusal to donate organ and tissue for transplant. **Methods:** A qualitative phenomenological approach was used to conduct this study. A sample of eight family members who refused to donate organ and tissue for transplant participated in the study. **Results:** Participants reported ten reasons for refusal to donate organ and tissue for transplant. **Final considerations:** Reasons for the family members' refusal to donate organ and tissue was interconnected to their beliefs and values system, and the inadequate information received during the interview to consent for the donation of organ and tissue for transplant.

**Keywords:** Organ transplantation; Tissue transplantation; Tissue donors; Brain death; Family

### RESUMO

**Objetivo:** Conhecer a percepção de familiares de potenciais doadores sobre os motivos de recusa para doação de órgãos e tecidos para transplante. **Métodos:** Trata-se de uma pesquisa qualitativa, na vertente fenomenológica, modalidade "estrutura do fenômeno situado". Participaram do estudo oito familiares que recusaram a doação dos órgãos e tecidos. **Resultados:** Após análise das entrevistas, foram revelados dez motivos de recusa, considerados pelos familiares. **Considerações finais:** As proposições que emergiram revelaram que os motivos de recusa familiar para doação de órgãos e tecidos estão relacionados à crença, valores e inadequações no processo de doação e transplante.

**Descritores:** Transplante de órgãos; Transplante de tecidos; Doadores de tecidos; Morte encefálica; Família

### RESUMEN

**Objetivo:** Conocer la percepción de familiares de potenciales donadores sobre los motivos de su negación para la donación de órganos y tejidos para transplante. **Métodos:** Se trata de una investigación cualitativa, en la vertiente fenomenológica, modalidad "estructura del fenómeno situado". Participaron del estudio ocho familiares que se negaron a la donación de órganos y tejidos. **Resultados:** Después del análisis de las entrevistas se revelaron diez motivos de negación expuestos por los familiares. **Consideraciones finales:** Las proposiciones que emergieron revelaron que los motivos de la negativa familiar para la donación de órganos y tejidos están relacionados a la creencia, valores e inadecuaciones en el proceso de donación y transplante.

**Descriptores:** Trasplante de órganos; Trasplante de tejidos; Donadores de tejido Muerte encefálica; Familia

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## INTRODUCTION

The family refusal represents an obstacle for the transplantations accomplishment, along with other problems, such as the failure to identify and notify about potential eligible donors, as well as the high level of clinic counter indication for donation.

According to Brazilian Transplant Records (Registro Brasileiro de Transplante) data, in 2007 the number of potential donors was of 29.8 per million population a year (pmp/year), family refusal rate was of 27.4% over the total number of potential donors, medical counter indication, 33%, and the number of effective donors was of 6.2 pmp/year<sup>(1)</sup>.

It is estimated that, in general, up to 100 patients per million population a year present the brain death diagnosis, due to accidents and intra-axial hemorrhage, thus demonstrating the existence of a high number of potential organ donors. However, in Latin America, the potential donors notification rate is lower than 50-60 pmp/year. In developed countries, the rate is 50-60 pmp/year and 20-40 per million inhabitants a year become effective donors<sup>(2)</sup>.

Studies developed in the United States, Germany, and United Kingdom evidenced that the main obstacle for the organ donation accomplishment is represented by the high level of families that do not consent with the donation<sup>(3-5)</sup>.

Another study developed in Belgium verified that the main impediment factors when converting patients presenting clinic signs of brain death, and potential donors, was the Intensive Care Unit disinterest in diagnosing the brain death (BD), followed by medical counter-indication, family refusal, and professionals' non-request for donation<sup>(6)</sup>.

In our reality, it is still possible to find the difficulties evidenced by the study mentioned, along with team's lack of knowledge and appropriate prepare to perform the clinic exams to confirm the BD diagnosis, which seem to be the reality present in hospitals. In some situations, the professionals' lack of knowledge on how to proceed upon the brain death suspect is possibly a factor that obstructs the potential donor notification to the Organ Notification, Collection, and Distribution Central (Central de Notificação, Captação e Distribuição de Órgãos - CNCDO).

The family refusal contributes to an insufficient donor number to meet the growing demand of receptors in the waiting lists, and therefore, has been pointed out as one of the responsible factors for the scarcity of organs and tissues for transplantation.

Taking these facts into consideration, it is clear that the knowledge of the refusal reasons may offer elements to the professionals who work with the donation and

transplantation process, whose main purpose is to obtain organs and accomplish the process in an appropriate way, based on ethical, legal, and human principles, preventing the donor's family members from suffering more, and aiming to correct possible inadequacies that may contribute, not only to the family's dissatisfaction regarding the assistance given to the potential donor, but also to high family refusal rates.

Therefore, the objective of this research was to find out about the perception of potential donors' family members on the reasons for the refusal to donate organs and tissues for transplantation.

## METHODS

A qualitative approach study was performed, with a phenomenological perspective, according to the modality of "situated phenomena structure"<sup>(7)</sup>. Such research modality does not search for statistical results and generalizations<sup>(8)</sup>. The inquiry region for the present study was an Organ Procurement Organization (OPO) in São Paulo municipality chosen for the analysis of the family refusal to donate organs and tissues of potential donors for transplantation.

Data were collected after the institution authorization and the project approval by the Research Ethics Committee. The eight family members who agreed to participate in the research were requested to sign an Informed Consent.

In order to obtain the study participants' deposition, the following guiding questions were utilized: "How was the decision making process that resulted in the refusal to donate the organs and tissues of your family member who passed away" and "What motives were considered in order to refuse to donate", which enabled an understanding of the reasons why families refused to donate organs and tissues for transplantation.

Initially, calls were made and interviews were scheduled in the day, location and time the research subjects would prefer. The interviews were recorded upon the participants' consent.

For the interviews content analysis, the methodological moments of the situated phenomenon qualitative analysis took place: the meaning of the whole, the meaningful units discrimination, the transformation of the subjects' expressions into the researcher language, and the meaningful units synthesis and their transformation into propositions, thus enabling the situated phenomenon structure understanding<sup>(7)</sup>.

The speeches were analyzed individually through an ideographic analysis. Through a nomothetic analysis, an attempt to uncover the interpreted meaningful units convergences and divergences was made, towards the phenomenon general structure. In the results

construction, parts of speech were used in order to illustrate the findings. For the different speeches denomination and identification the numbers I, II, III, IV, V, VI, VII, and VIII were used so as to preserve the family members' anonymity.

## RESULTS

Eight family members who had lost their relatives and refused to donate participated in the study, from January to December, 2005, respectively: a son, 23 years old, concluded high school, quality inspector, and protestant; a wife, 40 years old, uncompleted superior education, unemployed, and spiritualist; a mother, 42 years old, uncompleted elementary education, cleaning assistant, and catholic; a brother, 60 years old, uncompleted elementary education, administrative agent, and protestant; a father, 56 years old, concluded elementary education, retired, and catholic; a wife, 68 years old, uncompleted superior education, retired, and protestant; a sister, 38 years old, uncompleted high school, hairdresser, and catholic; a wife, 36 years old, uncompleted superior education, nursing assistant, with no defined religion.

### Presenting the reasons for the refusal to donate organs and tissues for transplantation

Regarding the reasons for the organs donation refusal, the following were mentioned: religious beliefs; the hope for a miracle; the non-understanding of the brain death diagnosis and a belief that the picture could be reversed; the non-acceptance of the body manipulation; the fear of the family's reaction; information inadequacy, and the brain death confirmation absence; distrust regarding the assistance and the fear of the organs trading; donation process inadequacy; the deceased patient's wish, manifested during life, not to be an organ donor, and the fear of losing a beloved family member.

#### The religious belief

The religion was considered one of the reasons for the refusal to donate organs and tissues for transplantation:

*And he said he didn't want it because of his religion and I respected it. He used to say: no, I don't like it, this is not for me, it doesn't fit me. He never accepted it (VIII).*

#### The hope for a miracle

The belief in God gives families hope that a miracle can happen. The belief that God can resurrect or bless the patient with a miracle is so big that, even when they learn about the brain death, the family member prefers to believe the patient is going to get better:

*(...) we have this hope, it seems to me, I don't know, as if the*

*person is going to live, you know? Even knowing he is dead (...) there is always a light in the end of the tunnel. Deep inside I believed God would resurrect him. I had faith he would get better (VII).*

*Then he started talking about faith again. Don't you have faith? The heart is still beating, perhaps God can work a miracle and he can come back (I).*

### The non-understanding of the brain death diagnosis and the belief that the picture could be reversed.

The family's non-understanding of the brain death diagnosis is difficult when the person that may be dead is under advanced life support. Under this circumstance, the organs donation is interpreted by the family as being the same as kill, decree or authorize the relative's death:

*But what we see in the donation, when you talk about donation, it's as if you were signing the death sentence. Because you know the heart will be taken away and will stop beating (...). When you sign for the organs donation it is as if you were signing the death certificate (VIII).*

*But both the husband and the whole family thought she would resuscitate, she would go back home, that she would go through this, through the exams. All the children, the whole family were expecting her to go back home. Her heart was beating with the equipment. Even so I said: the problem with brain death is not easy to solve. Not everybody can escape from that (IV).*

### The non-acceptance of the body manipulation

The family member has difficulties to accept the manipulation of the relative's body in order to remove the organs for transplantation, and the non-acceptance is the reason for the donation refusal, the belief that the body is God's untouchable sacred temple:

*Why don't we donate? It is not because of religion, not religion (...). The reason for the non-donation is the following: we were made by God like this; we are made at His image. Everything that is in our body is our Lord's sacred temple. Therefore, it is untouchable (VI).*

### The fear of the family reaction

The family member who is favorable to the donation does not make a point of donating for being afraid of other family member's reaction:

*Thus I ended up accepting the boy's father's decision, because he is kind of a violent person, kind of angry... If I had agreed with the donation, he would have got very angry (...). Then I got scared, because of his ignorance (II).*

### Information inadequacy and the absence of brain death confirmation

The absence of brain death diagnosis confirmation

and the inadequacy of information transmitted to the family by the hospital team generate doubts with regard to the patient general state and is a reason for organ donation refusal:

*(...) I said: so he is not dead? And he said: no, he is brain dead and we can't even prove it without performing these three exams (III).*

#### **Distrust in the assistance and fear of the organs trading**

There is a belief that the relative's death may be anticipated or inducted aiming the organs donation:

*We would say: do not donate my organs because it will accelerate death (...), because of the organs trading; we saw it on tv, on the internet, on the newspapers (III).*

The excessive interest demonstrated by the team in order to obtain the donation generates corruption suspects:

*(...) it seemed they were too interested in his organs. (...) we hear there is too much corruption, that doctors are paid when there is an organ, around 10 thousand people depend on that organ (...)(V).*

#### **Inadequacy in the donation process**

When the medical team requests the organs donation before the diagnosis is confirmed, family members get revolted and exasperated:

*And so I said: send him to a reference hospital and I'll sign it afterwards. And he said: no, you have to sign the organs donation authorization first so that he can, he can... So we saw it was an exchange. I got revolted (III).*

When the family feels they are being forced by the team in order to authorize the organs donation, they become distrustful and refuse to donate, even being sorry for disrespecting the deceased person's wish to be a donor:

*(...) the doctors started forcing us to donate, saying the boy didn't have any possible salvation. So we indirectly said they seemed like vultures over the prey. This made us distrustful, so we disrespected his wish (...)(V).*

#### **The deceased patient's wish, manifested during life, not to be an organ donor**

The deceased patient's wish, manifested during life, not to be an organ donor is respected. The family members consider important to respect the beloved relative's wish, even when some of them do not consider the patient's wish important after death, or believe the refusal to donate is a selfish attitude.

*He asked me, and as his wife, I respected his wish manifested in*

*life. People would say: what he wanted when he was alive does not matter after he is dead. But it has to! This was our decision, neither to accept donation nor to donate. It may be selfishness, and for a lot of people think it is (VII).*

#### **The fear of losing a beloved family member**

One find was the family member expresses his fear of loss by refusing to donate organs:

*When we do not want to donate, it is first because we respect what the person thinks, and second for fearing loss. You do not want to loose (VIII).*

## **DISCUSSION**

One of the alleged reasons why families refuse to donate is related to religious belief. The cultural beliefs, more than the religious beliefs oppose to the donation. The Roman Catholic, Buddhist, Hindu, Muslim and Protestant religions are favorable to the donation, classifying the act as generosity<sup>(9)</sup>.

Families manifest faith, they believe God will give their beloved one his/her life back<sup>(10)</sup>. The belief in a higher entity strengthens hope that a miracle can happen. The family member believes that if the heart is beating, this is an indication that God may work a miracle and the patients' condition may be reversed.

The brain death is not the mostly culturally divulged and accepted concept in our society. The medical and legal definition of death is not only the cardiorespiratory arrest, but also the brain functions arrest, including the brain stem, that is, brain death is the same as death, but not all people understand/accept it. For families against organs and tissues donation for transplantation, the non-understanding of the brain death diagnosis and the belief in the reversal of the picture are very strong reasons for refusing to donate.

The body condition itself, artificially maintained in the ICU, warm, with the heart beating, is contrary to the general ideal of a corpse. In the family member's fantasy, and even in some professional's fantasy, somehow that person is still perceived as being alive<sup>(8)</sup>.

The brain death, accepted as death by scientific communities of different countries, is not fully understood by population yet, for they find it difficult to recognize that a person that still presents heart beating is dead. The brain death concept faces resistance not only among the population, but also among some healthcare professionals who assist the potential donor, and this represents an obstacle for great part of the families when deciding on the organs donation.

The inadequacies along the donation process perceived by families and considered as reasons for the organs and tissues donation evidence that, before implementing any



educational program directed to the population, it is necessary to initiate permanent educational programs directed to the multi-professional team, emphasizing the implications due to lack of knowledge regarding the donation and transplantation process.

Among the family members responsible for the donation authorization, one clearly takes the responsibility for the decision when there is a disagreement concerning the donation. In this context, some do not participate in the decision making process<sup>(8)</sup>. It is evident that the family member who is favorable to the donation prefers not to donate for fearing repression from the other family members.

The reasons for and against the donation are complex. The solidarity, although important, does not seem enough of a reason so as to motivate the organs donation. Besides, the emotional support, the assistance, and information offered to family members during the process seem to be essential to encourage the donation. For families who authorized the deceased relative's organs donation, knowing the person's wish manifested during life regarding organ donation was important for the decision making process<sup>(11-12)</sup>.

Fear of disfiguration and physical integrity loss makes the deceased person's family believe donation is a mutilation, not a surgical procedure. The family members who refuse to donate do not accept the deceased person's body goes through a surgery<sup>(4,11)</sup>.

Besides that, the negative publicity with regard to the organs donation in the communication vehicles contributes to the family member's belief in the organs trading. Media has an important role in the opinion formation, for families

state that organs trading is a reality and the information was obtained through communication vehicles. For many families, the media represents the only access to information regarding organs donation.

Some authors believe that the potential donor's family, many times, does not accept the brain death diagnosis, and upon this situation it is not recommended to force a conversation or request for the organs donation. They also state that, in case the family member is interviewed, he/she will refuse to donate<sup>(10)</sup>.

## FINAL CONSIDERATIONS

The family refusal to donate organs and tissues for transplantation revealed that the reasons for refusal are related to beliefs, principles, lack of understanding of the brain death diagnosis, and inadequacy in the donation and transplantation process. Family is the main element, and the process transparency only occurs when families are informed and clarified about the relative's condition, for the lack of clarification is perceived as a condition that generates doubts, anguish, pain and despair. The team should offer support to families regardless of the decision in favor or against the donation. The ethical posture and the respect for the family's suffering is a duty of the healthcare professional who is taking care of the donor and his/her family members.

Moreover, it is essential to implement permanent educational programs directed to the healthcare professionals concerning the donation process and the implications due to the lack of knowledge regarding the process.

## REFERENCES

1. Associação Brasileira de Transplante de Órgãos (ABTO). Causas da não efetivação da doação por Estado: analisadas sobre o número de não-doadores: ano 2007. *RBT Registro Bras Transpl.* 2007;13(2):28-30.
2. Mizraji R, Alvarez I, Palacios RI, Fajardo C, Berrios C, Morales F, Luna E, Milanés C, Andrade M, Duque E, Giron F, Alfonso J, Herra S, Soratti C, Ibar R, Garcia VD; Punta Cana Group of Latin American Transplant Coordinators. Organ donation in Latin America. *Transplant Proc.* 2007;39(2):333-5.
3. Sheehy E, Conrad SL, Brigham LE, Luskin R, Weber P, Eakin M, et al. Estimating the number of potential organ donors in the United States. *N Engl J Med.* 2003;349(7):667-74. Comment in: *N Engl J Med.* 2003;349(7):704-6. *N Engl J Med.* 2003;349(21):2073-5; author reply 2073-5. *N Engl J Med.* 2003;349(21):2073-5; author reply 2073-5. *N Engl J Med.* 2003;349(21):2073-5; author reply 2073-5.
4. Barber K, Falvey S, Hamilton C, Collett D, Rudge C. Potential for organ donation in the United Kingdom: audit of intensive care records. *BMJ.* 2006;332(7550):1124-7. Comment in: *BMJ.* 2006;332(7550):1105-6. *BMJ.* 2006;332(7552):1274.
5. Wesslau C, Grosse K, Krüger R, Küçük O, Mauer D, Nitschke FP, et al. How large is the organ donor potential in Germany? Results of an analysis of data collected on deceased with primary and secondary brain damage in intensive care unit from 2002 to 2005. *Transpl Int.* 2006;20(2):147-55.
6. Roels L, Cohen B, Gachet C, Miranda BS. Joining efforts in tackling the organ shortage: the Donor Action experience. *Clin Transpl.* 2002;111-20.
7. Martins J, Bicudo MAV. A pesquisa qualitativa em psicologia: fundamentos e recursos básicos. São Paulo: Moraes; 1989.
8. Sadala MLA. A experiência de doar órgãos na visão de familiares de doadores. *J Bras Nefrol.* 2001;23(3):143-51.
9. Sá MFF. Biodireito. Belo Horizonte: Del Rey; 2002.
10. Lima AAF. Sofrimento e contradição: o significado da morte, do morrer e da humanização para enfermeiros que trabalham no processo de doação de órgãos para transplante [dissertação]. São Paulo: Programa de Pós-graduação do Centro Universitário São Camilo; 2006.
11. Siminoff L, Mercer MB, Graham G, Burant C. The reasons families donate organs for transplantation: implications for policy and practice. *J Trauma.* 2007;62(4):969-78.
12. Roza BA. Efeitos do processo de doação de órgãos e tecidos em familiares: intencionalidade de uma nova doação [tese]. São Paulo: Departamento de Enfermagem da Universidade Federal de São Paulo; 2005.