

FAMILY REFUSAL TO DONATE ORGANS AND TISSUE FOR TRANSPLANTATION

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Moraes EL, Massarollo MCKB. Family refusal to donate organs and tissue for transplantation. Rev Latino-am Enfermagem 2008 maio-junho; 16(3):458-64.

This study aimed to discover how potential eligible donor families perceive the decision-making process to refuse organ and tissue donation for transplantation. A qualitative research was performed in order to understand the families' perception, based on the situated-phenomenon structure. Eight family members were interviewed, with four themes and fourteen subthemes emerging from the analysis of the statements. The propositions that emerged from the study indicated that the essence of the phenomenon was manifested as a shocking or despairing situation, experienced through the hospitalization of the family member; distrust regarding organ donation; denial of brain death; grief and weariness due to the loss of the loved one, family conflicts for making the decision and the multiple causes for refusing donation. Therefore, the knowledge of this phenomenon can provide information to guide professional action involving the families of potential donors.

DESCRIPTORS: organ transplantation; brain death; family

EL RECHAZO FAMILIAR AL PEDIDO DE DONACIÓN DE ÓRGANOS Y TEJIDOS PARA TRANSPLANTE

La investigación tuvo como objetivo conocer la percepción que tienen los familiares de potenciales donadores sobre el proceso de toma de decisión para rechazar la donación de los órganos y tejidos para trasplantes. Para comprender la percepción de los familiares fue utilizada la investigación cualitativa, según la modalidad estructura del fenómeno situado. Fueron entrevistados ocho familiares, de los que después de analizar los discursos, se obtuvieron cuatro temas y catorce subtemas. Las proposiciones que emergieron revelaron que la esencia del fenómeno fue revelada como vivenciar una situación de choque y desesperación con la internación del familiar, de desconfianza con la solicitud de la donación de los órganos, de negación de la muerte encefálica, de sufrimiento y desgaste ante la pérdida del ser querido, de conflictos familiares para la toma de decisión y de múltiples causas para rechazar la donación. Sendo así, el conocimiento de este fenómeno puede ofrecer elementos que orienten la actuación de los profesionales en el tratamiento dado a los familiares de potenciales donadores.

DESCRIPTORES: transplante de órganos; muerte encefálica; familia

A RECUSA FAMILIAR PARA A DOAÇÃO DE ÓRGÃOS E TECIDOS PARA TRANSPLANTE

A pesquisa teve como objetivo conhecer a percepção dos familiares de potenciais doadores sobre o processo de tomada de decisão para recusar a doação de órgãos e tecidos para transplante. Para compreender a percepção dos familiares, foi utilizada pesquisa qualitativa, segundo a modalidade estrutura do fenômeno situado. Foram entrevistados oito familiares, resgatando quatro temas e quatorze subtemas, após análise dos discursos. As proposições que emergiram revelaram que a essência do fenômeno foi desvelada como vivenciar uma situação de choque e desespero com a internação do familiar, de desconfiança com a solicitação da doação dos órgãos, de negação da morte encefálica, de sofrimento e desgaste diante da perda do ente querido, de conflitos familiares para a tomada de decisão e de múltiplas causas para a recusa da doação. Sendo assim, o conhecimento desse fenômeno pode oferecer elementos que norteiem a atuação dos profissionais junto aos familiares de potenciais doadores.

DESCRITORES: transplante de órgãos; morte encefálica; família

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INTRODUCTION

Donation and transplantation constitute a complex process, starting with the identification and maintenance of potential eligible donors. After that, doctors notify the family about the possible brain death, run exams to support the brain death diagnosis, and notify the Center for Organ Sharing (COS) about the potential donor, which forwards the notification to the Organ Procurement Agency (OPA). The OPA professional evaluates the clinical conditions of the potential donor, the eligibility of the organs to be extracted and performs an interview to request the family consent for the donation of organs and tissue. When the family refuses this request, the process is closed. If the family authorizes the donation, the OPA communicates the eligibility of the donor to the COS, which distributes the organs, indicating the transplantation team that will be in charge of their removal and implantation.

After the notification, a series of actions is needed for the effective maintenance of the donor, keeping the appropriate eligibility of his organs for the transplantation⁽¹⁾. According to this protocol, the knowledge of the donation-transplantation process and the adequate execution of its stages allow the procurement of organs and tissue with safety and quality, so that they can be provided for transplantation⁽²⁾.

Besides ensuring the quality of the organs, the knowledge of the process avoids the emergence of non-conformities in some stages, which could be a reason for families to question, or even refuse the donation of the organs.

It is the family that authorizes the donation of organs and tissue for transplantation. Law No. 10211, issued on March 23, 2001, defined the informed consent as a way of manifestation for donation; as such, the removal of organs, tissue and parts of the body of deceased people for transplantation or other therapeutic purposes, shall depend on the authorization of the spouse or adult relative, following the straight or collateral successive line, until the family's second degree, authenticated with a document signed by two witnesses present at the verification of death⁽³⁾. The Brazilian law is clear and demands family consent for the removal of organs and tissue for transplantation. – In other words, the donation only happens after authorization by the legal responsible for the deceased. Nevertheless, one's manifestation

in favor of or against organ donation, when still alive, is extremely important, since it facilitates the decision of the relatives on whether to consent or not after death. Yet, the family's wish is what should be respected in Brazil.

People generally do not have the necessary information for making the decision about organ donation, or do not understand the donation process clearly, which increases family consent refusal rates. The reasons for donating or not are complex and, despite the relevance of altruism, it does not seem to be enough for encouraging organ donation. The awareness of the patient's wish, manifested in life, is important at the moment of decision. Besides, emotional support, assistance provided to the family and information about the donation process seem to be essential for encouraging the act of donation⁽⁴⁻⁶⁾.

Donors' families often ignore the meaning of brain death, and either do not understand the information provided by the health professionals or misunderstand the concept. The non-perception of the patient as a deceased person makes the family members believe in the reversibility of the situation, or manifest doubts about the real death condition of their relative, due to the removal of organs⁽⁷⁻⁸⁾. Some cultures and religious groups do not accept death while the vital functions of the subject do not cease, because the individual seems to be alive, even though the body is being kept through artificial support⁽⁹⁾. This situation evidences the need for clarification to the population about the concept of brain death.

There is still significant confusion about the concept of brain death. A study carried out in 15 Pediatric Intensive Care Units (PICU) in Canada, with 54 intensive care professionals, showed that 48% of the interviewed doctors wrongly considered that the permanent loss of conscience was a diagnosis of brain death, and 34% did not feel comfortable to turn off the ventilator of the brain-dead patient when the family did not authorize the removal of the support. This behavior suggests that these doctors consider that brain death is different from death⁽¹⁰⁾. Therefore, there is still a lot to be clarified, discussed and demystified, both in the medical and lay communities⁽⁹⁾.

Experiences of the donation and transplantation process show the existence of two concepts of death, not only for the population, but also for health professionals: one with transplantation purposes, and another represented by the moment

when all body functions cease. This perception derives from the fact that, after brain death is confirmed, in case the family authorizes the donation, the eligible donor is sent to the surgical center for the removal of his organs. Nevertheless, when the family does not consent, there is some resistance from health professionals and the family to suspend the therapeutic support used to keep the eligibility of organs for possible transplantations.

In this context, knowledge about the perception of families that refused the donation of organs and tissues of a relative with a brain death diagnosis can contribute to the implementation and optimization of actions that do not favor the occurrence of non-conformities during donation and transplantation processes, offering better assistance to these families and preventing these factors from being an obstacle for donation.

Thus, this study aimed to discover how the families of eligible donors perceive the process of deciding to refuse the donation of organs and tissues for transplant.

METHODOLOGICAL COURSE

The present study used a qualitative approach for achieving its purposes, in the phenomenological line and based on the situated-phenomenon structure. phenomenological research aims at capturing the phenomenon, to allow for its understanding. A phenomenon is everything that is shown, manifested and revealed to the subject who questions it⁽¹¹⁾. The present study inquired about the situation of experiencing family refusal in the process of organ and tissue donation for transplantation by families of eligible donors, in the Organ Procurement Agency of São Paulo.

After obtaining the approval of the Research Ethics Committee, institutional authorization and the signing of the Term of Consent by the study subjects, statements were collected through the following guiding questions: how was the decision made to refuse the donation of organs and tissues of your deceased family member? What reasons were considered for refusing the donation? Eight people participated in the study, who had experienced the loss of a relative and refused the donation from January to December 2005.

Interviews were carried out according to the place, date and time determined by the study subjects. At the moment of the interview, the subjects were asked to read the Term of Consent. The necessary clarification was provided, and once they confirmed their willingness to participate, they were asked to sign the aforementioned document. Interviews were recorded with the consent of the subjects. For content analysis of the interviews, this study followed the methodological procedures of the situated-phenomenon qualitative analysis: the whole meaning, the discrimination of meaning units, the transformation of the subjects' expressions into the researcher's language and the synthesis of the meaning units turned into propositions, thus allowing for the disclosure of the situated-phenomenon structure⁽¹¹⁾.

Statements were analyzed through ideographical analysis, which corresponds to the individual analysis of each statement. Meaning units that presented a theme in common were identified and grouped, and the following themes (in bold) and subthemes emerged: *the hospitalization of the family member; the experience of the family member's loss* – notification of brain death and the request for donation of organs and tissue, the grief over the family member's loss; *the decision to refuse donation of organs and tissue* – the discussion about the donation of organs and tissue, respect for the decision made; *the reasons for refusing the donation of organs and tissue* – religious beliefs, the hope for a miracle, the lack of understanding about brain death diagnosis and the belief in a possible reversion of the situation, non-acceptance of the manipulation of the body, fear of the family reaction, information non-conformity and the lack of brain death confirmation, distrust in the health care and the fear of organ trafficking, the donation process non-conformity, wish of the deceased patients, manifested in life, not to donate their organs and the fear of the family member's loss. This study aimed at disclosing, through nomothetic analysis, the interpreted meaning units' convergences and divergences, towards the general structure of the phenomenon.

Discourse extracts have been used in the construction of the results, in order to illustrate the findings. The different statements were denominated and identified as D1, D2, D3, D4, D5, D6, D7 and D8, in order to preserve family anonymity.

BUILDING RESULTS

The theme *hospitalization of the family member* evidenced that the patients' hospitalization was due to both natural and traumatic causes. In this context, people who were healthy and unexpectedly, presented a sudden disease or were victims of trauma, are assisted and hospitalized in severe conditions. As the person was well and healthy at the beginning of the accident, the sudden disease, or even the hospitalization, and the occurrence of the event in such an unexpected way is a cause of shock for the family. These findings are evidenced in the following extracts:

Then it was a big shock, because, hours before that happened, she had called me asking if we were going to meet for lunch on Sunday. And then it all happened, it was very fast (D1).

We were watching television, when he suddenly moved his arms up and his head backwards. I jumped from the couch and noticed his eyes had turned inside out, you could only see its white part. And then I saw something had happened to him (D6).

Before receiving the information about the condition of the patient, there is the recognition of the seriousness of the situation. The perception of the family member's nearing death is a reason of despair for the family, since they do not feel ready to accept the loss of the loved one. The news of the severity of the case increases the family grief, as shown below:

When he felt sick, I took him to the Emergency Unit. I saw him getting worse there. I knew I was losing him. But you don't accept it. I couldn't enter the emergency room, because I knew he was getting worse. I was desperate. You can't accept it. You are aware of what is happening, but you act against it (D8).

At the moment of hospitalization, family members should be notified about the condition of the patient, but that does not always happen, generating the wrong impression of a good evolution. Since the information about the patient's condition is not always provided, the lack of clarification on the severity of the case becomes a reason to believe in the patient's recovery, when the situation is, actually, really serious. The family does not always have the perception of the real situation, and the lack of information creates the doubt of medical errors, as illustrated in the following extracts:

He had two heart attacks. The doctor had explained everything, but he didn't mention he was in coma, and we thought he was getting better (D3).

His tumor was very big. Two days after he had a surgery, he had to go through another one, because he had a

stroke. The doctor said there had been a little accident during surgery; they cut his carotid artery, which sends oxygen to the brain. This vein was obstructed and it seems it was not supplying blood to the brain, and the brain started to die. I spoke to the doctor in charge of it. He told me the tumor was attached to this vein, and when they tried to remove it, the vein was ruptured and they couldn't stop the bleeding, and then he had the stroke. I can't say there was no medical mistake (D7).

The theme, *the experience of the family member's loss*, and the subtheme, notification of brain death and the request for donation of organs and tissue, indicated that the family was not notified about the start of the procedures for brain death confirmation and that such information was only provided after the diagnosis had been confirmed. Before starting the protocol for brain death confirmation, the family should be notified about this possibility and the beginning of the protocol. Once the diagnosis is confirmed, the assistant doctor gives the results to the family, and later, a professional from the Organ Procurement Agency (OPA), nurse or doctor, will perform the interview to request the donation of organs and tissue for transplantation. Nevertheless, the request for organ donation is made by the medical team that is assisting the patient, right after the information of brain death diagnosis, and without the participation of the OPA professional. In the donation and transplantation process, the request for organs and tissue donation should be performed by an OPA professional; however, the interview to request the donation, performed for the procurement of the organs, only happens after the request is made by the hospital's medical team.

In the donation-transplantation process, the request for organs donation should be performed after the clinical and graphical confirmation of brain death, since requesting that the family donates the patient's organs generates distrust. According to the statement:

Then a doctor said he had got into coma and his situation was very serious, but he had a minimum chance. In order to be sure he really had a brain death they would have to run three kinds of exams. And then he said a group of organ donation would come to talk to us. I asked: but did he die? And the doctor said no, he did not die. We found it very unusual (D3).

The family members who legally answer for the potential donor should be present at the moment of the interview to request family consent to donate the organs. The OPA professional presents the possibility of donation and the family reflects on the subject, giving an answer immediately after that, or

asking for some time to reflect about it. Not all the family members participate in the interview and, sometimes, the OPA professional has to talk to the other members of the family, at different moments, which evidences that the willingness to donate is not always everyone's wish.

The family should be prepared to receive the news of brain death. Then, when they are notified about the start of the exams for the diagnosis confirmation, they have the chance to prepare themselves for the patient's death, because such news makes the family deny the condition, and allows them to imagine that the situation is a mistake. As doctors maintain the potential donor's breathing, heartbeat, blood pressure and body temperature, through therapeutic support devices, the family believes that clinical death (death by circulatory or systemic criterion) is different from brain death (death by neurological criterion), since the condition of the patient being kept by support equipment allows them to imagine the person is either alive or in coma, but not actually dead. This evidence is exemplified in the following extract:

Doctors said there was nothing else they could do. We did everything we could do. It is an irreversible case. But I thought it wasn't. I thought he was sleeping, and that he would eventually get out of the coma. I thought it could be a mistake, that he was still alive. When it is a sudden death it is hard, an accident is different from a person who is hospitalized. Because the person seems to be alive, due to those devices and the drugs (D7).

The maintenance of the heartbeat, the mechanical ventilation, the body temperature and the blood pressure, in order to keep the organs' eligibility until the time they are properly removed in an operating room, complicates the authorization of donation by the family. Authorizing the extraction of the organs means losing the family member, since they believe death is confirmed as the donation is authorized and the patient is sent to the surgical center for organ removal, which reveals the non-acceptance of brain death as real death. This perception is indicated by the following extracts:

You are sure that, from the moment you are approached and authorize the donation, the patient will be sent to the surgical center, his organs will be removed, and his death will be confirmed (D8).

The person is still there with those devices, and her heart is beating. You touch the person and she is warm, her blood is running. Only the brain mass died, but the rest is still alive. When you authorize the donation it seems like you are killing the person (D7).

The subtheme, grief over the family member's loss, showed that the family member's death is perceived by the family as an unexpected and sudden event that arouses feelings of affliction, suffering, grief and pain. The evolution of a patient's condition to brain death, most of the times, happens very fast, and the family does not have the time to assimilate the situation. Therefore, experiencing the loss of a loved family member is a reason for grief and causes great distress. In the face of the tragic situation, the family manifests the need for information, and anxiety leads to misinterpretation of information, which makes the loss even more consuming and causes inconveniences to the family routine, as observed in this statement:

During the seven days he was hospitalized, I had to be there everyday. It was an affliction, nobody would eat, nobody would sleep, and nobody lived anymore. For the family, it was very sad, painful, critical and shocking. There is great psychological distress (D2).

The suffering in the face of the family member's loss encourages the family to seek a solution for the situation. Thus, authorizing the organ donation and turning off the devices is the best way to end that suffering, since keeping the patient on an advanced life supporting device is the same as extending the pain through hopeless waiting, which has only one inevitable ending: a heart attack. On the other hand, they also believe that refusing the donation of the organs is the best way to decrease suffering, even when they admit they could save many lives and make the recipients happy. The family prefers to keep the faith that the situation can change than to accept the death of the loved one, since the pain of loss is only known by those who experience it. Since hope and death do not walk hand in hand, hope is what should prevail in this situation.

The family is the main element in the donation process, and the transparency of the facts is only evident when the family is properly aware of and informed about the patient's situation, since the lack of clarification is perceived as a condition that causes affliction, pain and desperation.

The medical team should provide support to the family, regardless of the contrary manifestation to donation. Respect and an ethical attitude towards the grieving family is health professionals' duty. The team's lack of sensitivity is a factor that adds more suffering, as the family realizes the only interest of the professional who is taking care of the potential donor is the donation of his organs. This situation

causes the wish not to donate the organs, even if the patient had manifested the intent to be a donor in life. Not making the wish of the loved family member come true is a reason for suffering, grief, regret and sadness, since the chance to help other people is wasted. Families perceive death, in this condition, as a useless event, because the organs were not used to save other lives. This perception is revealed in the following statement:

They were aggressive in their words. It is sad to see a son lying on that bed, and the doctors telling you: there is nothing else we can do, why don't you just donate his organs? Isn't it hard? They didn't know how to deal with us. At the end our son died and they could not use his organs to save other lives. We wanted to help because when he was alive he always said that if something happened, and if any of his organs were useful, he would like to be a donor (D5).

Families' difficulty to accept the death condition of loved ones keeps up the hope in their recoveries. In this context, the family believes in the reversion of the situation and refuses to talk about the donation of the organs, since talking about it brings more pain and suffering for those who are already grieving over the loss situation.

The theme, *the decision to refusing the donation of organs and tissues*, regarding the subtheme, the discussion about the donation of organs and tissue, showed that the decision-making process is shared by the whole family. Favorable family members believe the donation act can save lives, or that it is the way they find to keep the loved one alive. Nevertheless, when the subject is discussed with other members of the family, the wish to donate is not always everyone's wish, generating diverging opinions or establishing a conflict in the face of the situation.

The interview to request the donation should be performed when the family presents emotional conditions and is properly clarified to make the decision with awareness and autonomy. The request for family consent is a delicate moment that requires health professionals to be emotionally prepared, because each family reacts differently to the news of the patient's death.

The knowledge of the opinion of the deceased family member, in life, regarding organ donation, is important at the moment of making this decision. The families mention that refusing the donation means respecting the patient's wish, as observed in a statement:

Then I was fast, there was no reason for hesitating, because we talked a lot about this. We had come to the conclusion that we would take care of the one who died first, and that none of us would donate our organs. We renewed our identity cards and requested the information to be there (D6).

The clarification about the subject is necessary so that people can decide consciously, since there are people who would like to donate, but are afraid or doubtful due to the lack of clarification. Information is essential so that the population can form an opinion on the issue of organ donation, and communication mediates a relevant role in this process of awareness. Besides, the subject should be approached at school, so that people could grow up and be aware of whether they are going to be donors or not, since people lack knowledge about brain death and there are also those who do not accept it.

The difficulty to understand the concept of brain death complicates decision making regarding the donation of organs, because authorizing the donation is a difficult and complex situation, causing the sensation of authorizing the patient's death. Monitoring the patients, with all the therapeutic support that maintains their body working, and authorizing donation in these conditions brings the feeling of authorizing the death of loved ones.

We did not have the courage to donate. With those devices, his heart is beating. I know it is just because of the equipment. I know the person is dead, but it is a very difficult situation. I sincerely did not have the courage to do it. It seems that you are going to kill the person. It is an awkward feeling (D7).

When you accept the donation, it is as if you were signing the person's death confirmation. Because you know they will take his heart off and it will stop beating. I know it is the medication that is making his heart beat. But from the moment I sign the organ donation it is as if I were signing his death confirmation (D8).

The subtheme regarding the decision that was made showed that the family member who is favorable to donation ends up respecting the decision that was made in the face of a contrary manifestation by another family member, in an attempt to avoid conflicts among family member. The opinion of the family member who is against the donation prevails, as evidenced in these statements:

Then I stuck to his decision. I am 23 years old, he is 36 and married. What would I say? I accepted what he decided (D1).

I said he should donate, but he is quite ignorant and rude, and then I silenced (D4).

Nevertheless, when the family is aware of the potential donor's wish, the decision to refuse donation is a doubtless situation, since the family member is confident about the decision made, even though other family members consider it a questionable attitude. Moreover, people lose their power to decide after brain death, and the correct thing for the family to do is to respect what the deceased person believed in life.

When you talk about brain death, it means the person is not able to decide by herself anymore. Then, the person who stayed, who is still alive, who is taking care of her has to respect what the person believed (D8).

Regarding the theme, *the reasons for refusing the donation of organs and tissues*, the statements showed that each family member presented between two and five reasons for refusing the donation of organs and tissues for transplant: the religious belief; the hope for a miracle; the non-comprehension of the brain death diagnosis and the belief in the reversibility of the situation; the non-acceptance of the manipulation of the body; the fear of the reaction of the family; the information non-conformity and the lack of confirmation of the brain death; the distrust in the healthcare institutions and the fear of organ trafficking; the donation process non-conformity; the

wish of the deceased patient, manifested in life, on whether to be a donor or not; and the fear of the loved one's loss.

SYNTHESIS

This study allowed the researchers to learn about the phenomenon of family refusal to donation organs and tissue for transplantation in the Organ Procurement Agency of São Paulo, which solved the primary question.

The propositions that emerged in this study show that the essence of the phenomenon was disclosed as the experience of a shocking or despairing situation, due to the hospitalization of a family member; distrusting the request for organ donation; denial of brain death; grief and weariness for the loss of loved one; family conflicts for making the decision, and multiple causes for donation refusal.

Therefore, the knowledge of this phenomenon provides support for professionals who work in the processes of donation and transplantation. Besides, it aims at correcting possible non-conformities that may be contributing not only to the dissatisfying assistance to these family members, but also to the high rates of family refusal.

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