

# Stressor experienced by family members in the process of organ and tissue donation for transplant\*

ESTRESSORES VIVENCIADOS PELOS FAMILIARES NO PROCESSO DE DOAÇÃO DE ÓRGÃOS E TECIDOS PARA TRANSPLANTE

ESTRESORES EXPERIMENTADOS POR LOS FAMILIARES EN EL PROCESO DE DONACIÓN DE ÓRGANOS Y TEJIDOS PARA TRANSPLANTE

Valdir Moreira Cinque<sup>1</sup>, Estela Regina Ferraz Bianchi<sup>2</sup>

## ABSTRACT

The purpose of the present study is to identify the stressors experienced by family members during the process of organ donation, evince the most distressful moment of the process and verify the association of variable with the family members' experience. The sample consisted of 16 family members that were making the donation through a Organ Search Organization, in São Paulo, in 2007. A structured instrument was used, containing question addressing the family members' experience and their evaluation of the donation process. The main stressors reported were: dissatisfaction with the service (31.25%); receiving a harsh notification about the individual's brain death (62.50%); and the wait to release the body (62.50%), which was considered the most distressful moment of the process. Using the phi coefficient, it was found that there was a moderate association between the variables of interest with the family's experience. In conclusion, the donation process is stressful on the family and nursing care is necessary in each stage of the process to offer support and reduce the distress on the family members.

## KEY WORDS

Transplants.  
Family.  
Stress.  
Brain death.  
Nursing care.

## RESUMO

O estudo propõe identificar os estressores vivenciados pelos familiares no processo de doação de órgãos, evidenciar o momento mais desgastante do processo e verificar a associação de variáveis com a experiência vivenciada pelos familiares. A amostra constituiu-se de 16 familiares que realizaram a doação por meio de uma Organização de Procura de Órgãos, na cidade de São Paulo, em 2007. Utilizou-se um instrumento estruturado com questões versando sobre a experiência e avaliação dos familiares no processo de doação. Os principais estressores foram: insatisfação com o atendimento (31,25%); receber a notícia da morte encefálica de forma intranquila (62,50%); e a demora para a liberação do corpo (62,50%), sendo este o momento mais desgastante do processo. Pelo coeficiente phi, verificou-se associação moderada entre as variáveis de interesse com a experiência da família. Conclui-se que o processo de doação é estressante para a família e que a assistência de enfermagem torna-se necessária em cada etapa da doação, oferecendo suporte para diminuir o sofrimento dos familiares.

## DESCRIPTORIOS

Transplantes.  
Família.  
Estresse.  
Morte encefálica.  
Cuidados de enfermagem.

## RESUMEN

El estudio propone identificar los estresores experimentados por los familiares en el proceso de donación de órganos, evidenciar el momento más desgastante y verificar la asociación de variables con la experiencia afrontada por los familiares. La muestra se constituyó de 16 familiares que realizaron la donación en una Organización de Búsqueda de Órganos de la ciudad de São Paulo, en 2007. Se utilizó un instrumento estructurado con preguntas referidas a la experiencia y evaluación de los familiares en el proceso de donación. Lo principales estresores fueron: la insatisfacción con la atención (31,25%); recibir la noticia de muerte encefálica en forma impropia (62,50%) y la demora para la liberación del cuerpo (62,50%), siendo éste el momento más desgastante. Por el coeficiente Phi, se verificó asociación moderada entre las variables de interés con la experiencia de la familia. Concluyendo, el proceso de donación de órganos es estresante para la familia, y la atención de enfermería se vuelve necesaria en cada etapa de la donación, brindando apoyo para disminuir el sufrimiento de los familiares.

## DESCRIPTORES

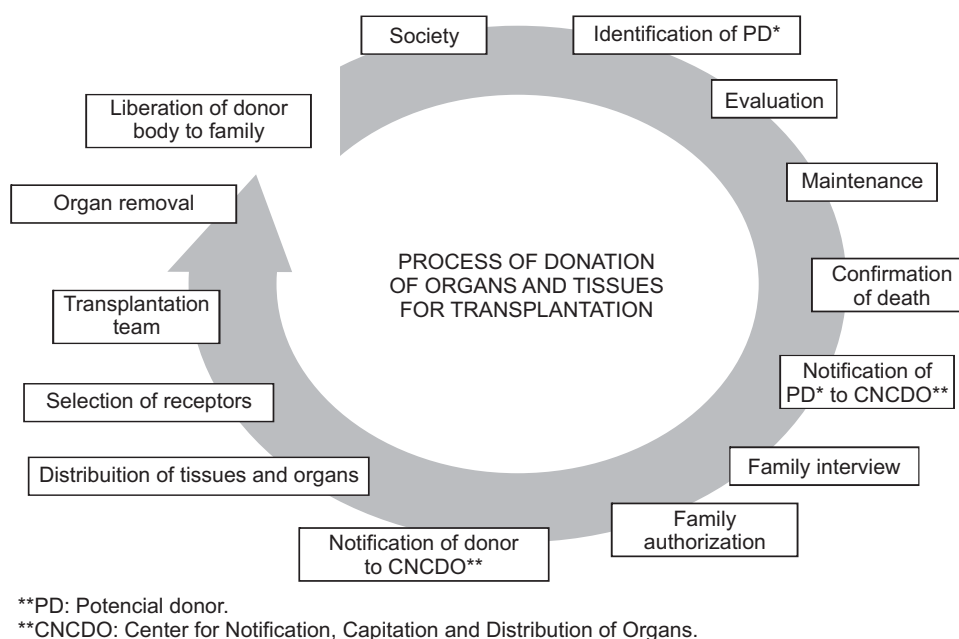
Trasplantes.  
Família.  
Estrés.  
Muerte encefálica.  
Atención de enfermería.

\* Extracted from the dissertation "Fatores de stress vivenciados pelos familiares no processo de doação de órgãos e tecidos para transplante", School of Nursing, University of São Paulo, 2008. <sup>1</sup>Specialist in Intensive Care. Master in Nursing by School of Nursing, University of São Paulo. Nurse at the University of São Paulo School of Medicine Clinics Hospital. São Paulo, SP, Brazil. valdir\_cinque@yahoo.com.br <sup>2</sup>Nurse. Associate Professor at School of Nursing, University of São Paulo. São Paulo, SP, Brazil. erfbianc@usp.br

## INTRODUCTION

The process of donating organs and tissue for transplantation involves several stages (Figure 1), starting with the identification and maintenance of a patient with the criteria of brain death (BD) and ending only at the conclusion of the

transplantation<sup>(1-2)</sup>. Nevertheless, the families who experience the process consider that it starts with the hospitalization of the patient and ends only at the burial, which may take hours or days. For the relatives, this is a hard, long, bureaucratic, consuming and tiring process, a perception that unfavorably compromises the number of donations<sup>(3-6)</sup>.



**Figure 1** - Stages of the donation process of organs and tissue for transplantation - São Paulo - 2008

The donation process is defined as a *set of actions and procedures that can transform a potential donor into an effective donor*<sup>(1)</sup>. After the identification, the doctors must talk to the family about the BD suspicion and perform the corroborative exams. After that, the potential donor must be notified to the Central for Notification, Capitation and Distribution of Organs (CNRDO), as preconized by the law no. 9.434/97<sup>(7-8)</sup>.

The CNRDO sends the notification to the Organ Search Organization (OSO), which evaluates the clinical conditions of the potential donor and, if feasible, proceeds to an interview with the family regarding the donation. In case the family refuses the donation, the process is closed. When the family authorizes it, an internal protocol is initiated, which contemplates several essential technical and administrative procedures for making the organs feasible. The OSO notifies the donor to the CNRDO, which performs the selection of recipients and indicates the transplantation teams in charge of removing and implanting the organs.

The CNRDO informs to the OSO the transplantation teams in charge of removing the donated organs and tissue and the teams contact the OSO in order to obtain specific information about the donor. It is the transplantation teams' responsibility to make the decision on whether to use a certain organ or tissue.

The family must receive the body appropriately recomposed, which is also mandatory according to the Law no. 9.434/1997, in order to recover, as much as possible, its previous appearance<sup>(7-8)</sup>.

Due to its complexity and length, the donation process causes stress and may be traumatic to the family. Stress is defined as any event that demands from the internal or external environment, which limits or exceeds the adaptation sources of a social system or person. This concept is seen as an interactionist model, which proposes that the evaluation of the stressors by the subject is made through a cognitive process. The interactionist model is about the importance of the individual evaluation in the response to stress, placing the subjectivity of the subject as a determining factor for the stressor's seriousness<sup>(9)</sup>.

The organic alterations, related to stress, have a biological stage, as well as a stage in which cognitive functions take part. In the interactionist model, there is a processual and dynamic interaction between the person and the stressor. Acting as mediator, the cognitive evaluation participates in this interaction, as a mental process that intervenes between the moment the stressor is faced and the reaction. The stress reaction happens when the stressor is evaluated as a threat or challenge<sup>(10)</sup>.

A stressor is an internal or external event or situation that triggers a series of behavioral, cognitive, physiological or emotional alterations and manifestations in a subject, promoting the adaptation of the organism, characterized as that which produces stress<sup>(10)</sup>. These concepts were adopted for the interpretation and development of this study.

In face of the situation experienced by the family regarding the decision to donate organs, and due to the lack of studies about the stressors perceived by the families during the facts that comprehend the donation, the following questions were formulated: What are the stressors experienced by the families in the process of organ donation? What is the most consuming moment for families in the process of donation? Are the BD cause and the characteristics of the donors and family members related in the process of donation?

## OBJECTIVES

The objectives of this study were to identify the stressors experienced by family members in the process of organ donation, evidencing the most consuming moment and verifying the association of their characteristics (gender, age, religion, type of relationship, education and period since the relative's loss) and the profiles of the donors (gender, age and BD cause) to the experience of the relatives in the donation process.

## METHOD

This is a descriptive, exploratory and field study, with quantitative approach.

### Sample

The sample consisted on 16 relatives of deceased organ donors who experienced the donation process at an OSO in the city of São Paulo in 2007. In that year, there were 44 effective donations. However, most of the families (63.64%) did not participate in the study, since in 22 cases (50%) the family members refused to participate in the interview and in other six cases (13.64%) the families were not located.

### Data collection and analysis

The interviews were performed from March to June of 2008, after the authorization of the Institution, the approval of the Committee of Ethics for the Analysis of Study Projects

(Protocol no. 1204/07) and the signature of the Term of Free and Clarified Consent (TFCS) by the participants.

Data were collected through an instrument of structured interview that consisted on two parts. The first part included data regarding the characteristics of relatives and donors. The second part presented open questions about the experience and evaluation of the relatives in the donation process, including: the family member hospitalization, the care given to the family and to the donor, the BD news, the decision and authorization for donation, the body release and the questioning about the most consuming moment in the donation process. The interviews were recorded with the consent of the families.

The interviews were scheduled at the place, date and time determined by the participants. Interviews were not taken on special dates, such as: birthday of the deceased, day of death, day of hospitalization and other significant dates, in order to avoid any additional suffering to the families.

The donors' relatives were interviewed at least three months after the donation, given that the intensity and the period of suffering experienced by the families, who face the loss of a relative, may vary, but the critical stage happens in the first two months following the death<sup>(4,11)</sup>.

The recorded data were explored and analyzed after being repeatedly read aimed at focusing on the stressors and the most consuming moment. Afterwards, there was the establishment of the numerical codification, the determination of the frequency in which each event took place and the grouping of items by similarity.

The coefficient *phi* ( $\phi$ ) was used to verify the level of associations between the satisfaction regarding the care and the donor's age and between the authorization for the donation and the relative's age and BD cause. It is important to highlight that the closest to 1, the highest the association. The Odds Ratio (OR) was calculated with the trust interval of 95% for the variables in **which** there was a significant association indicated by the coefficient *phi*. The significance level adopted was 5%.

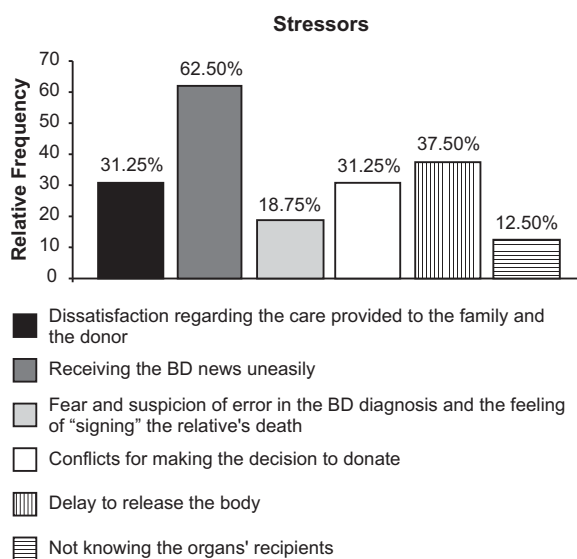
## RESULTS

From the total number of 16 relatives who were interviewed, 10 (62.50%) were female and 6 (37.50%) were male, their age varied between 25 and 64 years old, with the mean of 41.50 ( $\pm 10.95$ ) years old. The period of time since the loss of the donor varied from 3.97 to 15.73 months, with the mean of 10.75 months ( $\pm 03.52$ ). The characteristics of the relatives are presented in Table 1.

**Table 1** - Distribution of the donors' relatives according to their gender, age, religion, type of relationship, level of education and period of time since the relative's loss - São Paulo - 2008

Variables	N	%
<b>Profile of the Relatives</b>		
<b>Gender</b>		
Female	10	62.50
Male	06	37.50
<b>Age group</b>		
Less than 40 years old	09	56.25
Over 40 years old	07	43.75
<b>Religion</b>		
Catholic	06	37.50
Evangelic	05	31.25
Spiritualist	02	12.50
Protestant	01	06.25
Agnostic	02	12.50
<b>Type of relationship</b>		
Parent and children	12	75.00
Siblings and spouses	04	25.00
<b>Level of education</b>		
Elementary school	05	31.25
High school	06	37.50
College	05	31.25
<b>Period since the relative's loss</b>		
Less than 12 months	10	62.50
Over 12 months	06	37.50
<b>Total</b>	<b>16</b>	<b>100</b>

Regarding the BD cause of the donors, 10 cases (62.50%) were due to natural causes and 6 (37.50%) to external causes. There was a discrete difference between the percentage of men and women, with the frequency of 7 (43.75%) and 9 (56.25%) respectively, with the minimum age of 15 years old and the maximum age of 72 years old, the mean was 44.44 years old ( $\pm 18.15$ ).



**Figure 2** - Distribution of the stressors experienced by the relatives in the donation process - São Paulo - 2008

Figure 2 evidences the stressors experienced by the relatives in the donation process: 5 (31.25%) relatives were dissatisfied with the care provided to the family and the donor, 10 (62.50%) received the BD news uneasily, 3 (18.75%) felt fear and suspected of an error in the BD diagnosis and felt like *signing* the relative's death.

Regarding the conflicts for making the decision to donate (31.25%), 3 (18.75%) were against the donation and 2 (12.50%) were uncertain about the BD. The delay to release the body was indicated as a negative fact in the donation process by 10 (62.50%) relatives. The answers of the relatives showed that the expectation for the body release was the most consuming moment for 5 (31.25%) relatives, followed by the confirmation of the BD news by 4 (25%).

According to the coefficient *phi*, there was a moderate and significant association observed between satisfaction with the care provided to the family and to the donor with the variables type of relationship and donor's age, as well as between the variables lack of conflicts to decide and authorize the donation with the variables relative's age and BD cause. On the other hand, the lack of stressful situations regarding the relative's hospitalization, the BD news and the donor's body release did not present any statistically significant association with the BD cause and the characteristics of the donors and their relatives.

As for the Odds Ratio, it was observed that the chance of a satisfactory response to the provided care was almost 11 times more probable for relatives whose donors were less than 40 years old than for those whose donors were older than 40 years old (OR= 10.782), as well as the possibility of satisfaction with the care was almost five times more probable between parents and children than between siblings and spouses (OR= 4.658).

The chance of not having conflicts to decide and to authorize the organ donation was approximately 17 times higher for relatives whose donors' BD was caused by natural causes than by external causes (OR= 16.404), as well as the probability of not having conflicts was almost 11 times higher for relatives who were less than 40 years old than for those who were older than that (OR= 10.998). These results are presented in Table 2.

The variables gender of the donors and relatives, religion, education and time of loss did not present statistically significant associations.

**Table 2** - Association between the situation experienced by the relatives in the donation process and the variables type of relationship, donor's age, relative's age and BD cause - São Paulo - 2008

Association between the variables		Odds Ratio	Trust Interval 95%	Φ	p - value
Satisfaction with the care provided to the family and to the donor	Type of relationship (ref. parents and children)	4.658	3.143 – 6.902	0.311	<0.001*
	Donor's age (ref. < 40 years old)	10.782	7.111 – 16.349	0.478	<0.001*
Lack of conflict to authorize the donation	Relative's age (ref. < 40 years old)	10.998	7.246 – 16.693	0.482	<0.001*
	BD cause (ref. Natural cause) *p< 0,05	16.404	11.062 – 24.326	0.592	<0.001*

## DISCUSSION

The family is the main element for the donation process to be successful, thus, they must be assisted before and after the BD evolution.

In the present study, the dissatisfaction with the care provided to the family and to the donor during the hospitalization (31.25%) was manifested in the indifference and in the lack of care perceived by them. The time spent in the countless procedures and tasks that a critical patient needs often limits the time spent with his relatives. However, the health team must be planned in order to reduce this imbalance between the care to the patient and to the family.

The family evaluates the care provided to the patient during hospitalization as satisfactory when they observe that this care is appropriate and that the professionals are engaged in his treatment. As they perceive this care is inadequate, they express attitudes of indignation, which may be manifested against the organ donation<sup>(3,12-13)</sup>.

Hospitals in the states of Ohio and Pennsylvania have developed a study aimed at exploring the factors associated to the donation decision which observed that families who complained about a dissatisfactory care were less likely to donate (p=0.004), as well as those who were surprised with the organ donation proposal (p<0.001) or who felt pressured to make a quick decision (p=0.002)<sup>(14)</sup>.

Received in an uneasy way, the BD news was evaluated as one of the most frequent sources of stress (62.50%), either due to the lack of necessary clarification about the patient's condition or due to doubts and uncertainties regarding his diagnosis.

The BD comprehension facilitates the permission for the donation<sup>(3-4,12-15)</sup>. The lack of knowledge, by the families, is reflected in their insecurity, in their affliction at the moment of authorizing the donation and in the uncertainty regarding the possibility that the donor may be alive, which complicates, firstly, the decision making and, later, living with the decision of having donated<sup>(15)</sup>. In this case, there were highly stressful events, such as: relatives who were

against the donation (18.75%), uncertainty about the BD (12.50%), fear and suspicion of an error in the BD diagnosis and the feeling of *signing* the relative's death (18.75%).

The lack of information gives the family hope for the recovery of the clinical condition and the fact that the body is warm and that the heart keeps beating makes the BD comprehension more difficult, being a sign that the person may be still alive even with the evidences presented. Some relatives claimed to know the identity of the organs recipients, as it happens in the United States. This lack of information reinforces the family's doubts and uncertainties regarding the donation process, being a reason of frustration for the family, who constantly lives with this expectation<sup>(4)</sup>. These situations were also found in the present study.

In this study, waiting for the body release was one of the greatest sources of stress (62.50%), being also considered as the most consuming moment (31.25%).

The delay in the process to remove the organs causes suffering and discomfort to the family and, associated to the lack of care, discourages the donation process<sup>(15)</sup>. Literature data showed similar results in which 53.6% of the families indicated the delay to release the body as a negative aspect<sup>(5)</sup>.

The distressing situation and the feeling of weakness, in face of the time they wait, wear out the family, leaving them in a miserable condition. The stress is intensified and becomes unbearable when there is any delay to release the body or pressure from other relatives for a quick release<sup>(3)</sup>.

In 1992, in Canada, a qualitative and innovating study on the theme used a theoretical referential identical to this study to interpret the stress factors. Nine relatives were interviewed, five parents, three spouses and one sister, in a period between 10 and 15 months after the relative's death. The main stressors were: the threat of losing the relative, the doubts and uncertainties regarding the tragedy or the disease, the change in the health condition, the interaction with the health professionals, the BD news, giving the consent for the donation, waiting for the body release and the memories of the relative<sup>(16)</sup>, similar results to the present study.

In China, a study evaluated the impact of organ donation during the first six months after the loss, through interviews with 22 relatives of donors who participated in the donation process. This study identified the following sources of stress: concern and fear of the deformation of the donor's body, conflicts and family controversies about the decision to donate. Another factor recognized was the incomprehension of other relatives and friends, devaluing the act of donating, with the thought that they did it in exchange for the funeral aid, which results in emotional weariness for the people in charge of the donation as they feel pressured to give explanations<sup>(17)</sup>.

The loss of a person to whom you are emotionally bonded is a consuming moment, a marking experience, and at times reaches high levels of stress. The health team, and especially the OSO nurse, must know that the satisfaction with the care provided during hospitalization, the doubts that emerge regarding the BD and the body release are vital moments in which they must offer support and clarification in order to reduce the pain and the suffering of the donor's family.

The nurse must be present and support the family during the body release, which is a moment considered as highly stressful. It is also important to remember that, based on the interactionist theory of stress, each person may evaluate this stage differently and present reactions and repercussions about this moment with sadness, crying, indignation, among other types of manifestation due to the loss.

Stress is present in human beings, but some measures may be adopted in order to prevent that it becomes exces-

sive. On the other hand, nursing, regardless its working area, is also a stressful profession that needs investment from hospital institutions to support its activity and from graduation and postgraduation courses in the preparation for the professional performance. The success of the provision of care to the family and to the patient takes place with professionals who are prepared, in terms of knowledge, emotions and performance with an appropriate structure<sup>(18)</sup>.

## CONCLUSION

The main stressors experienced by the families in the donation process were: receiving the BD news uneasily and the delay to release the body with 62.50% of the cases, being the body release the most consuming moment.

Statistically significant associations were observed between the satisfaction with the care provided to the family and to the donor and the variables type of relationship and donor's age; as well as between the lack of conflict to decide and authorize the organ donation and the variables relative's age and BD cause.

These results indicate strategies that may be used to help the family in the donation process. The experiences lives by the families expose the essential part of recognizing the suffering and embracing, which must be performed by the health team. Offering the necessary information, mainly regarding the BD and the release of the donor's body, as well as transparency during the donation process allows the family to experience less suffering and stress in this process of loss and grief.

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