



## Factors that facilitate and hinder family interviews in the process of donating organs and tissues for transplantation\*

*Fatores que facilitam e dificultam a entrevista familiar no processo de doação de órgãos e tecidos para transplante*

*Factores que facilitan y dificultan la entrevista familiar en el proceso de donación de órganos y tejidos para transplante*

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### ABSTRACT

**Objective:** To unveil the perceptions of professionals working in Organ Procurement Organizations about the factors that facilitate and hinder family interviews in the process of donating organs and tissues for transplantation. **Methods:** This qualitative, phenomenological research used the “structure of the situated-phenomenon” modality. The study included 18 professionals who worked in Organ Procurement Organizations. **Results:** After analyzing the interviews, the factors that facilitate and hinder family interview were revealed. **Conclusion:** The proposals that emerged revealed that the factors that facilitate and hinder family interview were related to the interview site, assistance provided to potential donors and their families, the explanations provided to the family and the manifestations to the potential donors’ lives on the decision regarding organ donation.

**Descriptors:** Transplant; Interview; Family; Tissue and organ procurement

### RESUMO

**Objetivo:** Desvelar a percepção dos profissionais que atuam em Organizações de Procura de Órgãos sobre os fatores que facilitam e dificultam a entrevista familiar no processo de doação de órgãos e tecidos para transplante. **Métodos:** Trata-se de pesquisa qualitativa, na vertente fenomenológica, modalidade “estrutura do fenômeno situado”. Participaram do estudo 18 profissionais que atuavam em Organizações de Procura de Órgãos. **Resultados:** Após a análise das entrevistas, foram revelados os fatores que facilitam e dificultam a entrevista familiar. **Conclusão:** As proposições que emergiram, revelaram que os fatores que facilitam e dificultam a entrevista familiar estão relacionados ao local da entrevista, à assistência prestada ao potencial doador e aos familiares, aos esclarecimentos fornecidos à família e a manifestação do potencial doador em vida sobre a decisão quanto à doação de órgãos.

**Descritores:** Transplante; Entrevista; Família; Obtenção de tecidos e órgãos

### RESUMEN

**Objetivo:** Develar la percepción de los profesionales que actúan en Organizaciones de Búsqueda de Órganos sobre los factores que facilitan y dificultan la entrevista familiar en el proceso de donación de órganos y tejidos para transplante. **Métodos:** Se trata de una investigación cualitativa, en la vertiente fenomenológica, modalidad “estructura del fenómeno situado”. Participaron en el estudio 18 profesionales que actuaban en Organizaciones de Búsqueda de Órganos. **Resultados:** Después del análisis de las entrevistas, fueron revelados los factores que facilitan y dificultan la entrevista familiar. **Conclusión:** Las proposiciones que emergieron, revelaron que los factores que facilitan y dificultan la entrevista familiar están relacionados al local de la entrevista, a la asistencia prestada al donador en potencia y a los familiares, a las aclaraciones dadas a la familia y la manifestación del potencial donador, en vida, sobre su decisión respecto a la donación de órganos.

**Descriptor:** Trasplante; Entrevista; Familia; Obtención de tejidos y órganos

\* Study carried out in the organ harvesting services, located in the city of São Paulo, SP, Brazil.

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## INTRODUCTION

The process of organ and tissue donation for transplantation is complex<sup>(1)</sup>. Knowledge concerning the donation process and the appropriate execution of its stages by professionals enable organs and tissues to be obtained for transplantation<sup>(2)</sup>.

Many factors are indicated as causes for not obtaining a donation, though authors who assess the factors that intervene in or condition the donation process, assert that the family interview is the main stage for continuing the donation process<sup>(3-5)</sup>.

A family interview is defined as a meeting among family members of the potential donor and one or more professionals from the harvesting team or some other trained professional to obtain consent for donation<sup>(2)</sup>.

Professionals initiating the work of holding such interviews wish to find a set of rules to follow. Unfortunately, it is not possible to establish a list of infallible rules because the interview is processed among human beings who cannot be reduced to a formula or common pattern.

However, the search for improving interview techniques is common among professionals who play such a role because the family interview is constantly indicated by professionals in the transplantation field as one of the factors that significantly influence decision-making concerning organ and tissue donation<sup>(1,6-7)</sup>. In Spain, a country with the highest rates of donation in the world, the family interview is considered a factor that limits the increase of the number of donations<sup>(6)</sup>.

Despite the relevance attributed to the interview, there are not many publications or investigations concerning this phase of the donation process. Identifying the factors that facilitate or hinder the family interview for the donation of organs or tissues for transplantation can help professionals develop strategies to improve the donation interview process.

This study identifies the perception of professionals working in organizations harvesting organs concerning the factors that facilitate or hinder the family interview in the organ and tissue donation process.

## METHOD

This is a qualitative study with a phenomenological approach in the modality "situated-phenomenon structure"<sup>(8)</sup>. The phenomenological method was chosen to capture the phenomenon in order to understand it. The object of study was the family interview in the process of organ and tissue donation for transplantation in an organization that harvests organs, located in the city of São Paulo, SP, Brazil.

Data were collected after the institutions authorized

the study and the Ethics Research Committee approved the project (protocol no 029/08) at the Brotherhood of Santa Casa da Misericórdia of São Paulo. The professionals who consented to participate in the study signed free and informed consent terms.

A total of 18 professionals from three of the four organizations harvesting organs in São Paulo were interviewed. Data collection ceased when the obtained data presented, in the researchers' opinion, a certain redundancy or repetition. Repetition of testimonies indicates there are sufficient descriptions for revealing the phenomenon<sup>(9)</sup>.

The collection of testimonies was guided by the following question: "Would you please tell me what factors facilitate or hinder the family interview in the process of organ and tissue donation from transplantation?"

Participants were initially contacted by telephone and interviews were held on a day, at a place and time determined by them. A form addressing age, religion, profession, degree, time since graduation, and time working in organizations that harvest organs was completed to characterize the participants. Interviews were recorded after gaining the consent of participants.

The following methodological stages were used in the content analysis of reports: meaning of the whole, discrimination of meaning units, transformation of the expressions of the participant into the researcher's language, and synthesis of the meaning units transformed into propositions, enabling one to unveil the structure of the situated phenomenon.

The reports were individually analyzed through ideographic analysis. We sought to uncover convergences and divergences of meaning units through the nomothetic analysis toward the general structure of the phenomenon. Excerpts of the reports were used to illustrate the findings. Roman numerals from I to XVIII were used to identify the different reports aiming to preserve the professionals' confidentiality.

## RESULTS

A total of 18 professionals who experience family interviews during the donation process participated in the study. Ages ranged from 25 to 41 years old; participants reported being Catholic (14), Spiritualist (2), Evangelists (2). Time since graduation ranged from two to 14 years and experience working in organizations that harvest organs ranged from two months to 13 years. Six among these professionals were specialists in organ harvesting, six were specialists in intensive therapy, four in emergency, one was a specialist in teaching in higher education, and one had a master's degree in Nursing.

### Aspects that facilitate the interview

The factors that facilitate interviews are presented in

the categories below:

### **Assistance provided to families and potential donor**

Appropriate assistance provided to the potential donor and welcoming provided to family members facilitates the interview and requires the involvement of a multidisciplinary team to treat the family with honesty and dignity.

*"the assistance one receives from the beginning facilitates the interview. It facilitates a lot... whether the family is being instructed, is informed about the procedures that are being performed... it makes it a lot easier [...]"*. (III)

*"[...] the multidisciplinary team, physicians, nurses have a very important role at this point, they have to prepare the family for the loss and facilitate the work of the organ donation professionals".* (XI)

*"How the family is prepared over the course of diagnosis for its family member, [...] it facilitates a lot. Another thing that helps [...] is the involvement of health professionals who are assisting the family and the potential donor [...] people being really willing to contribute, to provide appropriate assistance, welcome this family [...] in an appropriate way, with honesty and dignity. [...] it is important, dignity within the process and treating the family with extreme honesty [...] I guess that honesty within the process with the family facilitates it a lot".* (XI)

### **Clarifying encephalic death for family members**

The interview is facilitated when the patient's physician informs and provides clarification for the family members about the progression of the patient's condition, indication and initiation of protocol to confirm encephalic death, the need to perform two clinical exams by different physicians and a complementary exam to confirm the diagnosis. Such information enables the family to accompany the patient, from the beginning, in the performance of exams, and to perceive and acknowledge the irreversible nature of the patient's condition, and thus prepare itself for the patient's death.

*"[...] the factors that facilitate the interview... [...] are [...] when the hospital's team has already informed the family about the possibility of encephalic death and provided information, [...] with the multidisciplinary team, [...] for me, it's much easier to approach a family and explain the possibility of donation, when the family already knows there is the possibility of encephalic death and follows the entire process, since there is just suspicion until confirmation, [...] the family already knows there is no way back, [...] it is easier to talk, [...] the family is no longer angry. In fact, you find a family who is already resigned".* (IX)

*"[...] what facilitates the interview is the family being really informed about the facts. Right from the beginning. Of what*

*happened, of all the hospitalization period, providing accurate information [...]"*. (XVII)

*"It facilitates when all those working there are informed about the process, the protocol, and better inform the family, because information is everything".* (XIV)

### **Language used by the interviewer**

The use of a clear and honest language appropriate to each of the families on the part of professionals facilitates the interview.

*"The way the physicians transmit information is also very important, as well as the way we talk to the family... appropriate language used with each type of family".* (V)

### **The family members' emotional state and the potential donor's wishes concerning organ donation**

The interview is facilitated when family members are calm and when the potential donor has declared in life to be in favor of organ donation.

*"for me [...] a family who is calm, [...] I guess it facilitates the interview a lot".* (VII)

*"[...] everything is easier when the donor, the potential donor, has manifested his desire in life. The family already has the intent to talk... no... you mention encephalic death and the person already says: 'can we donate his organs?' It gets easier"* (VI)

### **The place where the interview is held**

Having an appropriate place to hold the interview facilitates it. The environment has to be comfortable, calm, welcoming seeking to avoid agitation from the ward, which can hinder understanding of information. Additionally, it should be distant from where the donor is hospitalized so the family does not observe the patient during the interview.

*"[...] an appropriate place also facilitates [...] a calm place where you can talk with the family [...]"*. (II)

*"[...] the environment for me, I guess it is interesting... a calm environment away from the donor, not close to the patient, so the family doesn't see the donor. It is a very emotional situation... and you have to detach the family from that hospital environment. I guess the family gets... it is in an emergency room, in an ICU, during visiting hours, all that movement, it really hinders the family's understanding of the information provided".* (IV)

### **Aspects that hinder the interview**

This study makes clear that the factors hindering the interview are related to the place, to clarification provided to family members concerning the diagnosis of encephalic death, assistance provided to the family and potential donor during the entire hospitalization process,

to when the interview is held, to the interviewer's posture, and to the fact that family members may not have previously talked about the organ donation issue.

### Place of the interview

The environment can hinder the interview. A disorganized place, with noise, transit of people, lacking privacy and chairs to accommodate family members, as is the case of corridors and units where potential donors are hospitalized, hinder the interview.

*"What hinders the interview? [...] the environment!"* (IV)

*"[...] holding an interview in the middle of a corridor, inside an ICU, with all those people around, talking... I guess it's very complicated".* (VI)

*"[...] the reality of our situation does not allow stages to be followed as we'd like to. We find many hospitals where there is no place to accommodate the family so you can talk to them[...]".* (VIII)

*"[...] holding the interview in a place where there are a lot of people passing by is very difficult!"* (XV)

### Clarifying the encephalic death diagnosis for family members

The interview becomes difficult when the family has not been informed nor received clarification about how a patient's condition has progressed or through the process of the encephalic death diagnosis. Such a fact impedes the family to prepare itself for the patient's death, makes apparent the indifference of the medical team in relation to the family members, potentially generating in the family a certain resistance in relation to the professional from the organ harvesting service. Sometimes, the physician may not be able to clarify the idea of encephalic death to the family. Hence, the responsibility of clarifying the progression of the patient's condition for the family may fall on the interviewer, who already has to explain the issue of organ donation.

*"[...] the physician always... talks superficially with the family, then I get there and say the patient is facing an encephalic death and the family doesn't believe it. The family starts to question me, this is the worst situation for a family interview".* (II)

*"[...] the reality of our situation does not permit the stages to be followed the way we'd like to. [...] you can't find a physician to talk clearly about the diagnosis [...] and you end up with all this responsibility. In addition to talking about donation we also talk about the case to the family members [...]".* (VIII)

*"the factors that hinder the interview? [...] lack of preparation of the family on the part of the team who is assisting the potential donor. This is the biggest obstacle [...] when the physician or nurse does not appropriately inform the patient's family. Why has the patient progressed to an encephalic death? A misinformed family*

*in regard to the encephalic death of its dear one results. It hinders the process a lot [...]"* (XI)

Divergent information provided by the organ harvesting service and the physician to family members can generate conflicts hindering the interview.

*"[...] when there is conflicting information among the various physicians, between the hospital's team and us... it really hinders the interview".* (V)

*"[...] it's very complicated because you say one thing and some professional from the hospital says another[...]".* (XIII)

### Assistance provided to the potential donor and family members

Quality of care provided to the patient and family members also influences the interview. Hence, family members who did not trust or had no access to the patient's physician, or were not appropriately treated or authorized to visit the hospitalized patient, may criticize care received at the time of the interview.

*"What hinders the process is the care provided to the patient at the hospital, right from the beginning, how the patient is being cared for, how health care providers are relating with the family, it hinders the interview later on. [...] The care provided at the hospital...".* (VII)

*"[...] Indifference to the potential donor and family, difficulty accessing the physician, lack of information, lack of trust in the involved professionals... that's it." (VIII)*

*"the type of care provided to the patient and family during hospitalization may hinder the interview [...]"* (XVIII)

### The time of the interview

The interview may be difficult when it is held immediately after the confirmation of encephalic death because the family may not be in a good psychological condition or be in a state of shock. Denying the patient's death, the belief there is a chance to revert the condition of encephalic death, and religiosity may also hinder the interview.

*"The factors that hinder the interview? [...] when we approach the family when it just received the news... So, it's very complicated, because the family is in shock, actually they just learned the patient died, that a family member died, and there is already someone there asking for organ donation, so sometimes, it is kind of a conflictive situation for the family".* (IX)

*"[...] understanding of the family concerning encephalic death; the religious family members [...] are convinced there may be a miracle, that the patient can return from encephalic death [...] family members who are not in a psychological condition to talk, who have not yet acknowledge the death of their dear one".* (I)

*"[...] when the family receives the news about encephalic death,*



*it gets into an emotional condition...it is difficult to talk about donation at a time like this.*" (XVI)

### **The interviewer's posture**

If the interviewer is standing when talking to family members while the family itself is sitting, then this may harm communication. There are situations in which the interviewer stays at a higher position than the interviewees, hindering visual contact with family members, who because of their current experience, are downcast and tearful.

*"Most of the time I stay higher than the family; the family has always to look up and in a time like this the family never looks up; they look down; they are downcast and tearful, so [...] attention the family pay to me, to what I'm talking... it's a little... there's some loss... what I'm saying is that the family does not pay attention [...]"*. (II)

### **The family members had never discussed the issue of organ donation before**

Lack of a previous dialog among family members concerning the issue of organ donation may be an obstacle for the interview.

*"[...] when there is doubt about it or the family has never talked about donation... it is more difficult to talk with the family, even worse if the conversation is being held in a place not appropriate for that..."* (VI)

## **DISCUSSION**

Professionals who work in organ harvesting organizations indicate that the environment is one of the factors that may either facilitate or hinder the family interview. The existence of an appropriate place to hold the interview favors the dialog between interviewer and family members<sup>(10)</sup>. Hence, it is recommended that the interviewer seeks out and asks the institution to provide an appropriate place to talk with the family of a potential donor.

Many facilities, given the lack of infrastructure or the perception concerning the importance of this aspect, do not provide a specific and private room to accommodate the family during the interview, which forces the professional to use other places, even if they are inappropriate, such as a corridor, beside the bed of the potential donor, or any other free area to hold the interview, a fact that hinders the interview and may influence the family's decision.

Attention provided to the family members and how they evaluate care provided to the patient can also either facilitate or hinder the family interview. Families who consider care to have been satisfactory are more receptive

to dialog and to the possibility of organ donation, as opposed to those who feel dissatisfied and accuse the clinicians and the institution for the patient's death; factors that may affect the family's decision-making<sup>(11-12)</sup>.

The family considers care to have been satisfactory when it observes it was appropriate and the professionals were committed to the patient's treatment. Seeing that all material and human resources necessary to lead the patient to recovery were used softens the family member's anguish and comforts them<sup>(11)</sup>.

In a study carried out with family members who experienced the donation process, it is shown that 68.7% of the family members were satisfied with care provided to the family and donor, while almost 25% were dissatisfied<sup>(13)</sup>. These data are corroborated by another study conducted with 69 families of patients experiencing encephalic death, which revealed that 22 families (31.8%) experienced feelings of disgust and rudeness on the part of the staff at some point of the hospitalization period. The nurses were impatient and uninterested and the physicians were considered to be cold and insensitive<sup>(14)</sup>. It is unfortunate that health care providers still show little concern with welcoming and providing assistance to hospitalized patients.

Another factor influencing the interview is related to the clarification family members receive concerning the procedures implemented for the patient during hospitalization. The family that is informed right from the beginning about the exams performed to confirm the diagnosis of encephalic death is able to prepare itself for the patient's death<sup>(11,13)</sup>. On the other hand, those families who receive the information right after the diagnosis is confirmed experience shock<sup>(11)</sup>.

A survey conducted of families who refused to donate organs identified complex situations related to the period of hospitalization. Difficulties accessing information, the low quality and contradictory information provided produced in these families a feeling of abandonment and lack of attention, aggravated by lack of knowledge concerning the type of care that was effectively being provided to the patient. The study's participants reported difficulties keeping informed about the real condition of their family members, a fact that seems to have harmed the analysis of families concerning the possibility of donating organs<sup>(15)</sup>.

The great challenge for those working with organ and tissue harvesting is to have ethical competence to ensure continuous improvement in this process, emphasizing appropriate communication between the team and families<sup>(16)</sup>.

The time chosen to talk with the family of the potential donor can also hinder the interview, revealing despair, lack of knowledge of the team, and an inappropriate

conduct of the donation process. Interviews are usually held immediately after the patient's death<sup>(11)</sup> and even before such a confirmation. However, a study reports that when donation is requested some time after encephalic death is confirmed, the rate of family consent was 81% while if the solicitation is made before or simultaneously with the news of death, this index is of only 50%<sup>(17)</sup>. Hence, family members become more receptive when explanation of encephalic death and the organ donation interviews are held at different times<sup>(18)</sup>. Such a fact may be attributed to an insufficient time for the family to assimilate the news, that is, when the organ donation is asked right after being informed of encephalic death.

Although most religions are favorable to donation, religious reasons are frequently mentioned as barriers for organ donation<sup>(19)</sup>. Belief in God may give the family hope that a miracle will happen, even when the family is aware of encephalic death<sup>(20)</sup>. Because the patient was a very good person, families may believe that God will give back the life of their dear one and make promises, pray, and go to services hoping for a miracle<sup>(21)</sup>.

The belief that the condition of the potential donor may be reversed may occur due to the fact that there is still a heartbeat, the complementary exam provides evidence that there is flow in the arteries that irrigate the brain, due to misleading information concerning the patient's condition, and also because the patient is being cared for in an intensive care unit, facts that give the family hope.

Some people refuse to believe that death is real. Asking for organ donation at this point is not advisable because the family may refuse it<sup>(22)</sup>. Acknowledging the loss takes some time and involves not only intellectual but also emotional acknowledgment. The mourning person may be intellectually aware of the loss but emotions do not permit her/him to totally acknowledge the information as being truthful<sup>(23)</sup>. Denying death, the practice of religiosity and belief there is a chance for the patient to recover are not only factors that hinder the interview but are also reasons for the family to refuse

organ donation<sup>(20)</sup>.

Knowledge concerning the opinion of the deceased person facilitates the interview. Studies show that knowledge concerning the person's desire expressed in life in relation to organ donation was an important factor that facilitated the decision-making of all the families who either authorized or refused organ donation<sup>(20,24-25)</sup>.

As opposed to other studies trying to identify the reasons used to refuse organ donation<sup>(15,20)</sup>, this study reported the perception of professionals working in organ harvesting organizations concerning the factors that may either facilitate and/or hinder the interview process. The results show that some of factors that hinder the interview are also indicated as motives to refuse donation.

The intention was not to exhaust the subject. Hence, there is a limitation in this study concerning the unilateral perception of the family interview; only the interviewers who dialog with families participated in this study. Hence, further studies are required to identify the perception of family members about factors that hinder or facilitate the interview to better understand the phenomenon.

## FINAL CONSIDERATIONS

The aspects that facilitate or hinder the interview related to organ and tissue donation for transplantation cannot be totally controlled by the interviewer since some of them are related to the desire manifested in life by the potential donor, to clarification provided to families and other actions implemented during the hospitalization period involving other professionals.

Knowledge of these factors permits us to conclude that to optimize the donation process, in addition to technically and scientifically qualifying interviewers, educational programs should also encourage discussion concerning organ donation within the family sphere and among health professionals. Additionally, actions designed to provide dignified and humanized care to patients and families should be implemented.

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