



## Family interview in the process of donating organs and tissues for transplantation\*

*Entrevista familiar no processo de doação de órgãos e tecidos para transplante*

*Entrevista familiar en el proceso de donación de órganos y tejidos para transplante*

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### ABSTRACT

**Objective:** To understand the meaning attributed to the family interview by professionals working in Services Procurement of Organs and Tissues, to the process of donating organs and tissues for transplantation. **Methods:** Qualitative research from the phenomenological angle, according to the modality “structure of the situated phenomenon.” Study participants were 12 professionals. **Results:** After analysis of the interviews, the meaning attributed by the professionals was unveiled at a meeting. **Conclusions:** The statements that emerged revealed that the family interview is an important step, because it addresses the possibility of donating organs and tissues to save and / or improve the quality of life of people needing a transplant. This procedure is complex, since it involves aspects related to interviewer, the interviewee and the interview location, as well as ethical and legal questions. It also highlights the need for professional training to know, identify and cope with factors that facilitate or hinder the dialogue with the family members.

**Keywords:** Transplantation; Interview; Family; Tissue and organ procurement

### RESUMO

**Objetivo:** Desvelar o significado atribuído pelos profissionais que atuam em Serviços de Procura de Órgãos e Tecidos à entrevista familiar no processo de doação de órgãos e tecidos para transplante. **Métodos:** Pesquisa de abordagem qualitativa, na vertente fenomenológica, conforme a modalidade “estrutura do fenômeno situado”. Participaram do estudo, 12 profissionais. **Resultados:** Após a análise das entrevistas, foi desvelado o significado atribuído pelos profissionais à entrevista. **Conclusões:** As proposições que emergiram revelaram que a entrevista familiar é uma etapa importante, pois trata da possibilidade da doação de órgãos e tecidos para salvar e/ou melhorar a qualidade de vida de pessoas que necessitam de um transplante. Este procedimento é complexo, visto que envolve aspectos relativos ao entrevistador, ao entrevistado e ao local da entrevista, além de questões éticas e legais. Também evidenciam a necessidade de capacitação profissional para conhecer, identificar e lidar com fatores que facilitam ou dificultam o diálogo com os familiares.

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

### RESUMEN

**Objetivo:** Develar el significado atribuído por los profesionales que actúan en Servicios de Procura de Órgãos y Tejidos a la entrevista familiar en el proceso de donación de órganos y tejidos para transplante. **Métodos:** Investigación de abordaje cualitativo, en la vertiente fenomenológica, conforme la modalidad “estructura del fenómeno situado”. Participaron en el estudio, 12 profesionales. **Resultados:** Después del análisis de las entrevistas, fue desvelado el significado atribuído por los profesionales a la entrevista. **Conclusiones:** Las proposiciones que emergieron revelaron que la entrevista familiar es una etapa importante, pues trata de la posibilidad de la donación de órganos y tejidos para salvar y/o mejorar la calidad de vida de personas que necesitan de un transplante. Este procedimiento es complejo, pues involucra aspectos relativos al entrevistador, al entrevistado y al local de la entrevista, además de preguntas éticas y legales. También evidencian la necesidad de capacitación profesional para conocer, identificar y lidiar con factores que facilitan o dificultan el diálogo con los familiares.

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

\* Study conducted at the Organ Procurement Services of Sao Paulo city - Sao Paulo (SP), Brazil.

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## INTRODUCTION

The progress of science, technology and organizations have collaborated for the worldwide increase in the number of organs and tissues transplants, enabling many people to benefit from this therapy. However, the insufficient number of donors, to meet the growing demand of patients on the waiting list, has become the biggest obstacle to perform this procedure.

In Brazil, the small number of donations to meet the demand may be related to the donation process of organs and tissues for transplantation, because the inadequate performance or non-performance of any stage in this process can directly affect the number of donations. The donation process is defined as the set of actions and procedures that can turn a potential donor to an effective donor. It is considered potential donor, the patient with a diagnosis of brain death or the first clinical test for brain death, in which clinical contraindications do not represent risks to organ recipients, and effective donor, any potential donor, in whom, at least, one organ has been removed for transplantation purposes <sup>(1)</sup>.

The knowledge of professionals about the donation process and the proper performance of its stages provide the organs and tissues procurement in order to be available to perform transplantations <sup>(2)</sup> and allow the family to tolerate, with less pain and stress, this process of loss and mourning <sup>(3)</sup>.

After confirming the diagnosis of brain death, usually, it is a very difficult moment for the family, since the process of organ donation, itself, begins. At this moment, transplant coordinators, mostly nurses, who work in the Organs and Tissues Procurement Services, make an assessment of the potential donor and, if feasible, conduct a family interview regarding donation <sup>(4)</sup>.

Several factors are cited as causes of non-performance of the donation, however, authors who evaluate the factors which influence or intervene in the process of donating, point to the family interview, as the main stage for the continuation of the process <sup>(5,6)</sup>. Nevertheless, the publications on this topic are scarce.

The knowledge about the perception of professionals who perform the family interviewing process of donating organs and tissue for transplantation may contribute to improve the quality of the process of donating organs and tissue for transplantation. Thus, this study aimed to reveal the meaning that professionals working in the Organs and Tissues Procurement Services of Sao Paulo city attribute to the family interview in the donation process.

## METHODS

To achieve the proposed objective, a qualitative approach was adopted, using a phenomenological method, structure modality based on the phenomenon, as the theoretical framework of Martins; Bicudo <sup>(7)</sup>. The choice for the phenomenological method in this research aimed at capturing the essence of the phenomenon, allowing its comprehension. The inquiry area of the present study was the situation of experiencing the interview process in family donation of organs and tissues for transplantation in the Organs and Tissues Procurement Services of Sao Paulo city. Individuals who experience this situation, and participants in this study, are the professionals from the Organs and Tissue Procurement Services who conduct the family interview.

Data were collected after the institution's authorization and approval of the Ethical Committee number 320/09, as the guiding questions: "Talk about the family interview in the process of donating organs and tissues for transplantation", "Talk about the meaning of the family interview in the donation process", "What should be considered in the family interview?" and "What would you propose to improve the interview?". The interview was conducted with 12 professionals in three of the four Organs and Tissues Procurement Services of São Paulo city; the interviews were performed and recorded on a specific day, time and place established by the research subjects, after signing a Consent Form.

To analyze the speeches, we followed the methodological steps proposed by Martins Bicudo (the sense of discrimination of all meaning units, the transformation of the subject's expressions in the researcher language and the synthesis of the meaning units transformed into propositions). Thus, the ideographic analysis was done, in which corresponds to the analysis of individual speeches. In every speech, we sought for the essentiality of the interview process in family donation of organs and tissues for transplantation, through the identification of the meaning units. After identifying the meaning units, we proceeded to the phenomenological reduction process, when the expressions of the subjects were transformed into the researcher language.

Then the meaning units which represented a common theme were identified and grouped. Thus, the following thematic categories were built: "The meaning of the interview"; "Relevant aspects of the interview," "Characteristics of the interview," "Proposals to improve the interview"; "Considerations about the interview process." After this step, we performed the nomothetic analysis which corresponds to the identification of general ideas contained in the interpreted meaning units, it allowed us to understand the similarities and differences found in the descriptions. The last

step consisted of the synthesis which revealed some essential aspects of the phenomenon.

In the construction of the results, quotes from the testimonials were used to illustrate the findings. For the identification and denomination of different interviews (E) the numbers 1 to 12 were used in order to preserve the anonymity of professionals.

## RESULTS

For professionals working in the Organs and Tissues Procurement Services, the family interview is characterized as the beginning of the process of donating organs and tissue for transplantation. "... the meaning of the interview? It starts from the interview, the donation process, not death, that ... when you talk of brain death, the family thinks the donation starts there and it is not like that! It starts from the interview [...]" (E06)

It is a complex stage, for being the moment when the possibility of donation is placed to the family, and it is fundamental to clarify about the possibility of donating to save and/or improve the quality of life of people who need a transplant. "[...] The family interview is a delicate moment [...] the meaning [...] of an interview requesting donation, [...] is the question of saving lives. [...] Through an interview, you can [...] clarify [...] a family about the possibility of donation in order to promote, to save the life of a recipient [...] improve the quality of life through the death of another person." (E11)

There are professionals who consider the interview an important stage, others as one of the most important stages and there are also professionals who consider it the most important part of the donation process due to the fact that this is the time when the possibility of donating is placed to the family, because they consider that the interview addresses and determines the consent or refusal of the donation, for reporting that the interview process defines continuity and without the interview there is no donation. "[...] The family interview ... most professionals think, it is the most important part of the donation process, actually, I think it's an important part [...]" (E01)

The interview is considered appropriate when the interviewer explains to the family about the diagnosis of brain death, the possibilities and procedures, if they authorize or not the donation and as the questions presented by the family. "[...] A well done interview is when I explain what brain death is, in which the family, from that moment on can decide [...] being in favor of donation or not ... and the family ask me ... for me, this is a well done interview, because I know that the family understood well." (E02)

Due to the questions addressed to the families, the interview is seen as complex; because each family brings different experiences and perceptions in relation

to the hospital, about the care and diagnosis of brain death and it involves mainly the interviewer's emotional state and family members who are sensitized by the death of the patient. Therefore, the interview should be planned at all stages, from preparation to how to act, besides, it requires knowledge about the case plus preparation from the interviewer to clarify the family doubts, so that they can decide on the donation of organs and tissues for transplantation. Although planned, the interviewer may not be able to follow the schedule and some steps of the interview may be suppressed or supplemented, depending on the degree of awareness of the family, which makes each interview unique and singular. "[...] It is a difficult process [...] it is a process that involves much more emotional states, both from the interviewer and the family being [...] interviewed, requires [...] a preparation, a knowledge about the reason why led the potential donor to his/her death, to talk with the family [...] it is a difficult time, [...] It is a delicate moment, it is a moment that the family is sensitized [...]" (E04)

To experience a successful interview, the setting must be appropriate. The information should be told to the family by the patient's physician throughout the hospital stay until the time of death; there must be clarity regarding the diagnosis of brain death, and the interviewer should know the donation process to be able to clarify any doubts. The interviewer should also be sensitive to notice when the family is in shock, unstructured and needs time to assimilate the news or the support of other family members for taking decision regarding donation. However, this perception is gained from professional experience. "[...] I think in order to have a successful interview, you must have an appropriate place, the physician has to have well transmitted information, not only to report the death, but also during the whole process of hospitalization. Moreover, some clarification of these points should be done: diagnosis, recognize when the family is not ready to make a decision. This is something that I think comes with professional maturity: knowing how to recognize when the family is in shock; when the family needs to go home to return the next day; when the family needs other members to take a stand to make this decision; and especially know the donation process, so you can answer questions; and, not promise anything for the family that will not be fulfilled." (E05)

For the interview to be performed, it is important to consider the degree of relationship of the person who will be interviewed and their involvement and proximity to the potential donor. Testimonials reveals that the participation of people who have no kinship with the potential donor or family, who are not considered legal representative for the decision regarding the donation, may interfere, disrupt and influence the legal representative person in decision making. "The first thing I take into account is the degree of kinship, if he is a brother, if

*she is a spouse, in conclusion, first-degree relative. I think that's the main thing, because there is neighbor, people ... friends from work, often find that the interview has to be as they wanted. It cannot be. It does not mean they are not important, but they are not going to decide on the donation, although they influence, but they are not deciding.*" (E06)

The preparation for the interview was essential; therefore, the interviewer should check the medical records to know the name and background of the potential donor; the cause of death and how it has happened. *"Knowing the history, learning about the case, knowing if there was anything different in that case, knowing if the family suspect that it had been a medical error which happened by negligence, [...] some insertion that comes out of what is written. Because, for sure, they will ask, during the interview, and you say: 'I'm not from here, I'm from another hospital, I'm just here for the interview,' No! You have to know everything, you have to know the name, you have to know everything that you're talking about. I always write down who's in front of me and the degree of kinship with the donor. The place is also important and to check the documentation is also very important."* (E07)

It is common for the interview to happen in an improvised environment, uncomfortable and without seats to accommodate the people, or beside the bed of the potential donor, however, the existence of an appropriate place is relevant to the interview, and it must ensure privacy and provide them a telephone so that family members can use. *"The first thing that I think is important in the interview is the appropriate place, usually, there is not such place, it is improvised, we feel very uncomfortable; relatives stands up [...]"* (E12)

The presence of a professional from the institution who accompanied the case is important to give credibility to the process and support the interviewer. *"I think it is important that a hospital employee accompany the interview, [...] because it gives a bit of credibility to the process ... because this is a person who works in the hospital, who has followed the case and then a person from outside comes ... perhaps this is a support for us too, like a witness [...]"* (E09)

According to the testimonials of the research subjects, the way professionals talk to the families, how they explain the diagnosis of brain death and the donation process, as well as the language used are important aspects and should be appropriate to the social status of the family. The interviewer has to be friendly, demonstrating to know the case and that he/she is not there just to request organ donation. The assistance provided throughout to the family, the team treating the potential donor, is an important aspect of the interview process, it may direct a favorable or unfavorable decision regarding donation. *"[...] The way you talk to the family, the way you explain all the diagnosis, all donation process, the assistance you give to the family at that time, will direct this family to a donation or not."* (E03)

For some interviewees, it is necessary to be sensitive to assess the best moment to talk with relatives. Thus, the interviewer must realize and accept the moment of mourning that the family lives. It is impracticable to conduct the interview when the family is very shocked with the news of the death of the patient, so it is essential to assess the emotional state of the family. *"[...] The emotional aspect is also very important, because if the family is very shocked with the news of the death, there is no use to do the interview [...] then, there is the right time, a moment of coherence to talk to these relatives."* (E04)

The opinion, knowledge, clarification and understanding of family members on the evolution of the clinical potential donor and the procedures performed, since the hospital admission are important aspects to the interview, as pointed by some quotes. *"For the interview performance, it should be considered, first, if the family is able to go through with this interview, if they are able to talk, if they are able to understand about what is happening with this potential donor, since the beginning of treatment [...]"* (E03)

Professionals reported that the training of the interviewer is an important factor for the interview performance, as well as the ethical and legal issues surrounding it. Thus, the interviewer has to know the laws of the country on organ donation, knowing that only the spouse and relatives of first and second degree may be responsible for the consent, and if the potential donor does not have a legal guardian/representative, as required by law, the donation may not happen. The professional cannot impose his/her position regarding donation or judge a refusal as absurd, because their function is not to convince the family to donate, but to clarify, respect and support the decision made by the family. The family rights to have access to the physician and the medical records about the examinations performed for the diagnosis of brain death must be considered, as well as the possibility of relative's clarification of doubts. There should be guaranteed the freedom of the family to reschedule the interview and the time for reflection on the issue of organ donation. These are relevant topics for the interview. *"[...] It should be considered in the interview [...] the ethical and legal aspects [...] in the ethical point of view, I do not have to impose my opinion regarding the donation. [...] My role here is not to convince the family to donate, but clarify and above all respect and support the decision made by the family, the legal guardian/representative. The legal aspect is to know the law. [...] I have to know the organ donation law in my country, [...] I have to know who can be responsible for donating organs and tissues of a person in this condition [...]. If this is not followed there will be legal problems, [...]"* (E11)

The enhancement of the interview depends on the interviewer training, which can occur through training courses that provide technical, scientific and theoretical

content to support the practice of the family interview. However, there are no courses, case discussions and exchange of experiences among professionals conducting the interview for later implementation. Therefore, the professional of this service learn to interview with experience acquired in their daily work. “[...] *I think there is a lack preparation, preparation courses, discussions, sitting, I think that those who participate ... even by arguing about what is better and what is worse, case discussions, [...] a stage of the interview that you conducted in a manner, I might perform differently or not, maybe talking as you did, I may have some other tips to apply in my interview.*” (E03)

The professional from the captation service should study to acquire knowledge and prepare themselves theoretically before conducting the first interview. “[...] *The professional needs to be theoretically prepared for the interview. [...] They need to do a course for it, study about it, to know what it is about, before going out interviewing family members [...].*” (E08)

The interviewer should also take continuing education as well as professionals who have direct contact with potential donors and their families. Consequently, filming interviews can be used as a training strategy, as it allows the discussion of weaknesses, the strengths and those that need to be improved in the interview. “*For improving the interview, I think we should have courses [...] both for people who work in capturing ... and for people who work directly with potential donors, [...] who have contact with the families; the entire staff of the hospital [...].*” (E09)

The professional from the captation service should know the history of the hospitalization of the potential donor and their current situation. Thus, the interviewer should talk with the physician of the potential donor, with the nursing staff and verify the medical records in advance, in order to obtain information and to confirm that the diagnosis of brain death has been completed.

In order to improve the interview, the interviewer should also check the family's knowledge about brain death, their participation in the process of diagnosis and understanding of medical information; adapting the language and be clear about the progress of patient during hospitalization. Also, they need to demonstrate security when talking about the protocol on brain death and organ donation. “*To check with the family, if they really know what brain death is, if they have participated in the protocol examinations, if they understood what the physician said, leaving the family at ease regarding the visits, it helps a lot for the family to visit and see that the patient has no more chances [...].*” (E01)

“*I think it is also important to enhance the language, if you speak in a clear way about what happens and about what have happened to the patient [...].*” (E05)

Welcoming families, providing water and/or touching the interviewees are attitudes that can make the difference. The appropriate touch is the one that conveys

comfort for the other person and may be important and valid as long as you are sincere. “[...] *Some attitudes which makes a difference, a glass of water ... even a touch. I think all that is sincere demonstration is valid.*” (E05)

It was also mentioned, the importance of identifying the characteristics of the family in advance, since one family is different from another and there are aggressive people, docile people and inquiring or not. “[...] *To identify the characteristics of the family before the interview ... because there are families with people who are more aggressive, there are families with people who are more docile, and never go thinking that you will be sure of what you will find. Because every family is a different family. Each person has a different answer, some will ask a lot, others will not ask anything, and be a wise, be a student of the process, because the questions happen, the family wants to understand the whole process.*” (E10)

Some consider that, to improve the interview, it is also important to identify the person with greater discretion and understanding of the facts. “*I think it is important, during the interview, you know how to recognize the person in that family who is the basis, who will be the most important person in the family decision. The person who has the highest level of understanding of what is happening; I think it is important to be identified during the interview.*” (E05)

In this context, it was noted that the interviewer can be blamed for the family's refuses. “[...] *Sometimes, I feel that the family refusal is the professional fault who interviewed the family [...].*” (E01)

Therefore, professionals should provide time for the family to think on the issue of organ donation and they should not use, during the interview, the statement that the donation will help other people or that the donor may evolve into cardiac arrest if the decision takes a lot of time. There is also the consideration that the performance of a new interview can be seen by the family as a form of pressure, which can lead to a refusal on the donation and dissatisfaction with the service. “*I've seen interview that person looks like: 'Look! you may be helping a child', you may be helping ... you know, and therefore I do not agree! If it was with me, I would not like! [...].*” (E07)

## DISCUSSION

The interview is one of the most complex stages in the process of donating organs and tissue for transplantation because it involves ethical, legal and emotional aspects <sup>(8)</sup>, since it occurs minutes or hours after the notification of brain death, concretizing the family impotence, death and separation from the potential donor <sup>(9)</sup>.

Although the family interview is cited as determinant in the donation of organs and tissues process, it is important to note that this stage of the process is as important as the others, there is no stage which is

more important than another. It is important to note that there is no point in obtaining consent for donation and subsequently the potential donor evolve into cardiac arrest due to poor clinical maintenance, invalidating the process the same way that a refusal would.

Some authors state that the donation process begins with the identification of potential donor<sup>(2,10-13)</sup>. However, in this study, it was evident that for professionals working in the Organs and Tissues Procurement Services, the beginning of the process of donation is characterized as the family interview. This aspect becomes even more intriguing when compared to a study conducted with family members of dead donors who considered that the donation process begins with the patient hospitalization<sup>(4)</sup>. It is explicit the difference in the literature, the professionals and family members, as the definition of the point where donation process starts.

The aspects identified as relevant to the interview, it is observed that these factors are related to the interviewer, the interviewee, the setting of interview, the communication process, the assistance given to the potential donor and relatives during the hospitalization and also the ethical and legal issues. The moment of the interview is also explained as an important factor, because that is the time when the family has to deal with the reality of death, therefore this time is crucial to their willingness to consider organ donation<sup>(14)</sup>.

It becomes quite clear that the success of an interview depends not only on the interviewer, but also on the aspects that involve other professionals, and family members' perceptions about the attention and care received during the patient's hospitalization. The interviewer can control some of these aspects, but not all of them, a fact which makes it impossible to exclusively blame the professional when a refusal on the donation happens.

It is important to emphasize the need to train technically and scientifically the interviewer<sup>(15)</sup>. This evidence is also clear in the proposals for the improvement of the interview conducted by professionals who consider this a warning being reinforced by the revelation that there are no courses, case discussions and exchange

of experiences among professionals conducting the interview for later implementation. The implementation of group discussions and/or training courses can help minimize errors and assist in practical learning.

It is also interesting to note that most of the proposals for the improvement of the interview is something already expected from the interviewers, because these are actions which aim at obtaining information on the potential donor and their relatives, the assessment of family clarification regarding brain death, aspects related to communication, the family welcome, among others. This fact brings us to the reflection about such actions, although considered basic to conduct any interview, it may not have been performed by professionals and therefore are identified as positions that, if adopted, would improve the interview and would optimize the donation.

This paper also contributed to the construction of a concept hitherto nonexistent about what is a proper family interview, a term widely recommended in the literature, however, undefined, which leads to different interpretations.

This study was limited to the perception of unilateral family interview, having as subjects only professional interviewers who talk to families. Thus, it is important to carry out further studies in order to reveal the meaning assigned to the interview of family members who agreed and refused to donate organs and/or tissues for transplantation to a better understanding of the phenomenon.

## CONCLUSION

This study enabled us to unveil that the family interview is an important stage, since it deals with the possibility of donating organs and tissues to save and/or improve the quality of life of people who need a transplant; and complex because it involves aspects of interviewer, the interviewee, the setting of interview, and ethical and legal issues, thus emphasizing the need for qualified professionals to meet the demand, identify and address the factors that facilitate or hinder the dialogue with the family.

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