

# The Family Interview in the Process of Donating Organs and Tissues for Transplantation: Perceptions of Potential Donors' Relatives

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## ABSTRACT

**Background.** The family interview is a complex phase of the organ donation process because it involves aspects of the interviewer, the interviewee, the interview location, and ethical and legal issues. However, there are few publications on this phase of the donation process. This study aimed to reveal the meaning assigned to the interview phase, in the process of donating organs and tissues for transplantation, by the families of potential donors.

**Methods.** We performed a qualitative study of the phenomenologic aspect, within the modality “structure situated phenomena.” The study included the participation of 10 families.

**Results.** After analyzing the interviews, the meaning of the interview was unveiled by the family members.

**Conclusions.** The statements revealed that the family interview is considered to be an important step for warnings, clarifications, and encouraging families to think about the possibility of donating to save and/or improve the quality of life of people in need for a transplant, and that studies contribute to the technical and scientific qualification of the interviewer as well as stimulate discussion among health professionals to improve the interviewing process.

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**T**HE INSUFFICIENT number of donors to meet the growing demand of patients on the waiting list has become the biggest obstacle to the execution of transplantations. This fact may be associated with failures in recognition of brain death, maintenance of clinical deceased donors, and family approach [1].

The family interview phase of the process is very complex, because it involves aspects of the interviewer, the interviewee, the interview location, and ethical and legal issues, highlighting the need for training to meet, identify, and address factors that facilitate or hinder dialog with the family [2].

The facilitating or troublesome aspects of the interview process can not be fully controlled by the interviewer, because some are related to the desire expressed by the potential donor in life, the explanations given to relatives, and actions involving other professionals during hospitalization. However, the technical and scientific qualifications of the interviewer, the implementation of educational programs that encourage discussion of the issue of organ donation among health professionals, and the implementation of actions aimed at humane and dignified care to patients and

their families can optimize the possibility of donation at the time of the interview [3].

Therefore, knowledge of the perception of relatives of deceased donors on the family interview can contribute to improving the quality of this phase of the donation process. The present study aimed to reveal the meaning that family members of organ and tissue donors attach to the family interview in the donation process.

## METHOD

To reach the proposed goal, we adopted a qualitative approach, using the phenomenologic modality structure of the phenomenon, according to Martins and Bicudo [4]. The adoption of the phenomenologic method in this research aimed to capture the essence of the phenomenon, allowing its understanding.

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**Table 1. The Meaning of the Family Interview**

Excerpts of Testimonials
"[T]hey said it was brain death! For me it would end, the heart would stop. But they spoke of the possibility of helping people who are in need ... then, it already "clicked." It is necessary for someone to say something so that we can act and do something about it, the interview was important to think about the possibility of donating." (I07)
"I think it was to attest that the death had happened, because things really come together ... a notice of brain death linked to the issue of brain donation. It is a very fast reframing, you have the meaning of a loss that is difficult ... At the same time you have a loss, you can help someone, then it is a mixture of loss with a mixture of ... Oh God! It is nice to know that in the midst of loss, we can help someone, I think this is the meaning." (I03)
"The interview had very little meaning, it was just a formality, since a decision was already made." (I05)

The subjects who experienced the interview and participants of this study were the families of organ and tissue donors who consented to donation. Data were collected after authorization of the institution and approved by the Ethics in Research committee (346/11), with the use of the following guiding questions: "Talk about the meaning of the family interview in the donation process," "What should be considered in the family interview?," "Talk about the factors that facilitate and hinder the family interview," "What proposals would you do to improve the interview?" Ten donors' relatives took part in this interview. The interviews were conducted and recorded at a time and place established by each research subject, after they signed a statement of free and clarified consent.

After obtaining the interviews, we performed ideographic analysis, which corresponds to the analysis of individual interviews. Then, units of meaning were identified and grouped according to a common theme. Thus themes were built. After this phase, we performed nomothetic analysis, which corresponds to the identification of the general ideas contained in the meaning units interpreted, enabling the understanding of similarities and differences found in the descriptions. The last step consisted in the synthesis, which revealed some essential aspects of the phenomenon.

On building the results, some excerpts of the testimonials were used to illustrate the findings. For the name and identification of different interviews, we used the numbering I01–I10, to preserve the anonymity of the family.

## RESULTS

Regarding the meaning of the interview, it was found that the participants considered it to be very important because the interview alerts and encourages the family to reflect on the possibility of donation. There is the consideration that, at first, the interview confirms the occurrence of death and

explains the loss of the patient to the family, generating a bad feeling. Nevertheless, in a quick way, this dialog can provide the reframing of the loss, because it couples a good feeling that emerges with the possibility to help someone who needs a transplant. Some family members pointed out that the interview has little meaning, because it serves only to formalize the previous decision (Table 1).

As the relevant aspects of the interview, the families suggested that respondents should be prepared before the time of the interview regarding the donation of organs and tissues for transplantation. The interviews also showed that it is important for the interviewer to have patience to explain and answer questions of the family, to show empathy and respect for the grief of the family, as well as to exercise caution and project calm when talking. Also relevant were some explanations about the time required for completion of the procedure after the approval of the donation (Table 2).

Regarding the factors that facilitate the interview, it was shown that the presence of a professional with some connection to the family provides safety and facilitates the interview. Another aspect mentioned was the clarification to the family about all procedures related to the donation. On the other hand, there is the consideration that the unpreparedness to deal with the situation of death, the pain, and the despair associated with ignorance of the families about aspects relating to the donation of organs and tissues may hinder the interview (Table 3).

Referring to the proposals for the improvement of the interview, the family explained that the development of a guide for the professional to transmit all the necessary information to family members can enhance the interview

**Table 2. The Relevant Aspects of the Interview**

Excerpts of Testimonials
"The interview can not be something sudden, I had the feeling of being prepared slowly." (I01)
"I think that conscientization has to come first, because if you go through a shock like that and there is a professional who asks coldly if the person wants to donate, it's complicated, I think it's harder." (I04)
"[Y]ou have to have patience to explain and solve all the doubts, empathize, have respect for the person's pain, while you're asking her to make a decision, the way you talk, you have to be careful about that speech ... have to be tactful in time to talk ..." (I06)
"I think that the professional has to be that way, delicate, to talk to the family, because the family is already under a violent stress ..." (I04)
"In my case, they failed to explain that the procedure would take so long. I understand it does, but at the time, I did not think about it. I think it was a failure, someone had to have it better clarified about the whole procedure so I could know it would not be so fast." (I02)

**Table 3. Factors that Facilitate and Hinder the Family Interview**

Category	Excerpts of Testimonials
Factors that facilitate the family interview	<p>"I think it is necessary that you have a relationship with the professional who interviews. It's something that confers security, for I have already seen that professional, he had already been together with me for some time." (I07)</p> <p>"Explain all the procedures for the donation, because there are some obvious things, but in a time like this, we do not think." (I09)</p>
Factors that hinder the family interview	<p>"I think what makes it difficult is the pain, the despair allied to the ignorance of the human being, not having sufficient understanding concerning the donation." (I06)</p> <p>"Most people are not prepared to deal with death. The very lack of knowledge of the people ... if you do not know anyone who is in need, there is no information." (I08)</p>

process. There was also the reference that as soon as the interviewer achieves his goal, he leaves the family helpless (Table 4).

## DISCUSSION

The interview is one of the most complex phases in the process of donating organs and tissues for transplantation because it involves, beyond the technical, ethical, and legal issues [5], different perceptions regarding the care and diagnosis of brain death as well as the interviewer's personality and family members' emotions who are sensitized by the death of the patient [3].

In the present study, family members considered relevant to the interview process, factors inherent to the interviewer and the communication process. This corroborates the perception of professionals engaged in Services of Organ and Tissue Demand reporting that the interviewer should be charismatic, sympathetic, and empathetic to understand what family members are experiencing; cautious, clear, and objective for the respondents to understand the information; and trained, professional, dedicated, and prepared to be able to welcome and comfort the family [6].

Also important is the prior preparation of the family for a dialogue on the issue, which influences the understanding of the family about the evolution of the clinical picture of the potential donor and the procedures performed since the beginning of hospitalization.

Although it is not a commonly adopted practice, it is interesting to note that the presence of a professional who has followed the case and established a bond with the family facilitates the interview, providing safety to the family. This fact is also pointed out by interviewers, who reported that the presence of this professional adds credibility and supports the interviewer [3].

Another aspect highlighted in this work is related to the factors that hinder the interview. For family members, these

factors are related to feelings that emerge at the time of experiencing loss and the mourning process, combined with ignorance about aspects relating to the donation of organs and tissues, whereas for professionals it is related to the site, to clarify the family regarding the diagnosis of brain death, the care provided to the family and the potential donor during the hospitalization period, the time of the interview, the interviewer's posture, and the fact that the family had not spoken in advance on the issue of organ donation. The existence of different perceptions are evident, a fact that highlights the importance of this work [3].

Although the development of a guide for the professional to give all necessary information to the family contributes to the enhancement of the interview process, it is interesting to note that, even planned, the interviewer may not be able to follow the schedule, and some phases of the interview can be deleted or supplemented depending on the clarification needed by the family.

This study did not intend to exhaust the subject, so it was limited to the perception of family members who consented to donate organs and/or tissues for transplantation. Thus, it is important to carry out further research to reveal the meaning assigned to interviews by family members who refused to donate organs and/or tissues to get a better understanding of the phenomenon.

## CONCLUSION

The family interview is considered to be an important step for warning, clarification, and encouraging families to think about the possibility of donating to save and/or improve the quality of life of people in need for a transplant. The knowledge of the perception of family members who consented to donation contributes to the technical and scientific qualification of the interviewer, stimulates discussion among health professionals, and can improve the interview process.

## REFERENCES

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**Table 4. Proposals to Improve the Interview**

Excerpt of Testimonial
<p>"I think it would be important to have a script. Prepare a script with all the information that the professional should take, including time variables, all possibilities for the family to have any clarification." (I10)</p>

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