



Family Interview to Enable Donation of Organs for Transplantation: Evidence-based Practice

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ABSTRACT

Background. In this study we propose a theoretical and practical basis for the best practices for interviewing relatives of brain-dead eligible organ donors.

Methods. This investigation was a reflective study of the methodologic factors of the family interview that affect their decision regarding the donation of a deceased patient's organs for transplantation. The articles that formed the empirical basis of the trial were obtained from PubMed, which is a free-access tool of the MEDLINE database of the United States National Library of Medicine. Published articles that allowed us to reflect on evidence-based family interview practice were selected.

Results. Thirty-six scientific articles were used to guide our assessment the family interview, providing evidence for its adequate execution in view of the following prerequisites: When should the family interview be performed? Where should it be done? How many and which people should participate in the interview? Who should perform it? How should it be done?

Conclusion. Scientific studies offer evidence to donation and transplantation specialists that can help them in their daily work regarding their interactions with relatives in the process of decisionmaking and family consent.

ORGAN donation presents the possibility of saving and improving the quality of life of recipients waiting for transplants. Thus, a family interview to enable donation occurs in the face-to-face interaction between the relatives of the deceased donor and the specialists in donation and transplantation, the purpose of which is to offer help to the family and clarify the donation process, making decision-making with autonomy possible [1]. This process requires knowledge, skill in communication, and experience on the part of the interviewer. The requirements for autonomous decisionmaking presuppose the freedom of choice, clarification, and competence of those involved in this process. The pain of loss, fear of death, and the psychological, physical, and economic dependence of family members are limiting factors of autonomy in the face of the possibility of organ donation for transplants. Therefore, the purpose of the family interview is not to convince eligible donors' relatives to agree to organ donation but to provide a supportive environment to discuss the paths the family will take and to explore what the deceased thought about organ

donation during their lives. The interview must allow family members to feel comfortable in their decisionmaking [2,3].

Effective communication is the key to a successful family interview. Thus, requesting organ donation involves communicating with family members about their opinions on the possibility of donating, and it is essential to provide enough information for autonomous decisionmaking. Obtaining authorization for donation is not simply asking the family if they wish to donate [4]. The family interview should be planned and follow a method with specific characteristics; that is, it should be semistructured in nature, and the content and the direction of the dialog with the relatives of the brain-dead eligible donor should ensure an informed choice regarding the possibility of organ donation for transplantation.

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Table 1. Characterization of the Studies Used for Elaboration of the Reflective Trial

| Reference | Country of Origin | Year | Type of Study |
|------------------------------|-------------------|------|--------------------|
| Williams et al | United States | 2003 | Review |
| Doran | Ireland | 2004 | Review |
| Díaz | Spain | 2006 | Review |
| Jacoby et al | United States | 2006 | Review |
| Rodrigue et al | United States | 2006 | Quantitative |
| Sanner | Sweden | 2007 | Qualitative |
| Moraes et al | Brazil | 2008 | Phenomenology |
| Sque et al | United Kingdom | 2008 | Quantitative |
| Long et al | United Kingdom | 2008 | Review |
| Martínez et al | Spain | 2008 | Qualitative |
| Rodrigue et al | United States | 2008 | Quantitative |
| Simpkin et al | United Kingdom | 2009 | Systematic review |
| Stouder et al | United States | 2009 | Quantitative |
| Siminoff et al | United States | 2009 | Quantitative |
| Thomas et al | Australia | 2009 | Qualitative |
| Manuel et al | Canada | 2010 | Phenomenology |
| Jacoby et al | United States | 2010 | Quantitative |
| Brown et al | United States | 2010 | Quantitative |
| Vicent et al | United Kingdom | 2012 | Review |
| De Groot et al | Netherlands | 2012 | Integrative Review |
| Sque et al | United Kingdom | 2012 | Quantitative |
| Kompanje et al | Netherlands | 2012 | Quantitative |
| Meyer et al | Norway | 2012 | Quantitative |
| De Groot et al | Netherlands | 2014 | Focus group |
| Moraes et al | Brazil | 2014 | Phenomenology |
| Trzcinska et al | Poland | 2014 | Review |
| Ebadat et al | United States | 2014 | Quantitative |
| Santos et al | Brazil | 2014 | Phenomenology |
| Ralph et al | Australia | 2014 | Systematic review |
| Skwirczynska-Szalbierz et al | Poland | 2014 | Quantitative |
| Bertzen et al | Norway | 2014 | Qualitative |
| Siminoff et al | United States | 2015 | Quantitative |
| Moraes et al | Brazil | 2015 | Phenomenology |
| Kompanje et al | Netherlands | 2015 | Review |
| Siminoff et al | United States | 2015 | Quantitative |
| Hume et al | United Kingdom | 2016 | Quantitative |

This stage of the donation process is centered on a theme that allows the construction of a script with key questions, complemented by other questions inherent to the immediate circumstances of the interview. The interview is based on an adaptive and not predetermined guide, with consequential (what), evaluative (how), hypothetical (which), and categorical questions (how much). Normally, the semi-structured interview is composed of questions that use adverbs (where, how, and when) and pronouns (that, who, which, and how much). When formulating the questions, the donation and transplantation specialist should pay attention to the language, form, and sequence of the questions.

Thus, the acquisition of effective communication skills enables the specialist in donation and transplantation to use communication tools, through active listening, that will help the relatives of the deceased in making a decision about their loved one's organ donation.

Families often have to decide on the fate of the organs and tissues of the deceased in difficult circumstances, and the help offered by the health team is crucial in coping with this situation. Psychosocial support and the family's satisfaction with the care they receive play a key role during the decisionmaking process. When family members are interviewed about organ donation, a time of intense emotion, they become temporarily "patients" who need attention, understanding, respect, patience, and support from those who interact with them. Doctors and nurses who establish an empathetic relationship with these families often cannot provide the necessary support due to excess work, inadequate training in organ donation, and inability to provide effective communication [1].

Thus, this reflective trial proposes to establish the theoretical and practical links related to interviews with relatives of brain-dead eligible donors. The analysis is based on scientific research and proposes guidelines to specialists in donation and transplantation regarding the interaction with family members during the decisionmaking process and family consent.

METHODS

This study was a reflective trial about family interviews regarding the donation of a deceased person's organs for transplantation. It consisted of introducing ideas and points of view on a given theme, seeking originality in the focus and without exploring the subject exhaustively. To do this, it was necessary to adopt the logical structure of a scientific text and to carry out in-depth bibliographic research on the chosen theme. The theme presented must be argued with solid scientific evidence.

Once the theme was chosen, the trial was planned, and the general lines of the questions involved in the reflection, the different perspectives that were approached, and the available scientific references were established. In this way, planning presupposed the determination of the questions to which the trial must respond. The purpose of ulterior reading and research was to find the answer to each of these raised questions.

The articles that would provide the content for this reflective trial were obtained from PubMed, which is a free-access tool of the MEDLINE database, offered by the United States National Library of Medicine. The texts that allowed us to reflect on evidence-based family interview practice were selected. In this article, evidence-based practice pertains to the use of strong scientific evidence produced by studies conducted with methodologic rigor to the decisionmaking process about the best way to conduct the family interview to enable the donation of organs for transplantation.

RESULTS

Through published academic studies, we sought to base the practice of the evidence-based family interview on scientific evidence, thereby elucidating the main doubts of the donation and transplantation specialists regarding the prerequisites of this stage of the donation process. The articles used for the reflective trial, which served as guidelines for the discussion of the interview, are presented in Table 1.

DISCUSSION

Each prerequisite of the family interview is addressed separately, aiming to provide greater didactic clarity

regarding the methodologic path of this phase of the donation process and to enable the acquisition of theoretical elements that may guide the practice of the interview.

Prerequisites for Family Interview

Many scientific articles offer evidence that allows the construction of a theoretical-practical model that permits direct interaction with the family of the deceased donor at the time of the family interview. In this scenario, the most frequently asked questions are: When should the family interview be conducted? Where should it be done? How many and which people should participate? Who should perform it? How should it be performed? In the light of scientific findings, each of the prerequisites is discussed with the intent to provide a safe path for donation and transplantation specialists.

When Should the Interview be Conducted?

The family interview should be performed after confirmation of the diagnosis of brain death, clarification of this condition to the relatives of the deceased, and evaluation of the emotional conditions of the family members. Therefore, it is essential that family members understand the concept of brain death and accept that the person has died. Thus, a strategy used by physicians is to allow the presence of members of the family of the potential donor at the time of diagnosis of brain death in order to improve the understanding and acceptance of this condition [5,6].

The health team's ability to communicate is critical to ensuring the clarity and objectivity of the information transmitted to these families. Professionals working with critically ill patients should receive specific training in communication, as it is a basic tool for carrying out their daily activities. This aspect is of great importance when communicating brain death and aims to prepare the relatives of the donor so that the specialist can perform the family interview with the intention of presenting the possibility of donating organs and tissues for transplantation [7-9].

From this perspective, the role of the specialist in the family interview includes the primary goals of helping the family understand the meaning of organ donation, conducting the conversation in a respectful and empathetic way, respecting the right of each family to make an informed decision, and offering the family the unique opportunity to save or improve the quality of life of organ recipients [10-12]. It is important to mention 3 fundamental precepts in donation of organs from deceased donors: (1) if the family has a chance to save someone's life, they will usually do so; (2) organ donation is a family right and a good decision; and (3) the role of the donation and transplantation specialist is to defend the rights of the family of the deceased and the patients waiting for transplant [10].

There is evidence that the family consent rate is higher when the donation request is dissociated from the discussion of brain death and when it is done by a trained specialist. In this context, working in partnership between the intensive care unit and the donation and transplantation specialist is

of fundamental importance [13-15]. When the possibility of donating organs and tissues is presented at the right time and in the right way, family members receive assistance in the decisionmaking process, with their own values and beliefs as a reference. Relatives who are comfortable with the decision to donate are less likely to experience complicated grief in the face of unresolved grief reactions [16].

Regarding the most adequate time for the family interview, a study done in Texas showed that the family refusal rate is higher at night, with refusal increasing after midnight. The authors believe that interviewing the family about donation during the day may increase the rate of consent [17].

In addition, the following recommendations are essential: (1) Do not request the donation very quickly, that is, immediately after communicating the diagnosis of brain death. When the request is made too soon, family members refuse the donation in advance. (2) Focus on communicating with family members rather than insisting on organ donation. The time spent with the family in combination with the support offered by a well-trained donation professional has a positive impact on the family consent rate. (3) Allow time for the family to make the decision. Many denials are not based on a deeply reasoned view but are correlated with the feeling of not having had enough time to discuss the donation. (4) The family needs to be comfortable with the donation request; this means not giving the impression of being "stressed-out," hurried, or pushing the family members to make a decision quickly [17-19].

The factors that positively influence family consent are providing time for the family to discuss and consider organ donation; transmitting information with respect, trust, sensitivity, and sincerity; and health professionals' having received training in effective communication [20-22].

Where Should the Interview Be Held?

The appropriate place for the family interview should be private, quiet, and comfortable for the family. The environment for this type of interaction should not be too far from the donor, as the family will often ask to see their loved one. Environmental factors, such as furniture and architectural styles, interior decoration and lighting conditions, colors, temperature, and additional noise or music, affect the relationship with the family of the donor and, consequently, the quality of family interview [14,23]. Therefore, the organ donation request is more likely to be successful when it is performed in a private setting with resources that meet the minimum needs of family members of the brain-dead eligible donor. It is advisable to conduct the interview during the day, and, if there is another type of care being provided for the family, it is recommended not to use it as an argument for obtaining the donation or to reverse a refusal.

How Many and Which People Should Attend the Interview?

It is not appropriate to limit the number of people who will participate in the interview. All people who are important in making decisions should be present, and contact should be maintained with all of them. Identifying those who can have

great influence in the decisionmaking process is of fundamental importance. One must remember that the main factors that help families in the grieving process include support offered by the family itself and friends as well as their cultural and religious beliefs [24].

Who Should Conduct the Interview?

The team should be composed of 2 experts in donation and transplantation trained in communication techniques. Acquiring effective communication skills increases the experts' confidence in requesting the donation, the time spent discussing the donation with the donor's family members, and the number of discussed topics related to the subject, increasing the rate of family consent. Therefore, improving the communication skills of these professionals may be the best way to optimize donation rates [25,26].

The model of donation centered on the performance of the specialist nurse significantly increases the rate of family consent. The professional's ability to communicate, dialog, deal with, and contact relatives of deceased donors is an important factor in increasing the number of effective donations [27–30]. Professionals asking for the donation should be specialists, with specific training in donation and transplantation, help relationships, and techniques for communicating bad news. These professionals should receive training periodically, even if they were previously trained.

How Should the Interview Be Conducted?

The first step that the donation and transplantation specialist must take is to make a diagnosis of the situation experienced by the family. Remember that the interviewer is facing a family with a loved one who has received a diagnosis of brain death due to an unexpected and tragic event. Undoubtedly, the relatives of the deceased will always cling to the hope of reversal of the condition and reject the idea of death [8,12]. Therefore, the family interview should be conducted by specialists with experience and training in communication in critical situations.

The process of mourning, properly speaking, begins with the communication of the diagnosis of brain death. At that moment, the relatives of the deceased donor will manifest the reactions of psychophysiologic nature of biologic origin. The news of death drastically and negatively alters the family's perspective of the future. The result is an emotional disorder emerging as a profusion of feelings and behaviors such as anguish, impotence, depression, emptiness, confusion, fear, denial, guilt, anger, frustration, anxiety, irritation, and shame, which linger for a time after the news is received [31,32]. The donation and transplantation specialist needs to identify and work with these reactions at the time of the family interview.

At the initial contact, the physician responsible for the eligible donor initiates the interview and introduces the donation team by their names. At that time, these professionals should not be introduced as specialists in donation and transplantation, except in situations when the family previously expressed a desire to donate organs. Once the

interview has been started, the intensivist, with the support of the donation and transplantation specialists, can proceed to the communication of death. It is recommended to start with established phrases such as: "As you already know, the situation of your relative was very serious; unfortunately, we have bad news," or "Unfortunately, the situation has worsened, and we have to communicate bad news." These sentences enable the communication and exploration of death. There is no recommendation on how to communicate death. It may be through the statements such as "The patient died" or "The patient has brain death." However, Swedish law emphasizes that there is only one death, and the Swedish Health Council recommends that only the term "death" be used, replacing the term "brain death," so that there will be no doubt as to what death is the true death [33].

The word "death" should be used in the interview, and the doctor should provide the time of death and reinforce that the person is not in a coma. The word "patient" should be avoided and replaced with "the deceased"; this helps the family completely assimilate the death of the loved one. The words "death" and "deceased" should be used consistently to avoid euphemisms and vague terms [11].

The family's quiet moments should be respected during the interview, and it is considered inappropriate to try to fill that time with additional explanations because these can generate undesirable chaos. It is fundamental to adjust the way the information is offered according to the family's capacity for understanding and to let the family speak without interruption. In addition to answering all the questions of family members, the specialist should encourage them to clear their doubts through open questions [11].

After the death is communicated, the specialist in donation and transplantation assumes a more important role with the family. The doctor who reported the death may leave the room and continue his/her work, explaining this to the family.

Before presenting the possibility of donation, it is important that the specialist ensure that the family understands the death of the loved one. Studies recommend that, during the family interview about organ donation, the health professional should explore what the family understands about the term "brain death" and what the implications of this condition involve. Does the family think that the loved one will not recover? Does the family think the loved one is dead? These issues are more important than the family correctly defining brain death. The discussion to evaluate individual understanding of the definition of death is widely recommended [34–36].

The specialist in donation and transplantation needs to make a diagnosis of the family situation, which will indicate the appropriate time to present the possibility of donating organs and tissues for transplantation. At this point, the interviewer should explore what the family has understood about the concept of brain death through 2 open-ended questions: What do you understand about the diagnosis of brain death? What does this condition mean to you? When the specialist is sure that the family has understood the

concept of brain death, he/she plays an important role in helping families of the brain-dead eligible donor, relieving tension in the face of death, and allowing the donation of organs for transplantation. The help relationship must be maintained until the end of the interview. The help relationship is a benefit to the family and should not be applied only to the donation. Regardless of the outcome of the interview, this relationship should be kept to the end, with signs of sympathy and affection.

One of the instruments of great relevance in the process of organ donation is developing the ability of active listening, which will enable the use of the techniques of reformulation of the same. It is recommended to use the tools of communication through active listening, which is a psychological process that means paying attention to what one hears, because what is heard emerges from the inner world of the person expressing these thoughts. Active listening is a voluntary act that requires attention and interest to feel what the other feels when expressing his/her doubts and fears. Active listening means overcoming the barrier imposed by these elements. When this obstacle is overcome, listening becomes therapeutic. The factors that help active listening are patience, respect, calmness, proper posture, and a facial expression that shows interest.

When communication occurs in situations of aggression, listening can ease tensions. Allowing family members to express their emotions reduces hostility. It is essential that the family not feel observed but listened to. Feeling heard in situations of emotional crisis means being accepted and understood. Therefore, the message must be heard with the ears, with the body, with the senses, and without prejudice.

The health professional should focus on the message being sent by each family member and on the way the person sends the message, and should strive to understand him/her, summarize the most important points, reformulate the key points, and confirm the understanding [31]. Active listening is the main element of the help relationship that is established between the donation and transplantation specialist and the relatives of the brain-dead eligible donor. It is at that moment that the active-listening techniques of reformulation should be used. The use of these elements of effective communication makes it possible to materialize, through verbal or nonverbal expression, the acceptance and understanding of the emotions experienced by these families in the face of the loss of a relative.

The main tools or techniques for reshaping active listening are the reflex of the emotions or mirroring, which consists of verbally expressing the emotion that the person is feeling; clarification, which means clarifying, elucidating, and explaining the message; paraphrasing or metaphrasing, which is the non-literal repetition of the message, aiming at a greater understanding; summarizing, which means synthesizing the exposition of events through a set of paraphrases and reflexes of emotions that are added to the messages of the interlocutor; and open and closed questions, which are useful for understanding opinions and feelings, allowing freedom of reply, and encouraging responses.

When presenting the possibility of organ donation, the language should be clear, direct, and simple, and the professional should offer the information about the donation as a way for the family to attribute meaning to the suffering experienced. Donation should not be presented as the last thing that can be done, but it should be described as a unique privilege, an option, a right, or an opportunity to help others [10]. Remember that disrespect and doubts can undermine family trust. It is important to identify the family member who will have the primary role in the final decision due to the relationship with the deceased. It is critical for the family to understand that the loved one is dead. Therefore, discussion of key topics include clarifications of the diagnosis of brain death, how the body of the deceased is treated, preparations for the funeral, any desires the deceased had expressed about donation, the costs the family will be responsible for, and statistical data on the benefits of organ donation [4].

The family interview may be more likely to have a positive outcome if performed in a private environment, when the relatives understand brain death before the discussion of organ donation, and when the consent process involves the participation of the specialist in donation and transplantation. Each of these 3 elements will significantly and independently increase the rate of consent to organ donation. The rate is almost 3 times higher when all elements are present. One study estimated that less than a third of all family interviews meet this standard [14]. Therefore, the family interview should be conducted after the family has had enough time to receive and assimilate the information, think of and ask questions, discuss the matter, and resolve all doubts. After several days, it is recommended that the specialist thank the family for the donation by letter or phone call.

In cases of refusal, the interviewer should use the learned communication techniques. First, the family should be asked about their reasons for refusal. It is critical that this issue be addressed in a way that the family does not feel they are being forced to explain or find excuses for their decision [10]. Some restraint is necessary, and the specialist should avoid starting the sentence with the word "why" when exploring reasons for family refusal. Therefore, it is advisable for the interviewer to use the following phrases: "Could you talk about the reasons for your decision?" "What are the reasons for your decision?" "People who refuse to donate organs usually have definite reasons. I would like to ask about the reasons for your decision." In some cases, it is recommended to talk separately to the person who is most strongly opposed to the donation to determine his/her role in the family. The family should define the limits of the interview [10].

The specialist conducting the interview should complete it when there is no sign of progress, the family shows signs of fatigue and loss of empathy, the family does not recognize any benefit from the donation, and there is no doubt about the decision made [10].

Interviews should be documented and analyzed, especially denials, and it is important that practitioners receive specific training. It is advisable that the medical professional who communicates death has training in techniques for

communicating bad news. It is important to promote specific training for professionals in intensive care units through courses and seminars held at the hospital.

CONCLUSIONS

Scientific studies provide donation and transplantation specialists with evidence that can help them in their daily work regarding their interactions with the relatives of deceased potential donors. Putting the results of these surveys into practice during interviews may increase the rate of family consent. In addition, it is of fundamental importance to offer a permanent education program to these professionals to foster the development of effective communication skills that could enable a good relationship with family members in the process of organ and tissue donation.

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