

Bioethics and organ donation in Brazil: ethical aspects in approaching the potential donor's family

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Abstract

Bioethics and organ donation in Brazil: ethical aspects in approaching the potential donor's family

This article is a theoretical reflection aiming at identifying the ethical issues that might influence on family's consent rates regarding organ donation. The lack of clarification during the process of obtaining consent from the family was identified as the main ethical issue and information on brain death diagnosis, corpse's appearance and disfigurement were identified as deficient. It was found that other ethical issues may also influence this process, such as respect for the moment lived by family member, to his beliefs and values, as well as interviewer's reception and availability, in addition to the assurance that the family has chosen the most appropriate alternative for the situation. Therefore, one emphasizes the importance of health professionals trained to approach the family, aiming, thus, at greater acceptance and an assistance guided by ethics.

Key words: Organ transplant. Bioethics. Professional-family relations.



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Donation and transplantation is a complex process that begins with the identification and it passes through potential donor's evaluation and maintenance, brain death diagnosis, family approach, documentation of the brain death diagnosis, logistics process, removal of organs and tissues, distribution and, finally, the transplantation¹.

The technological progress, the improvement of surgical techniques, the development of immune-suppressive, and the understanding of compatibility and rejection have enabled the transformation of classification of transplant from experimental treatment to safe and effective therapy in the control of terminal shortcomings and failure of some organs' tissues².

However, the families' consent of patients considered potential donors is currently the greatest limitation in the success of transplantations in Brazil. It is, therefore, important to discuss, among other issues, the ethical aspects



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involved in familiar approach to the potential donor³. Under such assumptions, this article consists of a theoretical reflection that aims at identifying ethical issues that could influence family's consent rates in relation to organ donation.

General aspects on organs' donation and transplantation

The transplantation of human organs and, especially, organs' donation are controversial themes that have aroused interest and discussions. The lack of clarification by the population, the sensational news about trafficking of organs, the absence of effective programs aimed at the population's awareness and encouraging fundraising bodies contribute to the current situation of insufficient number of donors and significant loss of potential donors, prolonging the suffering of patients who depend on the donation⁴.

In addition to the lack of knowledge about the theme, organs' transplant is still a costly therapy and inaccessible to large portion of the Brazilian population. This causes legal, humanitarian, and cultural dilemmas that decisively influence the life of the receiver, the future of science based on advances in the attempts to discover several diseases' healing process and alternative treatment⁵. Regarding the type of transplantation, there is a series of classifications, including the allotransplantation, which consists of transplantation between different members of the same species; and the xenotransplantation, which is the transplantation between different species⁶.

Any patient whose treatment was evaluated as ineffective or brain death is imminent or has already occurred is a potential donor. However, it should be pointed out that the issue of donor corpse with brain death

causes many conflicts in human relationships between the donor's family, the professionals involved and the receiver³. It should be noted that, currently, the majority of organs for transplants come from donor cadavers and that with them it is impossible to supply the demand, given that the number of deceased patients with a brain death picture is greatly reduced⁵.

In Brazil, the legislation is clear and it requires family's consent in removing organs and tissues for transplantation, that is, donation happens only after legal guardian's authorization¹. Organs and tissues' transplantation is regulated by Law No. 9.434 of February 4, 1997⁷, which sets forth for the alleged donation, unless otherwise explicitly manifested; by Decree No. 2,268 of June 30, 1997⁸, and Ordinance No. 3,407, of August 5, 1998⁹, from the Ministry of Health (MOH). Subsequently, the federal Government issued provisional measure revoking the presumed donation. Thus, it was established that organ donation depends on the willingness of family members. The organ transplantation therapy can only be performed by hospitals and medical teams previously accredited by the Single Health System (SUS)¹⁰.

As described, although ruled and supported by advanced techniques already, organ and tissue transplantation between humans still finds strong limitations to its full success, and family refusal is one of the major barriers to its development⁴.

In view of such a framework, it becomes relevant to discuss issues targeted to the process of obtaining the consent of the potential donor's family, identifying ethical issues that permeate this process.

Process for obtaining the consent for organ donation

The consent has represented important progress in matters involving the respect to the autonomy of the person and in the relationships regarding clinical practices. Accordingly, its relevance has been uncontested; however, the controversy appears when looking at how to approach subjects to obtain it. Consent obtained bureaucratically, with signature and witnesses, becomes a mere administrative figure, losing its larger meaning and it can be viewed with suspicion, worsening rather than improving such relationships. Different is the consent (or even the refusal) that emerges from extensive and respectful analysis between the two parties¹¹.

Consent cannot be a cold document given to the subject to sign. It should be a set of clear and objective information, in a language that can be understood, thoroughly explained to the patient or family member¹¹. The exercise of the consent has as assumptions the junction of elements such as autonomy, ability, willingness, information and clarification. It should be stressed that, among these elements, information is one of the most

important and, therefore, it must be in clear and unambiguous language compatible with each subject's individual understanding¹².

Considering the context of organ donation in Brazil, it is worth mentioning that the family's refusal, or the family's non-consent, has been the main reason for not collecting organs from potential donors. Approximately, half of all families approached for donation in the United States said no. In Brazil, the refusal rate reaches 70% in less developed regions of the country¹³.

Our system of organ donation operates in an altruistic and voluntary basis, in which patients or their families can choose between donating or not organs after death. In contrast with the Brazilian system, several European countries deal with organ donations based on the principle of presumed consent, where any dead individual is considered as a potential donor, unless, in life, he has chosen not to be¹³.

Even in countries where applicable legislation of presumed consent or when the patient is a carrier of a donor's card, worldwide collecting teams seek the families' consent for the organs removal. In this perspective, it should be discussed which are the ethical aspects that permeate the consent practices for organ donation, considering that, in the Brazilian context, the family's inadequate approach echoes in increase of its refusal rate¹³.

Approaching the potential organs donor's family: ethical aspects

The family approach should be done by trained professionals: physicians, nurses, psychologists, or even social workers¹³.

A study pointed out social and cultural issues as determining factors for organ donations by the family, such as: ethnicity, religious beliefs, socioeconomic levels and information about organ donation and transplantations, knowledge of the dead donor status, family's prior experience with donation or transplantation, credibility in the transplantation and distribution of organs system, the level of satisfaction with medical care and understanding of brain death, conditions and the time of the family approach, interviewer's level of training, explanations about costs and the funeral, presumed consent legislation and educational campaigns¹³.

According to the *basic guidelines for collection and withdrawal of multiple organs* from the Brazilian Association of Organs Transplantation (ABTO)¹⁴, the success of family interview depends basically on three factors: predisposition to donation, the quality of hospital care received and interviewer's skill and knowledge. Additionally, we further emphasize that the conditions for the family involve broad understanding, by the interviewer, of the situation that the family experiences, when, at such difficult period as mourning, will have to decide on the donation of loved one's organs, knowing that it can mean a new life for another individual. Other important conditions

of the interview involve conversation with the doctor who cared for the patient, the identification of the best person to offer the donation option and, also, a calm and comfortable environment¹⁴.

Without any doubt, the decision is complex and delicate and if the entire staff is not trained, little can be done to collaborate with the family decision-making process regarding organ donation². The doubts of relatives are many and they influence expressively on the decision to donate. The disturbing thought about the future consequences of the decision, authorizing or not the removal of organs, persists in an unsettling way up to the moment of choosing. Whatever the option is, the interviewer's goal is the same: to relieve the emotional and physical suffering of all, by means of the certainty of having chosen the alternative they consider most appropriate².

The family must also know that the answer need not be given at the exact moment of the interview, that it can meet and discuss the matter in order to make the best decision. This decision should be respected, whatever it may be. It is not recommended trying to convince the relatives about the good of the donation or try to influence them with religious or moral arguments¹³. Exposing statistics does not represent any validity at that moment¹³. The interviewer should, in fact, explain that some bodies may not be donated and orient that the decision on

donation may be revoked at any time, even after the signing of the deed of consent, it is recorded that explaining specific points can be associated with higher consent rate, also related to the timing that the interviewer is with the family¹³.

The social base has great influence in reducing uncertainties. Everything is getting clearer while the family interacts with the environment, communicates with more confidence with health professionals, other family members and friends. These relationships help highlighting values, feelings, perceptions and to better understand the reality. The beliefs may differ between family members and also among this health professional team².

In a family system, what happens to the individual can be justified by influence/relationship with the other members of his family. This way, not only the patient considered as potential donor should receive attention: the family as a whole must be seen by the team of health care unit. This broader view of family's interactions and needs increases the chances that the family has a better understanding of the moment, feel more welcome and secure, favoring the professional -potential donor-family relationship and, consequently, the whole process².

Another important point that interferes with the decision is the obligation to decide on a subject, which the deceased family member may never have talked about

or which has never been addressed in the circle of family relationships. It is a subject that family members may have different opinions, since it is a moment when the grieving process has just begun. This difficulty is aggravated when the death has occurred and perceived as something uncertain by the family, considering that brain death barrier is misunderstood by the majority of population¹⁵.

Therefore, in order to have the consent it is important that any doubts related to the brain death diagnosis should be left in the family. Accordingly, it is emphasized once again that the interviewer needs to have the skills to communicate through accessible language, explaining a complex and technical subject with simple words and easy understanding¹⁶. An action that transplantation Protocol usually provides greater security and peace of mind for the family member making the decision and the knowledge that after acceptance of organ donation, his family member will be transferred to a hospital, whenever necessary, to conduct additional tests aiming at confirming brain death diagnosis¹⁵.

It is essential to highlight that dissatisfaction with the prior hospital care is among one of the frequent reasons for family refusal. The family becomes more flexible when believing that the loved one received humanized and worthy care during his stay in the hospital¹⁷. In view of the lack of clarification to relatives about the brain death concept has been one of the major ethical dilemmas, exerting influence on consent rates, it is worth

discussing about the concepts and definitions related to it.

Death and brain death: concept and definitions

Death is a biological event that ends a life, being able to raise intense emotional reactions in individuals that experience and in those who are around¹⁸. Dying is an inexorable process that exposes our human condition of vulnerability and it characterizes both what we have as universal and what is unique to us⁴.

Currently, death is faced as a socially constructed process that is not distinguished from other dimensions of the social relations universe. Therefore, it is present in our daily life and, regardless of its causes or ways, hospitals and healthcare institutions continue as its great stage¹⁸. So, death can be regarded still as something institutionalized and medicalized, especially nowadays, when hospitals have high-tech equipment which enable the maintenance of the patient's body, regardless of the life quality condition¹⁹.

In 1968, the concept of death won a new definition when the Harvard Medical School's Commission (Committee of the Harvard Medical School), later known as *Harvard Brain Death Committee*, published a report in the Journal of the American Association entitled "A definition for the irreversible coma". This report became the official document disseminating brain death criteria, adopted by most countries.

Large portion of criteria currently used for defining irreversible coma still are the same as defined by said Commission, differing primarily by observation and by whether or not subsidiary examinations of death brain barrier, as evidence described in paragraph below⁴.

In Brazil, the term brain death was officially accepted from the publication of the Federal Council of Medicine (CFM) Resolution No. 1,346/91, updated by Resolution No. 1,480/97, which proposes a mix of protocols, emphasizing as clinical criteria the non-perceptive and non-reactive deep coma, apnea, bilateral paralytic mydriasis and the absent oculomotor reflex. These parameters must be kept unchanged for more than six hours, in addition to the requirement of confirmatory testing. Only then, the individual can be considered as a potential donor of organs and tissues⁴.

According to this resolution, the potential donor must be subjected to a clinical assessment and an additional examination by two physicians not participating in the transplantation teams and, at least, one of them should be a neurologist, neurosurgeon or pediatric neurologists duly accredited specialist¹⁰. Therefore, brain death can be characterized by permanent and irreversible loss of functions of the brain (cerebral hemispheres and brainstem),

of known cause and determined unequivocally, and the specificity of diagnosis shall be 100%¹⁰.

An important aspect to be considered in the definition of death is the various nuances that involve the whole process of dying. It is fact that family members and laymen question the criteria for the definition of brain death. Although it is characterized as clinical death, to the family it is only evidenced by cardiopulmonary arrest. Individual brain death does not cause individuals to see it like death, because the heart keeps beating and gives the impression that the individual is just sleeping. Unfortunately, this situation makes it difficult to distinguish between life and death and it causes intense excitement and anxiety for the family¹⁷.

In this sense, the brain death concept also refers to biological and psychic death of human beings; however, the physiological (function of organic systems) is still maintained until the time of organs removal. Note also that sociological death is the separation of important figures of his life, and can only be determined by the family³. According to the *basic guidelines for collection and withdrawal of multiple organs and tissues* from ABTO¹⁴, it can also be considered a potential donor, the individual with a recent cardiorespiratory arrest (up 6 hours), in which organs removal is possible, especially the kidneys.

If there is a major evolution of the transplantation team in implementing this practice, maybe the donor family's distress can decrease and the number of donations can expand in order to ease the long transplantation queue¹⁴.

Anyway, still today the death and the dying are seen and reflected in different ways, depending on the culture in which the individual is inserted. At the time of collection, the potential donor's family is weak due to the loss of its loved one and this situation may even deteriorate if its grief is not respected and the fact of having to decide, at that moment, for the other about organ donation³.

A study performed in an intensive care unit (ICU) revealed that patients with brain death may receive less care, as they are viewed as a whole, the care being directed only to the maintenance of functions that classify him as a potential donor. The study highlights the following question: the precarious maintenance of the patient with brain-dead hospitalized as potential donor can be the second cause of non-occurrence of organs and tissues donation in Brazil. This is due, probably, to the disproportion between the technological development in the maintenance of the body and the preparation of professional staff in family approaching²⁰.

It is estimated that, in general, up to 100 patients per year in each million inhabitants present brain death diagnosis,

as a consequence of accidents and intracerebral hemorrhage, evidencing the existence of significant number of potential donors of organs compared to a real number of donors in Brazil²¹.

With this scenario, it is clear that the advent of new technologies in the area of health, mainly those for sustaining life, can be confrontational, since that characterizes the living face of multiple concepts of death. By conception of death and dying, a patient with brain death diagnosis still has his organs alive and he would be, therefore, a being who contains elements that are alive. At the same time, however, would also have elements that determine his death, from the medical concept of brain death barrier. This ambiguity creates, in large part of the time, sharp discomfort on the part of relatives in opting for loved one's organs removal that still contains, somehow, the vitality of the organs²².

Based on the foregoing with relation to the delicate situation of the family approach, it is highlighted the reason for the insistent affirmation that it is essential that the potential donor's family is approached by trained professionals in a quiet environment, with appropriate accommodations to all family and friends who want to participate¹³.

Final considerations

Rescuing the essence of the content presented to the construction of this article, one may say that beyond an isolated

action, the desired rate increase in the number of transplantations depends on concerted efforts by health professionals directly involved in the process, on the family wanting to practice the good action, on the Government that seeks an advanced assistance and, finally, the media responsible for the mass dissemination of information. The increase in the number of organ donors in Brazil depends mainly on the quality of information provided to the population.

Appropriate communication in health can be considered a fundamental point to be thoroughly worked for the effectiveness of the family approach and the consequent increase in the number of organ donors. This practice may entail, when performed in order to enlighten and empower the potential donor's family, the respect to donor's autonomy, the understanding that the family should be considered as the primary expert of his wishes.

This article has identified as a major ethical issue in approaching potential organ donor's family, the shortage of explanations during the process of obtaining consent, identifying information about brain death diagnosis and the appearance and the defacement of the body as deficient. It was also found that other ethical aspects can influence this process, such as respect for the moment that the family experiences, its beliefs and values,

interviewer's hospitality and willingness and the assurance that the family has chosen the alternative that best suited to his situation.

Therefore, it should be emphasized the importance that this process be carried out by qualified health professional, aiming at, with this, a greater acceptance and an ethics based approach. Additionally, the health professional must be endowed with all the skills that make him capable to clarify any doubts of the family in aspects related to the collection, brain death brain process and technologies involved. Without forgetting, of course, its preparation for dealing with the social, emotional and moral issues surrounding the family.

Thus, it is also emphasized the importance of training programs focused on the therapeutic relationship and the behavioral approach, in which the professional can better know his values about life and death, learn to accept patients and their families' values, and been able, from his own emotional structuring, to provide quality assistance.

It is also suggested the intensification of information dissemination regarding the collection and transplantation of organs process, and the importance of the subjects declaring themselves donors to their families, through the media.

Resumo Este artigo consiste em reflexão teórica que pretende identificar questões éticas que poderiam influenciar nas taxas de consentimento de familiares em relação a doação de órgãos. Identificou-se como principal questão ética a falta de esclarecimentos durante o processo de obtenção do consentimento junto ao familiar, sendo identificadas como deficientes as informações acerca do diagnóstico de morte encefálica, a aparência e a desfiguração do corpo. Também se constatou que outros aspectos éticos podem influenciar neste processo, tais como o respeito ao momento que o familiar vivencia, as suas crenças e valores, bem como o acolhimento e a disponibilidade por parte do entrevistador e a garantia de que o familiar tenha escolhido a alternativa mais adequada para a situação. Portanto, ressalta-se a importância de profissionais de saúde capacitados para a abordagem ao familiar, visando, com isto, maior aceitação e uma assistência pautada na ética.

Palavras-chave: Transplante de órgãos. Bioética. Relações profissional-família.

Resumen

Bioética y donación de órganos en el Brasil: enfoque ético a la familia del posible donante

Este artículo es una reflexión teórica que trata de identificar las cuestiones éticas que podrían influir en las tasas de consentimiento de la familia respecto a la donación de órganos. Se identifica como la principal cuestión ética la falta de esclarecimiento en el proceso de obtención del consentimiento de la familia y se identifican como deficientes las informaciones sobre el diagnóstico de muerte cerebral, la apariencia y la desfiguración del cuerpo. También se encontró que otras cuestiones éticas también pueden influir en este proceso, tales como el respeto al momento que está viviendo la familia, sus creencias y valores, así como la acogida y el hecho de que el entrevistador esté disponible y la garantía de que el familiar haya escogido la alternativa más adecuada para la situación. Por lo tanto, debe hacerse hincapié en la importancia de los profesionales de salud capacitados para el acercamiento a la familia, visando así una mayor aceptación y una asistencia pautada en la ética.

Palabras-clave: Trasplante de órganos. Bioética. Relaciones profesional-familia.

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Participation of the authors in the article

Alba Ottoni wrote and discussed the topic *General Aspects on organ transplantation*. Vanessa Cortes wrote and discussed *Death and brain death: concepts and definition* and Juliana Pessalacia the topic *Process for obtaining the consent on the donation of organs*. The topic *Approach to the family of a potential donor: ethical aspects* was written and discussed by the three authors.