Revision Article

Organ and tissues donation: relation with the body in our society

Doação de órgãos e tecidos: relação com o corpo em nossa sociedade

Donación de órganos y tejidos: relación con el cuerpo en nuestra sociedad

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ABSTRACT

This is a study of literature review aimed to develop theoretical considerations on the donation of organs and tissues and on its relationship with the human body, in our society. Increasing donation rates depends on a perspective that goes beyond the technical issues of the process of donating organs and tissues. Several countries, with large time frame experience, working systematically in this process with an approach that incorporates social and ethical aspects, based on volunteers, and respecting the families right to autonomy of potential donors. Accompanying the body, after donation, usually requested by the family, represents the beginning of mourning for the death of a relative, which is part of the funeral ritual in the culture of our society. The actions to ensure an ethical-legal sequence, defined by the law of transplants, imply a commitment to quality and safety of the process of organ and tissue donation, which must be strictly followed by professionals working in this area. Thus, it is hoped that these attitudes can build a positive culture on the donation in the country, contributing in the long run to increase donation rates.
Keywords: Directed tissue donation/ethics; Organ transplantation; Bioethics; Family

RESUMO

Este estudo, de revisão bibliográfica, objetivou tecer considerações teóricas sobre doação de órgãos e tecidos e sua relação com o corpo em nossa sociedade. O aumento da taxa de doação depende de um olhar ampliado além das questões técnicas do processo de doação de órgãos e tecidos. Vários países, com larga experiência temporal e, que trabalham sistematicamente nesse processo, incorporaram a abordagem social e a perspectiva ética, baseadas no voluntarismo das famílias e no respeito ao direito de autonomia dos potenciais doadores. O acompanhamento do corpo, pós-doação, solicitado pelas famílias, representa o início do luto pela morte de um parente, parte da prática de ritual fúnebre cultuada em nossa sociedade. As ações que asseguram uma sequência ético-legal, definida na legislação dos transplantes, pressupõem compromisso com a qualidade e segurança do processo de doação de órgãos e tecidos, que deve ser rigorosamente perseguida pelos profissionais que trabalham na área. Espera-se, assim, que essas atitudes construam uma cultura positiva sobre a doação no país, contribuindo, a longo prazo, para o aumento nas taxas de doação.
Descritores: Doação dirigida de tecido/ética; Transplante de órgãos; Bioética; Família

RESUMEN

Se trata de un estudio de revisión de literatura dirigida a elaborar consideraciones teóricas sobre la donación de órganos y tejidos y su relación con el cuerpo en nuestra sociedad. El aumento de la tasa de donación depende de una visión que va más allá de las cuestiones técnicas en el proceso de la donación de órganos y tejidos. Varios países con gran tiempo de experiencia, trabajando sistemáticamente en este proceso con un enfoque que incorpora el punto de vista social y ético, basado en voluntarios y respetando en las familias el derecho a la autonomía de los posibles donantes. El acompañamiento del cuerpo, después de la donación, generalmente solicitado por la familia, representa el comienzo del luto por la muerte de un pariente, lo que hace parte del rito funerario en la cultura de nuestra sociedad. Las acciones que aseguren una secuencia ética-legal definida por la legislación de trasplantes, presuponen un compromiso con la calidad y seguridad del proceso de la donación de órganos y tejidos, que debe ser rigurosamente seguida por los profesionales que trabajan en esta área. Así, se espera que esas actitudes puedan construir una cultura positiva en materia de donaciones, en el país, contribuyendo en el largo plazo al aumento de las tasas de donación.
Descriptores: Donación directa de tejido/ética; Trasplante de órganos; Bioética; Família

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INTRODUCTION

In 2008, according to the *Registro Brasileiro de Transplantes* (Brazilian Record of Transplants), the number of patents waiting for kidney, liver, heart and lung transplants in Brazil was 34,789; 6,505; 381 and 158, respectively; and the number of transplants of such organs, performed between January and December of the same year, was 3,780; 1,174; 200 and 53, respectively. Although there has been a significant increase of 15% in donations, in the last year, the rate of 7.2 donors per million people (pmp) obtained only returned to the levels achieved in 2004 (7.3 donors/pmp). Family refusal to donate organs continue to be one of the determinant factors for low numbers of donations and, as a result, of organ transplants all over Brazil[1].

The insufficient number of organ donations has been traditionally associated with the lack of public awareness of the need for organ transplants and the lack of opportunities for donation. Such reasons influence the lack of public understanding and willingness to donate organs. Strategies to improve organ donation, including the need for legislation, public information, campaigns and recording of potential organ donors in official documents (driver's license and identity card), have failed, because they have caused the difference between the number of donors and that of individuals waiting for transplants to become significant[2].

The question of organ transplants certainly has characteristics that make it different from any other health issue. First, it is not restricted to the relationship between the health team and patient. Its continuance depends on a third aspect, the organ donor. In this way, although transplants are based on technically advanced procedures, they cannot occur without an organ donor. It is important to emphasize the many socio-cultural changes that are necessary to enable public understanding and acceptance of organ donation and transplant.

Organ and tissue donation for transplants is directly associated with moral, ethical and religious values, because they cause individuals to think about the notion of life being finite and the relationship with the body after death.

OBJECTIVE AND METHODOLOGY

In view of what has been exposed, the present study aimed to associate theoretical considerations about organ and tissue donation with the relationship with the body in Brazilian society, after a narrative review of the literature, considering articles and documents published after the second half of the 1990s.

The search in the literature was performed in electronic databases, using the following key words: organ and tissue donation, donors' family/family members, meaning of death, transplant and bioethics.

TISSUE AND ORGAN DONATION AND THE RELATIONSHIP WITH THE BODY IN BRAZILIAN SOCIETY

Historically, in the 1990s, studies with families of donors of deceased individuals began to be performed, creating a new context of its meaning and requiring national and international governments to change their legislations to promote and prioritize, from the beginning of the 21st century, the service and support needed by these families. Sudden death, as a result of severe and acute brain injuries, is the precursor of multiple organ donation; thus, families who experience this situation were the first ones to have real contact with brain death[3-4].

Respect for a dead body is a characteristic of all religious belief systems and secular moral codes. The body represents the memory of a former life that should be guarded as close as possible to the loved person. To lose respect for the body of a dead human being means to disrespect this person, family members and human beings in general[5]. There are no religions that formally prohibit the donation or the receiving of organs, or that are against the transplant of such from life or dead donors[6].

On the other hand, human beings are the only species that manifests moral respect for the dead in a systematic way, and the only one that gives meaning to death. Thus, in the majority of religions, the meaning of death is associated with the notions of an afterlife or some type of continuity of existence. Regardless of the meaning given to death, this has been accepted as an empirical question, not requiring an accurate definition or subsequent improvements. However, technological intervention in the death process has required a philosophical, ethical and clinically applicable condition, a secular equivalent to religious concepts that were often defined according to the soul leaving the body or the breath of life being lost[5].

Following the body after donation, as requested by families, is the beginning of the mourning for the death of a deceased relative. Consequently, this follow-up must be provided until the body is returned, as part of the funeral ritual performed in Brazilian society. To achieve this, families need to have the possibility of keeping vigil by the bodies of relatives, not regretting the donation subsequently. Otherwise, this corroborates the socially negative image of organ donation, constructed from experiences that are harmful to society.

In addition, since October 2007, the suspension of therapeutic support procedures has been legal and ethical, when brain death is confirmed in non-donors of organs, tissues and human body parts for the purpose of transplants. Therefore, the fulfillment of this decision must be preceded by communication and clarification

about brain death to the patient's family members or their legal representative, founded on and recorded in a medical chart, under the responsibility of a doctor[7].

However, the difficulty that permeates this activity, in terms of the moment when professionals do not feel comfortable about turning off life-support machines or when they refuse to do so, even at the family's request, when their decision, upon learning about their family member's brain death, is not to donate his organs or tissues. Such question casts doubts on the diagnosis of brain death and the relationship between society and body, maintaining the culture of non-acceptance of irreversibility of brain functions as the cause of death of an individual, thus aggravating the relationship of trust established between health professionals and the public. These are examples of how far we have advanced technically, yet not morally, from a society that has kept science apart for a long time and now attempts to bring back the philosophical reason, which, at the same time, prevents us from advancing further.

Another example refers to the request of families seeking support from the institution during the entire donation process, expecting information and authorization of visits to the donor before, during and after removal of organs[3,8]. It is in this context that organ donation and transplant occur. Thus, it is not surprising that this involves feelings which aggravate the pain or suffering[9] of these families for the loss of their loved one, increasing disintegration of the family unit[3].

By imagining that death has diverse meanings to different individuals, authors in this study thought about the moral difficulties regarding the decision about the donation and what the impact would be on the routine of families who decide in favor of donating their loved ones' organs. In this context, death presents another possibility that, until then, had not been common in our society, representing a new paradigm of the value of the body after death. This is because, through a donation, it is possible to save or increase survival of ill individuals with organ failures.

For this reason, studies recommend individualized follow-up of donors' family members, offering them a relationship of consistent support, in the sense of meeting their needs at a moment of mourning and loss[4,10]. However, professionals involved in providing care to each patient and their families can also feel discomfort and fears and distance themselves from the donation process, not to suffer with such experiences[3].

This process is also full of meanings to health professionals, given their personal and/or religious beliefs. In this way, those who intend to provide safety during the process of organ and tissue donation need to identify the problems that hinder this. In addition, the act of taking a family member's body away, without an expected time to return it to the family during the donation process and the difficulties to visit it in this period, deeply change the religious rituals and habits performed when saying good-bye to this family member[4,11].

Part of the process of suffering of relatives of a deceased person involves the willingness to donate body parts after death. The funeral ritual expresses the loss and respect for the dead one. This suffering can be exacerbated by procedures of organ removal[9]. This may explain the high frequency of donation of organs, when compared to that of tissues, due to the fear of the organ removal surgery disfiguring the body, when family members are neither adequately informed about the procedure, nor sufficiently supported during the process.

Analysis of use and donation of organs in the United States showed that a number of organs procured are influenced by the families' conditioned consent to certain organs being donated, expressed by emotional, cultural or religious reasons, or yet due to a family conflict[12]. Problems that hinder organ donation and the practice of transplants are still classified as being of a clinical-biological, logistical-administrative, geographic, cultural and moral nature[13].

A phenomenological study on the relatives of organ donors' perspective on the experience of consenting to a donation for a transplant revealed an association between successful experience of donation, in the family's view, and situations where family members of donors could make the conscious choice of donation, always expressed by the donor, while alive. The study concluded that the support and guidance provided to relatives by professionals and the institution involved in the procurement process appear as key aspects for these relatives to assess the experience of donation as positive[4].

The beliefs and feelings of each family member towards donation appear as a central issue. Sometimes, the decision causes conflicts in the family nucleus that will be overcome or not, according to the dynamics of such nucleus. Families' limited knowledge about brain death appears as a hindering factor. Initially, there is the decision-making process and, subsequently, the experience of living with the decision about donation[4,14-15].

Apart from the family being unaware of organ donation, authors in this study also realized they did not know its impact on family relations, this being a challenge to health professionals, policy makers and society itself. Although donation is a morally good and altruistic social conduct, i.e. "to do good", it could be inferred that this has not been incorporated into the common morals for several reasons. Among these, the following should be emphasized: distrust in the health care system functioning and structure, resource allocation, the relationship of trust between the health professional and patient, equal and fair access; the donor/receptor confidentiality; free

informed consent; respect for autonomy; defense of life and the innovative and recent character of this therapeutic possibility, still under construction.

Thus, this is an ethical debate, which forms the basis for a correct and fair conduct, supported on the responsibility of one's acts, such as not killing. The simple application of different principles of autonomy, beneficence, non-malevolence and justice to determine when a principle is justified to be prioritized over others does not help to clarify moral issues, such as the equal distribution of organs due to the low availability of donors, psychological and philosophical problems to identify donors, the definition of death and protection of donors' autonomy, in view of the informed consent form (particularly in the case of live donors)[16].

In this context, health professionals need to understand human behavior to be able to "do good". However contradictory the situations of sadness and happiness for the death and, at the same time,

for the possibility of treatment of another may be, the presence of a technically and psychologically qualified professional is required to adequately care for these families. Another factor refers to the needs for information and emotional support of families, in the critical stage of hospitalization of their family member; in addition to the possibility of frequent visits to the intensive care units and consent for donation. Such conducts must be permeated by a consensus of opinion between the family and the wish expressed by the deceased family member while alive[8].

In 1995, an Australian study evidenced that the most important aspects associated with the donation process, causing less stress to families, were related to knowledge about their relative's wish and the opportunity to see the body, after the donation in intensive care units, to enable the beginning of the mourning process[17].

In Brazil, a study revealed that the situation experienced by family members of seven deceased organ donors was permeated by suffering and stress, including reports of regret for the donation. Although the pain of loss continues, the attitude of donation comforts and brings satisfaction[18]. This corroborates the idea that there are two values to be preserved, the life and dignity of the deceased donor, because this continues to represent the quality of the person to which it belonged[19]. In addition, there is a tendency of relatives consenting to a donation, when they are well informed about the concept of brain death and the humanistic purpose of donating[20-22].

In another study using logistic regression, authors in this study found the confirmation that socio-demographic variables could interfere with a new donation; this is due to the fact that individuals earning between four and six minimum wages are approximately 7.25 times more likely to donate their cornea again than those with an income of up to three minimum wages[23].

Brazil has a high level of illiteracy, in addition to a number of semi-literate individuals, thus compromising their autonomy, once the absence of necessary and indispensable information limits their free decision about their destinies[24]. Lack of information or inadequate information combined to a low level of education of family members could produce unreal interpretations about how the body will be returned, as well as the equal distribution of organs. Naturally, these interpretations could cause discomfort or regret for the decision of donating their relatives' organs and tissues.

On the other hand, the lack of organs is often attributed to the population not being aware of the structural problems of the health system in the process of organ procurement. The family's refusal to consent to organ donation is mentioned as the main difficulty for the practice of transplants[20,25]. In addition, these regrets can spread like indirect and silent campaigns against donation.

According to bioethical principles, questions such as the lack of information obviously do not guarantee an autonomous, and much less fair, decision, due to the vulnerability of those involved. The exercise of autonomy is only possible when knowledge and information are shared between the health team and the patient, providing important data in an accessible language, so that any decisions can be made, guaranteeing the competence of all members involved in the situation[26].

In this way, organ and tissue donation should only occur when an individual's right to informed consent and the donor's or their relatives' autonomy are respected. Health professionals' respect for the autonomy of individuals was an important socio-cultural victory for Bioethics. An example was the encouragement to change the term cadaveric donor to the current deceased or dead donor, as recommended by the World Health Organization (WHO) 1987, 1989 and 1990 World Health Assemblies[27].

Another study, performed in nine hospitals of the states of Pennsylvania and Ohio, concluded that there are no magic formulas to improve the rates of organ donations, although there are a number of factors that influence family consent. As an example, families who were aware of the patients' wishes were seven times more in favor of donation[15].

In Europe, there was a study to assess predictive factors of donation rates per million inhabitants. Among the factors that had a positive influence on the prediction of donors, the following stood out: the infrastructure of the health system, the high level of education of citizens and the type of donation defined by the legislation of each country[28].

It could be suggested that, in the modern capitalist model, the concept of donation should be updated to

"an act of solidarity of the potential donor, expressed in life and confirmed by their family, after their death". This is because the concept of altruism cannot be generalized to all families who perform the act of donation, being aware that this doctrine, which considers another individual's interest as the purpose of a human life, can be summarized in the following statements: "live for others" or "love others more than you love yourself"[29-30].

A recent study on incentives for organ donation shows that the only ones who do not benefit from a transplant are the donor's family. Thus, a financial incentive would make the process more equal[31]. Among those who oppose this argument, considered to be unethical, are health professionals, who do not wish to be in the position of offering an incentive to families, because this would affect the relationship of trust established, discouraging them from donating. For these, a direct (monetary) incentive would seem like bribery, whereas an indirect (non-monetary, such as the *auxílio-funerário*/funeral-support) seems like a reward from society for the act of donation[31]. This has been an important debate at the main congresses on transplants, in view of the lack of organ donors in the world and the growing need of patients waiting for a transplant.

In addition, authors in this study realized that the increase in the rate of donors depends on a perspective that goes beyond the technical issues involved in the organ and tissue donation process. Several countries have worked systematically in this process for a long time, incorporating the social approach and the ethical perspective, based on families' volunteering and respect for the potential donors' right to autonomy[23,32].

This needs to be integrated into the view of those who dream about this process assuring that just and helpful work will be developed for the community[23]. In addition to the Brazilian health context being prioritized, one of the commitments that should be expected from the government is the establishment of adequate legislation, followed by relevant health infrastructure that stimulates and facilitates the control of a complete and new *Sistema Nacional de Transplante* (Brazilian Transplant System)[33].

Thus, the major challenge for professionals who work with organ and tissue procurement is to have ethical competence to guarantee permanent improvement of this process, with an emphasis on adequate communication between the team and family members, apart from investing in work processes which identify routine questions that cause the service provided to be impersonal and rude. Finally, organ and tissue donation campaigns should include relatives of deceased donors and their experiences.

FINAL CONSIDERATIONS

Improvement actions, guaranteeing the ethical-legal sequence already established by law, legislation and decree on transplants, presuppose the commitment to the quality and safety of the organ and tissue donation process, which should be rigorously pursued by professionals who work in this area.

It is hoped that these attitudes create a positive culture of donation in Brazil, contributing to an increase in donation rates in the long term. This is, in fact, the permanent organ and tissue donation campaign which can be performed.

In conclusion, the perspectives of a promising future will depend not only on the regulations that may be established by governments of different countries, but especially on the political will to enable these systems to function.

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