



Family, Patients, and Organ and Tissue Donation: Who Decides?

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ABSTRACT

Objective. To identify who is responsible for the decision to donate organs and tissues from a deceased donor.

Methods. This cross-sectional study was performed with 69 family members of deceased donors, identified by the Organ Procurement Organization.

Results. The decision of the family regarding the request for donation took place after they had enough time to reflect on the matter (81.8%). The decision was made by the family (43.5%), by both family and donor (76.8%), by the family with previous knowledge about their deceased relative's wish (63.2%), or only by the donor (11.6%). There was familial conflict after the decision in about 7.2% of donations; 63.2% of the families were aware of their deceased relative's wish, and 90.5% were aware that their relative's wish helped them make the decision. Women were most frequently responsible for the decision to donate (55%).

Conclusion. The donation process is experienced by all the family, regardless of who signs the consent form. At times, it is precisely the discussion about what is conflicting that will enable the familial decision. The donor's autonomy alone was shown to be a poor indicator, as the ones who decide about the donation are the family. This, therefore, legitimizes the alteration made to Law No. 9,434/97, which gives family members the responsibility for the decision about organ and tissue donation from their deceased relatives.

IN THE 1960s, with the advent of transplantation, questions concerning the limitations of life maintained by life-support machines arose. The criterion of death exclusively being cardiorespiratory arrest evolved to include death by encephalic criteria. As a result, life and death matters involve several characters: the patients, the family, and the health care staff, in addition to the health institution. In a symmetrical relation, any decision involves all these characters, with the pros and cons of each option.

Death is evidently the object of studies and investigations in other areas of scientific knowledge. In the biological field, it is the antithesis of life, whereas in the philosophical-dialectic field, it is the antithesis of birth.¹ Thus, death is not seen as part of the life process, so, when one falls ill, treatments must be aimed at the quality of one's life and well-being, even when a cure cannot be achieved.² The legal regulations concerning the diagnosis of brain death (BD) through the Federal Council of Medicine³ only occurred in Brazil in 1991. BD is defined as an irreversible situation of respiratory and circulatory functions or the irreversible

cessation of all brain functions, including the brain stem.⁴ Consequently, the potential organ and tissue donor could be defined as a patient who was given a BD diagnosis.

During almost 30 years from 1968 to 1997, a period known as "heroic and romantic," the activity of transplantation was little regulated and developed on an informal basis in terms of recipient application, transplant allocation, organ removal, and distribution criteria.⁵ Since 2001, after changes in the legislation, donation from deceased individuals after BD diagnosis has depended on family consent, whether or not representing the donor's wishes.⁶

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Organ and tissue transplantation is a safe and efficient therapeutic alternative in the treatment of several diseases, yielding improvements in life quality and perspective.⁷

In recent years, the predominant moral principles in Brazilian society have been revealed to be possessive, relentlessly competitive, "profit-above-all" to the detriment of being and sharing, resulting in a collective supposition that is not favorable to organ donation.⁸

The progress achieved by biology has been so extraordinary that it caused transformations in humanity's way of living and dying itself.⁹ Even though donation represents a moral good, altruistic social conduct, one may infer that it has not been incorporated into morals due to several reasons, such as the discredit regarding the workings and structure of the health care system, fund allocation, relation of trust between health care professional and patient, equal and just access, donor/receiver confidentiality, clarified free consent, respect for autonomy, protection of life, and the recent, innovative character of this therapeutic possibility, still under development.

Sudden death resulting from severe and acute brain aggravations is the precursor of multiple organ donation. Thus, families that are going through this situation constitute the first real contact with BD. However, there is no preparation to experience sudden death that can maintain the integrity of the familial unit.^{10,11} Organ donation and transplantation take place in this context, so it is no surprise they involve feelings that deepen the suffering and pain¹² of families, worsening family unit disintegration.¹⁰ It can be realized, therefore, that organ donation is a complex, multifactorial matter that not only has an impact on the donor, but also on their family, on the recipients family, and on society as a whole.

Even with such legal support, organ and tissue donation in Brazil still shows a low donors rate when compared with other locations in the world. In Europe, for instance, there are about 40 donors per million inhabitants (pmi), whereas in Brazil there are about five pmi.¹³

The recent publication in the Brazilian Registry of Transplants points to a decreasing or, at best, stagnating tendency in the rate of effective donors. There were 532 donors in 2006, which corresponded to 5.8 pmi per years; in 2004, this rate was 7.4 pmi, and in 2005, 6.3 pmi.¹⁴

Thus, the individual decision about organ and tissue donation is everyone's right, after informed consent, respecting individual rights, as well as the benefit to the recipient, who is awaiting on a list, as well as to society, which greatly profits from this altruistic action.¹⁵

MATERIALS AND METHODS

This descriptive, exploratory study was conducted among families of organ and tissue donors at 2 years after donation, using information from the *Organização de Procura de Órgãos da Escola Paulista de Medicina-OPO-EPM* (Organ Procurement Organization) between the years of 2000 and 2001. In 2000, 327 notifications occurred (0.91 notifications/d), among which 66 donations were effected: 10.5 donors pmi/y. Then, in 2001, 354 notifications

occurred (0.98 notifications/d), among which 73 were effected (11.6 donors pmi/y), totaling 139 donations. Letters were sent to family members to locate relatives of the deceased donors, including a phone number to contact the hospital that provided the BD diagnosis. This study was submitted to the Research and Ethics Committee, approved under protocol No. 1217/02.

Thus, menses the sample of 69 (49.6%) among the 78 family members located from 139 donations from this particular period. Only two families refused to participate in the study due to a belief in organ commerce.

Family members who agreed to participate received a questionnaire sent by mail with 33 closed questions and three open-ended questions about the donation process. Only seven families did not return the survey instrument.

RESULTS

The majority of donors had experienced cerebrovascular accidents as the cause of death (60%), among which was a higher percentage of women (56.1% against 43.9%), as well as neoplasms, which were also more common among women (3:1). Among men, deaths resulted from external causes: homicides, traffic accidents, and cranioencephalic trauma due to a fall.

Among the family members who participated in the study, 55% were men (38) and 45% women (31). These family included 46% (29) relatives, including siblings, grandparents, uncles, aunts, and cousins, whereas 3% (21) were mothers and fathers of donors, and 20.6% (13), spouses.

A total of 39.7% (27) of family members had an elementary school level of education, followed by those who had a university level with 29.4% (20), and high school level with 27.9% (19), whereas 2.9% (2) had no formal education. This variable correlated with the intention to agree to their own donation ($P < .004$).

The decision of family members concerning the request for donation in the present study demonstrated that the great majority thought that they had sufficient time to reflect on this choice ($P = .550$, 81.8% against 18.2%).

Regarding the decision for donation, it was observed that 76.8% (53) of family members were the ones responsible for the donation ($P = .117$), including 33.3% (23) of both family and donor. In 11.6% (8) of cases, it represented the donor's wish and in 7.2% (5), it was the family's wish, even though it was not specified whose decision it was, except for the fact that it caused familial conflict. Finally 4.3% (3) respected the donor's wish, even though this caused conflict among family members (Fig 1).

Figure 2 shows that 63.2% (43) of family members were aware of their relative's previous wish to donate organs and tissues after death, whereas 36.8% (25) did not know their relative would like to be a donor ($P = .749$). This study showed that 90.5% (38) of family members declared that they had previous knowledge about their relative's wish to be an organ and tissue donor after their death. This information was instrumental when making a decision about donation, whereas 9.5% (4) did not believe that previous knowledge was useful (Fig 3).

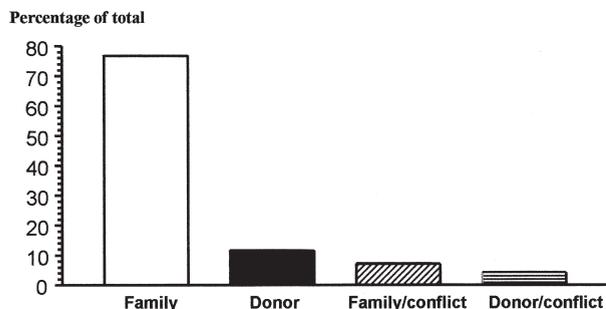


Fig 1. Distribution of family members of deceased donors, according to responsibility for decision about donation of organs and tissues. City of São Paulo, Brazil.

DISCUSSION

The fact that Brazil has a high level of illiteracy, in addition to a contingent of semiliterate people, compromises autonomy, that is, people deciding their own future freely, due to a lack of indispensable and necessary information.⁹

According to the principles of bioethics, questions such as the lack of information do not naturally guarantee an autonomous decision; on the contrary, it results in a much less fair decision, caused by the vulnerability of the subjects.

An exercise of autonomy can only exist when knowledge and information from the health care staff to the patient are shared, offering important data, in accessible language, for any decisions to be made, guaranteeing power to all members of the family involved in this situation.¹⁶

Thus, organ and tissue donation should only occur when there is respect for people’s right to informed consent and donor or family autonomy. Organ and tissue donation is a public asset that requires sacrifices from those who are alive and manipulation and removal of organs from deceased donors—at present not harming life at all, though this should not cause one to lose respect for the donor’s body

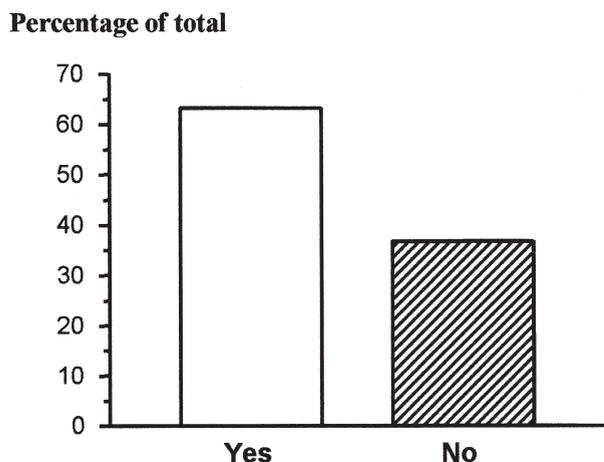


Fig 2. Distribution of family members of deceased donors, according to previous knowledge about relative’s wish to be an organ and tissue donor. City of São Paulo, Brazil.

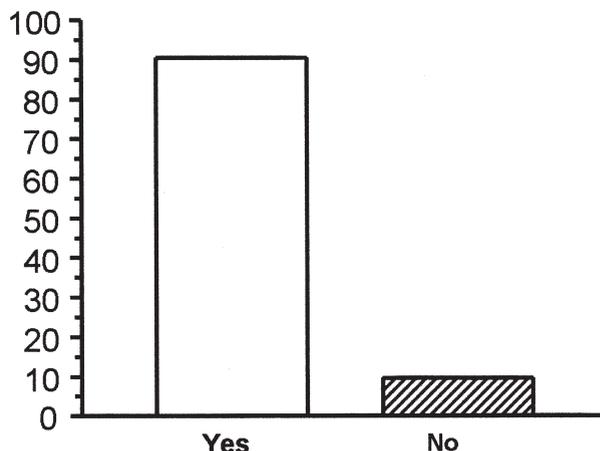


Fig 3. Distribution of family members of deceased donors, according to influence of previous knowledge about relative’s wish to be an organ and tissue donor on the decision for donation. City of São Paulo, Brazil.

and for the values expressed by the families connected to the deceased through a life-sharing bond.¹⁷

Individuals who have their autonomy diminished are controlled by others or are incapable of deliberating or acting according to their wishes and plans.¹⁸ For some, the interests of the living surpass those of the dead. At this moment, regardless of the paradigm, there is a consensus on the existence of vulnerability, as an individual does not have the possibility to defend his or her own wishes; instead, others make this decision.

According to the report on the *I Reunião de Diretrizes Básicas para Captação e Retirada de Múltiplos Órgãos e Tecidos da ABTO* (first Meeting on Basic Guidelines for Procurement and Removal of Multiple Organs and Tissues at the ABTO) in 2003, the success of the family interview depends on willingness to donate, quality of hospital service offered, and interviewer’s ability and knowledge.⁷ In the present study it was observed by means of statistical analysis that family members who were satisfied with the family interview showed a 9.53 times greater chance to donate again, compared with individuals who were dissatisfied. Furthermore, by analyzing correspondence about the intention for a new donation, the variable “to have enough time to reflect” was approached.

The teams responsible for the family interview must have technical and ethical competence to deal with moral issues involved in the donation process. It is possible to affirm that organ and tissue procurement services must also be responsible for the mourning process of family members, which begins at the postinterview welcome and ends with the accompanied return of the donor’s body to the Death Verification Services or at the Forensic Medicine Institute. In practice, the donation is experienced by all family members, regardless of who signs the donation terms. At times, it is precisely the discussion over what is conflicting that enables the family decision, as shown by the results,

where 46.0% of family members other than the mother, father, or spouse were responsible for the decision.

In the present study, the donor's autonomy alone was a poor indicator, as it was the family's decision. Thus, legitimizing the alteration made to Law No. 9434/97 from 2001, which returns the responsibility for the decision about donating the organs and tissues of the deceased to their family members.

A recent study performed by Sheehy et al reviewing records of 36 American organ procurement organizations showed that 54% of decisions about donations were made by the family, regardless of the donor's wishes.¹⁹ The responsibility for the decision about donation has a decisive influence on new donations. The statistical analysis showed that the decision of the family or of the family in conflict was the variable that was closest to a favorable response. Unemployment had a relation to the response "would not donate again," just as did the fact that the family member was a woman.

In conclusion, in the analysis of multiple correspondence, the variables that were closest to family members being willing to donate again were the following: The decision to donate coming from the family (43.5%), even among family members who were conflicted (7.2%), and to have sufficient time to reflect.

The donation is experienced by all family members, regardless of who signs the consent form. At times, it is precisely the discussion over what is conflicted that enables the familial decision. The donor's autonomy alone showed a poor indicator, because it was the family who decided. Thus, the legitimization by the alteration made to Law No. 9434/97, which returns the responsibility for the decision about donating organs and tissues of the deceased to their family members seems appropriate.

REFERENCES

1. Palhares FB, Bastos AF: Conceito de morte—aspectos legais e éticos. *Captção de órgãos para transplante*. Campinas: Tecla Tipo; 1997, p 17
2. Kovacs MJ: Bioethics concerning life and death. *Psicol USP* 14:115, 2003
3. Conselho Federal Medicina: Critérios do diagnóstico de morte encefálica, 1480. 1997
4. Guidelines for the determination of death. Report of the medical consultants on the diagnosis of death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *JAMA* 246:2184, 1981
5. Brasil. Ministério da Saúde, SAS. In SAS (ed) *Relatório de Gestão Secretaria de Assistência à Saúde 1998/2001*. 2ª ed. Ministério da Saúde; 2002, p 220
6. Lei no 10.211. Altera os dispositivos da Lei no 9.434, de 4 de fevereiro de 1997, que "dispõe sobre a remoção de órgãos, tecidos e partes do corpo humano para fins de transplante e tratamento." 2001
7. Pereira WA, Fernandes RC, Soler WV: I Reunião de Diretrizes para captação e retirada de múltiplos órgãos e tecidos da Associação Brasileira de Transplante de Órgãos. São Paulo: Associação Brasileira de Transplante de Órgãos; 2003
8. Anjos MF: Bioética: abrangência e dinamismo. *O mundo da saúde* 21:4, 1997
9. Garrafa V, Bioética e Transplantes. Encontro Comemorativo dos 10 anos do "Interior transplantes." 1997 Riberão Preto—São Paulo; 1997.
10. Pearson IY, Bazeley P, Spencer-Plane T, et al: A survey of families of brain dead patients: their experiences, attitudes to organ donation and transplantation. *Anaesth Intensive Care* 23:88, 1995
11. Sadala M: A Experiência de doar órgãos na visão de familiares de doadores. *J Brás Nefrol* 23:143, 2001
12. May T, Aulisio MP, DeVita MA: Patients, families, and organ donation: who should decide? *The Milbank Quarterly* 78:2, 2000
13. Roza BA: Impacto da legislação dos transplantes de órgãos sobre médicos e enfermeiros de uma comunidade universitária [Mestrado]. São Paulo: Universidade Federal de São Paulo; 2000
14. Garcia VD: Tempos difíceis. *Registro Brasileiro de Transplantes. Jornal Oficial da Associação Brasileira de Transplante de Órgãos—ABTO*. 12:3, 2006
15. Clark PA: To be or not to be a donor: a person's right of informed consent. *Current Opinion in Organ Transplantation* 8:334, 2003
16. Fabbro L: Limitações jurídicas à autonomia do paciente. *Bioética* 7:7, 1999
17. Sgreccia E: Bioética e transplante de órgãos no homem. *Manual de Bioética*. São Paulo: Edições Loyola; 1996, p 686
18. Zoboli ELCP: Bioética e Atenção Básica: Um Estudo de Ética Descritiva com Enfermeiros e Médicos do Programa Saúde da Família [Doutorado]. São Paulo: Faculdade de Saúde Pública da Universidade de São Paulo; 2003
19. Sheehy E, Conrad SL, Brigham LE, et al: Estimating the number of potential organ donors in the United States. *N Engl J Med* 349:667, 2003