

# Organ donation procedures: an epidemiological study

**Objective**—To evaluate the impact of organ and tissue donation processes on family members of deceased donors and the probability that they would be an organ or tissue donor in the future.

**Methods**—Cross-sectional survey of 69 families of deceased donors of the organ procurement organizations of the Federal University of São Paulo.

**Results**—Donors were predominantly men (57% vs 43%) with a median age of 35.9 years. The primary causes of death were classified as natural (65%), traumatic injury (33%), and other (1%). Of the family members surveyed, 40% had an elementary school education and 59% were unemployed. Family members expressed an understanding of the brain death diagnosis (67%). Among them, 74% had no doubt about brain death and had time to ask questions. The diagnosis was provided by the doctor responsible for the patient (89%). Family members also used funeral aid benefit (63%), perceived organ donation positively (97%), and indicated that they would donate again (79%). A significant relationship was found between families that took advantage of the funeral aid benefit and families that would donate again (79% vs 22%,  $P = .002$ ).

**Conclusion**—The intent to donate organs for transplantation may be based more on moral and cultural factors that go beyond the family members' knowledge about the donation process per se. (*Progress in Transplantation*. 2010;20:88-95)

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Organ transplantation is one of medical history's success stories. Even though that history is marked by countless attempts, conquests, losses, and disillusion, progress has unquestionably been made in a relatively short time. In Brazil, the 30-year period from 1967 to 1997 has been called "heroic and romantic." It was a time when hospital transplantation programs had few regulations and a casual regard developed toward the registration of potential recipients on transplantation waiting lists, the organ retrieval processes, and criteria for distribution of the organs.<sup>1</sup> Although this era helped advance the science of transplantation, it raised many moral and ethical questions that ultimately led to legislative regulation. Since 2001, after legislative changes, organ donation in Brazil now requires family consent, establishment of the diagnosis

of brain death, and confirmation that donation represents the donor's will.<sup>2</sup>

Upon family consent, the health system infrastructure must be capable of absorbing the technical demands of the donation process. In addition, protocols must be in place to ensure a quality evaluation that yields reliable results, guarantees safety, and maintains the high ethical standards of the process. Although these requirements have enhanced the integrity of the donation process, they have reduced the number of organs available for transplantation. Another important point, according to the National Report of the Secretary for Health Assistance,<sup>1</sup> with the creation of the Brazilian National Transplantation System in 1997,<sup>2</sup> Brazil now has the necessary requisites regarding safety procedures related to organ and tissue donation, for both patients and their families.

Today, the availability of deceased-donor organs does not meet the demand in most countries that perform transplant surgery.<sup>3,4</sup> In Latin America, the potential donor rate is from 40 to 100 donors per million inhabitants (pmi) per year, which is similar to the levels reported in developed countries.<sup>5</sup> However, the percentage of potential donor families who are approached to donate is only 5% to 25% pmi per year, and the actual donation percentage is from 2% to 12% pmi per year.<sup>5</sup> In 2003, donor rates in Brazil were 5.05 donors pmi per year (893 actual donors, for a population of 176 871 437 inhabitants).<sup>5,6</sup> These data suggest that opportunity exists for improvement in the recruitment of donor organs and development of transplantation centers in the less developed areas of the country.<sup>4</sup>

Although much has been written about transplantation techniques, immunosuppressant regimens, and patient/graft survival rates, few studies have examined organ and tissue donation from the perspective of the donor family.

## Methods

Ethical determinations regarding research are governed by the Brazilian Resolution 196/96 and are based on international documents derived from the Helsinki declaration and guidelines about research with human subjects. This project was approved by the institutional review board of Federal University of São Paulo. The data were analyzed according to the bioethical point of view, including the principles of autonomy, justice, death and life extension, and altruism versus use of funeral aid benefit.

A cross-sectional survey was sent to relatives of all individuals who had donated organs or tissue for transplantation to the organ procurement organizations of the Federal University of São Paulo, Brazil, between 2000 and 2001. In 2000, a total of 327 notifications of potential donors (0.91 notifications per day) yielded 66 donations (10.5 donors pmi per year), and in 2001, a total of 354 notifications (0.98 notifications per day) yielded 73 donations (11.6 donors pmi per year), creating a potential sample of 139 donor families. Data were collected in 2004, to ensure an interval of at least 2 years had occurred since the death of the donor.

To locate the deceased donors' relatives, research assistants sent letters directly to donor relatives (n=48), contacted the hospital that notified the organ procurement organization of brain death for assistance in locating donor families (n=19), and called donor families by telephone (n=72). Through these efforts, 78 families were located and only 9 (12%) declined to respond to the survey material after initially indicating a willingness to participate. The final sample consisted of 69 (49.6%) of the 139 donations that occurred during the target period. When the 69 study participants were contacted by letter or phone regarding participation in

the study, they were given the option of either having the questionnaire sent to them by mail for completion or having an interview over the phone or in person at their home or place of work.

The research instrument was a questionnaire with 33 closed questions and 3 open-ended questions. Closed questions queried participants about demographic, educational, and economic characteristics of the respondent; sociodemographic and epidemiologic profile of the organ donor; who communicated the diagnosis and cause of brain death; and whether the funeral aid benefit was accepted and used. The open-ended questions focused on the family's comprehension of the diagnosis, whether they felt the family had sufficient time to make the decision, and who was responsible for the donation decision.

The research instrument was developed specifically for this study by master's and doctorally prepared nurses with extensive experience in organ transplantation and research on the population to be studied. This arrangement helped ensure the clinical soundness, scientific integrity, and cultural sensitivity of the questionnaire. The questionnaire was submitted for content validation to a panel of specialists composed of nurses and physicians from the staff of 6 organ procurement organizations in the city of São Paulo and members of the Brazilian Association for Organ Transplantation. This panel offered suggestions for additional questions and clarification of language that were incorporated in a revised version of the questionnaire. The final revised questionnaire was pilot tested with 5 families of organ donors from the São Paulo organ procurement organization in a face-to-face interview in the respondent's workplace or residence.

Family members who participated in the pretest had no difficulty understanding the questions. The families reaffirmed their wish to know the recipients and also stated that the families should have received a letter of appreciation for their gift from the Brazilian National System of Transplantation or received information if the organs and tissues were used. According to the specialists' review and the results obtained at the pilot test, the questionnaire was considered valid.

Descriptive statistics were used to characterize the study sample and to describe response data. Both parametric and nonparametric statistical tests were used for data analysis as appropriate. Associations between study variables were determined by using  $\chi^2$ , Kruskal-Wallis, and Mann-Whitney analyses, and a logistical regression was conducted to examine how study variables affect organ donation.

## Results

Physicians from the patient's hospital were responsible for communicating the diagnosis of brain death in 58 (89%) of the cases. After this diagnosis

Table 1 Characteristics of donor families

Characteristic	No. <sup>a</sup>	%
Relationship to recipient		
Brother, sister, grandparent, uncle, or cousin	29	46
Grandparent/mother	21	33
Spouse	13	21
Total	63	100
Sex		
Male	31	45
Female	38	55
Total	69	100
Level of education		
None	2	3
Elementary school	27	40
High school	19	28
Undergraduate	20	29
Total	68	100
Marital status		
Married	34	51
Single	14	21
Widowed	8	12
Divorced	5	7
Consensual union	6	9
Total	67	100
Were you unemployed at the moment of donation?		
Yes	41	59
No	28	41
Total	69	100
Religion		
Catholic	48	70
Evangelic	8	12
Spiritualist	7	10
Other	6	9
Total	69	100
Do you participate in religious practice?		
Yes	45	66
No	23	34
Total	68	100

<sup>a</sup> One or more families did not answer some questions, so total is not always 69.

was conveyed, 46 (67%) of the relatives had no doubts about the diagnosis; however, 23 (33%) had doubts. Of those in doubt, 17 (74%) indicated that they understood the subsequent explanations; only 6 (26%) stated that they had no opportunity to clarify their doubts related to brain death. Family respondent data (Table 1) indicate that most respondents (46%) were siblings, grandparents, or uncles. Fifty-four respondents (82%) indicated that time was sufficient to decide about donation, and 43 (63%) of the relatives reported that they had previous knowledge of their relative's desire to donate. Notably, 38 (90%) of these indicated that knowledge of the patient's wishes was an important factor in the decision to donate (see Table 2).

For most donations ( $n = 50$ , 68.5%), the surgery for procurement of the organs and tissues did not occur at the facility where brain death was diagnosed.

However, 16 families (32%) would have preferred that it had. Kidneys were the most common organ donated ( $n = 69$ , 100%) followed by hearts ( $n = 67$ , 97%), livers ( $n = 65$ , 94%), pancreas ( $n = 63$ , 91%), and lungs ( $n = 60$ , 87%). The most donated tissue was cornea ( $n = 57$ , 83%) followed by musculoskeletal tissue ( $n = 47$ , 68%), bones ( $n = 23$ , 33%), tendons ( $n = 24$ , 35%), blood vessels ( $n = 26$ , 38%), and skin ( $n = 25$ , 36%). The majority of relatives ( $n = 37$ , 54%) expressed dissatisfaction with the time it took to release their relative's body (Table 3).

Among the 24 donors who died of a traumatic injury, 15 (62%) died of cranial trauma, 7 (29%) of a gunshot wound, 1 (4%) of a knife wound, and 1 (4%) as a result of another kind of violence. As required by law, all these donors' bodies were directed to the Legal Medical Institute for evaluation after recovery of organs and tissue for transplantation but before being released to the family. This delay undoubtedly contributed to 16 (84%) of the 19 donors' relatives who responded reporting negative opinions about the time from death to release of the body for the burial and only 3 relatives (16%) giving positive responses.

Legislation of the municipal district of São Paulo exempts families of organ and tissue donors from expenses for mortuary services. The majority of donors' relatives used this mortuary benefit ( $n = 43$ , 64%). Among the relatives who used the funeral aid benefit, 37 (92%) considered it important, and 3 (8%) did not (3 did not respond to this question). Regardless of whether they used the funeral aid benefit, 63 (97%) of 65 responding relatives agreed with it, even though a much smaller number actually used the benefit (Table 4).

At the time of donor death, families were interviewed by the professionals of the receiving service from the organ procurement organization. When questioned about this interview, 54 (84%) of the 64 donors' relatives who responded expressed satisfaction with the interview, whereas 10 (16%) did not. Family members who indicated that they would not donate a relative's organs again if faced with that decision ( $n = 9$ , 13%) were asked the reason why; their typical responses were "I don't know, as the process of transferring from the hospital is very slow, there is a large physical and emotional suffering for all the friends and relatives." Most (53/67, 79%), however, responded favorably about their donation decision, typically noting that, "If we think about the people that are in need of the organs, probably yes."

Several interrelationships existed among the sociodemographic characteristics of the deceased donor's relatives. Regional origin (South, Southeast, Central-West, Northeast and Northern Brazil) was associated with education and religion ( $P < .05$ ), and a trend toward an association between relatives' income

Table 2 Characteristics of the donation decision process

Characteristic	No. <sup>a</sup>		%			
Donation decision time						
Insufficient	12		18			
Sufficient	54		82			
Total	66		100			
Was it helpful in the decision to know the donor's wish?						
Yes	38		90			
No	4		10			
Total	42		100			
Who was responsible for the donation decision?	Was there previous knowledge of their relative's desire to donate?					
	Yes	%	No	%	Total	%
Family	9	21	20	80	29	43
Family and donor	20	47	3	12	23	34
Donor, but it caused a conflict with the relatives	3	7			3	4
It caused conflict within family	3	7	2	8	5	7
Donor	8	19			8	12
Total	43	100	25	100	68 <sup>a</sup>	100

<sup>a</sup>One or more families did not answer some questions, so total is not always 69.

Table 3 Time taken to release relative's body

Family's satisfaction with time taken to release the body	No.	%
Satisfied	23	33
Unsatisfied	37	54
No information	9	13
Total	69	100

and regional origin was noted ( $P < .10$ ). Regardless of the sociodemographic differences in regional origin, no association was found between variables related to the process of organ and tissue donation and the relatives' origin, or between demographic characteristics of the relatives (age, sex, education, occupation, and religion) and readiness or not to donate again ( $P > .05$ ). However, a significant ( $P = .002$ ) association was found between using the mortuary benefit aid and the intention to donate again. Most families that used the mortuary benefit found it important and indicated that they would donate again.

A forward stepwise logistic regression was conducted to determine what factors could be used to identify family members most likely to donate their deceased relatives' organs for transplantation. This analysis indicated that satisfaction with the family interview increases the likelihood of donation by 9.53

times (Table 5). It was found that 54 (79%) of the relatives would donate again, although there was not an explicit reason to do that (Table 6).

The multiple correlational analysis indicated that the intent to donate organs for transplantation after a previous organ donation experience is most often associated with the circumstances in which the prior donation decision was made. The circumstances that may determine a new donation were related to the quality of attention received at the hospital and the time allowed to reflect upon the donation decision. When the process of organ and tissue procurement occurred in the same hospital where brain death was diagnosed, it strengthened the link with the hospital staff and decreased the time to organ donation and receipt of funeral aid. This finding was apparent even when conflict existed among relatives (7%) and when the family members felt they had sufficient time to consider the donation option.

## Discussion

The Brazilian mortality coefficient was 5.7/100 000 inhabitants. In southeast Brazil, where approximately half of those deaths occurred (47.6% of that total), the risk of death was 5.9/100 000 inhabitants. Among the defined causes of death, circulatory diseases are associated with the greatest risk of death. In southeast Brazil, those diseases cause 33.4% of deaths, followed by cancer and traumatic injuries, which cause 16.7% and 13.6%, respectively, of deaths.<sup>7</sup>

Table 4 Association between variables

Variables		Would you donate again? <sup>a</sup>						P
		Yes		No		Don't know		
		No.	%	No.	%	No.	%	
Did the family use the funeral aid benefit?	Yes	34	64	6	67	3	60	.97
	No	19	36	3	33	2	40	
Was the funeral aid benefit important?	Yes	29	91	5	100	3	100	.67
	No	3	9	0	0	0	0	
Do you agree with this benefit? <sup>b</sup>	Yes	51	100	7	78	5	100	.002
	No	0	0	2	22	0	0	
Were you satisfied with the person you talked with at the moment of donation?	Yes	44	88	6	67	4	80	.26
	No	6	12	3	33	1	20	

<sup>a</sup> One or more families did not answer some questions, so total is not always 69.

<sup>b</sup> Considering just the families who used the funeral aid benefit.

Table 5 Logistic regression of demographic characteristics of relatives and donors

Variable (demographic characteristics and relative's opinion)	Coefficient	P	Odds ratio	Inferior limit	Superior limit
Relative's age	-0.07	.08	0.94	0.87	1.01
Donation happened in the same hospital where brain death was diagnosed (yes)	2.03	.09	7.61	0.72	80.56
Satisfaction with the person talked with at the moment of donation (yes)	2.25	.02	9.53	1.32	68.55
Constant	2.24	.22	9.42		

In a study<sup>8</sup> conducted in southwest Pennsylvania and northeast Ohio, researchers found that although consent rates were associated with deaths by trauma compared with nontraumatic deaths (65.1% vs 34.9%,  $P = .002$ ), no association was found between consent rates and education level or family income. Unlike North America, Brazil has a high level of illiteracy, in addition to a sizeable semiliterate population. This educational deficit severely compromises the capacity of individuals to acquire the information needed to make informed decisions regarding their destinies.<sup>9</sup> These circumstances present bioethical challenges to transplant professionals who are counseling families about organ donation decisions during a particularly stressful and vulnerable time, for without adequate information, autonomous decision making cannot occur. In order for families to exercise their decision-making autonomy, it is critical that the health care team share the knowledge and information in a language and manner understandable to the family so that informed decisions can be made.<sup>10</sup> By engaging the family in this manner, we can be more assured that

donors' and donors families' decision-making autonomy is maintained and their wishes respected.

Human beings are the only species to manifest moral respect for the dead, the only species to dispose of the dead in a systematic way, and the only ones to give a meaning to death. In most religions, the meaning of death is linked to notions of a subsequent life or some form of continuation of the existence.<sup>11</sup>

As family see their loved one's body after donation and begin the mourning process and related cultural rituals, some come to regret their decision to donate. The funeral ritual expresses the loss and enables the family to demonstrate their respect for the deceased. Suffering for some can be exacerbated by the procedures that accompany organ procurement.<sup>12</sup> Moreover, when organ procurement takes place without consideration for the family's wishes, the habits and religious rituals that celebrate the relative's farewell are significantly compromised.<sup>13</sup>

Data from the United States suggest that organ procurement is often influenced by many sociocultural characteristics of the family such as emotional reasons,

Table 6 Decision to donate again

Decision to donate again	No.	%
Yes	54	79
No	9	13
Don't know	5	7
Total	68 <sup>a</sup>	100

<sup>a</sup> One relative did not answer this question.

culture, religion, and family conflicts related to a lack of information.<sup>14</sup> It is therefore important, where possible, to offer the family the opportunity to begin the processes and practices surrounding funeral rituals worshipped in their society. In our study, for example, some families did not have the opportunity to veil their relatives' bodies and subsequently regretted the donation. The ability to fully participate in funeral rituals may also have contributed to the higher frequency of organ donation than tissue donation.

Organ donation in Brazil is presenting a new paradigm for the way death can be viewed in our society. In the context of organ donation, death now presents an opportunity to attach value in the presence of a terrible loss, in that through organ donation it is possible to save or to increase the survival of patients with organ failure. However, for some, the interests of the survivors take precedence because of the vulnerability associated with their loss and the perception that they are not able to represent their will appropriately. In this state of reduced autonomy, the individuals are vulnerable to being controlled by others or are unable of deliberating or of acting in a manner that is based on their desires and plans.<sup>15</sup>

This vulnerability assumes great significance when placed in the context of studies that report a lack of understanding of brain death among donor families. For example, results of a study<sup>16</sup> with 9 trauma hospitals in the United States showed that 28.3% of the family members are not able to define brain death correctly. In another study<sup>17</sup> with 211 brain-dead patients in Australia, 141 families were interviewed for donation; of these 79 families donated and 62 did not. Among the relatives, 20% gave only poor explanations of brain death, whereas 52% had satisfactory knowledge. Knowledge about cardiac arrest was better than knowledge about brain death ( $P = .002$ ).<sup>17</sup>

According to the report<sup>18</sup> of the first meeting on basic guidelines for reception and retrieval of multiple organs and tissues of the Brazilian Association on Organ Transplantations in 2003, the success of the family interview (permission granted for organ donation) depends on the disposition to the donation, quality of the hospital service, and the interviewer's

knowledge and ability. This report supports the hypothesis that the health care providers responsible for the family interview must have technical competence and moral-ethical competencies essential to the donation process. Embedded in the donation process is the responsibility to recognize and affirm the importance of the family's mourning process and the integration of it throughout the entire donation process. Beginning with the initial interview and ending with the release of the donor's body to the Services of Verification of Death or the forensic medicine institute.

Although previous knowledge of the donor's desire to donate their organs is an important factor in the relatives' decision making, in our study this reason was not the predominate one cited by family members for agreeing to donation. In practice, organ donation is a decision made independently by all members of the family who sign the consent for donation. As these independent decisions are made and a family consensus formed, conflict often occurs. It is through discussion of the issues concerning donation that are in conflict that issues can be resolved and a family decision reached. The donor's autonomy or wishes, although a part of this discussion, are only one issue in this discussion and are of minor influence; rather, our data indicate that it is primarily the donor's family that decides. This observation reflects the enactment of Brazilian law No. 9.434/97 that gave relatives the responsibility for decision making about organ and tissue donation from their dead relatives. This practice is further supported by a recent study<sup>19</sup> of 36 American organ procurement organizations that showed that 54% of the decisions for donation were made by the family, in spite of the donor's desire.

The ability to approach the family and retrieve donated organs at the same hospital has a positive effect on the decision to donate organs. When the process occurs at the same hospital, it apparently increases the bond between the family and the procurement team and contributes to reducing the time of the donation process. In contrast, there is a negative effect when the body must be transferred to another site. It could be inferred that this negative effect is related to the loss of the relatives' close relationship with the procurement team and the increased time before the body is returned to the family. When the teams or members of the organ procurement organization spend more time discussing aspects of the donation and transplantation with the families, consent for donation increases.<sup>20</sup>

Every death that occurs as result of unnatural causes requires examination of the body by the forensic medicine institute; this is seen by the relatives as a factor that increases the time to release of the body to the family, and negatively influences the donation

decision, although that examination of the body is not related to the donation process itself.

The mortuary benefit granted by the Municipal City Hall of São Paulo since 1994 was seen by donors' relatives as an important benefit and positively influenced the donation decision. Still, the action of donation could be considered altruistically motivated in that the organ is donated unconditionally and anonymously, and donation remains emotionally gratifying for the donor family. It constitutes an extraordinary social virtue,<sup>8</sup> even though indirect benefits derived from receipt of funeral expenses could be seen as interfering with an altruistically based decision. That argument is supported by our data that indicated that relatives desired to know the status of the organ recipients. Moreover, in a recent study<sup>21</sup> on altruism and incentives in the donation of organs, researchers observed that the only individuals who did not benefit in transplantation were the donor's family members; therefore, the financial incentive would bring equity to this process.

In the VI World Congress of Bioethics, a lecturer defended the proposition that donors should be compensated for their contribution to the enrichment and the prolongation of the human life. But the reciprocity should be sensitive to the peculiar needs of the benefactor. Although the organ donor's family benefits, at the same time their altruism addresses the patient's urgent need for an organ, it is this reciprocity of needs that drives the donor.<sup>22</sup> On the other hand,<sup>23,24</sup> no Brazilian study has defined the epidemiologic profile where organ and tissue donors intersect with recipients so that any inequality could be described.

The liberty paradigm, based on the defense of the rights and property of individuals in a pluralist world, may justify the purchase and sale of organs as an expression of free will. However, when donor families are economically disadvantaged and do not have resources to meet their basic needs, their situation may not reflect the conditions necessary for the exercise of free will. It is therefore essential that a detailed analysis of interactions between the relatives and the motivations for their agreement with mortuary aid be conducted to ensure the donation is an altruistic action.

Additionally, the expansion of transplantation since 1995 led to a considerable revision of the Guiding Principles for Human Organ Transplantation adopted by the World Health Organization. However, even in that document, there was no consensus as to how and where to place limits on the removal or promotion of financial incentives in the donation and transplantation process.<sup>25</sup> In a capitalist society which is based on the buying and selling of goods and services, it could be argued that mortuaries payment benefits is a means to provide the ethical principle of justice to those that

donate part of their relative's body for the prolongation of the life of another. Furthermore, our research indicates that the relatives approved of this benefit and consider this a reciprocity gesture. The principle of justice would provide an equal benefit for the donors' relatives and recipients.

## Conclusion

Previous experience with the donation process by itself does not seem to influence the intention of donating again, as demonstrated by the response of 79% of the relatives that they would donate again. Relatives of donors that had a violent death and thus required examination of the body by the forensic medicine institute, however, had negative opinions about time to release the body to the family.

The indirect benefit provided by the mortuary aid benefit had a positive influence on the donation decision. Our study leads us to conclude that some guidelines for professionals discussing the organ donation process with families must be established in order to promote and to ensure the dignity of donors and their families. In this way, society will build norms guaranteeing moral plurality, protection of vulnerable individuals, and the fair and equitable distribution of organs for transplantation.

## Financial Disclosures

None reported.

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