

Evaluation of the causes for family refusal to donate organs and tissue

Avaliação das causas de recusa familiar a doação de órgãos e tecidos

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Keywords

Nursing assessment; Education, nursing; Directed tissue donation; Tissue donors; Refusal to participate

Descritores

Avaliação em enfermagem; Educação em enfermagem; Doação dirigida de tecido; Doadores de tecidos; Recusa de participação

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Abstract

Objective: Evaluate the causes for family refusal to donate organs and tissue.

Methods: Correlational cross-sectional study regarding the causes for the family refusal to donate organs and tissue. Data were analyzed using chi-square and Student's t test.

Results: The study emphasized that the main reasons for the refusal are: incomprehension regarding the brain death diagnosis (21%), religion (19%), lack of technical competence of the team (19%), long process (10%), the deceased was a non-donor (9%), fear of mutilation (5.2%), being buried as the person came to this world (3.4%), quality of the service (3.4%), decision of a single member of the family (3.4%), negative previous experience from another donation process (1.7%), body transfer (1.7%).

Conclusion: The causes for family refusal are associated with the family members' lack of understanding regarding the brain death diagnosis, aspects related to religion and lack of preparation of the professional who performed the interview.

Resumo

Objetivo: Avaliação das causas de recusa familiar para a doação de órgãos e tecidos.

Métodos: Trata-se de um estudo transversal correlacional sobre as causas de recusa familiar para a doação de órgãos e tecidos. Para análise dos dados foi utilizado o teste Qui-Quadrado e o t-Student.

Resultados: A pesquisa destacou que os principais motivos de recusa relacionados são: não compreensão do diagnóstico de morte encefálica (21%), religiosidade (19%), falta de competência técnica da equipe (19%), tempo longo processo (10%), falecido não era doador (9%), medo da mutilação (5,2%), enterrado como veio ao mundo (3,4%), qualidade do atendimento (3,4%), decisão de um único membro da família (3,4%), experiência negativa em outro processo de doação (1,7%), transferência do corpo (1,7%).

Conclusão: As causas de recusa familiar estão ligadas a não compreensão do diagnóstico da morte encefálica pelos familiares, aspectos ligados a religião, despreparo do profissional que realizou a entrevista.

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Introduction

The word transplantation was first used in 1778, by John Hunter, a researcher, anatomist and surgeon who described in detail his experience with reproductive organs in animals.⁽¹⁾ Almost two centuries later, the world heard of the first successful transplantation performed in human beings.

Transplantation cannot be performed without a donor, and in this complex process there has been an increase in the number of active patients registered in the Brazilian technical database while the number of donors remains low.

In Brazil, the number of active patients in the Brazilian technical database waiting for the transplantation of a solid organ, in 2012, was 26,662, with a reduction of approximately 4% compared with the numbers of the previous year.⁽²⁾ Still in 2012, the country reached a historical mark of 2,439 donors, reaching a rate of 12.7 donors per one million inhabitants.⁽³⁾

The rates of family refusal have increased significantly in the last four years. In 2012, 2,315 families refused to donate the organs and tissue of a deceased family member, which corresponds to 28.8% of family refusal if calculated on potential donors, but when the denominator used is the number of family interviews performed, the rate of family refusal rises to 41%.⁽³⁾

According to a survey on the Brazilian transplantation records, between 1998 and 2012, there were 21,120 families who decided not to donate. If 80% of these families had accepted the donation and, if it was possible to recover four organs from each donor, 67,584 patients would have been transplanted.

In 2012, as per the report of the transplantation center of the state of São Paulo, 37.7% of the patients who waited for a heart transplant and 33% of those who waited for a liver transplant died without having the opportunity to receive the transplant.

The autonomy of the family must certainly be respected, and every family member has the right to take a stand as for the donation. Regardless their opinion, this family must be respected and followed up so as to assimilate grief better.

The purpose cannot be only the donation, as it is necessary to have a greater concern towards the

family who is frail and experiencing a delicate and conflicting moment triggered by the grief process. The efforts/attention must be turned to the family, but not in the sense of convincing them, even because the donation of organs is a task of embracement rather than convincing.

The process of family decision at the time of the interview to request the donation of organs and tissue of the deceased family member transforms the relationships of the society with the theme, because dying begins to represent a new paradigm over the value of the body, given that a donation may save or increase the survival of ill people.⁽⁴⁾

In order to identify the pathways of the donation, there is an inexorable need to understand the experience of the family, which happens in a context of interpersonal relationships that affect beliefs, emotions, behaviors and decisions. Brain death and organ donation are contemporaneous cultural practices.⁽⁵⁾

A study developed with the aim to evaluate the knowledge of individuals regarding brain death and its impact on the decision to donate revealed that these individuals did not understand the concept of brain death, which resulted in low trust in the diagnosis of brain death and in the capability of the physician to provide a correct diagnosis, thus influencing the donation decision negatively.^(6,7)

The lack of knowledge of the lay population and people from the health area regarding the process of organ donation is pointed by countless studies as being one of the reasons leading families to refuse to donate organs and tissue from the potential donor with brain death, as well as not knowing the deceased family member's wish as for the organ donation theme.⁽⁸⁻¹³⁾

The request for organ donation has a significant impact on the families, with effects that last long after the death of the loved one, regardless the decision made (to donate or not to), as the process as a whole is a complex and life-changing experience for them.⁽¹⁴⁾

The concept of organ recovery and donation should be extended to the care of the family, so as to understand what they are going through and to minimize their suffering, regardless the answer to the donation request.⁽¹²⁾

The objective of this study was to identify and analyze the causes for the family refusal to the re-

quest for donation of organs and tissue of deceased family members after the diagnosis of brain death in the organ and tissue procurement organization (OTPO) of the state of São Paulo, southeast Brazil, between 2009 and 2010.

Methods

This is a cross-sectional study regarding the causes for family refusal to donate organs and tissue, developed in the organ and tissue procurement organization (OTPO) of the São Paulo Hospital/Teaching Hospital of the Federal University of São Paulo, using an adaptation of an instrument used with families of deceased donors.⁽¹⁵⁾

In 2009, this service was notified on 431 cases of potential donors with brain death and, among those, 100 became effective donors and 79 families refused to donate the organs of their deceased family member. In 2010, there were 470 notifications, with 166 donors and 103 refusals.⁽¹⁶⁾

The study sample was selected with a non-probabilistic strategy by convenience, including family members who accepted to participate in the study voluntarily.

This sample consisted of 42 families who accepted to participate in the study, from a total of 52 families located among the 182 families that refused to donate the organs and tissue of a deceased family member in the years of 2009 and 2010, in the region of the studied service.

Data were collected by means of interviews, with a structured script that was completed at the moment of the interview. Professionals who work in the donation and transplantation area validated the instrument.

The results were analyzed using parametrical and non-parametrical statistical tests.

A descriptive analysis of the study variables was performed to characterize the profile of the interviewees and to evaluate the several characteristics pointing to a change in opinion as for a new possibility of donation.

The characteristics of the interviewees were identified by means of descriptive statistics. Qualitative variables were described using absolute (n)

and relative (%) frequencies, whereas mean and median values were computed for the quantitative variables; with the minimum and maximum standard deviation being the measure of variance.

Student's t test was used to analyze and verify the difference of the quantitative variables evaluated between the groups that changed, or not, their opinion regarding a new possibility of donation, considering a 5% level of significance. Therefore, the authors considered there was a difference in the groups that assumed the value of $p < 0.05$.

Qualitative data were analyzed to determine whether there was an association between the variables, compared with the group of interest, which consisted on those who would change or not their opinion towards donation. The chi-square test was used in this type of comparison, considering a 5% level of significance. Therefore, statistical significance was considered in groups with $p < 0.05$.

The study development complied with national and international ethical guidelines for studies involving human beings.

Results

The mean age of the potential donors with brain death was 41.2 years, ranging from a 12-day-old child to an older adult aged 82 years. Most of them were men 63%. The main causes of death were: 48% stroke, 42% traumatic brain injury and 10% tumor of the central nervous system. The mean age of the interviewees was 40.7 years.

The kinship relations of the family members with the deceased were: 31% first-degree relatives, 33% second-degree relatives, 5% third-degree relatives, 14% spouses and 17% fourth-degree relatives. Regarding the level of education of the family members: 29% completed primary education, 33% completed high school, 36% graduated and 2% had a Ph.D. degree.

Regarding their marital status, most (38%) were married, 26% were single, 12% were divorced, 19% were widowed and 5% had a common-law marriage. As for their origin: 64% were from the southeast, 31% were from northeast and 5% from

the south. Most of the family members were employed, 64% and 36% were unemployed.

Most of the families, 48%, had an income between one and three minimum wages, 19% of the families earned between three and five minimum wages and the other group of 19% earned over five minimum wages. Most of the families, 64%, declared they were Catholic, 17% were Protestant, 7% claimed to be Christians and 12% mentioned other religions. A total of 66% of the interviewees claimed to practice their religion.

Regarding the process of organ donation; 93% of the family members were aware of the cause of death of their next-of-kin. The opening information of the protocol of brain death was given to 83% of the families (Figures 1 e 2).

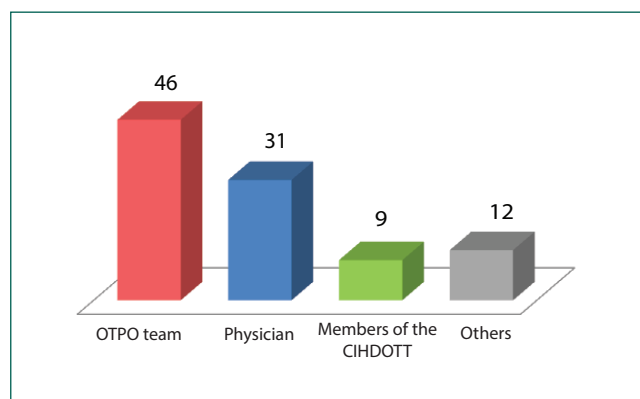


Figure 1. Requestor in charge of the family interview

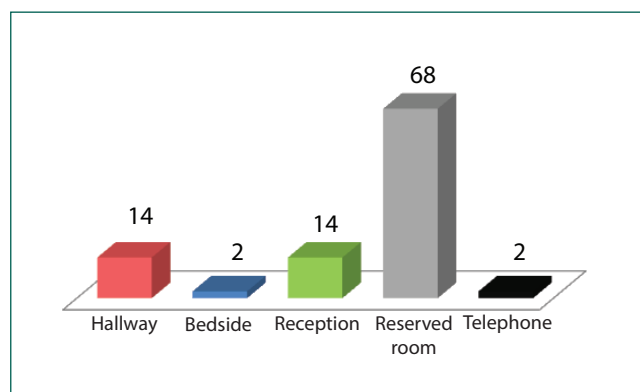


Figure 2. Place of family interview

The time to make the decision was considered insufficient by 43% of the families. Among the interviewees, 63% did not know the will of the de-

ceased regarding organ donation, and among the 36% of those who knew the will of the deceased, 60% were donors.

The process of decision-making, in this case the family refusal, was a responsibility of 40% parents, 22.5% siblings, 22.5% spouses and 15% children (Figure 3).

A great number of the family members, 67%, changed their opinion and would currently decide to donate, 7% of the family members did not manifest their opinion. Among those who changed their opinion, 93% pointed they did so because organ donation saves lives and helps people.

The analysis of the degree of kinship of the family members with the deceased revealed that 64% were related until the second degree and, if added to spouses, this number goes up to 78%. This is an important information since only family members until the second degree of kinship and spouses are authorized to donate the organs and tissue of a family members as per legal determination.⁽¹⁷⁾

A great number of the interviewees, 31%, was from the northeast and 64% were from the southeast.

Regarding religion, 64% of the interviewees claimed to be Catholic, 16% were Protestant and 8% were Christians, the remaining 12% claimed they practiced other religions.

More than 93% of the family members interviewed were aware of the cause of death of their loved one, and were able to identify that the brain death was a consequence rather than the cause. In addition, 83% of the family members were notified as for the opening of the protocol of brain death, as determined by law.⁽¹⁸⁾

Most of the interviews were performed by professionals from the organ and tissue procurement organization (46%).

The place chosen for most of the interviews (68%) was an appropriate environment, which assured the minimum privacy necessary for the family members.

Nearly half of the interviewees (43%) understood that the time they had to make a decision as for the donation was not enough.

The great majority of the interviewees (64%) was not aware of the will of their loved one as for the donation of organs.

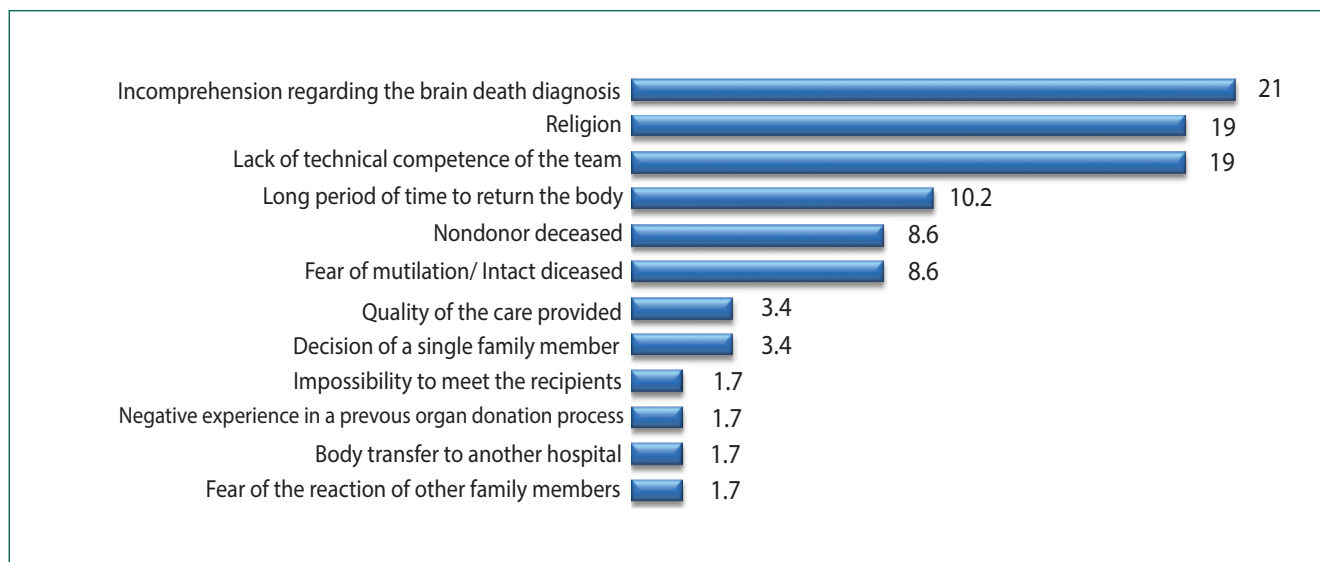


Figure 3. Reasons for refusal

At the time the interviewees were questioned on whether they would change their opinion, 70% of them stated they would currently decide to donate. The greatest percentage of the interviewees who would change their opinion in the group of family members who knew the will of the deceased regarding donation had a statistical significance of $p < 0.007$.

Discussion

The limitations of this study are related to its cross-sectional design, which does not allow the establishment of causal relations. The characteristics presented regarding the age and cause of death of the potential donors with brain death are similar to those presented by the Brazilian Institute of Geography and Statistics (IBGE, as per its acronym in Portuguese). The main cause of death in Brazil is attributed to circulatory system diseases 28% (285,543 deaths), followed by neoplasms 14% (140,801 deaths). Among the circulatory system diseases, 32% (90,930) are caused by cerebrovascular diseases and 30% (86,791) by ischemic heart diseases.⁽¹⁹⁾

The epidemiological profile of the potential donor also changed along the years, and traumatic deaths are no longer the main cause of death. These changes implicated in a new attitude on the part of

the transplantation teams, which had to adapt to an older donor, with more comorbidities.

Among the reasons for refusal pointed out by the interviewees, the poor knowledge of family members regarding this subject stands out. In the situation of incomprehension of the brain death diagnosis, which is pointed out as the main cause for refusal, the individuals involved cannot understand how a body that presents heart beats, breaths (on support equipment) and sometimes is even warm may be dead.

Regarding the refusals related to religion, it is worth highlighting that up to the present date no religion in Brazil has adopted an unfavorable stand towards the donation of organs and tissue. This study allowed to observe that the individuals involved are the ones who perform personal interpretations of doctrine books. In Brazil, a greater predominance of the Catholic religion is observed, followed by Protestants.⁽²⁰⁾

The personal interpretation of biblical excerpts may cause an unfavorable attitude towards donation, as well as in case the religious leader is against or does not take a favorable stand towards donation. This concept is confirmed by a study stating that when the religion takes a favorable stand towards organ donation, their followers present a greater motivation to perform the donation.⁽²¹⁾

A study revealed that, among the causes identified for the family refusal to donate organs and

tissue, religious beliefs/miracle were responsible for 22.2% of the negative decision of the family.⁽²²⁾

Another study indicated that individuals who described themselves as having strong religious beliefs had a less favorable opinion towards organ donation, being more inclined to oppose to the donation of organs and tissue.⁽²³⁾ Individuals who had less religious beliefs, on the other hand, had a greater inclination to donate their organs and tissue.⁽²⁴⁾

Another pertinent reason mentioned by 26% of the interviewees as the cause to refuse to donate was the lack of technical competence of the professionals who conducted the interview.

It is worth highlighting that the professional in charge of the interview does not always find an appropriate environment to talk to the family, due to the lack of hospital structure.

The professionals who work in the donation area emphasize that there are not courses, case discussions and/or exchange of experiences for professionals working in this area. The establishment of groups and courses to qualify professionals would minimize errors and facilitate the practical learning.⁽²⁵⁾

Countless studies point to the need to train and qualify the professional responsible for performing the family interview.^(10,11,15, 25)

A study developed with family members of donors and nondonors revealed that the conduction of the family interview by a professional from the donation area (who works and has experience in this field) was crucial for the decision to donate the organs and tissue of a loved one. On the other hand, when this professional is less considerate, the families become less willing to donate.⁽²⁶⁾

The family needs some time to think about the possibility of donating and to assimilate everything they are going through, the death of a family member and the request for donation.⁽¹⁰⁾

A great number of the family members pointed that the period of time to return the body so that they would start the funeral preparations is too long, as the interviewees claimed the mean time requested to return the body is 24h.

In some situations, the notifying hospital does not allow the recovery of the organs of the potential donor with brain death to be performed in the

hospital, and the body has to be transferred to the hospital where the Organ and Tissue Procurement Organization is established. This transfer is also pointed as a reason for refusal.

Family members are not supposed to understand the entire physiology of the brain death diagnosis, however, they must be able to understand that brain death equals death.

Almost all reasons for refusal pointed out by the family members are susceptible of intervention with training and education. It is still necessary to invest in the qualification of professionals who work in the donation field, mainly those who are involved in the care of the potential donors with brain death. Countless campaigns indicate the need for people to talk about the donation subject in their family environment, because when the next-of-kin knows the will of the deceased it is easier to make a decision, and this will is mostly respected.

The human factor involved in the donation process is a determining factor that facilitates the family's decision-making process.

The change of opinion observed in almost 70% of the interviewees is motivating, which leads to believe that even the families who have already refused a donation request at some point may change their convictions.

A factor of relevance in this study, with a statistically significant result, was the greater percentage of interviewees from the southeast region who changed their opinion regarding the donation ($p < 0.022$), and claimed they would accept to donate the organs of a family member if a new episode took place in their family.

As already pointed by other studies, the knowledge of the will of the potential donor with brain death provides family members with more confidence at the time of deciding on the donation, as the will of the loved one is respected in most cases. Despite that, this study pointed that, among those who knew the will of the deceased, 60% did not respect the will of their loved one to be a donor.

Nevertheless, the knowledge of the will of the deceased was a determining factor in the group that

changed their opinion, with a statistically significant difference of $p < 0.007$.

The main reason pointed out by family members to support their change of opinion regarding organ donation (70%) was based on the understanding that the donation saves lives and helps people who have the transplantation as their only alternative. This feeling perceived by the families shows that we are on the right path.

Conclusion

The causes for family refusal are associated with the incomprehension of family members regarding the brain death diagnosis, aspects related to religion and the lack of preparation of the professional who performed the interview.

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Collaborations

Pessoa JLE; Schirmer J and Roza BA contributed to the project concept, analysis and interpretation, literature review, study design, data collection, input, analysis and interpretation of data, composition of the article and approval of the final version to be published.

References

- Fonseca MA, Carvalho AM. [Life fragments: social representations of organs donation for transplants]. *Interações*. 2005; 10(20):85-108. Portuguese.
- Rodrigues U. Número de transplantes cresce 52% no DF [Internet]. Brasília (DF): Ministério da Saúde; 2013 [citado 2013 Fev 11]. Disponível em: <http://portalsaude.saude.gov.br/portalsaude/noticia/9276/162/numero-de-transplantes-cresce-52-no-df.html>.
- Associação Brasileira de Transplante de Órgãos. Dados numéricos da doação de órgãos e transplantes realizados por estado e instituição no período: janeiro/dezembro 2011. RBT Registro Brasileiro de Transplantes [Internet]. 2011 [citado 2013 Ago 10]; 17(4):1-16. Disponível em: <http://www.abto.org.br/abtov03/Upload/file/RBT/2011/RBT-2011-ANUAL-PARCIAL.pdf>
- Roza BA, Schirmer J, Pestana JO. Impacto da doação de órgãos em familiares. *Ser Médico* [Internet]. 2005 [citado 2013 Ago 10]; (33): [cerca de 2p]. Disponível em: <http://www.cremesp.org.br/?siteAcao=Revista&id=215>.
- Bouso RS. [The family decision-making process concerning consent for donating their child's organs: a substantive theory]. *Texto & Contexto Enferm*. 2008; 17(1): 45-54. Portuguese.
- Teixeira RK, Gonçalves TB, Silva JA. Is the intention to donate organs influenced by the public's understanding of brain death?. *Rev Bras Ter Intensiva*. 2012. 24(3):258-62.
- Long T, Sque M, Addington-Hall J. Conflict rationalisation: how family members cope with a diagnosis of brain stem death. *Soc Sci Med*. 2008; 67(2):253-61.
- Monteiro AM, Fernandes EC, Araújo EC, Cavalcanti AM, Vasconcelos MG. [Organ donation: the opinion of adolescents]. *Rev Bras Saúde Matern Infant*. 2011; 11(4):389-96. Portuguese.
- Bitencourt AG, Neves FB, Durães L, Nascimento DT, Neves NM, Torreão LA, et al. [Evaluation of medical students knowledge on brain death]. *Rev Bras Ter Intensiva*. 2007; 19(2): 144-50. Portuguese.
- Moraes EL. A recusa familiar no processo de doação de órgãos e tecidos para transplante [dissertação]. São Paulo: Universidade de São Paulo, Escola de Enfermagem; 2007.
- Moraes BN. Perfil, crenças, sentimentos e atitudes de familiares doadores e não-doadores de órgãos [tese]. São Paulo: Universidade de São Paulo, Faculdade de Medicina; 2009.
- Dell Agnolo CM, Belentani LM, Zurita RC, Coimbra JA, Marcon SS. A experiência da família frente à abordagem para doação de órgãos na morte encefálica. *Rev Gaúcha Enferm*. 2009; 30(3): 375-82.
- Lopes AG. Doação de órgãos: um estudo sobre produção de sentidos [dissertação]. Rio de Janeiro:Universidade do Estado do Rio de Janeiro. Instituto de Medicina Social; 2009.
- Manzari ZS, Mohammadi E, Heydari A, Sharbat HR, Azizi MJ, Khaleghi E. Exploring families' experiences of an organ donation request after brain death. *Nurs Ethics*. 2012; 19(5):654-65.
- Roza BA. Efeitos do processo de doação de órgãos e tecidos em familiares: intencionalidade de uma nova doação [tese]. São Paulo: Universidade Federal de São Paulo. Escola Paulista de Enfermagem; 2005.
- Saúde, S.d. Distribuição das notificações de doadores potenciais e viáveis, segundo organização de procura de órgãos (OPO) São Paulo 2009. 2009 [citado 2010 Out 16]; Disponível em: http://www.saude.sp.gov.br/content/cidadao_extras_servicos_informacoes_orientacoes_transplantes_doadores_segundo_opo.mmp.
- Brasil. Presidência da República. Lei n. 10211, de 23 de março de 2001. Altera os dispositivos da Lei n. 9434, 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". *Diário Oficial da República Federativa do Brasil, Brasília (DF); 2001 Mar 24. Edição extra.*
- Brasil. Decreto n. 2268, de 30 de junho de 1997. Regulamenta a Lei n. 9434, 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, e dá outras providências. *Diário Oficial da República Federativa do Brasil, Brasília (DF); 1997 p. 13739.*
- IBGE. Distribuição das principais causas de morte, Brasil – 1980, 1996 e 2004. 2005 [cited 2012; Available from: http://portal.saude.gov.br/portal/saude/visualizar_texto.cfm?idtxt=24421 c
- Instituto Brasileiro de Geografia e Estatística. Censo 2010 [citado 2012 Ago 10]. Disponível em: <http://www.censo2010.ibge.gov.br/apps/mapa/>

21. Saleem T, Ishaque S, Habib N, Hussain SS, Jawed A, Khan AA, et al. Knowledge, attitudes and practices survey on organ donation among a selected adult population of Pakistan. *BMC Med Ethics*. 2009; 10:5.
22. Ghorbani F, Khoddami-Vishteh HR, Ghobadi O, Shafaghi S, Louyeh AR, Najafzadeh K. Causes of family refusal for organ donation. *Transplant Proc*. 2011; 43(2):405-6.
23. Wakefield CE, Reid J, Homewood J. Religious and ethnic influences on willingness to donate organs and donor behavior: an Australian perspective. *Prog Transplant*. 2011; 21(2):161-8.
24. Wakefield CE, Watts KJ, Homewood J, Meiser B, Siminoff LA. Attitudes toward organ donation and donor behavior: a review of the international literature. *Prog Transplant*. 2010; 20(4):380-91.
25. Santos MJ, Massarollo MC, Moraes EL. Family interview in the process of donating organs and tissues for transplantatio. *Acta Paul Enferm*. 2012; 25(5):788-94.
26. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA*. 2001; 286(1):71-7.