

# Factors involved in the refusal to donate bone tissue

Fatores envolvidos na negativa da doação de tecido ósseo

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## Descritores

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## Abstract

**Objective:** To determine the main variables involved in the refusal to donate bone tissue among relatives of organ donors, and the prevalence of bone tissue donation.

**Methods:** This was a cross-sectional, quantitative study. Variables related to donation requests for bone tissue were studied, comprising information about the bones that would be procured, the reconstruction of the body, the reasons that led to the refusal to donate bone tissue, prior knowledge about donation, and intention to become a donor.

**Results:** We demonstrated three factors that influenced the refusal of family members, including: lack of understanding of which bones would be removed (92.9%), how the body would be reconstructed after bone removal (96.5%), and how the body would be presented after bone procurement. The prevalence of bone tissue donation was 17.2%.

**Conclusion:** The family decision to refuse to donate bone tissue was represented by the lack of comprehension of the subject. The low prevalence was due to the reduced request of this type of donation.

## Resumo

**Objetivo:** Determinar as principais variáveis envolvidas na negativa da doação de tecido ósseo em familiares doadores de órgãos e a prevalência da doação desse tecido.

**Métodos:** Trata-se de um estudo transversal, quantitativo. Foram estudadas variáveis referentes à solicitação da doação do tecido ósseo, compreendendo informações a respeito dos ossos que seriam captados, a reconstituição do corpo, os motivos que levaram à negativa da doação desse tecido, conhecimentos anteriores sobre doação e intencionalidade em ser doador.

**Resultados:** Evidenciamos três fatores que influenciaram a negativa pelos familiares incluindo o desconhecimento sobre quais ossos seriam retirados (92,9%), como ocorreria a reconstituição destas estruturas (96,5%) e como se apresentaria o corpo após a captação. A prevalência de doadores de tecido ósseo foi de 17,2%.

**Conclusão:** A decisão familiar de recusar a doação do tecido ósseo foi representada pelo desconhecimento do tema. A baixa prevalência foi devido à reduzida solicitação deste tipo de doação.

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## Introduction

In modern medicine the extraordinary progress in the removal and transplantation of organs, tissues and parts of the human body for therapeutic and scientific purposes is emphasized. For a long time transplant was considered a very bold and experimental technique, but currently it emerges as an unquestioned therapy, with the impact of rescuing and rehabilitating the human being.<sup>(1)</sup>

It is a treatment that arouses many questions, provokes numerous doubts and, because of its complexity, hinders donation of organs and tissues, making it impossible to execute without societal recognition and awareness to the act of giving, remembering that there will be no transplants if there are no donations.

According to the Brazilian Association of Organ Transplantation (ABTO), in 2013, Brazil reached the target of 13.2 donors per thousand people and the state of Santa Catarina reached 27.2 effective donors per thousand, which is the best result ever achieved by a Brazilian state. This result depends, largely, on the stimulus of the local public sectors, as well as the state government, in solving a sequence of small obstacles in the logistics of the process of donor identification through to the performance of transplants, which also depends on the harmonious relationship between health workers who provide care for potential donors and their highly committed and motivated coordination.<sup>(2)</sup>

In order to increase organ and tissue transplantation in Brazil, it will be essential to improve the four pillars that support the process of donation for transplantation, which are: legislation, funding, organization and education. Among the organizational measures deemed essential are: the training and motivation of medical doctors in intensive care, neurology and radiology; targeting the diagnosis of encephalic death; and maintaining potential donors. Finally, educational policies are also needed, both for professionals and for students of health areas and the population in general.<sup>(3)</sup>

Contributing to this aforementioned picture is the small number of Tissue Banks in Brazil, because without an appropriate and certified site for prop-

er handling and storage of this specific material, there is also no way to request families to permit donations. Currently, there are six Musculoskeletal Tissue Banks registered within the entire country: three in the state of São Paulo, one in Parana, one in Rio de Janeiro, and one in Pernambuco.

Despite the large potential, Brazil still has a much lower utilization rate of bone grafts than those seen in developed countries, and among neighbors in South America, specifically, Argentina and Uruguay. This is mainly due to three factors: the lack of knowledge of the population about the possibility of musculoskeletal donation; the lack of experience of surgeons regarding the possibilities of using homologous grafts, and little familiarity with the surgical techniques; and moreover, the bureaucratic obstacles imposed by the Ministry of Health, hindering the authorization of surgeons and health-care facilities for the use of grafts.<sup>(4)</sup>

In this context, to understand the decision of family members who donated organs, but refused bone tissue transplant, and also with a view to help guide future actions that may increase the number of donors and transplants, this study was developed to determine the prevalence of bone donation and to understand the main variables involved in the refusal of this tissue donation among organ donors.

## Methods

This cross-sectional study was conducted with family members of organ donors who had not authorized bone tissue donation, from the Organ and Tissue Procurement Service (OTPS) in Ribeirão Preto, a city in São Paulo state, in southeastern Brazil.

From January 2009 to June 2012, a total of 388 potential organ donors with encephalic death were reported; among these, 151 became effective donors and 87 families refused to donate the organs of their relatives.

The study sample consisted of 75 families who agreed to participate; exclusions from the study included nine relatives who were outside the OTPS area of operation, seven due to the age of the donors being outside the limit allowed by the tissue banks,

26 were of those who donated bone tissue, 11 families refused to participate, and 23 were not located during the data collection period.

Initially, sociodemographic and epidemiological data from the records of organ donors were collected; thereafter, a database was prepared, family members were contacted, and the interviews with the relatives were scheduled.

Data collection occurred through the use of interviews, using a structured form based on the instrument developed and validated by Roza (2005) for the survey of epidemiological data, after receiving authorization from the author. Other specific data, particularly on bone tissue, were evaluated and validated by a panel of experts.

The study variables consisted of the request for bone tissue donation, information about the bones that would be removed, the reconstruction of the body, the reasons that led to the tissue donation refusal, and prior knowledge about the donation of organs and bone tissue.

To describe the quantitative variables, the absolute (n) and relative (%) frequencies were calculated.

The study was developed following national and international standards of ethics in research involving human beings.

## Results

The majority of family members (62.7%) stated that there was no request for bone tissue donation, followed by 37.3% of respondents who reported that they were asked about this tissue donation.

Among the 28 total family members from whom the donation of bone tissue was requested, 92.9% responded that they did not have information regarding what bones would be removed from the body of the deceased donor.

For those family members (7.1%) who received this instruction, we asked what kind of information they received and the responses are described below, in their entirety:

*(The Social Worker) said that they were taking the biggest bones, and then I understood that to be the femur (?). And that she would be buried without her*

*legs. This is very distressing and that is why we did not donate! We went to check during the funeral to see if my mother was without her legs. We took all the flowers from the coffin and took a look. I do not think you need to deform the body in order to donate. They said they would take the big bones and the coffin should be sealed, then my mom got scared and did not accept this because we were going to take my brother to be buried in Minas Gerais.*

It was also found that 96.5% of family members reported that no information was provided regarding the procedures that would take place to reconstruct the donor's body after removal of the bone tissue. Only one (3.5%) relative said that, in her work as a nursing technician, she asked professionals about the reconstruction of the body and obtained assertive information about it.

Due to the lack of information about which bones would be removed and how the body would be reconstructed, some testimonials of the relatives were portrayed below:

*This thing of donating bone is very rough, we did not know how the body would be, and we had to bury something.*

*We were scared, wondering if she was going to get all bruised and deranged.*

*I was very upset and scared, not knowing that this type of donation existed or how my father would end up.*

When asked if they would donate this tissue if explanations concerning the removal of the bones and the reconstruction of the donor body had been previously provided, 85.7% of families responded that, in that moment, they would maintain the position of refusal, because they were totally ignorant about this kind of donation, as were other family members. For 14.3% of family members, if there had been an explanation of the procedure as a whole, the donation of bone tissue would have been permitted.

It was observed that the majority (60.7%) of family members reported prejudice against the idea of mutilation of the body and an unpreserved appearance of their family member, followed by displeasure; 39.3% of family members reported that they had not authorized the donation because they

did not know what would really be removed and what the final appearance of the donor would be.

To exemplify the content of these statements, we highlight:

*I thought my daughter was going to be all deformed, a monster! Were you going to put cotton inside to fill her face?*

*It is very strange that thing of donating bone. What we were going to bury? There has to be something for us to go to bury and to cry at the cemetery!*

*I did not authorize the donation of bone tissue; I did not know about that nor did I feel prepared for this type of donation.*

*What no longer serves for us can serve others, but this type of donation of bone I cannot approve, due to a spiritual matter, because something must rest there for us to be able to pray at the tomb!*

A majority, composed by 94.7% of family members, said they were knowledgeable about the subject, "Donation and Organ Transplantation" and its importance; 97.3% reported total ignorance about the subject, "Donation and Transplantation of Bone Tissue", with the two (2.7%) family members who were knowledgeable about donating bone acquiring this in their performance of professional activities in hospitals.

The intent to be an organ donor was expressed by 74.7% of family members, and only 32% expressed the intention to be a bone tissue donor, and that was only after obtaining specific information about the removal of bones and reconstruction of the body during the interview.

The means of communication most often cited by family members for the clarification of the public on the existence of bone tissue donation and transplantation was the television, with 54 statements, exemplified by prime-time commercials and images of great impact.

The prevalence of bone tissue donation by family members of organ donors was 17.2%.

the part of the relatives of organs donors, mainly on the subject of bone tissue donation and transplantation related to which bones would be removed and variables consisting of reconstruction of the body of their family member. These variables directly influenced the intent to refuse this tissue donation as evidence by the fact that when asked if, at the time of the donation request, information about it had been clarified, most families would still have chosen to refuse, due to misinformation and displeasure concerning the idea of mutilation of the body, shown in their surprise and disapproval.

Often, family members do not have a clear understanding of the donation process, increasing the refusal of family consent. It is evident that the reasons for denying or refusing donation are diverse in nature and motives may be covered by altruism, as it was noted in the present study that the type of approach used was not enough to motivate family members into action, a fact that could increase the number of donations. In reviewing literature data, authors mentioned that emotional support, assistance offered to families, and information about the process seemed to be essential to encourage the attitude for donation.<sup>(5,6)</sup>

Continuing with the analysis of published studies, we did not find a similar study that highlighted factors that led to the refusal for donating bone tissue among relatives of solid organ donors, but the theme was indirectly related with studies on organ and tissue donation and the refusal of donation by the family, so we attempted to find a convergence of findings reported in the literature with those found in this study.

A study conducted in Spain, which explored the perceptions of transplant coordinators on the reaction from relatives of deceased potential donors, exclusively multi-tissue, found the reasons given by the family not to complete donation included, with higher frequency: the alleged refusal in life of the potential donor; not wanting the body of their relative to be touched; not wanting to make this decision because they ignored the desire of the potential donor; as well as having conflicts with the health system, religion and other factors. We concluded that the variables that influenced the decision mak-

## Discussion

The results showed the total lack of understanding of the variables related to the process of donation on

ing of families regarding multi-tissue donation were similar to those cited by respondents in the bone tissue donation process, stating expressions of surprise, disapproval, and the urgency for making immediate decisions.<sup>(7)</sup>

For the experts on this theme, the encouragement to talk about death could result in an increase of acceptance of donation, since the discussion about it permits the deconstruction of the taboo and allows for the wishes of the deceased to be known - a factor that stands out as a facilitator to donation within transplant services.<sup>(8)</sup>

The high frequency of organ donation compared to tissue donation, found in this study, corroborates previously reported data that attributed this fact to fear of body deformity, when family members are not adequately informed about the procedure or do not have enough support during the process.<sup>(9)</sup>

Clarification on the topic is needed so that people can consciously decide, with certainty, and without doubt or fear.

Disclosure is of fundamental importance for the population, to create an opinion on the issue of organ and tissue donation, and the media has an important role in the formation of consciousness.<sup>(10)</sup>

It is believed that all the media can disseminate the possibility of donation and transplantation of bone tissue, guiding not only the professionals in the health field, but the public in general, and hence preventing inadequate concepts that are obstacles to increasing the number of donations.

The relevance of this study was based on the importance of improving information about the process of bone tissue donation, aiming to minimize one of the major problems evidenced in the area, which is exemplified by the lack of availability of this tissue within the transplant arena.

## Conclusion

The family decision to refuse donation of bone tissue was represented by the lack of understand-

ing of which bones would be removed during removal, as well as how these structures would be reconstructed, and how the donor's body would be presented after removal. The factor influencing the occurrence of low prevalence of bone tissue donation was the reduced request of this type of donation by the professional responsible for the family interview.

## Collaborations

Pompeu MH collaborated with the project conception, research development, analysis and interpretation of data, and draft of the manuscript. Silva SS; Roza BA and Bueno SMV collaborated with relevant critical revision of intellectual content and final approval of the version to be published.

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