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# Gap analysis and perspectives on body donation programs: experience report in Brazil

Análise de lacunas e perspectivas sobre programas de doação de corpos: relato de experiência no Brasil

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#### **ABSTRACT**

**Introduction:** International recommendations reinforce the practice of voluntary donation for providing bodies for the training of health professionals, replacing the system of unclaimed bodies in medical courses (MC).

**Experience report:** This work gathered information on Brazilian body donation programs (BDP), analyzed gaps and difficulties to the effectiveness of body donation, and proposed strategies to expand the information offered on the registration of participants in BDP and the effectiveness of the donation.

**Discussion:** In Brazil, there are 39 BDP – six in the Northeast, four in the Midwest, one in the North, 11 in the South, and 17 in the Southeast – and two committees for body donation. Documents may be easily available through registration during life as a participant in the BDP, but it does not guarantee donation. In general, Brazilian's institutions receive the donated body along with the documentation. When the death occurs in the same city of the institution, it is possible to have the transfer of the body provided by partnerships with funeral services and the city hall. There is no fee to be paid or received either for registration during life or for donation after death.

**Conclusion:** Although the legislation has regulated the donation of body in life since 2002, it is necessary to implement campaigns to inform about the donation, in addition to mechanisms that can promote speed in the deadlines for obtaining documentation for the purpose of donating body for scientific purposes, the exemption of notary fees and the possibility of transporting the body donated with no fees by funeral home of municipal governments. The MC support through the registration of the PDC as an extension activity collaborates to ensure ethical aspects related to the participation of donors in the living program, with regard to the treatment with respect and dignity of donors and their families.

Keywords: Body Donation; Anatomy; Legislation.

# **RESUMO**

**Introdução:** As recomendações internacionais reforçam o estímulo à prática da doação voluntária para a disponibilidade de corpos destinados à formação de profissionais de saúde, substituindo o sistema de corpos não reclamados nas instituições de ensino superior (IES).

**Relato de experiência:** Este trabalho reuniu informações sobre programas de doação de corpos (PDC) brasileiros, analisou lacunas e fatores impeditivos à doação do corpo, e propôs estratégias para ampliar as informações sobre o cadastro de participantes em PDC e a efetivação da doação.

**Discussão:** No Brasil existem 39 PDC em funcionamento – seis no Nordeste, quatro no Centro-Oeste, um no Norte, 11 no Sul e 17 no Sudeste – e duas comissões de distribuição de corpos para ensino. O cadastro como participante no PDC pode agilizar as providências documentais, mas não garante a doação na ocasião da morte. No geral, as IES recebem o corpo doado e a documentação necessária. Quando o óbito acontece no município da IES, é possível ter o translado do corpo providenciado por parcerias com funerárias e prefeitura.

**Conclusão:** Embora a legislação tenha regulamentado desde 2002 a doação do próprio corpo em vida, é necessária a implementação de campanhas de esclarecimento à população geral sobre essa possibilidade, além de mecanismos que possam promover a celeridade nos prazos de para obtenção das documentações com a finalidade de doação de corpo para fins científicos, a isenção das taxas cartoriais e a viabilização do translado do corpo doado por carro de funerária das prefeituras, sem custo. O apoio da IES por meio do cadastro do PDC como atividade de extensão universitária colabora para assegurar aspectos éticos relacionados à participação dos doadores no programa em vida, no que se refere ao tratamento com respeito e dignidade dos doadores e de suas famílias.

**Palavras-chave:** *Doação de Corpo; Anatomia; Legislação.* 

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#### INTRODUCTION

Although there are alternative available technologies, there is still no consensus on the possibility of replacing the dissected human body in anatomy teaching, ensuring perceptions of texture, dimensions and syntopy between structures of the human body<sup>1-5</sup>. The practical learning, using the human body, was related to a lower possibility of errors in medical procedures, due to the training of essential skills and competences for the training of health professionals<sup>6</sup>. In addition to technical learning, the ethical and moral burden involved, providing a humanized training, by placing the student, or professional undergoing training, in the presence of a dissected human body<sup>3,7,8</sup>.

The International Federation of Anatomists (IFAA) recommends that obtaining human material for teaching should occur through body donation programs, replacing the use of unclaimed bodies for this purpose<sup>9-12</sup>. Moreover, among the good practices recommendations of this federation to guide the adequate operation of body donation programs (BDPs) for scientific purposes, is the use of a term of donation that contains the notarized signature, as a form of consent of the donor who registers it during one's lifetime<sup>12</sup>.

In Brazil, most higher education institutions (HEIs) use unclaimed bodies to teach human anatomy, supported by Law N. 8,501, of 1992<sup>13</sup>. However, this number has been progressively reduced<sup>3</sup>, since the technological development and resources for identifying individuals and locating their family members, have resulted in a reduction in the number of unclaimed bodies available for this purpose<sup>14</sup>. A recent quantitative survey of BDPs found a total of 28 programs in Brazil in 2019<sup>15</sup>. The highest prevalence is found in public universities, preferably concentrated in the South and Southeast regions. However, according to the Federal Council of Medicine (CFM, Conselho Federal de Medicina), with 342 medical schools, Brazil currently has an average of 10.4 newly graduated medical professionals for each group of 100,000 inhabitants<sup>16,17</sup>. The disproportion between the number of BDPs and medical schools suggests that encouraging the creation of new BDPs can solve the lack of bodies for teaching and research purposes.

Another aspect to be considered is that the majority of the Brazilian population is unaware of the possibility of donating their own body, during one's lifetime, to science, although Law n. 10.406<sup>18</sup> of the Brazilian Civil Code has guaranteed this process since 2002 <sup>3,19-27</sup>. Given this context, a search was carried out for existing BDPs in the country and interviews were conducted with the team members of these programs aiming to assess the operating structure and difficulties related to the implementation of these programs by Brazilian universities.

#### **EXPERIENCE REPORT**

A university extension project was prepared and approved by the Pro-Rector of Extension Culture and Sport (PROECE, *Pró-reitora de Extensão Cultura e Esporte*) of Universidade Federal de Jataí, aiming at interviewing members of the BDP team operating in the country. The extension action was proposed in partnership with TV Câmara and the School of Management and Legislative Efficiency (EGEL, *Escola de Gestão e Eficiência Legislativa*) of the City Council of Jataí.

The survey of BDPs in operation initially considered data published by da Silva et.al.<sup>15</sup> in 2019 (28 BDPs), followed by a search on research sites using the terms "body donation program" and "body donation for scientific purposes". Two state commissions were identified in Brazil, which were in charge of attracting and distributing bodies to the HEIs, in addition to 39 BDPs organized in different HEIs, distributed in the Northeast (6), Midwest (4), North (1), South (11), and Southeast (17) regions. Based on these data, a schedule of activities was organized, with a list of BDPs and the respective virtual interview prediction. An invitation letter was sent via Official Letter (Process SEI n. 23854.001433/2022-51), together with the copyright transfer document, authorization to record the interview, and public disclosure of the material produced by TV Câmara. All positive responses were followed by the creation of the interview script with the interviewee. This document was shared for the editing of questions and topics to be discussed, according to the interviewee's preference, and filling in of information about the BDP: e-mail, contact telephone number, teacher/technician in charge, and virtual page. Such information was filled in by the team of each BDP so it could be made available on the interview screen without typing errors, with the aim of disclosing it.

Of the 41 invitations sent, 34 answered positively. The interviews were conducted with teachers, technicians and members of the organizing team of each BDP. The virtual meetings took place between March and September of 2022. Six BDPs did not participate due to unavailability of team members, such as: medical leave, transfers and dismissals. The interviews were recorded and made available as open access on social networks aiming to offer audiovisual material for local dissemination and information for the population about body donation for each BDP.

# **Body Donation through Body Distribution Committees**

A Committee was located at the state level (Paraná) and one at the municipal level (Brasília). The board members of these councils and committees that regulate body donation for scientific purposes were appointed to share, through recorded interviews, information aimed at providing information to

the population. According to the interviewees' reports, in most cases, donations take place through the action of family members, when there was a verbal manifestation of the intention to donate one's body, during the deceased person's lifetime. The documentation is provided by official letter from the death certificate or declaration issued by the Death Verification Services (SVO, Serviços de Verificação de Óbito) or Coroner's office (IML, *Instituto Médico-Legal*). When the body originates from the IML, in addition to the death certificate, it is necessary to wait for the Body Release document, and respective personal documents that confirm the family relationship with the donors. Then, the Death Certificate is requested through an Official Letter, which is free of charge, in accordance with Article 45 of Law N. 8935, of 1994<sup>27</sup>. In this document, the death certificate must be drawn up, mentioning the HEI that will receive the donated body.

In the Federal District there is great incentive and collaboration for the provision of biological material for scientific purposes. The Public Ministry of the Federal District and Territories (MPDFT) published Ordinance n. 01 of 2010<sup>28</sup>, which provides for the distribution of bodies donated by the *Pró-Vida* program to HEIs<sup>28</sup>. Around eight HEIs are registered to receive donations on a rotating basis through this program. If there is an available body, a teleconference is scheduled with the HEI at the time, within 24 hours of the family's expression of interest in donating, making it possible to prepare the body at the health units or IML, although the HEI can move the technical team for this purpose, or forward the body for preparation at the anatomy laboratory. Usually, there is a body distribution rotation system, so that all registered HEIs are contemplated equally, although the donor can choose the HEI of their choice. There are no notarial fees, although the cost of transferring and preparing the body is the responsibility of the HEIs.

In the resolution signed by the attorney general of Justice n. 2455 of 2016<sup>29</sup> which regulates the supervision of the Public Ministry in the state over the processes of distribution of unclaimed bodies, as well as those originating from donations to HEIs registered with the State Council for Distribution of Corpses (CEDC, Conselho Estadual de Distribuição de Cadáveres), for study and research purposes<sup>29</sup>. Approximately 38 HEIs are registered to receive donations. There is a rotation system for body distribution, which seeks to make an equal distribution between the HEIs. The territorial extension of the state and the rotation system may represent some difficulty for the HEI to receive the body, when the body to be donated is far from the HEI following the rotation queue. However, direct donation to the HEI is possible, especially when there is a BDP in operation at the HEI. Although some HEIs have an agreement with notary offices, notarial fees for donation terms are the responsibility of the family or donors. The costs of the transportation are the responsibility of the HEI that will receive the body and the expenses with the preparation of the body are also the responsibility of the HEI, which can also hire an outsourced technical team to go to the health unit or IML that received the body after death.

# Body Donation through the Body Donation Program (BDP)

It was observed that all the interviewed BDPs had the BDP project, when it was created, appraised and approved by an institutional council or committee, preferably the Pro-Rectory of Extension and Culture or the University Council. Then, generally, all terms of donation were appraised by the Institutional Legal Department. Although donation for scientific purposes is provided for in federal legislation<sup>18</sup>, the BDP registration as a university extension activity can guarantee users (internal and external academic community) not only compliance with institutional protocols, but also the transparency of the process, ensuring that good practices be followed when carrying out the BDP activities, in accordance with national and international recommendations<sup>10,11</sup>. An opinion from the Research Ethics Committee (REC) is not required for the creation of the BDP and the respective associated extension actions. This recommendation was sent on December 1, 2022 by the National Research Ethics Committee (CONEP, Comissão Nacional de Ética em Pesquisa), as an Official Letter number 26-2022/CONEP, for recommendations to all Research Ethics Committees in operation at Brazilian universities. However, as with any research, all protocols originated from BDPs must be appreciated by local ethical committee.

# Donor registration and signature of the Term of Donation (TD)

Among the recommendations of good practices cited to guide the adequate functioning of the BDPs, the consent of the registered participant during their lifetime is a prerequisite, in addition to the requirement of the notarized signature of the term of donation (TD) in life<sup>8,12</sup>. The TD consists of a statement authorizing the use of one's body in part or as a whole for scientific purposes, after death. This prerequisite is essential and consists of legal support for the HEI. Donors must be completely free in their decision to donate, thus this excludes donations from those under 18 years, death row inmates, and institutionalized individuals.

Only the donor's signature must be notarized and, usually, the notarial fees are the responsibility of the donor and the family. Some states such as Rio Grande do Sul and Espírito Santo have made available the use of the Notarial and Registral

Inspection Seal EQL-2. This seal consists of a unique identifier code and a QR code (in the case of external acts), which are printed directly on the documents. Its technology allows documents to be easily identified, authenticated and tracked at no cost, as it is a document qualified as a voluntary service. It was observed that all interviewed BDPs adopted the TD as a prerequisite for donor registration.

In addition to the TD, a Registration Form (RF) can be made available, which records personal data, such as: gender, age, level of schooling, religion, among other demographic data, for database purposes. In this sense, considering the future possibility of research with donated biological material, the Informed Consent Form (TCLE, Termo de Consentimento Livre e Esclarecido) must be presented to the donor, which registers the aforementioned permissions and refusals for education and research purpose. There is no need for a notarized signature on the RF and TCLE. Completion of the living donor registration can be consolidated by the issuing of the "Donor Card". This document, in addition to representing an important disclosure tool, confirms compliance with all the institution's documentary prerequisites.

The terms of donation by the donor (TD) and the term of donation by the family member or legal guardian (TF) must include the name of the HEI that will receive the body and may contain a clause that provides for the future possibility of transferring the body to other HEIs, which can be accepted or not by the person when registering. All consulted BDPs usually register and identify the collection of stored biological material (received bodies), as well as when a body is transferred to another HEI.

# Donation by the Family (TF) or legal guardian

Most programs accept both the donation through registration carried out by the donors themselves during their lifetime, and the donation made by family members or a legal guardian (without prior registration), when there has been a prior manifestation by the person of the intention to donate one's body, but the registration (TD) has not been carried out, and the family expresses a consensus on this donation. Donation by family members or legal guardians, without prior registration by the donor, is supported by law, and must include completion of the Term of Donation by the Family or legal guardians (TF). That is, in the absence of the TD with a notarized signature, Article 4 of Law 9,434 of 1997<sup>20</sup> (and Law 10,211 of 2001)<sup>23</sup> is used, which describes the need for a term signed by the family for the donation of organs, tissues or body parts. Among the donations by the family, we can mention the donation of stillbirths through the signature of the TF, which must be registered in a notary and delivered with the

death certificate. In the situation of a abortion (when the fetus weighs more than 500g, or is longer than 25 cm, or gestational age is greater than 22 weeks), the family is responsible for the fetal destination<sup>30</sup>.

## Donating organs or body parts during one's lifetime

When there is an abortion of the fertilization product, usually with parameters lower than the criteria described above, there is no legal need to issue a death certificate. In this situation, the responsibility for the destination of the fetal loss lies with the assisting health service, since the family is legally unable to carry out the burial or cremation procedures, except by formal request. Parts of the human body of living people, submitted to surgical treatment (limbs, organs, placenta and abortion products), are considered biological material whose destination is the pathology service (for examination of the part) or incineration by the assistant health service (hospitals, clinics, laboratories, health departments), if it is discarded material. By characterizing the scientific value, the material no longer meets the conditions of Group A of Collegiate Board Resolution (RDC, Resolução de Diretoria Colegiada) n. 222 of the National Health Surveillance Agency - Anvisa<sup>31</sup>. If the family wants to donate the fertilization product (abortion) for study purposes, it will be possible through the term of donation of organ or body parts (TO), prior to the surgical treatment of that organ.

# **Body Transfer**

When the registered donor dies, the family must contact the BDP to notify them of the death. At this point, the BDP must organize its team to start the process of collecting the body, which includes the presence of an HEI employee (most often the anatomy laboratory technician) and the undertaker, the latter responsible for transporting the body. The presence of the undertaker is a legal requirement for the procedures for releasing the body and transporting it. The HEI employee, duly identified, becomes the representative of the institution that becomes responsible for the body, after the process of issuing the death certificate containing the drawing up of the death settlement for the HEI of destination of the body (in the field destined at the placement of the cemetery where the body will be buried, will be placed the name of the HEI that will receive the body).

Some partnerships may make it possible to transport the body from the place of death to the anatomy laboratory of the HEI that will receive the donation, such as partnerships with the municipal government, funeral home or local hospitals. Another possibility is to carry out a bidding process by the HEI to hire a funeral service responsible for carrying out the legal release process, collecting the body and transporting it, considering

the short viability of the body after death. However, when the death happens far from the HEI, in view of the cost, the family can arrange for the transfer (funeral service and car).

The establishment of partnerships should aim to facilitate the collection of bodies, reduce the financial cost when it comes to transportation and notarial expenses. The donation of the body, in whole or in part, must be completely free and subject to voluntary consent, motivated by solidarity in favor of improving the quality of teaching and scientific progress in the health area9- $^{12,17,21}$  and, in addition, according to article 15 of Law 9,434 of 1997<sup>20</sup>, (and Law n. 10,211 of 2001)<sup>23</sup>, the trade in tissues, organs or parts of the human body constitutes a crime. In this way, other charges or financial considerations are not recommended, and only the expenses inherent to the death process, to obtain the relevant documentation, are the responsibility of the donor or their family members. All information on the preparation, handling of the body, and conditions of destination of the mortal remains must also be provided. The individual, when registering in a BDP, must be aware that formalizing participation in the extension action only organizes the documentary arrangements, but it is not a guarantee of acceptance of the body by the laboratory, having as main conditioning factors: the cause of death, place of death and family decision.

# **DISCUSSION**

The contribution to the qualification of medical learning was the biggest motivating factor for donation reported by respondents and confirmed in the literature<sup>13,32-39</sup>. The main limiting factor identified for the increase in body donations is based on the lack of knowledge by most of the Brazilian population about the possibility of donating one's body during their lifetime; however, other factors such as the difficulty of locating the BDP in the interior of the country, and the lack of knowledge about the registration process during one's lifetime are also factors that make the donation process difficult. However, a significant increase in the number of BDPs was observed in Brazil: of the 28 BDPs operating in 2019<sup>15</sup>, 39 were quantified in 2023, that is, there were 11 new BDPs in four years.

The lack of clear information about body donation and the whole process related to it favors the emergence of doubts, such as the possibility of having farewell rituals after the death (death wake), the lack of knowledge about the process of preparation, storage and disposal of the body after the study, how the body will be treated by the students and by the support team of the anatomy laboratories<sup>14,32-37</sup>. Although donors or their families may be afraid of disrespect for the donated body, it is important to highlight that the vilification of bodies is considered a crime against respect for the dead, provided for in article 212 of the Brazilian Penal Code.<sup>22</sup>

In a recent study, Riederer<sup>33</sup> stated that to maintain the BDP, it is essential to first understand the "common sense" of the population on the subject, and then adopt strategies that encourage donations. Moreover, the same author suggests that donor profile studies provide useful information about donors, and the reasons why they donate, which can be used to target potential donors when establishing BDPs, to circumvent difficulties in finding donors, or to monitor changes in the donor profile. In Brazil, da Rocha AO, et.al. (2017)<sup>37</sup> in an analysis of 400 donors registered in the BDP of Universidade Federal de Ciências da Saúde de Porto Alegre (UFCSPA), observed that most people who decided to donate their bodies (registered) were predominantly elderly, female, single or unmarried, affiliated with a religious group, middle class and who had at least finished high school or had finished or not a higher education course, with 60% of the donors being over 60 years old at the time of the registration. An absence of religious affiliation among potential donors has been described in some studies<sup>32,39</sup>. In this Brazilian study<sup>37</sup>, on the contrary, 89% of the donors registered in the BDPs declared belonging to some religious group, and this was not a factor that influenced the decision<sup>38-39</sup>. Thus, the study of the donor's profile helps not only to identify this group to direct awareness campaigns about donation, but also to dispel some myths about the donation.

All interviewed BDPs allow farewell ceremonies and death wakes on the occasion of death, provided that there is a prior dialogue allowing the process of preparing the body within the deadline. Some BDPs hold an annual ceremony in acknowledgement to body donors for science, which helps to demystify the donation process and demonstrates to the donors' families the students' respect when using these bodies to study<sup>24,40</sup>. Visits to anatomy laboratories are also not allowed by most of the interviewed BDPs, leaving the display of human material for academic-scientific purposes only.

The population's lack of information is frequently cited in the literature and was the main difficulty reported by the respondents<sup>26,27,33-40</sup>. Disclosure should start within the academic community itself, when the BDP is created, and go through the various Institutional instances, so that the students themselves act as information agents, when questioned. And, only after the complete internal structuring of the BDP, external disclosure through the media should begin. In some HEIs, the absence of virtual pages about the BDP linked to the institutional website, the lack of telephone contact or even institutional email was observed. On the other hand, some BDPs have pages on institutional websites with all the necessary information and documents, a toll-free dialing system, such as a 0800 number, or provide a "donor card" based on an institutional identification card.

Based on these observations, it is necessary to raise awareness in the internal (academic) community, including scientific evaluation committees, outsourced personnel and service providers to HEIs, about the importance of BDPs for teaching, training of health professionals and benefits for society. Many programs promoted dissemination to the population, through printed media, using pamphlets and educational lectures in nursing homes, hospitals and religious centers. However, all the interviewed BDPs agreed that the dissemination in the media (Radio, Newspaper and TV) led to an increase in the demand for information about the possibility of body donation and for registrations in the BDPs. The recognition of the donor's profile proposes the recommendation of special attention to dissemination in social networks, which are mostly used by younger individuals, different from the target audience of the BDPs, which are elderly individuals.

#### **FINAL CONSIDERATIONS**

The creation of BDPs is a growing reality in the country, due to the reduced availability of unclaimed bodies. Although the legislation has regulated the donation of one's body during their lifetime since 2002, it is necessary to implement campaigns to clarify the general population about this possibility, in addition to establishing mechanisms that can promote speed in the deadlines for obtaining documentation for the purpose of body donation for scientific purposes, the exemption of notarial fees and the feasibility of transferring the body donated by funeral home cars of municipal governments, free of charge. There is a consensus in the literature8-12,22,37-39, and among the interviewed BDP teams40, about the need to ensure ethical principles for the adequate operation of the BDP, regarding the treatment with respect and dignity of donors and their families. The HEI's support through the registration of the BDP as a university extension activity collaborates to ensure ethical aspects related to the participation of donors in the program during one's lifetime. All the interviewed BDPs submitted the project for the appreciation of the legal bodies of the HEIs and the Pro-rector of Extension and Culture (PROECE) or the University Council (CONSUNI). Promoting recommendations to society on the value of the donation ensures transparency to the process and increases the credibility of the BDP, in addition to society's confidence in the procedures necessary to make the donation.

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### **AUTHORS'CONTRIBUTION**

Bárbara de Lima Lucas: responsible for writing the extension project for consideration and approval by the Pro-Rectory of Culture and Sports Extension (PROECE) of Universidade Federal de Jataí, developing the study, carrying out the interviews, in addition to designing and approving the final version of the manuscript. Andréa Oxley da Rocha: responsible for reviewing the terms, forms and documents, preparing the discursive part and for reviewing and approving the final version of the manuscript.

### **CONFLICTS OF INTEREST**

The authors declare no conflicts of interest.

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