# CUIDADO É FUNDAMENTAL

Universidade Federal do Estado do Rio de Janeiro · Escola de Enfermagem Alfredo Pinto

RESEARCH

DOI: 10.9789/2175-5361.rpcfo.v12.8505

# UNIVERSITY KNOWLEDGE AND OPINION ON DONATION AND ORGAN TRANSPLANTS

Conhecimento e opinião de universitários sobre doação e transplantes de órgãos

Conocimiento y opinión de universitarios sobre donación y trasplante de órganos

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#### How to cite this article:

Hanauer M, Burille A. University knowledge and opinion on donation and organ transplants. Rev Fun Care Online. 2020 jan/dez; 12:450-456. DOI: http://dx.doi.org/10.9789/2175-5361.rpcfo.v12.8505.

#### ABSTRACT

**Objective:** To analyze the knowledge and opinion of university students about organ donation and transplantation. **Methods:** qualitative research, carried out in a small municipality of Rio Grande do Sul. In addition to residing in the scenario and not being included in training for health work, it was determined as inclusion criteria an active academic link. Semi-structured interviews generated the information, which was organized by analysis of thematic content. **Results:** evidenced sensitive to and engaged in talking about the topic, however, when questions about the process and the possibilities of donation were addressed, knowledge was incipient and, at times, surrounded by myths and for fears. The concept of brain death and stages of the donation process, could be explored in campaigns, doubts were placed in these fields. **Conclusion:** It is recommended that in university spaces discussions be held that are transverse, which strengthen the idea of solidarity. **Keywords:** Health education; Organ donation; Transplant; Students; Collective health.

#### RESUMO

**Objetivo:** analisou-se o conhecimento e a opinião de universitários sobre doação e transplante de órgãos. **Métodos:** pesquisa qualitativa, realizada em um pequeno município do Rio Grande do Sul. Além de residir no cenário e de não estar inserido em formações na área da saúde, teve-se como critério de inclusão vínculo acadêmico ativo. Entrevistas semiestruturadas geraram as informações, sendo estas apresentadas pela análise temática. **Resultados:** evidenciou-se sensibilidade e engajamento ao falar da temática, no entanto, quando direcionadas questões sobre o processo e as possibilidades de doação, o conhecimento mostrou-se incipiente e, por momentos, envolto por mitos e medos. Alguns assuntos, como conceito de morte encefálica e etapas do processo de doação poderiam ser exploradas em campanhas, à medida que muitas dúvidas dos participantes se situaram nesses campos. **Conclusão:** Recomenda-se que nos espaços universitários sejam asseguradas discussões transversais, que fortaleçam o ideário de solidariedade.

Descritores: Educação em saúde; Doação de órgãos; Transplante; Estudantes; Saúde coletiva.

DOI: 10.9789/2175-5361.rpcfo.v12.8505 | Hanauer M, Burille A | University knowledge and opinion on donation and organ transplants









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#### RESUMÉN

Objetivo: analizar el conocimiento y la opinión de universitarios sobre donación y trasplante de órganos. Métodos: investigación cualitativa, realizada en un pequeño municipio de Rio Grande do Sul. Además de residir en el lugar y de no estar cursando carreras para trabajar en salud, se determinó como criterio de inclusión vínculo académico activo. Entrevistas semiestructuradas generaron las informaciones, que fueron organizadas por análisis de contenido temático. Resultados: los participantes mostraron sensibilidad y compromiso al hablar del tema, mientras que, cuando se planteaban preguntas sobre el proceso y las posibilidades de donación, el conocimiento se mostró incipiente y, por momentos, cubierto de mitos y miedos. El concepto de muerte encefálica y etapas del proceso de donación, podrían ser explotadas en campañas, a medida que muchas dudas se situaron en esos campos. Conclusión: se recomienda que en los espacios universitarios sean garantizadas discusiones transversales, que fortalezcan el ideal de solidaridad.

**Descriptores:** Educación en salud; Donación de órganos; Trasplante; Estudiantes; Salud pública.

## INTRODUCION

Organ donation is an emerging theme that has received more and more attention in health spaces and in the media, as it offers a chance at surviving chronic illness and is an act of nobility. Transplant, besides being an opportunity for the continuation of life for the sick, improves the quality of life for those who live with it.<sup>1</sup> Although being a recurring theme, one of the contributing factors to the refusal of organ donation are inaccuracies – which make people insecure in authorizing or declaring the donation.

The donation can be based on different conceptions and the lack of clarification of doubts contributes to the refusal, which reveals the importance of encouraging people to think about donation and, if desired, to declare their intent to family members.<sup>2-3</sup> In this sense, organ donation implies the conscience of individuals: for those who need a transplant, there is the perspective of life that results from the failure of an organ, the solidarity that the act requires and the new possibilities glimpsed once the donation is confirmed. For those who donate or authorize the donation, it represents the comfort of changing someone else's life, even if experiencing the pain of loss.<sup>4</sup>

Brazil has one of the most recognized public organ donation programs in the world, with 95% of the procedures funded by the Unified Health System (SUS).<sup>5</sup> The Brazilian Association of Organ Transplants (ABTO) published a compilation from January to September 2017, which shows an increase in the rate of donations (16.6 per million people), reaching the proposed target for the year (16.5 per million people).<sup>6</sup> The increase in donations can be the result of educational actions that made society aware of the act of donating and investing in health - especially on the organization of a service network for organ localization and transplants.<sup>7</sup> Although the numbers achieved by the country are significant, according to ABTO<sup>8</sup>, there would be a possibility of expansion if professionals paid more attention to the notification and monitoring of brain death and in intensifying the work of sensitizing family members and society as a whole about the process, since the dissent of the family is one of the factors that leads to the low rate of donations. Given the above, aiming to contribute to the dissemination of knowledge and the awareness of the community on the subject, the study focused on analyzing the knowledge and opinion of university students about organ donation and transplants.

#### **METHODS**

This is a qualitative, descriptive and exploratory study<sup>9</sup>, which had as its setting a small municipality, located in the Caí Valley / Rio Grande do Sul. According to estimates by the Brazilian Institute of Geography and Statistics, it has a population of 13,273 people, distributed in urban and rural areas.<sup>10</sup> Among them many seek to continue their studies and thus attend universities both in the municipality as well as in neighboring municipalities.

The research adopted the following inclusion criteria: university students, residing in the municipality, enrolled in classes at the time of research. University students who graduated from the health sciences were excluded as well as those who, after two appointments, were unavailable for the interview, and those who did not allow the use of a tape recorder. As a technique for generating information, a semi-structured interview was chosen, consisting of three blocks: a) identification; b) knowledge; and c) opinions and positions about the problem.

The researcher invited a university student from her social relations cycle to participate in the research, who, when accepting, indicated another, using a recruitment technique that relies on reference chains among individuals called Snowball - also described as family universes.<sup>11</sup> The number of participants was determined by the saturation of information9, that is, when information collected is sufficient to respond collectively to the proposed objectives.

Twenty-three undergraduates were invited through the process, of which twenty remained, one was excluded for not agreeing to the use of a tape recorder, and two for incompatible schedules after two attempts at scheduling the interview. The statements were transcribed and organized, and subsequently followed the assumptions of thematic content analysis.<sup>9</sup>

The project was approved by the Research Institution's Ethics and Research Committee on June 20, 2017, under number 2,127,751. The study followed the determinations of Resolution No. 466/2012 of the National Health Council.<sup>12</sup> Regarding the presentation of the information, respondents were identified by flowers: men after flowers with male names, and women after flowers with female names.

# RESULTS

In order to better contextualize the information, before starting the questions about organ donation and transplantation, questions on the respondent's age, religion, marital status and undergraduate course were made. In general, the respondents were young university students who seek to continue their studies after graduating from high school: of the twenty interviewees, sixteen were between twenty-two and twenty-five years old, two were between twenty-six and twenty-nine years old and only two were thirty or older.

Majority were female, represented by fourteen women. The Snowball technique enabled the identification of the friendship relationship between the two genders: of the six men interviewed, four indicated women to follow up the research. The answers regarding religion and marital status were less varied, with seventeen students professed catholics and three evangelicals. Notably, none identified themselves atheist or agnostic. On marital status, twelve participants reported stable relationships, one claimed to be formally married, and seven said they were single.

The courses in which the participants were enrolled varied: four attended Agronomy; four Management Processes; three majored in languages - Portuguese and English; two, Accounting Sciences; two, Chemical Engineering; and two, Mathematics; one student majored in Architecture and Urbanism; one in Food Engineering; and one in Civil Engineering.

#### **Knowledge on Organ Donation**

Organ donation is seen by the society as an act of solidarity and love of neighbor, however, there is a significant lack of knowledge about the process of donation. When asked about what it took to be an organ donor, most respondents explained assertively, but none could answer completely. The statements were based on what they heard, what they read or experienced about the subject: the manifestation of desire, the authorization of the family and the health condition, as the following statements show:

*Have good health and declare yourself a donor.* (Chrysanthemum)

[...] I know that you have to tell your family, because they even talk about advertising, that it will be your voice [...]. (Dahlia)

Regarding the possible donation in life, several respondents were not sure to express their response, such as Gardenia, who reported that:

"Wow, that's hard, because actually, like, sometimes you have to die, don't you? (laughs). And I don't know, it has to be healthy, I think. [...] I think [...] the kidney can be donated even when the person is alive, because I've seen people who donated one kidney and continued with the other [...]."

When asked about organs and tissues that can be donated in both life and death, respondents associate the donation with kidney, liver, lungs, corneas, heart, skin, marrow, pancreas and bones. The answers also indicated that the participants know that heart valves, cartilage and blood can be donated, associating with the literature<sup>13</sup>. The participants listed the following factors as impediments to organ donation - the consent of the potential donor's family (who currently authorizes the process in the event of the patient's death), religion, ignorance and the distrust in the processes:

*I believe if she has any disease, cancer, AIDS, hepatitis I think it interferes.* (Lily)

[...] Some religion, some belief, I believe. (Magnolia)

[...] I think often the lack of information, because many people are afraid that suddenly someone will go there to take an organ when the person is not totally lifeless, I think. (Hydrangea)

When asked about brain death only one of the respondents did not answer. However, there was confusion between coma and brain death:

That's when you're in a coma, right? And I think the brain stops and the heart, I'm very lay person, but the heart is still beating and your brain is no longer working. (Magnolia).

When asked about the donation stages when the patient dies, most respondents could not answer.

#### Opinions on organ donation and public policy

In the interactions, interest, criticality and solidarity were emphasized when dealing with the topic of donation. When asked if they had already talked about organ donation with someone (and in what situations) and if they had read any material or attended a program on the topic, most of the students indicated that they had had some conversations on the subject with family members, colleagues or friends:

Usually, when there is a report or someone who talks about it, we talk, but not like, 'oh, today we will talk about donation' [...]. (Camellia).

[...] I've talked a lot about it, I think about it a lot, but I never said 'look, dad, mom, I'll donate my organs'. It's

*all very informal, you comment, you think, but you never decide.* (Jasmine).

I have already commented this with my mother. And her first answer was 'ah, talk to your children, because you won't die before me' [...]. (Gardenia).

Gardenia's speech epitomizes the hesitation that some families still have when talking about donation, since the conversation focuses on death and no one expects this to happen to their loved ones. In the dialogue, we observed that the mother does not discuss the topic because she believes that there is, in the revelation of the daughter, a contradiction of life marked by cultural context that naturalizes the departure of parents before children.

The responses of Lily and Margarida, who stated that they had never addressed the subject, also drew attention:

Nothing, no change of mind. I don't know, it's a little talked about subject. (Lily).

No, never. (Daisy).

The media discussion of the theme was reflected in the responses of Iris and Violet, who exemplified the series dealing with medical dramas - the title of the movie mentions anatomy textbook and the series deals with Meredith Gray's medical residency, a character facing adverse situations with staff and students, living professional and personal passions.<sup>14</sup>

The intention of the research to open channels to analyze the intention to donate organs and the decision-making process to see if college students felt safe with their choices was contemplated too. Two respondents were undecided about their organ donation:

I don't know, I don't think so. For insecurity. (Lily).

Yeah, I think there is fear, right? I'm not totally safe, but the moment I say I want to be a donor, I want to be totally safe [...]. (Jasmine).

Regarding the possibility of choosing to donate in life to someone in the family or to an unknown person, the respondents presented divergent answers: Lily and Violet stated that they would only do it for a loved one. Perhaps in this decision the certainty of the necessity and the process to be followed weigh in. On the other hand Hibiscus would donate regardless of who needed:

[...] If there really was no other way out, out of fear, insecurity. (Lily).

*I think only if it was someone from my family, because then, I'm a little afraid, so if it was here, yes [...].* (Violet).

I think if I had a way to donate, I would donate, because I think it's a donation that has no pain, regardless of whether it was family or not. (Hibiscus).

Regarding the possibility of excluding someone from the transplant waiting list if any family member could be a donor, more than half of the interviewees expressed their opposition to the decision, i.e. they would not exclude anyone, claiming that everyone deserves the opportunity to receive transplant. Although most university students were opposed to exclusion, the Hydrangea and Chrysanthemum considerations express moral judgment, especially the objection to donating to those who have performed actions not appreciated by society, such as stealing or killing:

*People who have never done good, for example criminals.* (Chrysanthemum).

# [...] If I was a bad guy I wouldn't donate, a killer, no, they don't deserve it. (Hydrangea).

The donation of organs and tissues in Brazil is regulated by laws, resolutions, decrees and ordinances, which based some of the questions. The first of them dealt with the consent of family members and the divergence of intentions between the potential donor and the family. In the statements, there were several opinions on the subject: some were in favor of the family deciding because the potential donor had already explicitly indicated in life their desire to donate organs; there were also those who considered that the opinion of the patient should be valid, regardless of the family; as well as those, who defended the preservation of the body of the loved one in a moment of sadness for all:

*I think so, because whether or not they want to donate, they will already have commented on it in life, so I believe the family will respect it later.* (Violet).

I think it hurt because it is a decision that each person makes, because sometimes the person may not have communicated that they wanted this, and the family decided to do it [...]. (Hibiscus).

Regarding the changes expressed in Law No. 10.211/01 in reference to the ease of family decision-making, most university students stressed the need to maintain some form of expression that legitimizes the opinion of the potential donor, as Geranium points out: [...] If I had a document saying I wanted to be a donor, I think it would be more coherent, fairer, you know? Because the will of the person who died would be clear, because even if I could donate the organs, I don't know if my mother would donate [...]. (Geranium).

Opinions largely agreed on the importance of potential donor's desire whether to donate their organs or not. The last question addressed included the issue of organ sales in Brazil.

In Brazil, I believe it would increase, unfortunately. It would have the good side, but it would have that capitalist side, which we know exists. It would surely increase. (Açucena).

More than half of the students did not hesitate to say that the donations would increase with the possibility of selling organs and tissues due to the socioeconomic condition of the country. From this perspective, the consequences would be negative.

## DISCUSSION

In the current context, the issue of organ donation demands reliable and coherent information, as emphasized by several articles.<sup>15-20</sup> Nogueira and collaborators<sup>21</sup> alert to the lack of knowledge about the conditions for donation in general, and with regard to the universities, highlight the need for emphasis during the undergraduate course, approaching the topic as a cross-curricular component. When considering a donation in life, it is important to remember that the donor has to be over eighteen, have blood compatibility with the recipient, be in good health, want the donation of a duplicate organ or one that does not affect the functioning of the body and to be a spouse, partner or relative up to the fourth degree.<sup>13,22</sup>

In the statements we identified uncertainties regarding brain death. Legally brain death is a situation when there is a complete and irreversible stop of all brain activity and cardiorespiratory function is maintained by equipment and medications. Therefore, the diagnosis becomes essential to determine death based on neurological criteria, that confirm that brain injury is irreversible.<sup>1</sup> In this sense, brain death had to be understood by the society as equal to the death of organism. It is complex and difficult to understand, therefore it is essential that health professionals seek ways to make it easier to understand, without distancing themselves from the sociocultural aspects that may be involved.<sup>24-25</sup>

Regarding the stages of organ donation, we emphasize that they are complex and mostly unknown to the population. Lack of knowledge interferes negatively in the decision-making process of family members and sometimes undermines organ and tissue donation rates.<sup>26</sup>

The positive influence of the media on the topic addressed by this research is explained and the need for programs and reports on donation is increasing in order to expand the discussion and raise awareness on the process of donation.

Notable in the interviews were the insecurity and fear of the possibility of dying, making someone suffer, having their organs sold, when considering whether to donate or not donate the organs. Such fears may result from several factors. The feeling of distrust in care provided and the fear of organ trade, the anticipation or induction of death of the loved one are some of the factors related to denial.<sup>27</sup> People's beliefs and lack of knowledge about the diagnosis of brain death generate uncertainty and apprehension, making understanding and decision making difficult.<sup>28</sup>

We recalled in this research that, according to Decree No. 9.175/17, the removal of organs and tissues after death can only be authorized by the family of the potential donor. This authorization should be by the spouse, partner or consanguineous relative, up to the second degree.<sup>29</sup> In the study by Barreto et al.<sup>30</sup>, the reasons for families' refusal to donate organs mainly included the fact that the donor was contrary to the donation in life; the wish of the family members to keep the body of the potential donor intact and the ignorance of the donor's wishes.

Although there are several opinions that help consolidate the issue of organ donation, it is worth reflecting individually on the desire to donate and sharing it with the family members, so that, at the crucial moment, the idea of the potential donor has already been expressed and is respected. From this perspective and in view of the wide range of pathologies and clinical conditions that have been affecting the population - especially chronic and degenerative diseases and traffic accidents – it is important to share knowledge and interest on the subject, given that transplants contribute to improving the quality of life of those who need an organ.

# FINAL CONSIDERATIONS

We found that college students have knowledge, although some demands for information can still be met by sharing knowledge, especially by health professionals. We also observed that specific knowledge on the process of organ donation, the concept of brain death and the stages of the donation could be explored and deepened. Respondents thus sought to relate prior knowledge and highlight critical arguments about current legislation, exclusion from the waiting list, intention to donate organs and tissues, and media interference in the process of disseminating information.

The information generated indicates the importance of health education in the promotion of organ donation, allowing a discussion and greater understanding on the subject. In this sense, we believe that approach to the topic can act as a tool in the amplification of knowledge and potentiality increase in donations. Thus, we intend this study to guide educational practices aimed at the population and, in some way, induce the discussion in universities, especially in health education sectors, thus providing one of the interfaces for university social responsibility.

In addition, continuing education is necessary, in view of the need to disseminate knowledge and reiterate its meaning, continuously and efficiently, in the daily routine of health services. The main limitation of the study is the fact that the information shared originated in a single type of public (university students), and it is recommended to bring other views on the subject.

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Received in: 12/01/2019 Required revisions: 13/08/2019 Approved in: 13/08/2019 Published in: 30/03/2020

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Disclosure: The authors claim to have no conflict of interest.