

Renan Kleber Costa Teixeira<sup>1</sup>, Thiago Barbosa Gonçalves<sup>1</sup>, José Antonio Cordero da Silva<sup>1</sup>

# Is the intention to donate organs influenced by the public's understanding of brain death?

*A intenção de doar órgãos é influenciada pelo conhecimento populacional sobre morte encefálica?*

1. Universidade do Estado do Pará - UEPA - Belém (PA), Brazil.

## ABSTRACT

**Objective:** To evaluate the influence of the understanding of brain death in relation to organ donation in patients from the Marco School Health Center, which is linked to the Universidade do Estado do Pará.

**Methods:** A total of 136 patients were interviewed based on a research protocol. The interview results were subsequently analyzed with regard to the understanding of brain death and organ donation in addition to the collection of sociodemographic data.

**Results:** The majority of patients were female and were in favor of organ donation, with a mean age of 39 years being observed. Only 19.9% of the patients understood the meaning of brain death, and 85.3% believed that physicians

may be mistaken in confirming the status of brain death of a patient, while 18.4% trusted the diagnosis of brain death. A statistically significant ( $p < 0.01$ ) correlation was observed between the degree of confidence in the diagnosis of brain death and the person's agreement to donate his/her organs after death.

**Conclusion:** The majority of the population under study did not understand the meaning of brain death and had a low degree of confidence in the diagnosis of brain death. This lack of understanding and confidence negatively influences the desire to donate organs.

**Keywords:** Brain death; Population; Directed tissue donation; Assessment; Knowledge; Teaching, hospitals; Health centers

## INTRODUCTION

Organ transplant is the last therapeutic option, i.e., it is used when no other treatment can safely maintain the life of a terminally ill patient. Several causes of organ failure requiring transplant, such as *diabetes mellitus*, systemic hypertension, alcoholic liver disease and viral hepatitis, are highly common diseases in the Brazilian population.<sup>(1,2)</sup>

For a transplant to be performed, an organ donor must be available, either alive or *post mortem*. The latter is more common and should be a patient with a diagnosis of brain death (BD) for the organs to be viable for transplant.<sup>(3)</sup>

However, when demand is high compared to the availability of organs, there is a chasm preventing an increased rate of transplants. In many countries, this organ shortage increases the number of people on the waiting list to receive an organ.<sup>(3)</sup>

There are limited data in Brazil regarding popular opinion on the process of organ donation.<sup>(4,5)</sup> Official data suggest that the family members of approximately half of the potential donors - patients who are considered brain dead and meet all of the criteria for donors - refuse to donate the organs.<sup>(6)</sup>

The reasons for this refusal are still not well-elucidated; it is only known that

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**Corresponding author:**

Thiago Barbosa Gonçalves  
Travessa Dom Romualdo Coelho, 722, apto. 2102 - Umarizal  
Zip Code: 66055-190 - Belém (PA), Brazil  
E-mail: tbgow@hotmail.com

the cause is multifactorial. It is believed, however, that the lack of understanding of BD is a major reason.<sup>(7,8)</sup> In addition, other reasons may also be cited as influencing organ donation, including religion, the occurrence of transplants in the donor's family and the first contact between the donor's family and the transplant team.<sup>(5)</sup>

The concept of BD, as stated by the Conselho Federal de Medicina - CFM in 1997,<sup>(9)</sup> defines that a person is dead. This definition is of crucial importance because only then can an organ be ethically removed from a person for transplant. In addition to avoiding the unnecessary use of advanced life support, the BD diagnosis and its understanding by family members give the family the confidence needed to authorize organ donation.

However, to date, the people's understanding of the subject is poorly studied, evaluated, discussed and disseminated. The suggested protocol to obtain the family's permission for organ donation consists of the attending physician explaining that the patient is brain dead and that he/she fulfills all the criteria for organ donation, therefore being considered a potential donor. After this first approach, a trained multidisciplinary team talk with the family regarding organ donation.<sup>(7)</sup> This strategy of explaining BD is crucial to facilitate organ donation by relatives or legal guardians because the literature indicates that mistrust by the lay population of the correct diagnosis of BD is a limiting factor in organ donation.<sup>(8)</sup>

There is a lack of studies dedicated to assessing the relationship between the public understanding of brain death and its influence on the decision to donate organs.<sup>(8)</sup> There have been no studies comparing these different regional realities within Brazil and between Brazil and other countries.

This study aimed to evaluate the influence of understanding BD in relation to organ donation in patients from the Marco School Health Center, an agency of the Universidade do Estado do Pará - UEPA.

## METHODS

This study began after approval by the Research Ethics Committee of the UEPA, protocol no. 39/2011. The work is characterized as prospective and observational, using interviews and based on a standardized questionnaire (Appendix 1) with 136 patients from the Marco School Health Center. Before answering the questionnaire, the participants were asked to sign an informed consent form (ICF). The questionnaire contained questions regarding the understanding of BD and its influence on

organ donation in addition to sociodemographic data (Appendix 1).

The inclusion criteria were admission and registration in the Marco School Health Center, age over 18 years and signing of the ICF. There were no exclusion criteria.

The BioEstat 5.0 software was used for statistical analysis, and the data were initially grouped and summarized in the form of percentages. The C contingency test was used to assess the relationships among the sociodemographic data, the opinions on organ donation and the understanding of BD. A value of  $p < 0.05$  was adopted to reject the null hypothesis.

## RESULTS

A total of 136 patients, of whom 93 were women (68.4%), were interviewed. The mean age was  $39 \pm 13.6$  years (ranging from 18 to 81 years old). Of the 136 patients, 63 were single (46.3%), 54 (39.7%) married, 11 (8%) widowed and 8 (6%) separated. With regard to education, 78 (57.4%) had secondary education; 38 (27.9%) had elementary education; and 19 (14%) had higher education; while 1 (0.7%) were illiterate. With regard to religion, 74 (54.4%) were catholic; 55 (40.4%) evangelicals; and 7 (5.2%) had other religions.

When asked about organ donation, 115 (84.6%) declared themselves in favor, 13 (9.5%) were opposed to donation and 8 (5.9%) had no opinion on the subject. Regarding the willingness to donate their own organs after death, 98 (72%) would agree to donate their organs, 21 (15.5%) were against it and 17 (12.5%) had no opinion on the matter. Regarding the possibility of consenting to the donation of organs from first-degree relatives, 98 (72%) responded that they would allow it, 28 (20.6%) chose not to give an opinion and 10 (7.4%) stated that they would not donate. Marital status ( $p=0.82$ ), religion ( $p=0.91$ ), gender ( $p=0.48$ ), age ( $p=0.98$ ), education ( $p=0.79$ ) and household income ( $p=0.30$ ) did not influence the decision on whether to donate organs.

Regarding to the condition of the patient diagnosed with BD, the responses were as follows: 19.9% stated that the patient was in fact dead; 48.6% believed that only the brain was dead and the patient had the potential to live; 28.4% believed that the patient was partially alive with the potential to live, if treated; and 3.1% did not know the meaning of the term BD. There was no statistical relationship ( $p=0.53$ ) between the respondents' education and their understanding of BD.

It was observed that 85.3% believed that the doctor

could be mistaken in giving a BD diagnosis, and the patient could still be alive. Regarding the confidence of the patients in the diagnosis, 26.5% did not trust the BD diagnosis given by a doctor, 55.1% partially trusted the diagnosis and 18.4% fully trusted the diagnosis. The respondents' confidence in the diagnosis was strongly influenced by their belief in the doctor's ability to confirm the diagnosis ( $p=0.003$ ).

Neither the understanding of the meaning of BD ( $p=0.15$ ) nor the respondent's confidence in the diagnosis of BD ( $p=0.08$ ) influenced the likelihood of being in favor of donation. However, there was a statistically significant relationship between the degree of confidence in the diagnosis of BD and the decision in favor of donating one's own organs ( $p<0.05$ ) (Table 1) or the organs from first-degree relatives ( $p<0.05$ ) (Table 2).

**Table 1** - Correlation between agreeing to donate organs and confidence in the diagnosis of brain death

	Fully trust the diagnosis N (%)	Partially trust the diagnosis N (%)	Do not trust the diagnosis N (%)
In favor of donating their organs	23 (16.91)	55 (40.44)	20 (14.7)
Against donating their organs	2 (1.47)	9 (6.6)	10 (7.35)
No opinion	0	11 (8.08)	6 (4.41)
Total	25 (18.38)	75 (55.14)	36 (26.47)

$p = 0.0199$  (C contingency test).

**Table 2** - Correlation between agreeing to donate the organs of first-degree relatives and confidence in the diagnosis of brain death

	Fully trust the diagnosis N (%)	Partially trust the diagnosis N (%)	Do not trust the diagnosis N (%)
In favor of organ donation	24 (17.64)	52 (38.23)	22 (16.17)
Against organ donation	0	5 (3.6)	5 (3.6)
No opinion	1 (0.7)	18 (13.2)	9 (6.6)
Total	25 (18.38)	75 (55.14)	36 (26.47)

$p = 0.0295$  (C contingency test).

## DISCUSSION

This study sought to analyze one of the limiting factors of organ donation, i.e., the understanding of BD. For this purpose, the Marco School Health Center was chosen as the study site because it is a reference center for primary and secondary care.

The sociodemographic data collected for this study were similar to the reality of the state population and assumed that there was no higher concentration of research subjects from any particular group. However, there was a

predominance of women in the study due to the higher number of this gender in primary care centers.<sup>(10)</sup>

The number of people who favored organ donation was high, similar to the population studied by Coelho et al.<sup>(11)</sup> and Faria et al.,<sup>(12)</sup> who found, respectively, values of 87.8% and 92% acceptance of organ donation. As in the present study, no sociodemographic factors influenced the opinion regarding organ donation.

Family authorization is essential for organ donation from deceased donors, given that in Brazil, informed consent has been in effect since 2001, which means that the decision to donate organs is given by the closest relatives of the potential donors and not by the patient's decision while still alive, even if the patient's decision is expressed in identification documents.<sup>(9)</sup> It is therefore highly important that the population understand that BD patients are dead, as brain death is one of the essential conditions for the family to allow organ donation from deceased donors, given that the organs no longer have any use in the patient and that the patient can save lives if the organs are transplanted.<sup>(9,13)</sup>

In this study, only 19.9% of the population under study believed that patients with a BD diagnosis are dead, with the remaining respondents believing that the patient could still be alive, showing a lack of understanding of the most important factor for transplantation. It is noteworthy that there was no statistical correlation between the level of education and the lack of understanding of BD. It is likely that this lack of understanding is linked to the belief that death only occurs after cardiac arrest. Public campaigns on the subject could be useful for better understanding by the population.<sup>(14)</sup>

In 2004, Siminoff et al. conducted a similar study involving 1,351 patients and observed that only 33.7% of the population believed that a person diagnosed to be BD is indeed dead. The remaining patients believed that BD was a reversible condition, and as in the findings presented here, this impression could influence their decision regarding organ donation.<sup>(15)</sup> However, not only the population suffers from gaps in understanding the concept of BD. Schein et al.,<sup>(16)</sup> in surveying intensive care physicians, showed that several of these professionals believed that the patient was dead only after organ removal, not immediately after BD diagnosis.

As for the trust in the doctor giving the diagnosis, the majority of respondents believed that the doctor could make a mistake and that the patient could still be alive. This finding was similar to the findings of a comparable national study concerning organ donation in Curitiba.<sup>(17)</sup>

In that study, there was also a strong disbelief in the diagnosis of BD, especially due to the current “crisis” in the credibility of doctors. Thus, the mistrust surrounding the diagnosis leads patients to have a certain fear of donating their organs. This mistrust already been shown as the major cause of refusal to donate organs according to Meneses et al.<sup>(8)</sup>

The mistrust in the diagnosis of BD and lack of understanding the concept influences the acceptance of organ donation programs. It is therefore a limiting factor for donation, as confidence in the diagnosis of BD increases the chances of a person agreeing to donate his/her organs or the organs of a relative. This information showed statistical significance ( $p < 0.05$ ). This finding is similar to the findings of Siminoff et al.,<sup>(17)</sup> who observed that families who understand the concept of BD are more likely to agree to the donation of organs; thus, it is important to increase the public confidence in the ability of the physician to diagnose a patient with BD. However, it is difficult to increase this credibility, considering that even medical students have declined to donate their organs due to their lack of belief in the Brazilian health system.<sup>(18)</sup>

It is noteworthy that there was a significant portion of the population with no formed opinion on the topic under study. Family discussion on this issue is of fundamental importance to increase people’s willingness to agree to organ donation. Therefore, there is a need for general education campaigns regarding transplants, BD and the concepts involved in BD to clarify the doubts and to fight the myths related to this topic.<sup>(19)</sup>

The most interesting finding made when analyzing the survey data on this topic in different regions is that despite the obvious regional, cultural and social differences, the problems are essentially similar, and the way that these problems can be solved is also similar. This discovery facilitates the decision-making process on how to address such issues and to raise the population’s

awareness regarding BD, which is essential to increase the number of donors.

## CONCLUSION

The majority of the population under study does not understand the meaning of BD and believes that the deceased potential donor might yet live. The degree of confidence in the process of BD diagnosis and in the ability of the doctor to verify such status is low, which can negatively influence the decision to donate organs.

## RESUMO

**Objetivo:** Avaliar a influência do conhecimento sobre morte encefálica relacionada à doação de órgãos dos pacientes do Centro de Saúde Escola do Marco, órgão vinculado à Universidade do Estado do Pará.

**Métodos:** Foram entrevistados 136 pacientes, com base em um protocolo de pesquisa, no qual foi analisado o conhecimento sobre morte encefálica e doação de órgãos, além de dados sociodemográficos.

**Resultados:** A maioria por pacientes era do gênero feminino e favorável à doação de órgãos, apresentando média de idade de 39 anos. Apenas 19,9% souberam informar o que era morte encefálica, 85,3% acreditavam que o médico pode se equivocar na firmiação do estado de morte encefálica de um paciente e 18,4% confiavam no diagnóstico de morte encefálica. Observou-se relação estatisticamente significativa ( $p < 0,01$ ) entre o grau de confiança no diagnóstico de morte encefálica e a pessoa aceitar doar seus órgãos após sua morte.

**Conclusão:** A maioria da população estudada não compreendia o significado da morte encefálica e apresentava um baixo grau de confiança no diagnóstico de morte encefálica, sendo que esse perfil influencia negativamente o desejo de doar órgãos.

**Descritores:** Morte encefálica; População; Doação dirigida de tecidos; Avaliação; Conhecimento; Hospitais de ensino; Centros de saúde

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### Appendix 1 - Research protocol

Protocol number: \_\_\_\_\_ Gender: ( ) Male ( ) Female Age: \_\_\_\_\_ years

Marital status: ( ) Single ( ) Married Religion: ( ) Agnostic ( ) Catholic ( ) Evangelical  
( ) Separated ( ) Widowed ( ) Spiritualist ( ) Other: \_\_\_\_\_

Education: ( ) Did not attend school ( ) Illiterate ( ) Elementary education  
( ) Secondary education ( ) Higher education ( ) Graduate school

Household income (minimum wage):  
( ) less than 1 minimum wage ( ) 1 minimum wage ( ) 2 or 3 minimum wages ( ) 4 to 6 minimum wages ( ) 7 to 10 minimum wages ( ) more than 10 minimum wages

Are you in favor of organ donation? ( ) Yes ( ) No ( ) No opinion

If you checked Yes, why? ( ) To save lives/To help others ( ) The organ is useless after death ( ) I might need an organ transplant in the future ( ) A relative has needed a transplant in the past ( ) Other: \_\_\_\_\_

If you checked No, why? ( ) Religion ( ) I do not trust doctors ( ) Fear ( ) Corruption/Organ trade ( ) Body mutilation  
( ) Other: \_\_\_\_\_

Would you authorize the donation of your organs after death? ( ) Yes ( ) No ( ) No opinion

If you checked Yes, have you already informed your family members of your willingness to donate your organs? ( ) Yes ( ) No

Would you donate organs to relatives or friends while still alive, if there was no harm to you? ( ) Yes ( ) No ( ) No opinion

When a person is brain dead, he/she is: ( ) Dead ( ) Partially alive ( ) Only the brain is dead ( ) Do not know

The diagnosis of brain death given by the doctor: ( ) is always correct ( ) could be wrong, and the patient could still be alive

Do you trust the diagnosis of brain death? ( ) I fully trust ( ) I partially trust ( ) I do not trust

Is there an organ trade in Brazil? ( ) Yes ( ) No ( ) Do not know

The average waiting time on the organ transplant list is: ( ) More than 3 years ( ) More than 1 year ( ) Less than 1 year

Who is more likely to receive a transplant? ( ) The rich ( ) The poor ( ) It does not depend on money

If you needed a transplant, would you agree to receive an organ? ( ) Yes ( ) No ( ) Do not know

Would you authorize the donation of organs from a first-degree relative? ( ) Yes ( ) No ( ) No opinion

Which of the following organs can be transplanted?

Cornea	( ) Yes	( ) No	( ) Do not know	Liver	( ) Yes	( ) No	( ) Do not know
Bone marrow	( ) Yes	( ) No	( ) Do not know	Brain	( ) Yes	( ) No	( ) Do not know
Bone	( ) Yes	( ) No	( ) Do not know	Leg	( ) Yes	( ) No	( ) Do not know
Kidney	( ) Yes	( ) No	( ) Do not know	Pancreas	( ) Yes	( ) No	( ) Do not know
Lung	( ) Yes	( ) No	( ) Do not know	Blood	( ) Yes	( ) No	( ) Do not know