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## Situational Diagnosis of the Profile of a Neurocritical Patient with Clinical Signs of Brain Death in a Hospital in the North of Brazil

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#### **ABSTRACT**

Objectives: To analyze the profile of patients with clinical signs of brain death in a hospital in the state of Rondônia (RO) using a donation process management instrument. Method: This is a quantitative, descriptive, and retrospective study carried out in a hospital and emergency room that serves as for reference in the organ donation process in RO. The study population included all medical records of patients who died in the critical patient units of this hospital. The Death Information Form, based on the Spanish quality model, was used for data collection, which occurred from December 2022 to February 2023. The data were analyzed with descriptive statistics. Results: Four hundred and ninety-three medical records were analyzed, of which 77 were related to deaths due to neurological causes. The predominant profile was of male patients, with a mean age of 49 years, with traumatic brain injury being the main cause of hospitalization. Thirty-five cases of brain death and 30 non-validated potential donors were identified. The main causes of donor loss were underreporting and hemodynamic changes. Conclusion: The study revealed the profile of patients admitted to critical units who progressed to brain death and identified the causes of loss of potential donors, providing information that can help managers develop strategies to address these weaknesses.

Descriptors: Brain Death; Health Profile; Epidemiologic Factors; Procurement of Tissues and Organs; Intensive Care Units.

### Análise do Perfil de Pacientes Neurocríticos com Sinais Clínicos de Morte Encefálica em um Hospital da Região Norte do Brasil

#### **RESUMO**

Objetivos: Analisar o perfil dos pacientes com sinais clínicos de morte encefálica (ME) em um hospital do estado de Rondônia (RO), utilizando um instrumento de gestão do processo de doação. Métodos: Trata-se de um estudo quantitativo, descritivo e retrospectivo, realizado em um hospital e pronto-socorro referência no processo de doação de órgãos em RO. A população do estudo incluiu todos os prontuários de pacientes que foram a óbito nas unidades de pacientes críticos desse hospital. Foi utilizado o Formulário Informativo de Óbitos, baseado no modelo espanhol de qualidade para a coleta dos dados, no período de dezembro de 2022 a fevereiro de 2023. Os dados foram analisados com estatística descritiva. Resultados: Foram analisados 493 prontuários, dos quais 77 estavam relacionados a óbitos por causa neurológica. O perfil predominante foi de pacientes do sexo masculino, com idade média de 49 anos, sendo o traumatismo cranioencefálico a principal causa de internação. Identificaram-se 35 casos de ME e 30 potenciais doadores não validados. As principais causas de perda de doadores foram a subnotificação e as alterações hemodinâmicas. Conclusão: O estudo revelou o perfil dos pacientes internados em unidades críticas que evoluíram para ME e identificou as causas da perda de potenciais doadores, fornecendo informações que podem ajudar gestores a desenvolver estratégias para abordar essas fragilidades.

Descritores: Morte Encefálica; Perfil de Saúde; Fatores Epidemiológicos; Obtenção de Tecidos e Órgãos; Unidades de Terapia Intensiva.



#### INTRODUCTION

In Brazil, brain death (BD) is defined as "the complete and irreversible loss of brain functions, defined by the cessation of cortical and brainstem activities", manifesting as apperceptive coma, with the absence of supraspinal motor response and apnea<sup>1</sup>. In this clinical condition, it is possible to temporarily and artificially maintain the functioning of the organs. Given this possibility, the patient is considered a potential donor of multiple organs, considering all the clinical and legal criteria established for organ donation in Brazil<sup>2</sup>.

Many neurocritical patients arrive at hospitals with unfavorable prognoses, which requires that these patients be closely monitored and followed up and that the healthcare team is prepared and confident to provide adequate care, in addition to speeding up the onset of the diagnosis of BD<sup>3,4</sup>.

When this assistance from the health team is not provided quickly, safely, and effectively, there is a possibility of losing potential organ and tissue donors<sup>5,6</sup>. According to the Brazilian Association of Organ Transplants (*Associação Brasileira de Transplantes de Órgãos - ABTO*), of potential donors notified to transplant centers, approximately 20% develop cardiac arrest as a result of hemodynamic changes occurring due to severe neurological injury<sup>3,4,7</sup>.

Considering this scenario, early identification and notification of all patients who meet the clinical criteria for BD allows for the timely identification of possible complications and the necessary therapeutic support to prevent cardiac arrest, in addition to enabling the diagnosis of BD in an agile and efficient manner. When there is no immediate identification of the neurocritical patient and immediate action on hemodynamic changes, the loss of the donor may occur, as well as the non-viability of these organs for transplantation.

From this perspective, instruments that allow monitoring this process and that can generate indicators that reflect aspects such as donation capacity, collection and transplantation of hospital units, structural characteristics, and physical and human resources, as well as failures or causes of loss of potential donors, directly impact the donation process<sup>13,14</sup>.

Measuring these aspects is essential to understanding how potential donor losses can be minimized and identifying possibilities for developing donation and transplant programs. The aim is to create conditions that increase the chances of organ donation and improve the reliability and quality of this complex process<sup>15-17</sup>.

In the state of Rondônia (RO), the organ donation service has shown growth in terms of the notification rate of potential donors. In 2021, 2022, and 2023, 69.6, 95.2, and 121.4 notifications per million population (pmp) were recorded, respectively<sup>18-20</sup>. The 148 pmp rate of potential donor notification in the first half of 2024 was the highest achieved in the service's history and the highest rate in Brazil that year<sup>7</sup>. However, since the number of BDs in hospitals is unknown, it is impossible to identify the state's accurate notification and donation potential.

The notifications of potential donors in RO originate from 18 notifying hospitals, with the *Hospital e Pronto-Socorro João Paulo II* being the reference health unit with the highest notification rate since the beginning of the organ donation service in the state. In the last 4 years, this hospital was responsible for 37% of the notifications and 43% of the effective donations registered in the state. Therefore, considering these results, the infrastructure of the specialized team and the central role in the state health network make this hospital a privileged setting for the in-depth analysis of the clinical and epidemiological profile of these patients, ensuring representativeness and fidelity to the regional reality in the context of care for neurocritical patients with suspected BD. In this context, this study sought to direct data collection to this institution, as it is a reference in donation in the state and, thus, identify opportunities for improvement in the donation scenario in this hospital, which will undoubtedly have a significant impact on the Rondônia State Transplant Center (*Central Estadual de Transplantes de Rondônia-CET*).

In this context, this study aims to understand the profile of patients with clinical signs of BD and identify the causes of potential donor losses. Based on the information acquired, the aim is to contribute to improvement strategies that can optimize the context of organ donation in RO.

The impact of this study on the organ donation process in the state lies in improving the quality of information, contributing to the early identification of patients with clinical signs of BD, and proposing measures to minimize the weaknesses observed in hospital institutions. The aim is to make the process safer and more efficient, increase the number of effective donors, and, consequently, increase the number of transplant patients in the country. The guiding question the study proposes to answer is: What is the situational overview of the profile of patients with clinical signs of BD in a hospital in RO? The objective is to analyze patients' profiles with clinical signs of BD in a hospital in RO using a donation process management tool.

#### **METHODS**

The present is a quantitative, retrospective, and descriptive study based on the analysis of medical records of patients who developed BD while hospitalized in the intensive care unit (ICU) and intermediate care unit (IMCU) of a hospital in Porto Velho, the capital of RO.



The choice of this single institution was intentional, considering its strategic relevance in the context of BD reporting in the region. It is the main state referral hospital unit for the management of neurocritical patients, with the highest rates of BD reporting in the state. In addition, the institution has an In-Hospital Committee for Organ and Tissue Donation for Transplantation (*Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos para Transplante- CIHDOTT*), duly registered in the National Transplant System (*Sistema Nacional de Transplantes - SNT*) and in full activity, providing support to other institutions in the region. These factors reinforce its qualification as an appropriate field for the present study. Thus, as this is a reference institution in the most significant number of donations, it will undoubtedly bring essential improvements in the context of donations.

This study's population was composed of all medical records of patients admitted to the aforementioned hospital's ICU and IMCU who died in 2019. The inclusion criteria covered the medical records of patients who died in the ICU and IMCU during the study period. Medical records that presented illegible information, erasures, or the absence of essential data were excluded from the analysis.

Data was collected from December 2022 to February 2023 using an instrument called the Death Information Form. This instrument is part of the management tools of the Quality Assurance Program (*Programa de Garantia de Qualidade-PGQ*) applied to organ donation and transplants in Spain<sup>21</sup>, translated, adapted, and validated for the Brazilian language<sup>22</sup>. The instrument aims to characterize patients who developed BD and track potential donors who died in critical care units and were not identified in the active search. Its objectives include determining the number of hospital deaths due to BD, mapping clinical signs of BD, why BD was not diagnosed and why the team did not detect BD, the reasons for the non-notification of BD, and the reasons for not opening the BD protocol. The variables that make up the instrument are sex, age, reason for admission to the ICU or IMCU, length of stay in the ICU or IMCU, Glasgow Coma Scale (GCS) score at the time of admission and before death, presence or absence of fixed mydriasis, trunk reflexes, polyuria, intracranial hypertension, definition of the cause of coma, notification for BD, notification for cardiopulmonary arrest (CPA), reasons for non-notification to the CET, and causes of death.

Researchers collected data with the support of CIHDOTT nurses from the selected hospital. The data obtained were organized in an electronic spreadsheet on the Google Drive platform and transferred to a database in Excel for Windows® 2016 for simple statistical and descriptive analyses. Frequencies were calculated in absolute numbers and percentages and presented in tables and graphs. This study was approved by the Research Ethics Committee of the Federal University of Santa Catarina, under opinion No. 5,748,716, registered with CAAE: 64122922.3.0000.0121. The research maintained the confidentiality of the participants at all stages of the study and of the information collected, whose access is restricted exclusively to the research team.

#### **RESULTS**

A total of 493 medical records of patients who died were identified, of which 101 were in the ICU, 361 in the emergency room, and 31 in the surgical center. Of these, 82 records were related to deaths due to neurological causes, five of which were excluded due to conflicting information and/or incomplete records, totaling 77 medical records for the sample of this research. The average age was 49 years. Fig. 1 shows the distribution by sex.

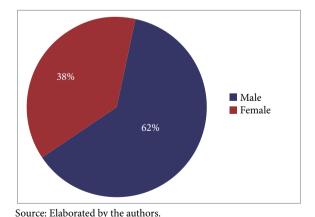


Figure 1. Distribution of deaths in the hospital according to sex, Porto Velho, RO, 2019.

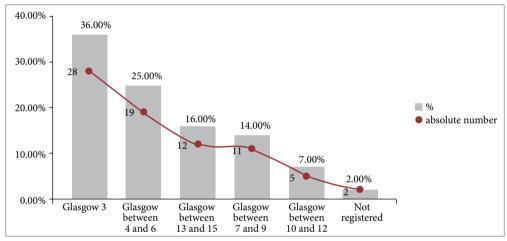
When analyzing the leading causes of hospital admission due to neurological injury, it was observed that most patients were admitted due to traumatic brain injury (TBI), followed by hemorrhagic stroke (hstroke) or ischemic stroke (Table 1). The average length of hospital stay, considering the date of admission to the date of death, was 5 days.

Table 1. Leading causes of hospital admission due to neurological injury, Porto Velho, RO, 2019.

Causes of hospital admission	Frequency	Percentage (%)	Cumulative percentage (%)
TBI	28	36	36
hstroke	22	29	65
ischemic stroke	5	6	71
Others (intracranial hematomas, encephalitis and hydrocephalus)	20	26	97
Non-neurological causes	2	3	100
Total	77	100	

Source: Elaborated by the authors.

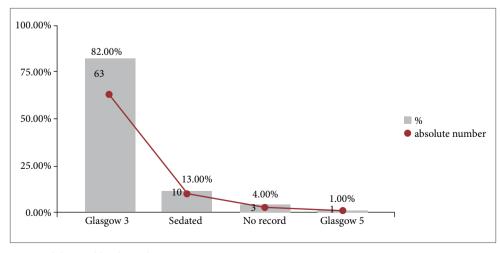
Regarding the level of consciousness, of the patients with a neurological cause of hospitalization, 28 (36%) were hospitalized with Glasgow 3, 19 (25%) with Glasgow between 4 and 6, 12 (16%) with Glasgow between 13 and 15, 11 (14%) with Glasgow between 7 and 9.5, five (7%) with Glasgow between 10 and 12 and two (2%) were not registered due to the presence of sedation, making it impossible to assess the level of consciousness. (Fig. 2).



Source: Elaborated by the authors.

Figure 2. Glasgow score at hospital admission, Porto Velho, RO, 2019.

Regarding the information collected in the medical records on clinical signs of BD before death, of the 77 patients, 63 (82%) had Glasgow 3, one (1%) had Glasgow 5, and 10 (12%) could not be evaluated according to the GCS because they were sedated. In three (4%), there was no record of the Glasgow score (Fig. 3).



Source: Elaborated by the authors.

Figure 3. Glasgow score in the last clinical evaluation before death, Porto Velho, RO, 2019.



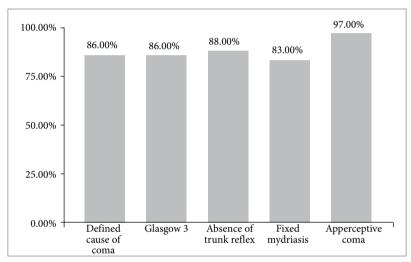
The distribution of notifications to the CET and patients who did not develop signs of BD, therefore, without the need for notification, is described in Table 2.

Table 2. Distribution of patient notifications and non-notifications to CET, Porto Velho, RO, 2019.

Variables	Hospital	
variables	n	%
Patients with BD reported to CET	35	45
Patients with one or more criteria for developing BD not reported to the CET	30	39
Neurocritical patients who did not develop signs of BD	12	16
Total	77	100

Source: Elaborated by the authors.

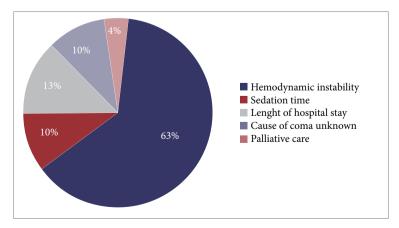
Regarding the possible underreported donors (30), 86% (26) of the cases had a defined cause of coma and Glasgow 3 in the last evaluation before death, 83% (25) of the cases had fixed mydriasis, and 97% (29) were in apperceptive coma, with no trunk reflex present. In 63% of the cases, there were clinical signs to start the BD protocol, according to the current resolution<sup>1</sup> (Fig. 4).



Source: Elaborated by the authors.

Figure 4. Distribution of clinical signs of potential underreported BD donors, Porto Velho, RO, 2019.

Fig. 5 shows the percentage of causes that made it impossible to open the BD protocol in cases of possible underreported donors (30): hemodynamic instability, absence of the minimum time without sedation, lack of the minimum hospitalization time, impossibility of knowing the cause of the coma and medical decision to institute palliative care.



Source: Elaborated by the authors.

Figure 5. Distribution of reasons for not starting the BD protocol, Porto Velho, RO, 2019.

#### **DISCUSSION**

In Brazil and worldwide, one of the main obstacles to identifying potential donors is the difficulty of measuring the actual BD-generating capacity in hospital institutions. Currently, the indicators used by the SNT only allow institutions to determine the number of notifications and the percentage of potential donors being transferred to CETs. This information alone does not allow in-depth analysis and improvement actions to make the donation-transplant process effective<sup>15, 23</sup>.

It is worth noting that 73% of neurocritical patients died in the emergency room. Some studies highlight the insufficient number of intensive care beds, which are considered the ideal place to assist and manage patients with BD since the diagnosis and clinical care of these patients require an adequate physical and human structure, which is not available in emergency rooms<sup>24,25</sup>. Added to this factor is the overload of the care team, which, in addition to providing care to these patients, needs to meet the free demand of the emergency department. Therefore, care for neurocritical patients outside of an ICU can be identified as a weakness when finding a donor, since the work dynamics of this department directly reflect the quality of care provided to the potential donor.

This study observed that 7% (35) of all hospital deaths were identified as BD. However, adding the number of deaths from neurological causes with criteria for BD this number increases to 12% (61). Patients who have suffered severe brain injury tend to develop BD. These patients require continuous monitoring and careful neurological evaluation to identify the clinical signs of BD and do so early<sup>25,26</sup>. Thus, it is understood that identifying and reporting clinical signs of BD early makes the donation process viable and helps to avoid the loss of potential donors, as it allows donation teams to plan the management of care for the potential donor at all stages of this process<sup>8-12,27</sup>.

In the analysis of the profile of neurocritical patients, it was observed that the predominant sex of deaths due to neurological causes was male, in the age range of 50-64 years and with an average age of 49 years. These results are similar to the national data found by ABTO, which showed the same prevalence of age group and sex<sup>19,20</sup>. It was also evident that the highest death rate was related to TBI, followed by hstroke, corroborating other studies already carried out on the epidemiology of neurocritical patients, in which TBI was presented as one of the leading causes of BD<sup>28,29</sup>.

It is worth noting that national research shows a change in the epidemiological profile of deaths from external causes in Brazil, in which strokes are outnumbering deaths from TBI<sup>5,6,30</sup>.

Regarding the level of consciousness of patients hospitalized for neurological reasons, 34% were admitted with the minimum GCS score, i.e., the patients did not show verbal, ocular, or motor response to any stimulus. This result is similar to another study conducted in Brazil, in which 31% of patients were hospitalized with Glasgow 3.15 Still analyzing the profile of neurocritical patients, in the last evaluation before death, 84% had no brainstem reflexes, 80% had no cough reflex and fixed mydriasis, 8% had intracranial hypertension, 15% had polyuria and, in 93%, the cause of coma was defined.

This research found that all deaths due to BD were reported as potential donors to CET by the Organ Procurement Organization (*Organização de Procura de Órgãos-OPO*) or CIHDOTT teams. However, regarding potential donors, in patients who presented one or more criteria for BD, it was observed that 38% were not validated. Considering these underreported cases, 63% presented one or more clinical signs to start the BD protocol, according to the Brazilian resolution. A similarity is observed when comparing the data of this study with the results of other studies, whose diagnosis was also not conducted in patients with criteria to start the diagnosis of BD<sup>15,31</sup>.

Other Brazilian studies highlight that the lack of validation of potential donors suggests the difficulty and insecurity of the healthcare team in defining the clinical criteria for BD<sup>31,32</sup>.

From this perspective, the active search for potential donors produces unique contributions, given that it makes it possible to effectively track/map patients with severe neurological injuries that already indicate one or more clinical signs of BD. The recommendations guide a systematic active search based on standardized and institutionalized criteria, supported by an instrument for collecting accurate data that allows for rigorous, continuous monitoring and timely identification of all patients with clinical criteria for BD, since only at this point can the diagnosis of BD be initiated. 8-12,33.

The focus of the active search is to evaluate all patients on mechanical ventilation with severe brain injury who are not under the influence of drugs that inhibit the central nervous system and to identify those who meet one or more criteria that indicate clinical signs of BD: apperceptive coma without response to any stimulus, absence of brainstem reflexes and absence of voluntary respiratory incursions<sup>2,34</sup>.

Such patients are considered potentially susceptible to developing BD. Therefore, they must be registered and monitored daily until their clinical condition is resolved<sup>15</sup>. The following prerequisites for determining BD are also subject to assessment during the active search: absence of sedation for at least 6 hours and absence of conditions that could confuse the cause of the coma<sup>1</sup>. Some authors suggest actively searching for patients with a score  $\leq 7$  on the Glasgow scale, with at least one of the clinical signs of BD mentioned, to expand the screening of potential donors, focusing on monitoring the patient's progress<sup>10,11,15</sup>. Another study associated the positive impact of increased active search activities by CIHDOTT teams in a hospital in Brazil on the number of



effective donations<sup>35</sup>. Carrying out active searches allows notification of all patients with BD $\leq$  7 on the Glasgow scale, with at least one of the clinical signs of BD mentioned, to expand the screening of potential donors, focusing on monitoring the patient's progress and facilitates the identification of potential donors, contributing to an increase in the number of effective donations<sup>7,15</sup>.

It is important to emphasize that professionals who perform active searches must have experience caring for neurocritical patients and know how to perform a rigorous neurological assessment to recognize the clinical signs of BD on time. Research shows that among the triggering factors for failures in identifying these patients is the lack of knowledge of the clinical signs of BD<sup>14,15,36-38</sup>.

In addition to underreporting, cardiorespiratory arrest (CPA) represents one of the biggest reasons for the loss of potential donors<sup>39</sup>. According to data from ABTO, 7% of notifications, equivalent to 997 potential donors, did not complete the donation due to CPA<sup>20</sup>. Studies show that many donors are lost due to a lack of management in the first 24 hours of hospitalization<sup>20,39,40</sup>.

The pathophysiological changes resulting from BD produce severe clinical instability, which requires intensive medical care from the healthcare team throughout the donation process. The lack of adequate clinical management of the potential or potential donor during hospitalization can cause a CPA, compromising the entire donation process. This issue represents a significant challenge in equalizing the supply and demand for organ transplantation<sup>41,42</sup>.

The present study identified hemodynamic instability as the main reason for failing to open the BD protocol for potentially underreported donors. The literature also cites this result as a reason for not starting the BD diagnosis<sup>23,10,11,15</sup>.

Other studies identified the obstacles presented in this research, reinforcing that the local difficulties reflect the structural challenges of this system. The high mortality rate even in emergency rooms, the lack of ICU beds, the underreporting of cases with clinical criteria for BD, and hemodynamic instability as a factor impeding diagnosis reveal the vulnerabilities of the system that compromise the effectiveness of the donation process<sup>3,5,15,23</sup>.

Given the findings of this research, it becomes evident that there is a need for actions aimed at improving the quality of the identification and notification stages, in addition to clinical support for potential donors in hospital institutions with a profile for organ donation. Excellence in donation services that focus on improvements in these stages highlights the strategic role of simple actions, such as systematic active search, audits of hospital records, strengthening of specialized donation teams, and ongoing training of care teams, with an emphasis on rigorous neurological assessment and intensive clinical management of patients with suspected BD. Such measures can increase safety in decision-making, promote standardization of procedures, and, most importantly, increase the number of effective donations<sup>17,23,42</sup>.

Therefore, this study not only contributes to the epidemiological mapping of neurocritical patients at the main hospital reporting BD in RO. This Brazilian state currently ranks highest in reporting potential pmp donors, but also highlights healthcare and institutional bottlenecks that directly impact the donation-transplant process.

In this sense, further research is recommended to identify the causes of potential donor loss and underreporting, which were presented as the study's limitations.

#### **CONCLUSION**

Understanding the organ donation scenario based on the profile and characteristics of neurocritical patients provides an opportunity to guide donation teams in developing strategic actions to improve the quality and safety of care for potential organ donors.

This study allowed us to outline the clinical and epidemiological profile of neurocritical patients with clinical signs of BD admitted to a referral hospital for the donation process in RO, highlighting essential weaknesses in identifying and notifying potential donors and their clinical care. Data analysis highlighted, among other aspects, the high mortality rate even in emergency settings, the underreporting of potential donors with clinical criteria for starting the BD protocol, and hemodynamic instability as a barrier to making the diagnosis.

With this data, it was possible to understand the profile of patients with clinical signs of BD, the number of BDs in the institution studied, and the losses and causes of losses using a quality management tool for the donation process. This information made it possible to identify the real problems of the institution studied, which prevented an increase in the number of effective donors.

These findings reinforce the need to implement strategies for continuous quality improvement in organ and tissue donation processes.

In this sense, the results of this study not only contribute to the advancement of regional scientific knowledge on the subject but can also support public policies and institutional practices aimed at increasing organ donation rates in RO and expanding transplant opportunities in Brazil. Indeed, providing these data to CET will assist in constructing indicators and planning targeted activities with the health teams that work in the donation process.

#### **CONFLICT OF INTEREST**

Nothing to declare.

#### **AUTHOR'S CONTRIBUTION**

Substantive scientific and intellectual contributions to the study: Restier RBO, Knihs NS, Salum NC; Conception and design: Restier RBO, Knihs NS, Salum NC; Data analysis and interpretation: Restier RBO; Article writing: Restier RBO, Knihs NS, Salum NC; Critical revision: Nascimento KC, Pessoa JLE; Final approval: Knihs NS, Salum NC.

#### DATA AVAILABILITY STATEMENT

All dataset were generated or analyzed in the current study.

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