


# Gaps and Impediments to Organ Donation in Brazil: A Literature Review

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## ABSTRACT

**Objective:** To explore the factors that hinder organ donation in Brazil. **Methods:** A literature review was carried out, seeking the main factors that hamper organ donation, using the following descriptors: organ referral, brain death, and intensive care. **Results:** 54 studies published in the last five years were found: PubMed (n=15), EMBASE (n=32), Lilacs (n=1), Mendeley (n=16) and SciELO (n=0). Family members' refusal is the main difficulty in the organ donation process in Brazil. The systematization of organ capture and distribution and the efficiency of diagnosing brain death proved predictive factors for higher rates of family acceptance and efficiency in the process stages. **Conclusion:** Measures to systematize organ procurement and distribution and the health team's training can benefit the Brazilian organ donation scenario.

**Descriptors:** Tissue and Organ Procurement; Brain Death; Intensive care; Professional Training and Transplantation.

## *Lacunas e Fatores Impeditivos da Doação de Órgãos no Brasil: Revisão de Literatura*

## RESUMO

**Objetivo:** explorar os fatores que dificultam a doação de órgãos no Brasil. **Métodos:** foi realizada uma revisão de literatura buscando principais fatores que dificultam a doação de órgãos, utilizando os seguintes descritores: encaminhamento de órgãos, morte encefálica, cuidados intensivos. **Resultados:** foram encontrados 54 estudos publicados nos últimos cinco anos: PubMed (n=15), EMBASE (n=32), Lilacs (n=1), Mendeley (n=16) e SciELO (n=0). A recusa de familiares parece ser a principal dificuldade no processo de doação de órgãos no Brasil. A sistematização da captação e distribuição de órgãos, e a eficiência para diagnóstico de morte encefálica mostraram-se como fatores preditivos para maiores taxas de aceitação familiar e eficiência nas etapas do processo. **Conclusão:** medidas de sistematização do processo de captação e distribuição de órgãos, bem como a capacitação da equipe de saúde podem impactar benéficamente no cenário brasileiro de doação de órgãos.

**Descritores:** Obtenção de Tecidos e Órgãos; Morte Encefálica; Cuidados Intensivos; Capacitação Profissional e Transplante.

## INTRODUCTION

In 1933, the first organ transplant in the world was performed in Ukraine and used a kidney. Although the patient progressed to death, the procedure was considered a technical success. In 1964, the first kidney transplant was performed in Brazil at the Hospital dos Servidores of the State of Rio de Janeiro.<sup>1</sup> From this, the techniques and technology used evolved, using protocols and a multidisciplinary approach<sup>2</sup>, providing better quality and life expectancy for the transplant recipient.<sup>3-5</sup> In 2018, Brazil ranked first in the public organ transplant program in the world, corresponding to 96% of procedures in the public system, Sistema Único de Saúde (SUS).<sup>5-7</sup> However, during the COVID-19 pandemic, the spread of the disease considerably restricted transplant programs worldwide.<sup>8</sup> In Brazil, in the first half of 2020,

there was a decrease in liver transplants (6.9%), kidney (18.4%), heart (27.1%), lung (27.1%), pancreas (29.1%) and mainly corneas (44.3%), due to the interruption of most services.<sup>9</sup>

Spain has held the world record for organ donors per million population (PMP) since 1992, totaling 46.9 PMP donors. In 2017, only 4,896 patients remained on the waiting list. However, in Brazil, in 1992, the average number of donors corresponded to 16.6 PMP; in 2017, 32,402 patients were on the organ waiting list.<sup>4</sup> In 2022, the Brazilian Transplant Registry (*Registro Brasileiro de Transplante*- RBT) presented 52,989 people waiting for an organ in Brazil<sup>10</sup>, suggesting growth in the demand for transplantation. The relationship between the number of patients entering the waiting list compared to the organs available is increasingly disproportionate.<sup>4,11,12</sup>

A rigorous process safeguards the conclusion of the brain death diagnosis and the effectiveness of the organ and tissue donation process: 1) identification of patients in severe condition and with suspected Brain Death (BD); 2) opening of the protocol and notification to Organ Procurement Organization (OPO) or CIHDOTT; 3) confirmation of the diagnosis by the medical team; 4) communication of the death to the family; 5) carrying out the Family Interview (FI) for organ and tissue donation.<sup>13</sup>

According to the recommendations of the Brazilian Association of Organ Transplantation (*Associação Brasileira de Transplante de Órgãos*), only after verbal consent and family authorization expressed in writing the donation is confirmed.<sup>13</sup> However, according to a survey carried out between 2013 and 2018 at the Organs and Tissues Procurement Service of the Hospital de Clínicas at Unicamp (Campinas State University), among the reasons for not donating, family refusal (42.8%) was the leading cause, followed by medical contraindication (25.75%), cardiorespiratory arrest (21.63%), positive serology (4.21%), non-completion of the BD protocol (<0.1%), and in sixty cases (5.49%) there was no report of the reason for not donating.<sup>14</sup>

Thus, this work sought to list the impeding factors regarding organ donation, such as family refusal, challenges in the systematization of the process for the capture and viability of organs, and possible gaps regarding the brain death protocol and its diagnosis, collaborating to establish routines and protocols for the effectiveness of the donation process.

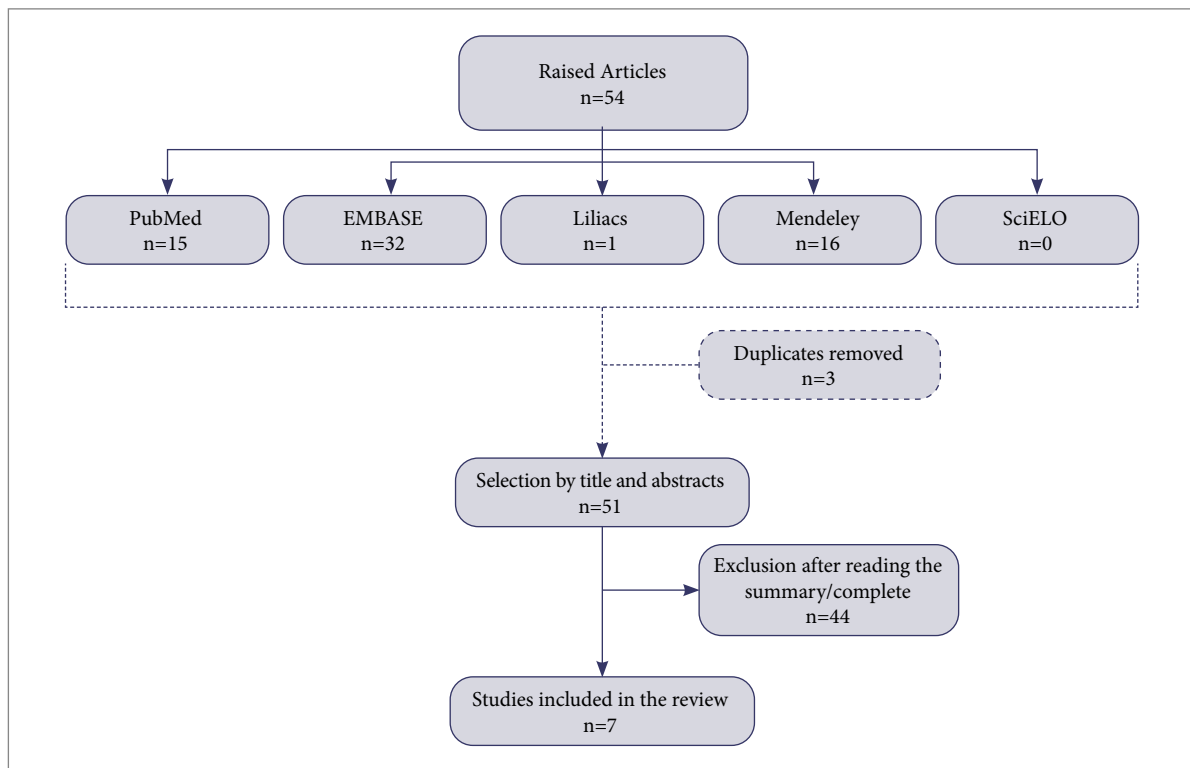
## METHODS

A bibliographic survey was conducted in the following databases: PubMed, BASE, Cochrane Library, Lilacs and SciELO. The search covered the period between 2018 and 2022 for works published in English and Portuguese, using only descriptors registered in the *Descritores em Ciências da Saúde* (DeCS) of the *Biblioteca Virtual em Saúde* (Virtual Health Library), developed from the Medical Subject Headings (MeSH) of the United States National Library of Medicine, which allows a single language in the indexing of publications. The following descriptors and their synonyms were used in combination, in Portuguese and English, respectively: “*encaminhamento de órgãos* (organ referral)”, “*morte encefálica* (brain death)”, e “*cuidados intensivos* (critical care)”, as well as the Boolean operator “AND” to refine the trace.

From the works, a review of the studies that cite the main difficulties related not only to the diagnosis of brain death promptly – and the short-term viability of organs and tissues –but also to the adequate identification of potential donors was carried out. Only articles that list the main difficulties in effecting organ donation worldwide were included. All articles that did not address possible solutions to the proposed problems were excluded from this review. After excluding duplicates between databases, abstracts of works and those that did not include human studies were excluded.

## RESULTS

Fifty-four studies published in the last five years were found: PubMed (n=15), EMBASE (n=32), Lilacs (n=1), Mendeley (n=16) and SciELO (n=0). Duplicates between databases (three studies) and studies that did not include possible obstacles to the donation process or other stages besides the suspected diagnosis of BD (43 studies) were removed. Eight studies were included according to the flowchart shown in Fig. 1. Other works found outside the search criteria were considered in the writing of the text but not included in the systematization shown in Fig. 1. The bibliographical analysis pointed to the refusal of family members as the main difficulty in the process of organ donation in Brazil, so both the systematization and the greater degree of medical knowledge about brain death stood out as predictive factors for higher rates of family acceptance and efficiency in the stages of the process. In addition, medical knowledge about brain death proved insufficient, especially among general practitioners, which is alarming since the urgency and emergency team are crucial in this context and include such professionals. The contributions of the study are shown in Table 1.



Source: Elaborated by the authors.

**Figure 1.** Flowchart of the adapted study selection process.

**Table 1.** Study Contributions.

Study Contributions.	
Main results	The literature review indicated the lack of knowledge about the system and the health team's declaration of brain death as the main gap.
Implications for services	Training of the health team related to potential donors. Dissemination of information among the academic community, professionals in training and those involved with the organ collection and distribution system.
Prospects	Indicate work protocols and suggest mechanisms to reduce the time between collection and distribution of human organs and tissues, making the donation system effective for treatment with transplanted human organs.

Source: Elaborated by the authors

## DISCUSSION

### Legislation for organ donation in Brazil

Surgery for organ transplantation was only regularized in 1997, with Federal Law nº 9,434,<sup>15</sup> which deals with the post-mortem allocation of organs, tissues and parts of the human body for transplantation; the criteria for living donor transplantation; and criminal and administrative sanctions for non-compliance. This law changed the type of donation in force in the country that, until then, was consented to; that is, it was necessary to manifest in favor or against the donation in case of death.<sup>4</sup> As of the Transplantation Law, authorization became presumed, and the dissenting party must formally state its position. This record, for or against the donation of organs, was made on the identity card or the National Driver's License. However, Law No. 10,211/2001<sup>16</sup> extinguished the presumed donation and determined authorization in writing from first or second-degree relatives or spouses with a proven relationship, without which the removal of organs would be prevented, regardless of the potential donor's desire in life. Previously made in identification documents, the records are no longer valuable.<sup>4,13</sup>

### Context of Brain Death Donation (BDD) in Brazil

Federal Law No. 9,434 of February 4, 1997<sup>15</sup> regulates the Brain Death diagnosis protocol, which deals with the disposition of organs, tissues, cells and parts of the human body for transplantation. It is regulated by Decree No. 9.175,<sup>17</sup> of October 18, 2017,

and by Resolution No. 2,137 of 2017 of the Federal Council of Medicine.<sup>18</sup> The diagnosis of BD in Brazil follows strict regulations and assigns a legal nature to the donation protocol, requiring compliance with all stages to declare a dead individual.<sup>19</sup>

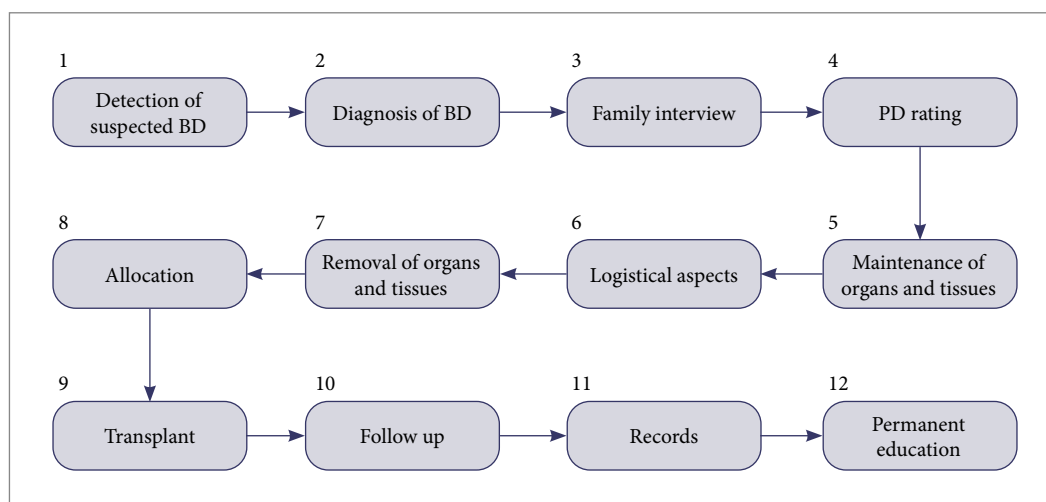
The procedures for diagnosing BD include 1) communication of suspected BD to family members; 2) notification to the State Transplant Center/OPO; 3) presence of brain injury of known cause, irreversible and capable of causing BD; 4) absence of treatable factors that could confound the diagnosis of BD (for example sedatives); 5) treatment and observation in hospital for a minimum period of six hours; 6) body temperature > 35°C, SatO<sub>2</sub> > 94% and blood pressure according to age group; 7) two clinical exams showing signs compatible with BD, such as non-perceptual deep coma or absence of brainstem reflexes, such as pupillary, corneal, oculocephalic, vestibular-ocular and cough reflexes; 8) apnea test and complementary exams, such as electroencephalogram, transcranial Doppler and cerebral arteriography.<sup>12</sup>

In 2022, Brazil had 13,195 notifications of potential donors (PD), of which 3,528 became effective donors, that is, 26.7% of the total. However, there are 52,989 active patients on the waiting list. Regarding the conversion of approximately only a quarter into effective donors, the most significant obstacles found in Brazil are family refusal (46%) and medical contraindications (18%).<sup>10</sup>

### The systematization of the donation process

In Brazil, the organizational structure of the organ donation process is based on the “Spanish model” of transplants, which integrates the three hierarchical levels in the donation process: the National Transplant System (*Sistema Nacional de Transplante – SNT*), the state Notification, Collection and Distribution Centers of Organs (*Centrais de Notificação, Captação e Distribuição de Órgãos – CNCDO*) and local Intra-Hospital Committees for Organ and Tissue Donation for Transplantation (*Comissões Intra-Hospitalares de Doação de Órgãos e tecidos para o transplante – CIHDOTT*). Hospitals with more than eighty beds must have their CIHDOTT. In addition, to meet the demand for organ donation in hospitals that do not have an active hospital transplant coordinator or partnership with coordinators, Organ Procurement Organizations (OPOs) were created.<sup>20</sup> The strategy of having a transplant coordination team within the hospital, whose responsibility covers the entire process from identification to collection and grafting, promotes a significant increase in donation rates. In Spain, this strategy made it possible to overcome several obstacles, such as the failure to identify donors and the reluctance of professionals to approach grieving families.<sup>21</sup>

In general terms, the donation process due to brain death (BDD) can be divided into twelve parts: 1) detection of suspected BD; 2) diagnosis of BD; 3) family interview; 4) evaluation of the potential donor (PD); 5) maintenance of organs and tissues; 6) logistical aspects; 7) removal of organs and tissues; 8) allocation; 9) transplant; 10) follow-up; 11) records; 12) continuing education; as shown in Fig. 2.<sup>20,22</sup>



Source: Elaborated by the authors, using data from Garcia *et al.* (2017)<sup>20</sup> and Araújo (2021)<sup>22</sup>.

Figure 2. Stages of brain death donation.

### Suspected brain death and donor identification

In the context of systematizing the DME process, active search is a crucial instrument to avoid underreporting. To this end, the CIHDOTT must systematically carry out an active search for potential donors in units with critical patients, covering all locations that have a mechanical ventilator. It is worth mentioning that the CIHDOTT must work together with the hospital's medical teams, mainly the ICU and Urgency and Emergency.<sup>22</sup> In addition, it is essential to highlight the referral of the potential donor by the hospital's emergency department since, in this sector, there is a higher success rate of donors, in addition to a tendency for donation of more than a single individual, compared to referrals from the ICU. Thus, the active search for CIHDOTT becomes crucial,

especially when there are recurrent failures in referral by the emergency medical team, and training for the specific qualification of these professionals by this intra-hospital body is beneficial.<sup>11</sup>

It is crucial to understand that, when done immediately, the detection of PD and its referral for evaluation results in higher success rates for any organ donation directly related to the prompt maintenance of organs and tissues. Barrier factors in this phase are the lack of specific training regarding detection, in addition to the accompanying work of the professional in the urgent care of other critical patients.<sup>2</sup> As a result of dealing with this problem, the application of communication technologies to speed up referrals proved effective, especially in identifying patients outside the ICU. During four years at the University Hospital of Vall d'Hebron (Barcelona, Spain), an instant messaging application was used for multidirectional communication between professional medical teams regarding the referral, evaluation and management of the PD with the coordinator of donation, concurrently with research, related to intensive care to facilitate organ donation. The result of applying this tool was greater efficiency in managing the PD precisely because communication between the donation coordinator and the other departments was made more accessible, in addition to engaging the collective learning of the professionals involved by sending immediate feedback on the case and indicating the final contribution of each professional in the donation process.<sup>23</sup>

## BD diagnosis

In Brazil, family members must be notified of suspected brain death, and they can choose a doctor they trust to accompany the exams. When the diagnosis of BD is made, family members are promptly notified, and the CIHDOIT tells the State Transplant Center (*Central Estadual de Transplantes-CET*), even if there is unfeasibility of organs or family refusal to donate.<sup>20,22</sup>

However, the BD declaration process still needs to overcome obstacles related to failures to complete the diagnosis. To investigate inefficiencies at this stage of the donation process, a survey in the United States studied the possible factors associated with Potential Donors by BD that were never declared during four years, and these represented 15% of all PD by BD. In this context, each cause of failure can be grouped into four groups that total 394 cases, with factors involving the patient (n=55), family (n=122), professional (n=110) and health system (n=107). In the family, the members' unwillingness to wait longer for the diagnosis (n=65) and family refusal to donate (n=17) stood out; already related to professionals, the early mention of donation (n=44) and the lack of cooperation with the organ procurement team (n=21); in the health system, delay in referral (n=48) and the transplant team not being on site (n=37); associated with the patient, previously known objection (n=55) and severe or terminal instability (n=26) remained.<sup>24</sup>

In addition to such general obstacles identified in the United States, the Brazilian scenario encompasses other more particular barriers, such as the lack of ICU beds in public hospitals, so that these patients end up being managed in crowded emergency rooms, and medical ignorance about of the subject, due to the disbelief of several professionals regarding the diagnosis of BD. This position corroborates with the questioning of the diagnosis by common sense.<sup>3</sup> It is also worth mentioning Donation after Circulatory Death (CDD), a modality that has been growing worldwide and can be used as a complement to BDD in terms of the insufficiency of BDD cases when meeting the demand for transplants. In its definition, CDD occurs when there is cardiorespiratory arrest and can be classified by the Maastricht categories, of which only IV (cardiorespiratory arrest before, during or after confirmation of brain death) is used in Brazil in a small number of kidney transplants. However, despite being strategically accepted by many countries, CDD is not used in Brazil due to ethical, legal and financial barriers. Therefore, because it is less complex and cheaper, investment in greater effectiveness of BDD proves to be satisfactory to meet the current demand for transplants in the country, except the lung, whose usufruct of CDD has greater potential.<sup>25</sup>

As an example of investment in efficiency in the process, the use of teleneurology, that is, the remote help of a specialist in the interpretation of complementary exams, proved to be efficient in the diagnosis of BD, increasing the percentage of organ donations in the hospital studied when compared to the period before the implementation of teleconsultations in the same location.<sup>26</sup>

## Medical knowledge about brain death and its impacts on organ donation

It is imperative to highlight that a poorly conducted donation process, carried out by poorly educated or insufficiently trained professionals, can weaken the trust of the entire service, leading to judgments and questions about this process. However, if well conducted and with successful experiences, it will help family members deal with loss and emotional upheaval and encourage society's desire to donate.<sup>8</sup> According to resolution 2.173/2017 of the Federal Council of Medicine<sup>18</sup>, physicians with at least one year of experience in the care of comatose patients and who meet one of the two following criteria are considered fit and capable of carrying out the clinical examination to determine BD: 1) carrying out or monitoring ten determinations BD; 2) carrying out a training course for determining BD.<sup>12</sup>

Vasconcelos (2021)<sup>8</sup> evaluated the knowledge of 313 intensive care and non-intensive physicians working in different regions of Brazil using a questionnaire with twelve questions about the BD protocol and organ donation. The results indicated an average of correct answers equal to five, corresponding to a need for more knowledge about diagnosing BD and organ donation in the

studied sample. Approaching BD during the undergraduate course was also considered insufficient by most participants (88.8%), emphasizing the need to include the theme in the curriculum of trails in the medical field.<sup>8</sup>

Knowledge of Resolution 2,173 of 2017 of the Federal Council of Medicine is essential<sup>18</sup>, whose central objective is to establish parameters to standardize the diagnosis of BD and consists of a relevant legal protocol on the need to standardize the methodology used.<sup>12</sup> By reaffirming the importance of the commitment of all physicians to the preservation of life through organ donation, the resolution protects the donor and the transplant recipient and offers credibility to the system. Thus, the need for training the health team and medical professionals on diagnosing BD is evident, as it is a fundamental strategy to fill the existing gaps in knowledge. Developing new studies that can verify professionals' understanding before and after participation in training courses is also advisable.<sup>5,8</sup>

### **Family refusal in the organ donation process**

Federal Law No. 9,434, of February 4, 1997, determines the legality of organ donation, in which it establishes the first-degree family as the exclusive source of authorization for the process, even if, in life, the donor has left in writing this wish.<sup>15</sup> In this way, prior dialogue with the family is the only way for this individual willingness to donate to be respected and met.<sup>27</sup>

According to the Brazilian Transplant Registry, among the reasons for not completing the donation procedure, family refusal represents 46% of all unfinished cases between June and September 2022.<sup>10</sup>

Therefore, it is known that the process not only covers the donation and transplantation of organs and tissues but also contemplates ethical, moral and religious issues in the family context. In this sense, understanding the diagnosis of brain death and the religious issue are still obstacles, in which lack of information is one of the main reasons for organ refusal. Family members do not understand what brain death is and think that, by agreeing to donate organs, the doctor and his team can induce the patient's death. In addition, the lack of preparation of the professional who approaches the family at the time of the loss of the loved one due to not having the necessary information and not showing sensitivity and empathy can lead to non-acceptance of the donation. Finally, due to the lack of clarification, the relatives are afraid of manipulating the body to remove organs and want to keep the body intact for the wake and burial and, thus, deny organ donation.<sup>28</sup>

## **FINAL CONSIDERATIONS**

Both the systematization measures of the organ donation process, whether for the training of the health team directly involved with potential donors, for the reduction of the time between the distribution and collection of organs, or the suggestion of new protocols and mechanisms for the confirmation of brain death can promote benefits for the Brazilian scenario of organ donation nationally. The transparency of the organ donation process ensures essential ethical aspects for system users, ensuring effectiveness and credibility in the donation.

## **CONFLICT OF INTEREST**

The authors declare no conflict of interest.

## **AUTHOR'S CONTRIBUTION**

**Substantive scientific and intellectual contributions to the study:** Oliveira AFCG, Cardoso RAB, Freitas KC, Lucas BL; **Conception and design:** Oliveira AFCG, Cardoso RAB, Freitas KC, Lucas BL; **Data analysis and interpretation:** Oliveira AFCG, Cardoso RAB; **Article writing:** Oliveira AFCG, Cardoso RAB, Freitas KC, Lucas BL; **Critical revision:** Oliveira AFCG, Cardoso RAB, Freitas KC, Lotte EJ, Lucas BL; **Final approval:** Freitas KC, Lucas BL.

## **DATA AVAILABILITY STATEMENT**

Not applicable.

## **FUNDING**

Not applicable.

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