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Organ donation: Professional support in the diagnosis of brain death from the perspective of family members

Doação de órgão: acolhimento profissional no diagnóstico de morte encefálica sob a ótica dos familiares

Donación de órganos: el acogimiento profesional durante el diagnóstico de muerte encefálica desde la mirada de los familiares

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ABSTRACT

Objective: to understand family members' perceptions of the welcoming provided by health professionals in the approach to organ donation after a diagnosis of brain death. **Method:** this is a descriptive and qualitative study conducted with family members who experienced the process of determining brain death in a hospital environment. Data collection was performed between September and December 2023 through in-depth face-to-face interviews, guided by a semi-structured questionnaire. The data were analyzed with the ATLAS.ti® software. Approval was obtained from the Research Ethics Committee. **Results:** ten family members participated in the study, revealing three themes: Determining death: barriers in communication and access to information; Communicating death: professionals involved during the BD protocol and the moment of communicating bad news; and Final outcome: immortalizing life. **Final considerations:** communication was considered essential to ensure quality and humanization in family reception, although it does not directly influence organ donation. There is a need for training to promote adequate reception.

Descriptors: Brain Death; Tissue and Organ Procurement; Health Personnel; Family; User Embracement.

RESUMO

Objetivo: compreender a percepção dos familiares sobre o acolhimento por profissionais de saúde na abordagem de doação de órgãos após o diagnóstico de morte encefálica. **Método:** estudo descritivo e qualitativo realizado com familiares que vivenciaram o processo de determinação de morte encefálica em ambiente hospitalar. Coleta de dados realizada entre setembro e dezembro de 2023, por entrevistas presenciais em profundidade~~,~~ guiadas por questionário semiestruturado. Dados analisados com o *software* ATLAS.ti®. Obtida aprovação do Comitê de Ética em Pesquisa. **Resultados:** participaram do estudo dez familiares, revelando três temas: Determinando a morte: barreiras na comunicação e acesso às informações; Comunicando a morte: profissionais envolvidos durante o protocolo de ME e o momento da comunicação de más notícias; Desfecho final: eternizando a vida. **Considerações finais:** a comunicação foi considerada essencial para garantir qualidade e humanização no acolhimento familiar, embora não influencie diretamente na doação de órgãos. Há necessidade de capacitação para promover um acolhimento adequado.

Descritores: Morte Encefálica; Obtenção de Tecidos e Órgãos; Profissionais de Saúde; Família; Acolhimento.

RESUMEN

Objetivo: analizar la percepción de los familiares respecto al acogimiento brindado por el equipo de salud durante el proceso de donación de órganos posterior al diagnóstico de muerte encefálica. **Método:** estudio descriptivo y cualitativo realizado con familiares que vivieron el proceso de determinación de muerte encefálica en un entorno hospitalario. La recolección de datos se realizó entre septiembre y diciembre de 2023, mediante entrevistas presenciales en profundidad, guiadas por un cuestionario semiestructurado. Los datos fueron analizados con el software ATLAS.ti®. Se obtuvo la aprobación del Comité de Ética en Investigación. **Resultados:** participaron en el estudio diez familiares, revelando tres temas: Determinando la muerte*:* barreras en la comunicación y acceso a la información; Comunicando la muerte*:* profesionales involucrados durante el protocolo de muerte encefálica y el momento de comunicar malas noticias; Desenlace*:* eternizando la vida. **Consideraciones finales:** los participantes destacaron que una comunicación clara y empática es fundamental para garantizar un trato humanizado hacia la familia durante el proceso, aunque su impacto en la decisión final de donación fue limitado. Queda evidente la necesidad de fortalecer la formación de los profesionales para optimizar el acogimiento brindado.

Descriptores: Muerte Encefálica; Obtención de Tejidos y Órganos; Personal de Salud; Familia; Acogimiento.

INTRODUCTION

The theme of "death and dying" remains a difficult subject to address in society, which can lead to doubts, debates and discussions, and its concept has been constantly modified throughout history[1]. Based on medical terms, death can be generally defined as the irreversible cessation of vital functions. However, more recently, it has also come to be

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related to the absence of electrical activity and loss of brain stem and cortex functions which characterize brain death (BD)[2]. When diagnosed, this defines the clinical, legal and social death of the individual[3].

People diagnosed with BD are considered potential organ and tissue donors, provided there is family consent and favorable clinical indications[4]. Therefore, notification to the State Transplant Center (*Central Estadual de Transplantes - CET*) of the related federation is mandatory, and a monitoring protocol must be opened at that time to communicate and clarify to the family members about the diagnosis of BD, from suspicion to the conclusion of the entire process of its determination[2].

Communication of a BD diagnosis can be characterized as an example of delivering “bad news” to the family. Therefore, information about the diagnosis should be given by considering a set of psychosocial factors related to family characteristics, such as: possible level of understanding of the information, degree of kinship, age group and the existence and quality of support networks for support[5].

In addition, communication to family members should avoid some difficulties/barriers, such as the use of scientific terms or jargon from the health area, poor psychological and emotional support, and the family’s antagonistic understanding that despite the absence of brain activity, the patient presents some “signs of life”, meaning that they maintain a breathing pattern and have flushed and warm skin, which can trigger the perception of the possibility of reversing the condition, generating hopes and expectations in the family for future improvement. In this context, inadequate communication has been identified as a direct influence on the refusal of organ donation and transplantation[6].

The loss of a loved one is a stressful and painful time for the entire family system, while the process of determining BD and donation can be complex and sometimes prolonged[7,8]. The suffering resulting from the sudden death of a loved one causes intense stress and emotional changes to family members, especially if the person is young. The greatest manifestations of sadness are attributed to death which occurs abruptly, as it almost always changes the perceived natural cycle of life, making mourning even more painful and often pathological[9].

In this context, the act of welcoming and being with the family and the patient ends up becoming a requirement of the ethical and moral stance of the health professional through active and qualified listening, promoting recognition of the leading role of the family system. With this, care focused on the family and the biopsychosocial needs of the patient alleviates the exhaustion and mental suffering of those involved[10]. Welcoming consists of meeting the most basic demands, offering refuge and protection, and accepting the other as an individual with their rights and desires; it is an action of approaching and including someone. In Brazil, it aims to guarantee the principles of the Unified Health System (*Sistema Único de Saúde - SUS*) through the National Humanization Policy (*Política Nacional de Humanização - PNH*)[10,11].

Involvement of a multidisciplinary team throughout the process of determining a BD diagnosis and organ donation is important, with professionals involved and committed to providing qualified family support. Among the team’s responsibilities, as a rule the nurse acts as the greatest link and intermediary between the health service and the family members, being the most active in all stages, and is therefore essential to guarantee the quality of care and the effective donation of organs and tissues[12].

The nurse has the opportunity to provide support and attention to families, developing empathy and active listening during the initial grieving process[12]. The Brazilian Association of Organ Transplants (*Associação Brasileira de Transplantes de Órgãos - ABTO*) published that 10,422 notifications of potential donors were made, with 5,998 family interviews conducted and a total of 2,573 refusals during the period from January to September 2023. According to these data, there is a high rate of rejections by families[13].

In this context, it is clear that the healthcare team which provides family support still needs to understand and assist the needs of families of patients with BD, considering their vulnerabilities, anxieties, fears and suffering as the main strategy to mitigate the effects of ineffective communication and support of bad news, and not only for the purpose of organ and tissue donation, but also to respect the grieving family members.

Therefore, this study is justified because it sheds light on the way families have been supported during the diagnosis of BD, in addition to enabling improvement in family support strategies with the purpose of minimizing the suffering of those involved.

In turn, the objective of this study was to understand the perception of family members regarding the support provided by healthcare professionals in the approach to organ donation after a diagnosis of brain death.

METHOD

This is a descriptive-exploratory study with a qualitative approach, developed with family members who experienced a diagnosis of BD and were welcomed by health professionals, including doctors, nurses, psychologists and social workers, working in hospitals that belong to a health region located in the Southern Region of Brazil. These hospitals compose the Organ Procurement Organization (OPO) Maringá, belonging to the Paraná State Transplant Center (*Central Estadual de Transplantes do Paraná - CET/PR*). This study was developed considering the recommendations of the Consolidated criteria for reporting qualitative research (COREQ)[14].

The State of Paraná is divided into four macro-regions, which in turn are divided into 22 health regions to integrate the organization, planning and execution of health actions and services[15]. The 15th Health Region of Paraná (HR) was selected to conduct the study, located in the northwestern macro-region of the state, with approximately 820 thousand inhabitants, with the municipality of Maringá as its headquarters, in addition to integrating 30 other locations[16].

The OPO consists of an organization of the State Department of Health responsible for organizing the logistics of the search for organ and tissue donors in hospitals located in its operation area and which are managed by the State Transplant Center, whose function is to organize, coordinate, regulate and monitor the state transplant system[17].

The list of potential participants was obtained from the OPO Maringá database. The database provided information such as the names and telephone numbers of family members so that the researchers could contact them in advance and invite them to participate in the study, and later schedule a face-to-face interview.

The family members participating in this study met the following inclusion criteria: being over 18 years old, residing in one of the municipalities of the 15th HR and being a family member of a person who died of BD. Family members who had difficulty communicating verbally and lived in municipalities more than 35 km away from Maringá were not included due to the difficulty of regional travel.

The data collection period took place from September to December 2023, and was divided into three stages: (1) after prior authorization from the OPO Maringá and *CET/PR*, the main researcher initially went to the headquarters of OPO Maringá to collect basic information from family members who had loved ones die from BD in the period from September 2022 to March 2023; (2) after obtaining the contact details of the family members, telephone contact was made with them to schedule in-person interviews in advance; (3) the in-person interviews took place in locations previously chosen by the family member, for example: home and public squares.

The interviews were conducted by the lead investigator, a nurse specializing in emergency medicine and urgency, who had direct contact with BD diagnostic processes during her undergraduate studies, residency, and later in her professional practice as part of the multidisciplinary team of the Intra-Hospital Commission for Organ and Tissue Donation (*Comissão Intra-Hospitalar de Doação de Órgãos e Tecidos - CIHDOTT*) of a university hospital, but who had no prior relationship with the potential research participants. In addition, the researcher already had experience in collecting qualitative data and had been previously trained by a team of researchers.

The interviews were guided by an instrument composed of items characterizing the family member (age, sex, profession, education, religion, and degree of kinship), followed by the triggering question: What was your experience with the professional support you received during the diagnosis of brain death of your family member? Other supporting questions were asked in order to expand information collection and meet the proposed objective. The dialogues were recorded and transcribed in full, and the audio files were duly destroyed after the data analysis stage.

In addition to the criterion of exhausting the list of potential participants, the researchers were attentive and guided the data collection based on the repetition of information[18], meaning that participation of the interviewees was encouraged until the moment in which no new analytical themes were found.

The qualitative data were analyzed based on the Thematic Analysis methodological framework[19] which allowed for a more detailed and differentiated description of the proposed theme. This analytical method consists of six phases: (1) Familiarization with the data involving the researchers' immersion in reading and rereading the data in order to provide support for the other analysis stages; (2) Generation of initial codes, in which the first codes were produced from the data, beginning their characterization; (3) Search for themes, which occurred from the coding and grouping of the data, immediately after which a screening of potential themes was performed in which some codes became main themes and others became subthemes; (4) Review of the themes, involving two levels: (a) review of the coded extracts and (b) refinement of the themes; (5) Definition and naming of the themes, a stage in which a thematic and explanatory map was prepared, passing the data through a final analysis and refinement of the themes; and (6) Production of the report, which contains a concise, coherent, logical analysis which captures the essence of the phenomenon under study[19,20].

This entire process was carried out using the ATLAS.ti® software, version 24, which is useful for enhancing data management and exploration, as well as streamlining the analytical process[21]. A word cloud was used to identify the frequency of words and the connections between them. The final themes were created from a convergence of the initially established themes, obtained after analyzing and organizing the data using the ATLAS.ti® software.

The interviews were audio-recorded and later transcribed for analysis to ensure methodological rigor. In addition, the analytical process and interpretation were conducted based on reflexivity. An audit trail was recorded and archived in order to guarantee the credibility, reliability, and confirmability of the data, ensuring that the supporting documentation was available for possible future consultations.

The research protocol met the established ethical requirements and was approved by the Research Ethics Committee of the institution involved. All participants voluntarily consented by signing two copies of the Informed Consent Form (ICF). In addition, the following coding was adopted in order to ensure confidentiality of the identity of the participating family members: family member interview and its numerical sequence (i.e. F1).

RESULTS

Among the 42 potential family members participating in the study, 10 who experienced a diagnosis of BD in hospitals which compose the 15th Regional Health Department of Maringá and the OPO Maringá actually participated. There were 16 family members refused to participate, four lived in cities more than 35 km away, and 12 had incorrect or no contact telephone numbers. Detailed information on the characterization of the family members was collected and analyzed as part of the study (Fig. 1).

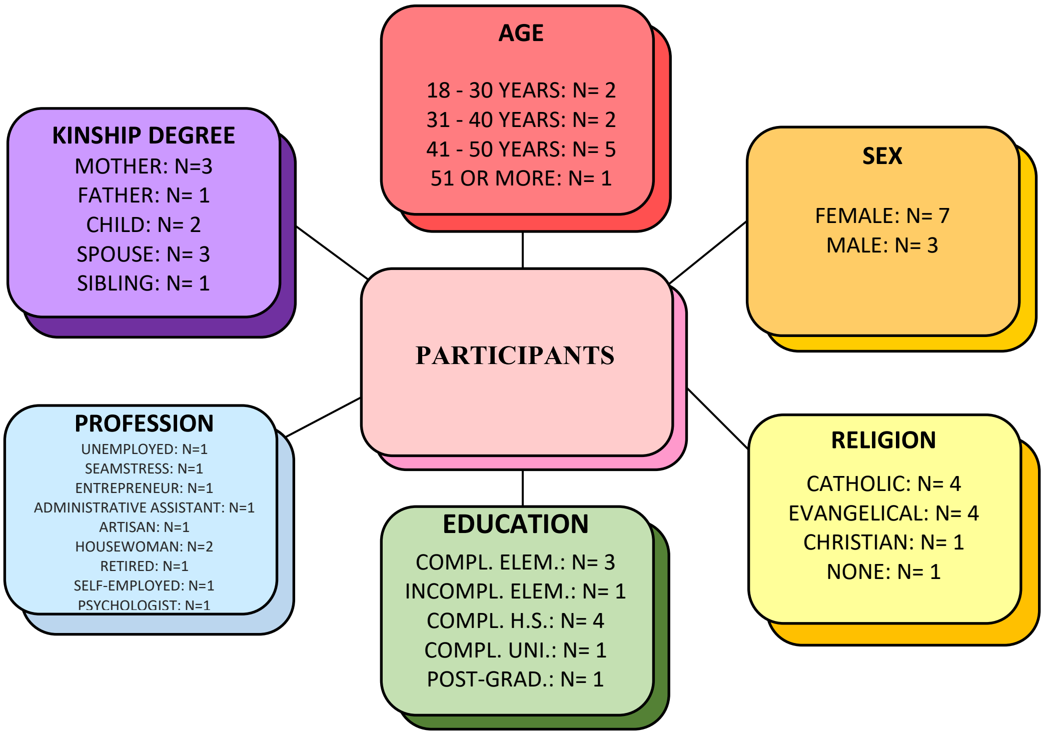

Figure 1: Characterization of family members in the study of patients who experienced a diagnosis of BD in hospitals. Maringá, PR, Brazil, 2023.

Through the word cloud it was possible to identify a greater occurrence of the words “Doctor”, “Death”, “Hospital”, “Organs”, “Donate”, “Nurse”, “Day”, “Exam” and “Moment” (Figure 2).

Figure 2: Word cloud: family members' perception of professional support during the diagnosis of BD. Maringá, PR, Brazil, 2023.

Among the indicated words, categories were created which helped identify the perceptions of family members about professional support during the process of determining BD. The "Death", "Day" and "Exam" groups came together and gave rise to Theme 1, called: "Determining death: barriers in communication and access to information". The "Doctor", "Nurse", "Hospital" and "Moment" groups resulted in Theme 2, entitled: "Communicating death: professionals involved during the brain death protocol and the moment of communicating bad news". Finally, the "Donate" and "Organs" groups gave rise to Theme 3: "Final outcome: immortalizing life".

Theme 1: Determining death: barriers in communication and access to information

The words "Death" and "Exam" are directly related in this theme, since tests which are part of the BD determination protocol were necessary to confirm the BD diagnosis. However, the word "Day" is presented as a correlation, which justifies the time needed to confirm the diagnosis. Furthermore, it is highlighted through reports that the protocol steps were also not properly explained to family members by health professionals.

> *"The doctor explained to me that he noticed something strange about him during the ICU routine, that he identified a change when examining his eyes, which was an indication of a very serious neurological injury and they would need to start a protocol to check if he was in the process of brain death." (F9)*
>
> *"They said he needed to stay for 24 hours to see if he would react, the sedative was taken away, but we didn't really understand, because after we left he was sedated again, so does that mean he reacted? (…) but the doubt remains to this day, did he react or not?" (F2)*

Inadequacies in access to information about the diagnosis were highlighted in addition to the diagnosis of BD, resulting in a lack of understanding of BD or misunderstanding. It is observed in the reports of family members that there was no effective communication with guarantee of adequate information about BD.

> *"There was no explanation, they just said that they had to do three tests to guarantee death, that was all." (F5)*
>
> *"I didn't understand what it was, so I looked it up on the internet and it said it was a vein in the head that had ruptured, but I don't know if that's really it." (F1)*
>
> *"The doctor just said there was no way out, everyone was sad and crying, it was over." (F3)*

Nurses played a fundamental role in clarifying doubts about the diagnosis for some family members, being seen as facilitators in accessing information.

> *"The nurses were super attentive, I asked some questions that I didn't understand and they explained why and how it was done, you know how the doctor speaks more difficultly, with technical terms, but the nurses explained it in a much easier way." (F7)*

Family inclusion during the process of determining BD appears to function as another factor which contributes to expanding understanding of the diagnosis and also in coping with grief.

> *"They asked how we would like to be notified about the tests, whether we wanted it at the end of each test or at the end of everything, and after talking to my husband and sister, we decided to participate in all stages, and they did so, but unfortunately the news was not good." (F7)*
>
> *"The whole family participated, me, his oldest son, his aunt and his ex-wife from his first marriage." (F9)*
>
> *"It was me, my daughter and my mother-in-law, and they talked to us, reinforcing once again how serious her condition was and that they suspected that her brain was not functioning." (F8)*

Theme 2: Communicating death: professionals involved during the brain death protocol and the moment of communicating bad news

Involvement of the multidisciplinary team is observed throughout the process in the second theme, from suspicion to confirmation of death, with this being a factor that provides family support.

> *"The diagnosis was given at the hospital and a psychologist, a doctor and a nurse were present." (F5)*
>
> *"When the doctor mentioned brain death, it was hard to take it all in, but after the doctor left, the nurses explained it again, in a much easier way, we were able to understand that his brain had died (…), even though his other organs were functioning." (F7)*
>
> *"We were welcomed by the doctors, a nurse, the social worker and a psychologist. After the shock of receiving the news that my husband had died, I was devastated, I thought I would have to be hospitalized there because I felt so bad, I couldn't think about anything." (F8)*
>
> *"The psychologist and the nurse asked to call my little daughter, they talked to her, explained what had happened and that her father was no longer here, I am grateful to them, because I wouldn't be able to cope." (F9)*
>
> *"We were welcomed well, they prepared us from the beginning, two nurses and two doctors came every day, that's how it was every day, morning and afternoon, they prepared us well." (F3)*

Another important aspect during the communication of death was the place where it happened, highlighting the importance of a welcoming space and environment.

> *"It was a small room, very close to the room where he was in the emergency room, it was very comfortable." (F5)*
>
> *"We talked in a kind of chapel, which is inside the hospital itself." (E5)*
>
> *"Inside the ICU, there was a room near the ICU, where the doctors used to hold meetings with relatives and family members." (F6)*
>
> *"They took us to a private room… When they gave us the news it was very sad, I didn't imagine that there would be no way out, when the doctor said that if she lived she would be in a bed completely dependent, it ended like that, everyone sad and crying." (F3)*

Theme 3: Final outcome: immortalizing life

The words "Donate" and "Organs" in the third theme mainly highlighted the family's desire to continue life through donation. Some reported that they chose to donate regardless of the support they received from professionals or any other influence.

> *"We had no influence whatsoever, we just wanted to continue the idea that she always did good for others." (F10)*

Other family members opted to donate based on positive family influences, some cases because they respected a decision previously made by the patient themself, and others with initial resistance due to lack of knowledge of the current donation and transplant process, but who ended up making the donation at the request of other family members.

> *"I said I wouldn't donate, but my son-in-law's mother lived for another 15 years after a transplant, and he came to me and told me about his experience with his mother, but I didn't want to donate (…)." (F3)*
>
> *"It wasn't influenced by anyone, he and I sometimes talk, not often, but we had already talked about donating at times, so it wasn't because of influence, it was because we wanted to try to help more people." (F9)*

Some family members described during the interviews how they were actually welcomed by health professionals. It is worth noting that no family member indicated that the donation was influenced by the welcoming provided.

> *"I think they did what they could. Only today, thinking about all this experience I had, I believe that when you realize that a patient is no longer fit to live (…) they should start preparing the family, especially those who are closest to them." (F9)*
>
> *"They tried to explain everything in the best way possible so that we all understood (…) I already had more or less an idea of what it was. The only thing we didn't know much about was the tests that are done to confirm it, but they explained the whole process very well." (F10)*
>
> *"The doctors reassured me, they told me what was happening and made her situation clear. They were there to answer my questions the whole time. When I arrived there to visit them, they would come and tell me, (…) this is happening." (F6)*

DISCUSSION

The sociocultural diversity of participants, including age, education, religion and degree of kinship, directly influences the way in which grief is experienced and the way in which support is perceived. Studies indicate that cultural factors, beliefs and family context affect understanding of the diagnosis and the relationship with health professionals[22-25]. In addition, empathy and effective communication must be adapted to the characteristics of each family[7].

The fact that those who said they did not feel comfortable remembering and/or talking about the death of their loved one refused to participate in the study may be related to the emotional complexity involved in the topic. Refusal or withdrawal may be related to factors such as the difficulty in reliving painful moments, a reluctance to share intimate experiences or even the perception that participation could generate a negative emotional impact[24].

Therefore, understanding the multiple dimensions of support and its possible implications for the bereaved becomes essential to improve care practices. In this context, the results of this study allowed us to identify, according to reports from family members, that most of them were welcomed and guided, while a minority of those interviewed demonstrated that they did not understand the information provided by health professionals, demonstrating that some family members still have doubts about the diagnosis and the process of determining BD.

It is possible to infer that there are professionals to date who are not properly prepared and/or qualified to approach families, especially with regard to communication, transmission of information and the way in which the reception is conducted. On the other hand, it is understood that communicating bad news, such as the death of a patient, also tends to produce emotional effects on the information transmitter, mainly frustration, which can cause the professional to avoid or even provide limited information, consequently limiting the family's support. However, it is known that the academic training of health professionals is still mainly directed towards curative practices, with the process of death and dying being little addressed[10]. This clearly has a direct impact on how professionals feel, whether they are qualified or not, to support grieving families.

In this sense, there is a need for training and qualifications in order to expand professional knowledge about the importance of qualified family support in coping with grief. It was noted that communication established by health professionals, from the suspicion to the final diagnosis within the BD protocol, is a complex factor, and at times difficult for family members to understand. This is possibly related to the emotional reactions they face at the time of the initial diagnosis of BD[22]. Therefore, based on the reports of family members, communication was identified as an important tool in building bonds and trust between the team and the family.

Studies conducted in Brazil and Australia showed that a welcoming space is necessary when communicating bad news, not only in terms of physical space, but also in terms of listening to family members. This should not only be a time for the professional to speak, but it is important that there is a shared dialogue that is consistent with family values[6,23]. Conducting a prior assessment of the socioeconomic level, knowledge and perspective of family members before providing any information is an essential conduct, constituting a strategy for organizing information according to the knowledge and needs of family members, avoiding repetitions and prolonged exposures, in addition to the excessive use of technical language which can hinder understanding of the diagnosis and procedures involved[6].

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In this sense, a study performed with 179 family members who experienced BD in Canadian intensive care units identified that the modifiable factors to improve communication between family members and professionals, and consequently the results of mourning, included attention to the family's state of mind, the pace and repetition of discussions according to the expressed understanding and the preparation and invitation of families to be present at the clinical determination, including apnea tests[22].

It is noteworthy that family members generally have different doubts and questions about the diagnosis of BD, the protocol and even about the organ donation process. Such doubts, which are often not answered by doctors, can be clarified by other members of the multidisciplinary team, including social workers, psychologists and nurses, who will act as information translators and facilitators of the understanding process, in addition to offering emotional support during communication[5].

The work of a multidisciplinary team throughout the process ensures comprehensive care for family members, providing more effective interventions that promote quality in care, meeting the most basic needs of family members[10]. Multidisciplinary care with planning of approaches and use of communication strategies, such as the use of protocols and welcoming and private environments, favors understanding the diagnosis of death and even coping with grief[5], and the nurse must assume responsibility for explaining the entire process involved in an ethical, moral and legal manner, clearing up doubts and providing all necessary information to family members[8].

The family member is approached with the aim of making the organ donation after the BD protocol, which corresponds to a moment of high sensitivity and family fragility, but also in which a lack of understanding the diagnosis and a lack of access to information can directly impact the decision-making of those involved[8,12]. Furthermore, this is a topic which is not widely discussed in society and is affected by fake news circulating about the donation and transplant protocol, and trafficking and illegal trade of organs, which influences distrust and insecurity, as revealed by one of the family members interviewed.

A study conducted in Iran with 20 family members of people who had BD showed that the main obstacles to organ donation were a lack of knowledge about BD and organ transplants, cultural and religious beliefs, fear and concerns about the appearance of the body, as well as a lack of professional support during the application process, which led to the family members being unable to make a decision[24].

In contrast, a study conducted in India with 10 family members demonstrated that the significant motivators for making a donation were the family members' belief or conviction that it would help save other people's lives; a feeling of moral obligation to do so; prolonging the life of their loved one in other people; and being a role model for others[25].

The results of this study, as well as those available in the literature, indicate dual understanding of BD and the donation process, requiring more comprehensive awareness campaigns to develop awareness and eliminate misconceptions about organ donation. However, for family support to occur and ensuring that family needs are met, health professionals need to be properly trained and adopt strategies and protocols which facilitate understanding the donation process, so that this process is as painless as possible for both the family member and the professionals involved. It is important to expand training of health professionals to address BD, providing conditions for applying it in daily life.

Study limitations

The small sample size and geographic scope are noteworthy, which limit generalization of the findings. Difficulties in access, refusals, and contact problems may have influenced the diversity of perceptions. Data collection months after diagnosis may have affected the accuracy of memories, and response bias should be considered, since only a few family members agreed to participate. The emotional burden of the topic may also have impacted the reports.

The limitations faced regarding refusal to participate and difficulties in contacting family members are not exclusive to the present investigation. Previous studies which have addressed the theme of brain death and family support also identified similar barriers, especially related to the high emotional burden of the topic, the refusal to relive traumatic experiences, and the fragility of the moment experienced[24,25]. Thus, the findings of the present study are consistent with national and international literature, which contributes to the robustness and coherence of the analyses presented.

FINAL CONSIDERATIONS

Based on the results of this study, it was possible to understand the perceptions of family members regarding the care provided by health professionals during the diagnosis of BD. It was identified that a lack of communication is related to inadequate care, from the suspicion to the completion of the diagnostic process and its lack of understanding, as well as some unanswered questions that the family members still have today.

Some family members reported positive experiences in coping with the phenomenon, while others did not. However, the donation was not directly influenced by the way in which they were cared for, but mainly as a way of carrying out a good deed, to continue the life of their loved one and by the feelings of comfort and gratitude that the donation generated in the family members.

However, even identifying that the care does not directly impact organ donation, family members have the right to receive humanized and enlightening care, and which meets their needs. To this end, it is necessary to increasingly invest in continuing education to train professionals, especially multidisciplinary teams, to ensure the development of skills that promote comprehensive and humanized care for family members. It is also important to invest in academic training of health professionals, strongly including content on the process of death and dying, as well as the communication of bad news.

It is important to strengthen public policies, especially regarding to disseminating the topic, so that the population has access to relevant information, through social media, public campaigns and in schools, as well as in addressing the topic in the workplace, among others. In addition, it is important to invest in future research on the topic, especially in different contexts in Brazil, including health professionals on teams which support these families in the search to understand how professional performance has impacted the family's decision to donate organs and tissues when faced with a diagnosis of BD.

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Conceptualization, N.C.S., E.P.M., M.B.S., R.C.N.S. and M.C.F.L.H.; methodology, N.C.S.; investigation, N.C.S.; formal analysis, N.C.S.; software, R.C.N. and N.C.S.; manuscript writing, N.C.S., L.F.B. and F.F.; review and editing, N.C.S., E.P.M., M.B.S., R.C.N.S. and M.C.F.L.H.; visualization, N.C.S. and M.B.S.; supervision, M.B.S.; project administration, N.C.S., R.C.N.S. and M.B.S. All authors read and agreed with the published version of the manuscript.

Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript “*Organ donation: Professional support in the diagnosis of brain death from the perspective of family members*”.