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REVIEW ARTICLE

Grief in Families Who Have Experienced Organ and Tissue Donation: An Integrative Review

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ABSTRACT

Objective: To describe bereavement experiences among families who went through the process of organ and tissue donation, based on evidence from national and international literature. **Method:** An integrative literature review was conducted across five databases (CINAHL, LILACS, SciELO, PubMed, and VHL), utilizing descriptors related to bereavement, organ donation, and family experiences. The guiding research question was: what bereavement experiences are described in the national and international literature among families who experienced organ and tissue donation? The search was carried out in August 2024, covering the period from 2001 to 2024. The data were analyzed using conventional content analysis. **Results:** Nine studies were included, and the evidence was organized into three categories: (1) Stressors in bereavement; (2) Protective factors in grief; (3) Post-donation actions directed at families. Findings indicate that bereavement in this context is shaped by emotional, social, and institutional dimensions. **Conclusion:** Bereavement among families involved in organ and tissue donation is complex and influenced by factors that may either exacerbate or mitigate suffering. Qualified support, empathy, active listening, and understanding of brain death can foster healthier grieving processes. However, gaps remain in the literature, particularly in Latin American countries, highlighting the need for further studies to guide interventions, professional training, and the development of care protocols for families undergoing this experience.

Descriptors: Organ Donation; Death; Family; Bereavement.

Luto em Famílias que Vivenciaram a Doação de Órgãos e Tecidos: Revisão Integrativa

RESUMO

Objetivo: Descrever as experiências de luto em famílias que vivenciaram a doação de órgãos e tecidos, com base nas evidências disponíveis na literatura nacional e internacional. **Método:** Trata-se de uma revisão integrativa da literatura, conduzida em cinco bases de dados (CINAHL, LILACS, SciELO, PubMed e BVS), utilizando descritores relacionados ao luto, doação de órgãos e experiência familiar, com a seguinte pergunta de pesquisa: quais são as experiências de luto em famílias que vivenciaram a doação de órgãos e tecidos descritas na literatura nacional e internacional? A busca foi realizada em agosto de 2024, considerando o período de 2001 a 2024. Os dados foram submetidos à análise de conteúdo convencional. **Resultados:** Foram incluídos nove estudos e as evidências organizadas em três categorias: (1) Fatores estressores do luto; (2) Fatores protetores do luto; (3) Ações direcionadas às famílias no pós-doação. Os resultados apontam que o luto, nesse contexto, é influenciado por dimensões emocionais, sociais e institucionais. **Conclusão:** A experiência do luto em famílias que vivenciam a doação de órgãos e tecidos é complexa e atravessada por fatores que podem agravar ou suavizar o sofrimento. A presença de apoio qualificado, empatia, escuta ativa e compreensão sobre a morte encefálica pode favorecer um luto mais saudável. Contudo, evidenciam-se lacunas na literatura, especialmente em países da América Latina, ressaltando a importância de novos estudos que subsidiem intervenções, capacitação de profissionais e construção de protocolos assistenciais para o cuidado às famílias que vivenciam este processo.

Descritores: Doação de Órgãos; Morte; Família; Luto.

INTRODUCTION

Experience is something constructed and interpreted from a phenomenon, which must be analyzed, taking its meaning into account, as a starting point rather than an end in itself.[1] Organ donation is a complex process involving medical, legal, ethical, cultural, and emotional dimensions, requiring the diagnosis and determination of brain death and the consent of the family for it to take place[2].

In this context, the ethical and sensitive work of the multidisciplinary team is essential, because it is in this moment of vulnerability that lives can be saved and loss transformed into a legacy of solidarity.[2] The grieving process is an intimate journey; each experience of loss is unique, interwoven with emotions, thoughts, and reactions that unfold in a unique way for each individual.[3] It can involve feelings such as sadness, anger, guilt, and despair, with a dynamic oscillation between these. During bereavement, many people seek ways to express their feelings, making it possible to bring structure and symbolism to this process.[4,5]

The complexity of grief lies in its multiple dimensions, influenced by factors such as the nature of the loss, the type of bond with the deceased, the cultural context, the bereaved person's personality, and the social support available at the time of the loss. There is no universal formula for understanding it, as it is an individual experience.[5] In the context of organ and tissue donation, family grief takes on even more delicate dimensions, marked by the coexistence of ambiguous feelings between the pain of loss and the significance of generosity, which makes this experience especially complex and multifaceted.[6]

Therefore, providing rituals for the family during the grieving process after organ and tissue donation is a way to support and care for them, as this period tends to be difficult, involving the pain of loss and the awareness that the decision to donate saves other lives. Farewell rituals, such as funerals and celebrations of life, can help families express emotions, provide a legacy in memory of the loved one, and find meaning in the act of generosity through donation.[7]

The grieving process for the family does not begin solely with the confirmation of death; it often starts when the family member is admitted to an intensive care unit (ICU), extending for an indefinite and painful period.[8] In typical bereaved individuals, the behavior of "present-seeking" is evident, involving the continuous search for the deceased loved one, both physically and emotionally. This behavior can manifest through dreams, sensations of presence, sensory illusions, or even the belief that the deceased may return. These manifestations reflect the difficulty in accepting the reality of the loss and reveal the bereaved person's effort to preserve the bond with the departed. This is a natural response to grief, allowing the individual to confront the absence and progressively reorganize their emotional life without the loved one, thereby facilitating adaptation to the new reality.[9]

When organ donation takes place, a part of the deceased remains "alive," offering family members a unique experience of grief. Knowing that the organs of a loved one contributed to saving other lives can provide comfort and a sense of continuity, mitigating the need for present-day seeking. This specific experience of grief requires a synthesis of knowledge about accepting the loss and valuing the legacy left by the donor, promoting emotional healing and resilience.[10] Therefore, improving the care provided to families in the post-donation period is essential to support a healthy grieving process and facilitate the processing of the loss.[10]

Given the above, it is essential to support families from the moment their loved one is hospitalized, offering emotional support and ensuring that these family members do not feel isolated. During the organ donation process, this support is crucial to clarify doubts and assist the family in facing a difficult decision.

In the post-donation period, ongoing support can aid the grieving process by reframing the loss in light of the donation's significance. Support for these families can provide a smoother journey during the acceptance of the loss, transforming a period of pain into a more serene experience. However, evidence regarding family support in post-donation grief remains scarce, underscoring the need for this research.

Therefore, this study aims to describe the bereavement experiences of families who have experienced organ and tissue donation, based on evidence available in national and international literature.

METHODS

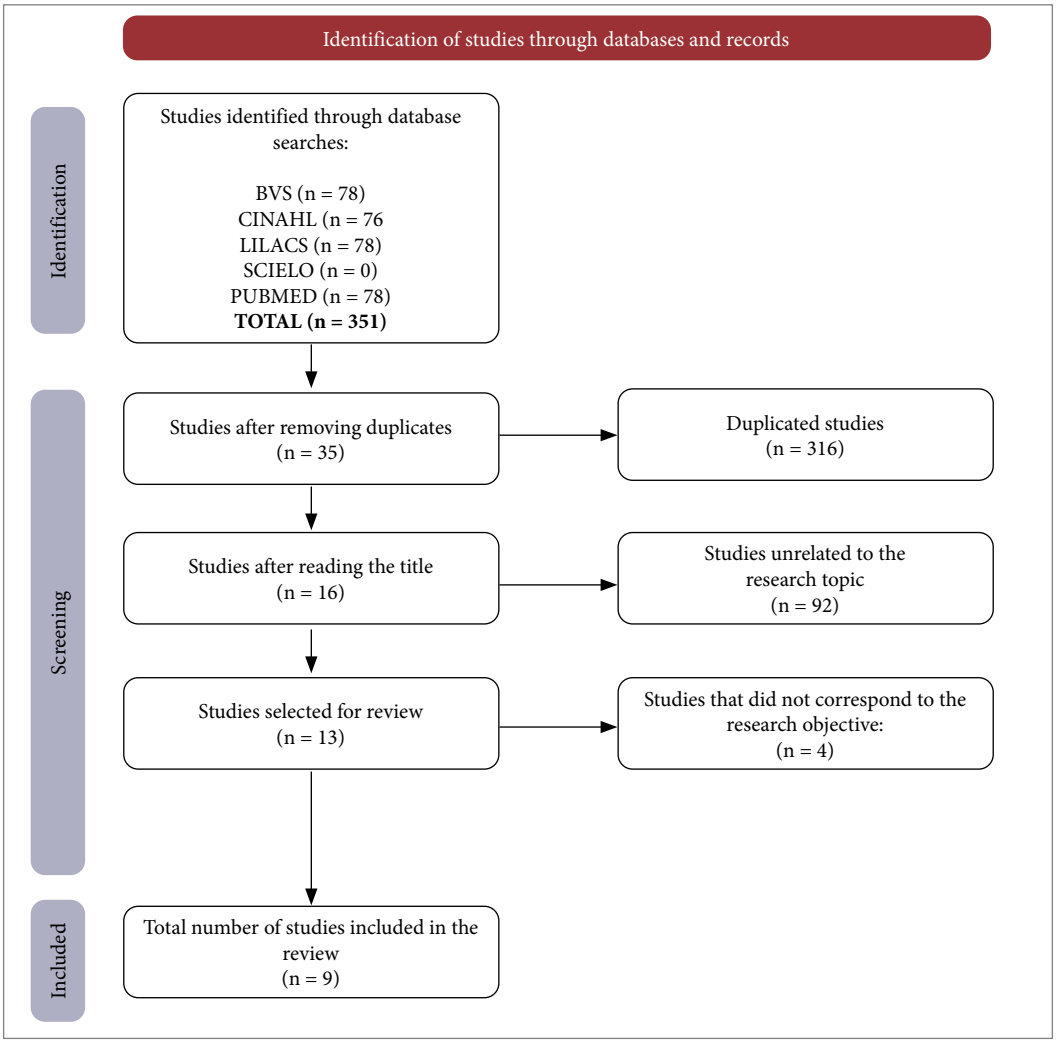
The present is an integrative literature review, based on six stages: 1) formulating the review question; 2) searching for and selecting primary studies; 3) extracting data from the studies; 4) critically evaluating the primary studies included in the review; 5) synthesizing the review results; and 6) presenting the review.[11,12]

For the construction of the research question, the first step in this review, the PICo strategy was employed, corresponding to the dimensions of Population (P), Interest (I), and Context (Co).[11,12] Based on this, the research question is: What are the experiences of grief among families who have undergone organ and tissue donation, as described in the national and international literature?

For the second stage, the selection criteria for inclusion of studies were: articles published in Portuguese, English, or Spanish; available in the selected databases; published between 2001 and 2024; in online format; and free of charge. The time frame is justified by the implementation of Law No. 10.211, of March 23, 2001, which clarifies that donations may be made only with the authorization of the spouse or a relative of the deceased.[13] Qualitative, quantitative, or mixed-methods research that addressed the bereavement experience of family members involved in the decision to donate organs and tissues was included. Exclusion criteria included: duplicate articles, review articles, opinion articles, articles that did not answer the research question, editorials, letters to the editor, dissertations, monographs, theses, reflective studies, books, book chapters, manuals, guides, or articles that did not align with the objective of this study.

For the construction of the search strategies, the descriptors "Grief", "Organ Donation", "Bereavement", "Mourning", "Experience", and "Family" were used, along with the Boolean operators AND and OR, as well as their Portuguese-language designations. The databases accessed were the Cumulative Index of Nursing and Allied Health Literature (CINAHL), *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS), Scientific Electronic Library Online (SciELO), PubMed, and the *Biblioteca Virtual em Saúde* (BVS). The accesses occurred remotely in August 2024.

The studies were managed using the Rayyan platform, which excluded duplicates, yielding 316 documents. Subsequently, titles and abstracts were read; then, the full text was read, including articles that met the inclusion criteria, objective, and research question. The article selection process was carried out in pairs by a nursing student and a doctoral nurse, using the program's "blind" mode for independent article selection. There was no disagreement regarding the study selection. The flowchart of the article selection process is presented in Fig. 1:



Source: Elaborated by the authors.

Figure 1. Flowchart of the record selection process, based on PRISMA.

The third step involves defining the information extracted from the selected studies. To extract and organize the data collected from the studies, a form was created in the Google Forms research management application, which automatically generated tables in Google Sheets. The extracted data are described in Tables 1, 2, and 3 in the Results section.

From the fourth phase onwards, the evaluation of the studies included in the literature review began. The analysis was carried out critically to identify any different or conflicting results that do not contribute to the study.[11,12] Therefore, this review considered the research question, the study methodology, and the results that answer the research question.

The fifth stage involves interpreting the results, including discussions of the main research findings.[11,12] A matrix was developed to systematize data collection, and the results were organized into tables for better visualization of the research material.

The data from the "results" of the articles were analyzed using the conventional content analysis proposed by Hsieh and Shannon.[14] Therefore, the analysis consisted of reading all the data to achieve immersion and obtain an understanding of the whole. Then, the reading was done line by line until codes were generated, and a Word table was used for this process. Twelve codes were constructed, compared, and text fragments were selected to identify themes, which subsequently gave rise to three categories: Stressors of grief, Protective factors of grief, and Actions for families grieving after organ and tissue donation.

The sixth stage involves presenting the review through a synthesis of the knowledge. Its objective is to outline and describe the steps taken by the researcher, along with the main results evidenced from the analysis of the included articles, to formulate and answer research questions.[11,12]

RESULTS

The empirical material for analysis consisted of nine studies, which are characterized in Table 1.

Table 1. Presentation of textual elements extracted from the studies.

Article	Authors	Year	Title	Country	Journal of Publication	Journal scope
A1.	Martinez-Lopez et al.	2023	Family bereavement and organ donation in Spain: a mixed-method, prospective cohort study protocol	Spain	BMJ Open	Medicine
A2.	Dicks et al.	2022	The bereavement experiences of families of potential organ donors: a qualitative longitudinal case study illuminating opportunities for family care	Australia	International Journal of Qualitative Studies on Health and Well-Being	Medicine
A3.	Ahmadiana et al.	2020	Stressors experienced by the family members of brain-dead people during the process of organ donation: a qualitative study	Iran	Death Studies	Psychology
A4.	Soria-Oliver et al.	2020	Grief reactions of potential organ donors' bereaved relatives: an observational study	Spain	American Journal of Critical Care	Medicine and Nursing
A5.	Kentish-Barnes et al.	2018	Grief symptoms in relatives who experienced organ donation requests in the ICU	FRance	American Journal of Respiratory and Critical Care Medicine	Medicine
A6.	Walker; Sque	2016	Balancing hope and despair at the end of life: the contribution of organ and tissue donation	United Kingdom	Journal of Critical Care	Medicine
A7.	Kim; Yoo; Cho	2014	Satisfaction with the organ donation process of brain-dead donors' families in Korea	South Korea	Transplantation Proceeding	Surgery and transplantation
A8.	Lloyd-Williams; Morton; Peters	2009	The end-of-life care experiences of relatives of brain-dead intensive care patients	England	Journal of Pain and Symptom Management	Medicine and Nursing
A9.	Merchant et al.,	2008	Exploring the psychological effects of deceased organ donation on the families of the organ donors	Canada	Clinical Transplantation	Medicine

Source: Elaborated by the authors.

It is noted that the first publication dates back to 2008[15], indicating that this is a relatively recent approach in the international literature. An increase in publications has been observed since 2020, suggesting an expansion of this topic in the global scientific literature.

Regarding the origin of the research, Spain leads with two publications.[20,23] No studies from Brazil or other Latin American countries were identified. Regarding language, all articles were published in English. Regarding the field of scientific journals, Medicine predominated, with five studies[15,18,19,22,23]. Regarding the type of consent adopted for organ donation, all the studies analyzed used the presumed consent model[15-23], with no publications using the informed consent model.

Table 2 summarizes the analyzed studies by objective, research approach, main results, and level of evidence.

Table 2. Presentation of the extracted textual elements.

Article	Study objective	Research approach	Main results	Level of Evidence
A1	To understand the factors that influence the grief of family members involved in the organ donation process and how these factors can affect their psychological well-being.	Mixed methods	The grief experienced by family members following organ donation is affected by the decision to donate, medical communication, understanding of brain death, type of death, family dynamics, beliefs, and emotional support. These factors influence the grieving process and psychological well-being.	II
A2	To identify links between pre-existing family and healthcare professional factors, an unexpected death, hospital experiences, and subsequent adjustments, to highlight new opportunities for team care for the family.	Qualitative	The way healthcare professionals position themselves in the hospital environment influences the likelihood of family participation, the organization of meaningful interactions, and the construction of meanings that impact family adjustment throughout the grieving process.	IV
A3	To explore the stressors experienced by family members of people with brain death during the organ donation process.	Qualitative	The stressors identified in this study highlight the need to support donors' families to maintain their psychological well-being and to identify and manage donation-related problems promptly.	IV
A4	To empirically describe the emotional reactions of family members of potential organ donors in the face of the death of a loved one, and to analyze the relationship of these reactions with factors that occur in the process of illness and death.	Quantitative	Unexpected deaths were associated with more intense emotional reactions and less acceptance of death than anticipated deaths. Additional stressors, such as perceived poor treatment by hospital staff, perceived deficient medical care, and poor relationships among family members, were associated with stronger reactions.	II
A5	To evaluate the experience of the organ donation process and the symptoms of grief in family members of brain-dead patients who discussed organ donation in the ICU.	Qualitative	The experience of organ donation processes varies between relatives of donor patients versus non-donors, with the latter experiencing more difficulty and burden. However, the decision (consent/refusal) was not associated with symptoms of grief.	IV
A6	To provide insights into the perceived benefits of organ and tissue donation for bereaved families who have experienced EoLC (end-of-life care) in the ICU.	Qualitative	The option of consent to organ and tissue donation seemed to give meaning to the life and death of the deceased and was comforting for some grieving families.	IV
A7	To investigate the satisfaction of the families of brain-dead donors regarding the donation processes and the emotions following the donation.	Quantitative	Satisfaction with the decision to donate organs was relatively high, while satisfaction with preparing the relevant documents and information and the guidelines for funeral arrangements was low. Religious practice and spending time with family and friends were considered helpful in alleviating psychological stress after organ donation.	II
A8	This study explores organ donation in ICUs and focuses on issues related to the palliative care and support needs of families of hospitalized patients who have suffered brain death during this period.	Qualitative	Although the technical care provided in ICUs has not been criticized, varying degrees of attention are given to the emotional and practical needs of the family, both while in the ICU and during bereavement. The contribution of a palliative care team in ICUs would be highly valuable.	IV
A9	To investigate whether the donation process hindered or improved the grieving process for organ donor families, specifically concerning depression, post-traumatic stress, and grief.	Quantitative	Organ donation can support the grieving process for donor families; therefore, it is prudent for healthcare professionals to discuss donation with these families. Failure to do so may deprive these families of a potential emotional and psychological benefit.	II

Source: Elaborated by the authors.

Regarding the unit of analysis for the study objectives, three emotional aspects related to organ donation were investigated[15,19,20]; One study focused on the stressors experienced by family members[21]; another study examined the family's satisfaction with the donation process[17]; One study analyzed family relationships and the care provided by the team to family members.[22]

Six studies described the reactions, sensations, and feelings experienced by families after donation, among which the following stand out: denial, crying, uncontrolled screaming, anger, silence, acceptance, apathy, fear, shame, guilt, pride, loneliness, financial stress, shock, hope for a miracle, disbelief, helplessness, and the feeling of not knowing how to move forward.[16,17,18,20,21,22]

Regarding the degree of kinship, men and women are fathers, mothers, siblings, spouses, children, and in-laws[15,16,17,19,20,21]. Regarding gender predominance, women participated more in 6 of the studies[15,16,17,18,19,21], while one study showed a predominance of male participants.[20] Two studies did not report the degree of kinship or the gender of the participants.[22,23]

The concept of grief, its types, and actions taken for the family after donation, as identified in the studies, are described in Table 3.

Table 3. Presentation of textual elements extracted from the studies.

Articles	Concept of grief	Types of grief	Post-donation actions
A1	Complicated grief	Complicated grief	Not found
A2	Not found	Complicated grief Anticipatory grief	Not found
A3	Not found	Prolonged mourning Acute grief Complicated grief	Not found
A4	Grief - Bowlby's Theory	Not found	Not found
A5	Inventory of Complicated Grief	Complicated grief	Not found
A6	Not found	Not found	Letters and cards from transplant recipients
A7	Not found	Not found	Contacts and letters to families 1 week and 1 month after organ donation, respectively.
A8	Complicated grief	Complicated grief	Not found
A9	Not found	Not found	Not found

Source: Elaborated by the authors.

Of the nine studies analyzed, five did not address concepts of grief.[15,17,18,21,22]. Two studies used the concept of complicated grief to support their analyses.[16,23] One study used the Inventory of Complicated Grief as a conceptual basis[19], and another used Bowlby's Theory to address the experience of grief.[22]

Regarding actions directed at families after organ donation, only two studies addressed this topic explicitly.[17,18] The others[15,16,19,20,21,22,23] did not include interventions or strategies aimed at post-donation care.

The synthesis of the analyzed studies, according to the "results" section, is presented in Table 4, organized into three thematic categories described below:

Table 4. Thematic categories and studies that addressed the explored content.

Categories	Studies that addressed the content
Stressors of grief in the experiences of families involved in organ and tissue donation.	A1, A2, A3, A4, A8, A9
Protective factors of grief in the experiences of families involved in organ and tissue donation.	A3, A5, A6, A7, A9
Actions to support families grieving after organ and tissue donation.	A6, A7 and A9

Source: Elaborated by the authors.

Stressors of grief in the experiences of families involved in organ and tissue donation

According to the Dual Process Model[24], used to understand grief, two categories of stressors were identified: one oriented towards loss and the other towards reparation. The loss orientation refers to the bereaved person's processing of aspects of the loss. In contrast, the reparation orientation invol-ves secondary stressors and is associated with actions aimed at reorienting in the world without the deceased.

The experiences of families dealing with organ and tissue donation are marked by stressors that can affect and complicate grief. These factors are related to (1) the characteristics of the deceased person and the circumstances of death; (2) the dynamics and relationships between family members and the deceased; (3) the care received at the hospital; (4) the organ and tissue donation process.

Regarding the characteristics of the deceased and the circumstances of death, stressors may be related to the degree of kinship, the age of the deceased relative[20,23], and the circumstances of death.[16,20,21,23] Considering the degree of kinship and the age of the family member, it is observed that intense adverse emotional reactions are present when children, adolescents, and young people die, more so in mothers than in fathers. Among these intense adverse emotional reactions are: anger, uncontrolled crying, screaming, aggression, immobility, silence, resignation, and absence of emotional expression.[18]

Regarding the circumstances of death, the most negative emotional reactions are related to unexpected, traumatic deaths, and/or suicides. It is noteworthy that, in cases of death by suicide, there is a higher frequency of denial of the death, anger, episodes of crying, and feelings of guilt attributed to that death.[20] The perceived threat of loss when there is an initial shock upon understanding the loved one's condition; a conflicting decision, where they are pressured to decide about donation; a painful farewell; a feeling of insecurity due to a lack of trust in professionals; the complexity of grief due to the inability to accept death; and the search for relief through the relentless pursuit of finding solace in donation[21].

Regarding stressors related to family members, when the family does not discuss organ and tissue donation beforehand, shared decision-making in the hospital can result in family conflicts due to differing views[19,22]. When disputes arise between family members or disagreements about the deceased's wishes, it can create an atmosphere of tension and stress[19].

Stressors related to care (hospital assistance) include a lack of physical infrastructure to accommodate families, the length of the family member's hospital stay, and ineffective communication between healthcare teams and the family, which can leave families confused or misinformed, increasing emotional distress; in addition to the insufficient attention given to the family to meet their emotional needs both in the ICU and during bereavement.[6]

The lack of privacy and a private space in the ICU was also identified as a stress factor, as families have difficulty having intimate moments of farewell, highlighting the problematic physical structure of hospitals in accommodating families.[15,16]

Regarding the stressors related to the organ and tissue donation process, these include: communication about the diagnosis of brain death, misunderstanding of the death diagnosis, the opportunity to donate and authorization for donation, pressure from the team to obtain consent from family members, and the short time offered for decision-making.[15,16,20,21]

One of the main challenges families face is the pressure to make quick decisions about donation.[16,21] The decision-making process regarding organ donation is often marked by internal and external pressures, such as conflicts between family members and disagreements about knowledge of the deceased's wishes, which can create an environment of tension and stress. Pressure for the family to make a decision quickly can increase emotional suffering, hindering the grieving process and potentially leading to the refusal of organ donation.[19]

The opportunity to donate to the family comes at a time of suffering due to the loss of a loved one, and this leads to intense emotional reactions[20]. Families often have to decide about organ donation shortly after being informed of their loved one's brain death, which can generate feelings of doubt, guilt, and regret[21]. Family members' lack of understanding of brain death is associated with symptoms of complicated grief.[19]

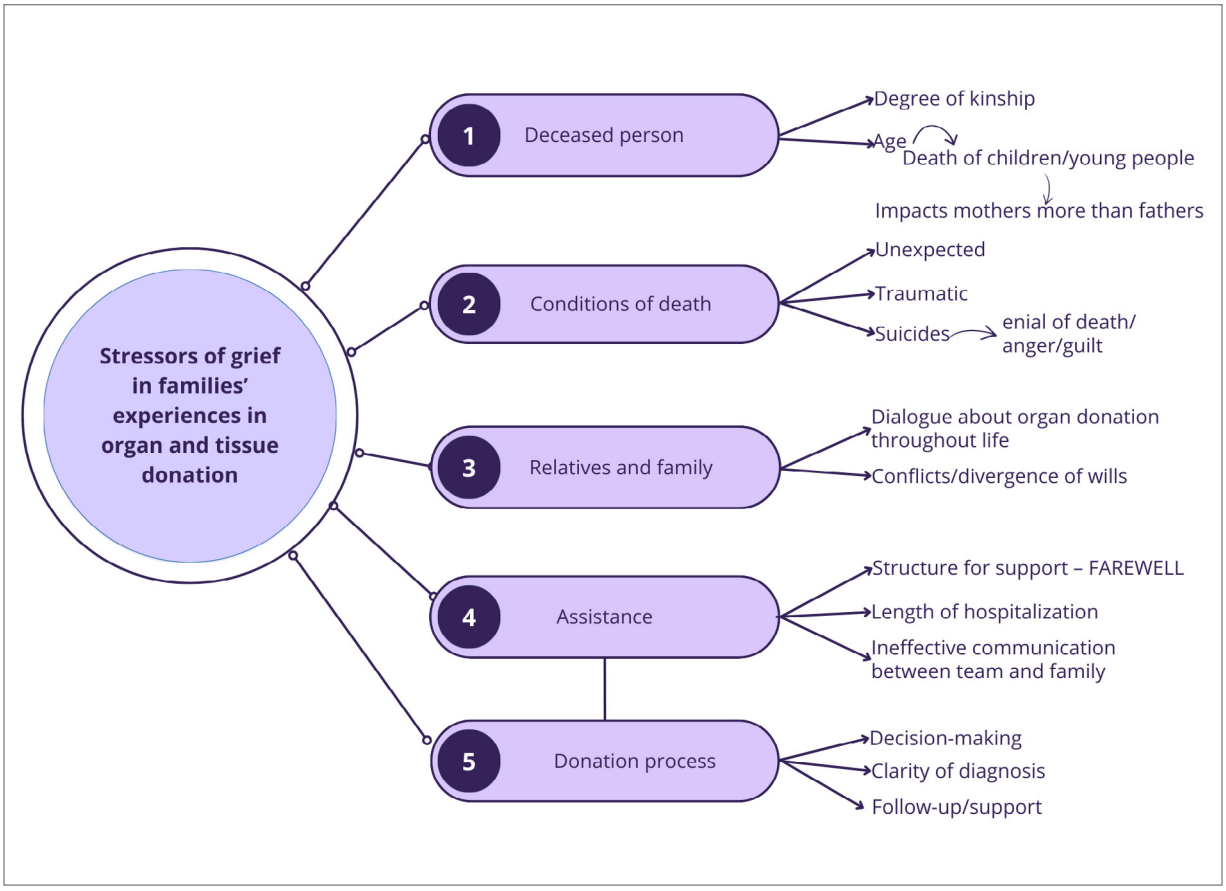
Communication between healthcare teams and families can be one of the most significant sources of stress during the organ donation process. Inadequate communication, with the news of brain death being delivered insensitively; lack of privacy, where families reported difficulty in having intimate moments of farewell due to lack of space and privacy in the ICU, highlighting the problematic hospital environment[16]. In this sense, one of the tasks of grieving, which is related to working through emotions and the pain of loss, can become more difficult for donor families due to the difficulty in recognizing emotions and lack of access to an adequate space that allows the expression of feelings such as sadness, anger, fear, or guilt[25].

Stressors mentioned include the opportunity to donate, authorization for donation, how communication about donation might affect grief, clarity about the diagnosis, circumstances of death, and the degree of relationship with the deceased[23].

The way the family understands the diagnosis, coupled with a lack of clarity, disrupts decision-making structures, destabilizes family dynamics, creates uncertainty, and affects interactions with healthcare teams and the management of hospital processes. This also leads to a rupture in the family's identity and sense of control[23].

Insufficient support and a lack of ongoing emotional counseling after the death of a family member have created feelings of loneliness in families. The lack of continuous support during and after the organ donation process also contributes to worsening grief, often leaving families without the necessary emotional support to cope with the situation.[16]

Stress factors highlight the need for a more empathetic and supportive approach in caring for families during the donation process, so that they can cope with grief in a less traumatic way. Assisting the donor's family with stressful events can be an essential contribution from healthcare teams, helping them understand the reality of the loss, which constitutes one of the tasks that make up the grieving process, as proposed by Worden[25]. Figure 2 presents the stressors of grief.



Source: Elaborated by the authors.

Figure 2. Summary of stressors.

Protective factors of grief in the experiences of families involved in organ and tissue donation

Factors that can be protective against complicated grief are related to the bond and relationship between family members; the quality and effectiveness of communication between the healthcare team and family members; a positive attribution to the meaning of organ and tissue donation; the possibility of establishing a bond with recipients; support from the healthcare team; and psychological support at all stages of the process.

Among the factors that can be protective and are associated with the bond and relationship between the family member and family: healthy family relationships seem to be associated with better acceptance of death and help to buffer the effects of loss[20]; in the lead-up to death, affectionate memories foster positive closeness and can be comforting; sharing stories helps family members organize their thoughts, make sense of their loved one's life and death; having well-defined and manageable tasks/activities can help monitor the progress and changes in grief, as well as provide some stability and the ability to move forward.[22]

Regarding protective factors related to donation, these include the positive meaning of donation, saving lives, and improving others' quality of life.[15,18,21] Donation offers an opportunity to transform death into a legacy of life, a source of pride and recognition, further highlighting the feeling of knowing that donation can save other lives, and through this comes both social and institutional recognition.[18,19]

The belief that a deceased relative will live on through others is considered a motivating factor for donating.[18] To give meaning to the death of this family member and to have a beneficial outcome from their death[17] are protective factors. Furthermore, during the donation process, family members' desire to receive information about the recipients and to establish and maintain a bond with them is identified.[15] The team should promote the well-being of these families and provide perspective on their decision regarding the altruistic act of organ donation, as well as remind family members of the benefits of their decision to donate.[21]

Factors related to healthcare team care include improving the knowledge and skills of organ procurement professionals through the use of more respectful and sensitive methods when requesting the family, to avoid negative feelings about donation and death[21]. High-quality family care and person-centered care should be characterized by dignity, compassion, and respect. Attitudes should be attentive, kind, empathetic, and supportive.[18]

The quality of communication between the team and the family has been described as one of the protective factors against complicated grief, as it can promote a better understanding of brain death, reducing long-term stress and emotional complications.[17] The use of different methods to illustrate and explain brain death includes the use of an anatomical model of the brain, a brain diagram, and the results of a computed tomography (CT) scan of the brain.[18] Furthermore, receiving clear, direct, and honest information, without false hope, helps families understand the tragic nature of the illness, death, and donation.[18]

Protective factors related to organ donation become essential during this delicate time. Assertive, transparent, and empathetic communication from the healthcare team strengthens families' trust, providing them with greater security when facing difficult decisions. The welcoming and active listening offered by trained professionals helps reduce feelings of helplessness. By receiving adequate, understandable information, families gain a sense of control over the situation, which improves their experience and facilitates acceptance of the loss, deciding to donate as a meaningful and comforting act.[15,18,19]

Another protective factor identified was receiving information about the fate of donated organs and the positive impact on recipients' lives, through meetings with family members who consented to the donation or through letters written by the recipients.[15,21]

The family's knowledge of the deceased's wishes regarding organ and tissue donation can also be protective during complicated bereavement. When families discuss the topic and express the desire to donate while the deceased is alive, the decision-making process is more straightforward.[15] In addition to family members, friends, and the healthcare team, the decision is influenced by others.[15] For the family, knowing what their loved one wanted is a source of emotional relief and helps reduce the distress associated with grief.[15,19]

Additionally, the family's active, conscious participation throughout the donation process contributes to the grieving process. To this end, the process stages must be clearly understood and accessible.[15]

When families have the time and adequate information to reflect on the deceased's wishes, they tend to reduce feelings of regret and guilt. Furthermore, families need to have a space within heal-thcare facilities where they can reflect on the situation they are experiencing and have privacy to do so, ensuring that the environment makes them feel welcome[15,19].

The emotional support offered by the healthcare team is fundamental for families going through the experience of organ donation. This support makes families feel heard and supported, providing a sense of security when making difficult decisions, facilitating acceptance of the loss, and giving greater meaning to donation, transforming the moment of mourning into an act of solidarity and hope.[15,17,18,21]

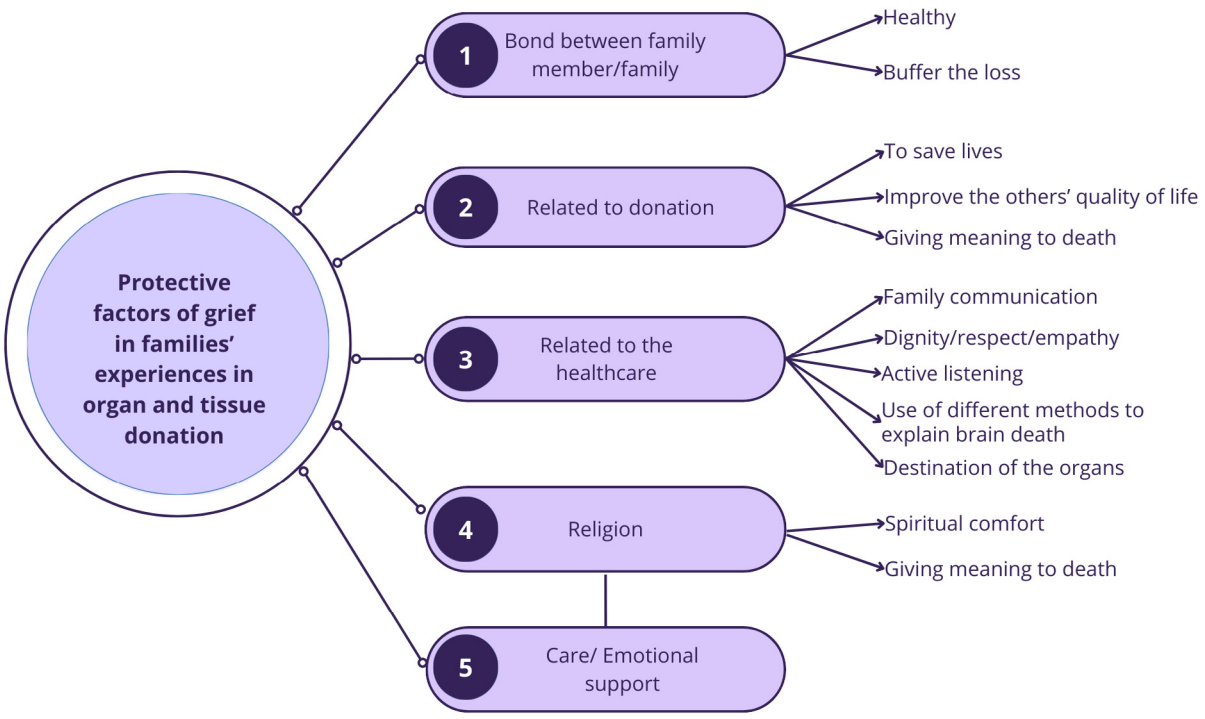
Religion can be an important source of emotional support for families who have experienced organ and tissue donation, providing spiritual comfort and a greater sense of meaning in their loss. Religious beliefs often help to give meaning to death, interpreting donation as an act of generosity or a legacy of life. Religious rituals, prayers, and faith in spiritual continuity can bring peace to families, easing the pain of grief and strengthening acceptance of the decision to donate, as they see the act as part of a greater purpose or as a manifestation of love for others.[19]

Some religions view organ donation as an act of charity and generosity, which, in fact, helps families find meaning in death. Rituals and the attribution of meaning related to death can also help lessen the emotional impact, providing family members with some form of support.[19,21] Considering the Grief Tasks model[25], organ donation can be one of the ways bereaved families find to create a new connection with the deceased person, in the course of the new life trajectory that unfolds after the loss.

Actions taken to support grieving families after organ and tissue donation

In the studies analyzed, three describe possible actions to support grieving family members.[15,17,18] The actions include sending letters and cards from transplant recipients to their families and relatives[15,18]; a phone call one week and one month after organ donation.[17]

The letters received by the families offer some insight into the impact of the donation, providing comfort amid their grief.[18] Figure 3 presents the protective factors against grief.



Source: Elaborated by the authors.

Figure 3. Summary of protective factors.

DISCUSSION

The number of studies analyzed in this review (09) was reduced; however, it should be noted that there was a time restriction, and the oldest study is from 2008. Similarly, no studies from Latin American countries on the subject were identified, a relevant gap given the region's cultural and legal specificities.

Despite widespread dissemination of information about organ donation in Brazil, family refusal still represents a significant obstacle to the process being carried out.[26] Although there are studies that investigate the reasons for families' refusal[27,28,29], There is a scarcity of research addressing both family members who consented to and those who did not consent to organ donation, especially considering that the model adopted in the country is that of informed consent.[30]

All studies correspond to countries that have presumed consent, which can influence organ donation rates and how families cope with donation during times of grief. Regarding Latin American, in the last 15 years, several countries have adopted this consent; however, donation rates have not increased.[31]

Regarding the research approach, both qualitative and quantitative studies are used. This reveals a concern in seeking to understand the phenomenon of grief in families following organ donation, given that qualitative research applies to the study of history, relationships, representations, perceptions, among other aspects, and is a product of the interpretations that human beings make about how they live, feel, and think[32]. Quantitative studies appear in similar numbers, and, among other things, they are essential for analyzing the magnitude of phenomena.[32]

There is a scarcity of longitudinal studies that allow for the follow-up and evaluation of families after organ donation. Although this type of research is costly and therefore underexplored, the data that can be obtained are highly relevant, enabling the identification of distinct behavioral patterns, including recurring ones.[33]

To define and understand grief, some studies have used the Inventory of Complicated Grief (ICG), while others have relied on Bowlby's Attachment Theory. These two models are complementary, allowing both a quantitative assessment of grief (through the ICG) and a more in-depth theoretical analysis (based on Bowlby's Theory). Thus, by addressing complicated grief

and highlighting the importance of emotional support, as proposed by Bowlby, it becomes possible to develop more effective interventions that help bereaved families cope with the pain of loss.[34]

Nurses play an essential role in caring for people experiencing complicated grief, offering qualified emotional support and using tools such as the ICG to identify associated signs and symptoms. By creating a welcoming environment, providing guidance on the expected stages of the grieving process, and proposing specific interventions, the professional contributes significantly to coping with loss. Based on Bowlby's Attachment Theory, nurses can also help family members understand and reframe ruptures in affective bonds, promoting greater understanding and processing of grief.[35].

The research results highlight stressors and protective factors related to complicated grief, as well as actions directed at bereaved families after organ donation. Among the stressors, the degree of kinship and gender stand out. In two studies, this information was not specified. Emotional closeness and the degree of kinship exert a significant influence on the experience of grief, as John Bowlby points out through Attachment Theory[36], and Colin Murray Parkes.[9] These authors argue that the intensity of grief is deeply related to the emotional bond and the social role occupied by the deceased person in the life of the bereaved.[9,36]

The loss of primary attachment figures, such as mothers and fathers, tends to have a more profound emotional impact, as these relationships are fundamental to an individual's psychological well-being and emotional structure. The bond established with these figures is essential for emotional development from childhood and, therefore, their loss can destabilize the bereaved, leading to a more intense and prolonged experience of grief[37]. Furthermore, it complements this view by exploring how the breaking of these bonds directly affects the individual's emotional and social reorganization, making the process of accepting the loss more complex and painful.[37]

Regarding the circumstances of death in organ donation, most are unexpected and traumatic. Organ donation often occurs in the context of accidental deaths or suicides, which can complicate the grieving process for families. When a family member is lost abruptly, grief becomes more intense and tumultuous, leading to a range of confusing emotions and often complicated grief. This form of grief is not merely a response to loss, but a challenging journey in which the reconstruction of identity and the meaning of life becomes essential.[9] In this scenario, adequate emotional support is crucial, as it helps families process their grief and understand the impact of the donation, while also seeking to honor the memory of the deceased and creating a space for hope amidst the tragedy.

This review identified that when families do not discuss organ and tissue donation, decision-making is more difficult and conflicts arise due to differing opinions. This lack of dialogue can be a significant stressor, hindering the identification of a consensus and exacerbating emotional distress at an already delicate time. Similar findings are reported in other studies[38,39] that highlight the importance of open and honest communication to facilitate this process, showing that families who discuss their wishes and feelings beforehand are less likely to experience conflict and stress during decision-making related to donation[38].

Organ and tissue donation is often considered a life-saving act of generosity. However, for families facing the loss of a loved one, this process can be a significant source of stress and bereavement complications.[39,40] Losing a loved one is a complex experience, marked by a range of emotions. When organ donation is brought up with families, they face feelings such as guilt, doubt, and regret, and deciding at a time of significant vulnerability can increase the emotional burden.[40]

The donation process, in addition to bureaucratic procedures, tends to be prolonged, since the body remains under the care of the medical team for an extended period, which can delay acceptance of death and hinder the grieving process. Grief is multifaceted, individual, and processual, and when combined with organ donation and the multiple processes involved, the need to understand the experiences of the donor's family becomes evident, to identify the type of assistance provided to them during the post-donation process.[24,41]

Although families report satisfaction with the care provided to their loved one, they also mention feelings of invisibility due to a lack of information or inadequate guidance on the donation process, a factor that, in some cases, contributes to the refusal to consent.[42] Another aspect that directly influences grief is social support, the absence of which can make it difficult to accept the loss.[24] In this context, ineffective, insensitive, or confusing communication intensifies the suffering and anxiety experienced by families, compromising their ability to make conscious and calm decisions. Furthermore, when they perceive that the deceased loved one was not treated with dignity or feel a lack of support, the grieving process tends to become even more complex[43].

Cultural and religious beliefs also influence how families deal with death and organ donation. For some, donation may be seen as a violation of cultural or spiritual values; for others, a violation of the body, which ultimately generates internal conflict.[44] These beliefs can create additional barriers, making it challenging to accept donation and potentially exacerbating grief, as death is seen as a ritual in which the funeral itself symbolizes a rite of passage.[44]

Organ donation can affect how people accept death. For some families, knowing which parts of their loved one's body will continue to "live" in another person can make it difficult to accept the loss, as there is still a connection to the continuity of life. This aspect of grief can prolong emotional suffering, as there is a feeling that death is not definitive.[45] Beyond the impact of organ donation, many families report feeling abandoned or forgotten by the healthcare system afterward. The absence of adequate psychological support or emotional counseling can lead to a lonely and prolonged grieving process, and can also cause families to feel unrecognized for their altruistic act.[46]

The factors that complicate the grieving process in the context of organ and tissue donation are complex and multifaceted, involving emotional, social, cultural, and structural aspects. To minimize the impact of these stressors, healthcare professionals must provide comprehensive support to the family through clear, sensitive communication, continuous follow-up, and respect for their needs and values. In this way, the donation process can be less traumatic and more recognized as an act of love and solidarity amidst grief.[46]

Organ donation is a process fraught with challenges, mainly when it occurs amidst grief, which can intensify the complexity of the family experience. However, the presence of protective factors can facilitate the grieving process, helping to give new meaning to the pain of loss. These factors assist in deciding on donation and offer emotional support after the process, strengthening families in the face of this experience.[46]

One factor that can ease the grieving process is related to the meaning attributed to organ donation. Many families find solace in positively attributing consent to organ donation, knowing that, through their loved one, it became possible to save and improve other lives. This act of generosity can offer the donor's family a sense of satisfaction, allowing the memory of the deceased to be perpetuated and linked to the contribution they made to others. Creating a legacy through organ donation is a source of protection for families[47].

The protective factors that ease the grieving process for families following organ donation are directly related to the emotional support offered to these families, the meaning attributed to the act of donation, and the quality of communication between healthcare teams and families. When these factors are present in the process, the grieving experience can become less traumatic and more meaningful, allowing families to find solace and peace amidst the pain of loss.

Actions directed at grieving families after organ and tissue donation are multidimensional, varying according to the profile of the family members that make up each institution. In light of this integrative review's findings, relevant implications for care practice are evident, as the experience of grief is influenced by the quality of communication, the organization of care, and the provision of emotional support. Clear, empathetic, and timely communication about brain death and the possibility of donation is fundamental to reducing emotional suffering and the risk of complicated grief. Training for professionals to provide information gradually, using accessible language and allowing adequate time for decision-making, is recommended. Furthermore, improvements in the hospital environment, such as the provision of private spaces for support and farewells, are essential to facilitate the processing of loss. Post-donation follow-up strategies, such as scheduled telephone contacts or support groups, should be incorporated into institutional protocols to strengthen continuity of care and the reinterpretation of loss.

Limitations include the predominance of international studies, which may limit their applicability to the Brazilian context due to cultural, legal, and organizational differences. Furthermore, the exclusion of grey literature, such as theses or dissertations, as well as extended abstracts published in conferences, and the temporal delimitation may have restricted the scope of the results.

Future research is suggested to expand knowledge about grief in families involved in the organ and tissue donation process, especially in contexts that adopt informed consent, such as the Brazilian one. Comparative analyses between families who consented to donation and those who did not, as well as investigations exploring gender differences and kinship ties, could deepen understanding of the phenomenon and support more sensitive, context-specific care practices. Investigating these aspects can help develop care protocols, support families, and develop training strategies for healthcare professionals involved in the donation and transplantation process.

CONCLUSION

The studies analyzed offered a comprehensive view of grief in families who experienced organ and tissue donation, highlighting the stressors and protective factors involved in this process. Decision-making during a time of intense pain, lack of adequate emotional support, and communication failures with the healthcare team can intensify suffering and contribute to complicated grief. However, emotional support, assertive communication, the possibility of expressing feelings, and the perception of donation as a positive legacy contribute to reframing the loss and adapting to grief.

The importance of ongoing support actions for families is highlighted, from the decision to donate to the post-donation period, including psychological support, farewell rituals, and support groups. Such measures promote a less traumatic experience of grief, allowing family members to process the loss gradually and with assistance.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantial scientific and intellectual contributions to the study: Costa MEO, Zillmer JGV, Marques VA; **Conception and design:** Macagnan KL, Marques VA, Zillmer JGV; **Data analysis and interpretation:** Costa MEO, Marques VA, Zillmer JGV; **Article writing:** Costa MEO, Ma-cagnan KL, Cordeiro FR, Marques VA, Zillmer JGV; **Critical review:** Macagnan KL, Cordeiro FR, Marques VA, Zillmer JGV; **Final approval:** Macagnan KL.

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All data were analyzed and presented in this study.

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DECLARATION OF USE OF ARTIFICIAL INTELLIGENCE TOOLS

We declare that this article was written without the use of Artificial Intelligence tools.

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