

# Exploring grief and acceptance: Experiences and needs of family members of deceased organ donors

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## Abstract

**Objective:** Before considering organ donation, family members must come to terms with the fact that their loved one is brain dead and that organ donation is a meaningful path forward. This acceptance enables their consent to organ donation following brain death. This study was conducted to explore the experiences and needs of family members of deceased organ donors.

**Method:** The study was conducted utilizing qualitative methods and conventional content analysis in accordance with Graneheim and Lundman's approach. Twelve family members of organ donors were chosen to participate through a combination of snowball and purposeful sampling methods. Data were gathered by using semi-structured interviews and critical discourse analysis.

**Results:** Participants were 8 females and 4 males with a mean age of  $55.25 \pm 13.02$ . Data analysis led to the emergence of 2 themes (supporting system and coping strategy), 6 subthemes (psychological issues, social issues, communication with others, social support, meaning-making, coping with their grief), 17 categories (grief processing, emotional resilience, understanding mixed emotion, social support networks, stigma, social interaction, communal narratives, narrative therapy approaches, open communication, coping strategies, professional support, support groups, honor their memory, practice self-care, seek spiritual support, create rituals, be patient with grief, and limit stressors), 65 subcategories, and 1237 initial codes.

**Conclusions:** To improve the organ donation process and support donor families, it is suggested that appropriate infrastructures and counseling groups for families be considered. The study recommends improving education and cultural sensitivity about brain death, providing counseling for families, and creating support networks. Furthermore, clearer communication about organ allocation can also help build trust between families and medical institutions.

## Keywords

Qualitative investigation, emotional needs, organ donor families

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## Introduction

The demand for transplants exceeds the available supply.<sup>1</sup> One reason for the shortage of organs for donation is the low rate of family consent for donation.<sup>2</sup> Family consent is a crucial factor in organ donation,<sup>3</sup> as organ transplants rely heavily on donation after brain death (DBD) as a primary source.<sup>4</sup>

In a hospital setting, the family members of patients with brain death are in a difficult and emotional situation. At the moment when they are trying to accept what has happened, they are faced with the decision of whether or not to consider organ donation.<sup>5</sup>

While experiencing the tragic situation of losing a family member, the organ donation process is viewed as complex and difficult to comprehend by families.<sup>6</sup>

Before deciding on organ donation, family members must come to terms with the fact that their loved one is brain-dead and that organ donation is a meaningful direction. This acceptance is what allows for donation through the DBD pathway.<sup>7</sup>

One of the natural reactions from close family members after death includes a conflation of the physical body and the personhood of their loved one.<sup>8</sup> The Dual-Process Model of Grief seeks to understand and describe adaptation to loss.<sup>9</sup> Stroebe and Schut describe “reducing, mastering, and tolerating” bereavement, and hypothesize that if coping is effective, suffering is reduced. This model highlights the dynamic interplay between Loss-Oriented and Restoration-Oriented coping strategies. Loss orientation focuses on grief processing and acknowledging emotional pain, while restoration orientation involves adapting to life without the deceased.<sup>10</sup> It is essential to show that while there is no correct or incorrect way to address a family’s needs, having an awareness of the kinds of reactions that often arise in recently bereaved individuals can assist transplant professionals in effectively navigating the situation.<sup>11</sup>

For example, losing a child is a deeply painful experience that leads to profound grief. The emotional toll of parental bereavement can have serious implications on mental and physical health, including a higher probability of anxiety, depression, and psychiatric hospitalization, as well as a decline in overall quality of life and an increased risk of mortality compared to parents who have not gone through the loss of a child.<sup>12</sup>

A study by Stouder et al.<sup>13</sup> emphasizes the significance of addressing the spiritual and cultural needs of families, which should be taken into consideration by hospital and organ procurement organization staff.

Grief is often viewed as a part of other issues, such as depression or the general reaction to becoming a caregiver after a relative’s brain injury.<sup>14</sup> A study of caregiver distress found that 32% of participants met the criteria for prolonged grief disorder, but did not explore the experiences of grief among the other participants.<sup>15</sup>

After searching several databases, we found limited qualitative research specifically focusing on the experiences and needs of family members of deceased organ donors. This population may face unique emotional, psychological, social, and other types of challenges that have been inadequately explored. They may have specific needs and experiences that warrant further investigation. To address this gap, a qualitative examination of this intricate and multifaceted subject is therefore necessary. This study, therefore, aimed to explore the experiences and needs of family members of deceased organ donors.

## Methods

### *Design of the study and selection of participants*

The present study was conducted using qualitative methods with conventional content analysis following Graneheim and Lundman’s<sup>16</sup> method. Inclusion criteria included close family members (parents or spouses) of brain-dead individuals who had consented to organ donation, provided that the donation occurred at least 3 months prior to the onset of the study.<sup>17</sup> Family members who had not been present for 3 months before to the donation, or those who lived in other cities, were excluded.

### *Data collection*

The study took place from May to August 2024. During National Organ Donation Week, researchers conducted interviews with visiting families at the donation section of Behesht Zahra cemetery in Tehran, known as the section of distinguished donors.

After explaining the study’s aims and obtaining written consent from all participants, researchers conducted the interviews at the cemetery.

The interviews began with guiding questions, such as How did you cope with the news of your family member’s brain death and the decision surrounding organ donation? What feelings do you have about donating your loved one’s organs? The complete interview research questions are in the Supplemental file.

Interviews were audio recorded with participants’ permission, and confidentiality was assured. All interviews were transcribed separately by one researcher and then analyzed thematically by another researcher.

The researchers selected one person from each family for a further, individual interview. The snowball to purposeful sampling method was used to select participants until we did not reach any new properties during the interviews, meaning we had reached theoretical saturation. Theoretical saturation was achieved after conducting 11 interviews with family members, with an average interview length of 35 min. No new codes were extracted after the 11th family interview. To

ensure no false theoretical saturation, one additional interview was conducted with no new codes extracted.

### Data analysis

A qualitative content analysis of the conventional type was used to perform data analysis. Content analysis is suitable for analyzing complex, significant, and delicate phenomena. Inductive content analysis involves abstracting and organizing data to answer research questions through concepts, categories, or themes. Each interview was transcribed on the same day. Transcriptions involved not only verbal answers, but also nonverbal cues such as crying, smiling, and silence.

Transcriptions were thoroughly read to immerse in the data and grasp the overall meaning. Key thoughts and concepts were identified by analyzing each transcription word by word and marking them accordingly.

These codes were then grouped into subconcepts, subcategories, and subthemes based on similar content. Subsequently, these were further organized into broader concepts, categories, and themes. Each interview was considered as a distinct unit of analysis. Subsequently, the text was segmented into meaning units. Each meaning unit comprises words, sentences, or paragraphs containing aspects related to each other through their content and context.

Categories were developed to encapsulate the core aspects of qualitative content analysis. A category consists of a collection of codes that share similarities at a manifest level. The main category represents a recurring thread of deeper meaning that runs through the codes and categories, reflecting the latent meaning of the text.<sup>6,18</sup>

The interviewees are presented in the form of “D1, D2, D3, D4, D5, D6, D7, D8, D9, D10, D11, and D12,” to protect the privacy of the participants. Units were coded using the actual words or researchers’ interpretations of the text.

The final identified themes formed the foundation for reporting the analysis results. Since this analysis is data-sensitive, researchers revisited the original data multiple times to ensure the findings accurately reflect the analyzed content.<sup>19</sup>

In this study, three methods were utilized to enhance accuracy, facilitate transferability, and reduce bias. Interviewing individuals from various backgrounds, including different genders, ages, and areas of study, added diversity to the data, thereby enhancing confirmability, credibility, and transferability.<sup>20</sup>

To ensure the trustworthiness of the qualitative research, triangulation was utilized through peer debriefings among the research team and by incorporating diverse profiles and perspectives, both insider and outsider. Three authors involved in the original data collection had extensive experience in qualitative research, and all authors had previously collaborated on organ donation studies. The research employed an inductive and emergent design, allowing categories to develop organically from the phenomenon rather than conforming to preexisting themes or theories. These

categories underwent continuous refinement, influenced by insights from the transcripts and peer debriefings.<sup>21</sup>

To ensure data accuracy, each interview was independently coded by two researchers; their coding processes were then compared and discussed to ensure consensus. Supervision by an expert in qualitative research further supported data integrity. Adequate time allocation and establishment a supportive rapport with participants also bolstered the study’s credibility.

Participants consented to voice recording and were assured of confidentiality, the ability to leave the study at any point, and access to results.

The two researchers were fully informed about the analysis process and provided written consent for their contributions to be analyzed. A psychologist interviewer offered emotional support to families who became distressed during the interviews.

To protect participant privacy, all potentially identifying data were securely deleted to further protect confidentiality. This version is concise while addressing key ethical considerations, including informed consent, emotional care, privacy, and data security.

It is worth mentioning that all transcripts were returned to participants for comment.

The study protocol was approved by the Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences (Ethical Code: IR.SBMU.RETECH.REC.1403.353).

### Results

Twelve subjects participated as family members of organ donors: mothers, fathers, and spouses. The average number of months after organ donation had passed was  $25.67 \pm 9.94$ . The general demographic data of the participants are shown in Table 1.

As shown in Figure 1, participants were 8 females and 4 males with a mean age of  $55.25 \pm 13.02$ .

Data analysis led to the emergence of 2 themes, 6 subthemes, 17 categories, 65 subcategories, and 1237 initial codes.

The two themes were support systems and coping strategies. The support systems theme includes 2 subthemes with 7 categories and 31 subcategories. The coping strategy theme includes 4 subthemes with 10 categories and 34 subcategories. Themes and subthemes derived from the participants’ perspectives and experiences are described in Table 2.

*Support systems:* The two subthemes around support systems are psychological issues and social issues.

The psychological issues subtheme focuses on the psychological aspects and emotional experiences related to processing the grief of a loved one. Based on this theme, the profound emotional journey that families undergo during bereavement is impacted by the unique elements that arise in the context of organ donation. Grief processing refers to the

**Table 1.** General demographic data of the interviewees (N = 12).

Number of months after organ donation	25.67 ± 9.94	
Age	<30	1
	30–39	1
	40–49	0
	50–59	7
	60–69	1
	>70	2
Relationship with donor	Mother	5
	Wife	3
	Father	2
	Husband	2
Level of education	Under diploma	5
	Diploma	5
	University degree	2

psychological and emotional experience individuals undergo as they cope with the loss of a loved one or a significant life change. The grief-processing subtheme includes the complex emotional terrain navigated by those families who feel ambivalent about donation following the death of a loved one who was an organ donor.

It addresses how grief manifests in various ways, influenced not only by the loss of a loved one but also by the nature of their death, the act of organ donation, and societal perceptions of both.

Psychological issues in families, as they have expressed, depend on their grief processes. Many families are still in mourning, and for example, one of the mothers stated: “. . . after the organ donation, no one asked us how we were coping with our grief or wanted to be in our place. . . The grief remains within me; on one hand, I lost my spouse, and on the other hand, there’s the perception that others might have of why my husband was donated. . . These conflicting feelings have created a struggle within me—what if he was still alive or if others think I made the wrong decision.” (D4)

In contrast, Mohammad’s mother, whose son was 18 years old, declared, “I believe that Mohammad made a sacrifice, and I am sure my actions were not in vain. I have learned how to cope with his absence. It’s hard, but knowing that he is not dead and that his spirit is still with me brings me joy in what I have done.” (D2)

“. . . I donated the breadwinner of my family; at that time, I could not make a sound decision, I was emotional, and perhaps influenced by what others said, but I don’t know how many more days he would have had if I hadn’t donated. There’s a sense of pride within me alongside the grief I am enduring from his absence and the hardship I have to face with the children after he is gone. Our life has become harder, and we have lost our source of income, but I tell my children to be proud of their father.” (D9)

“. . . When I agreed to donate, I was told that they would introduce me to the recipient. I made this promise to them so that my children would feel at ease, but now they are saying

it’s not legal. . . Seriously, why did they give us false promises?” (D9)

“When my daughter left, it felt like I lost everything. . . I couldn’t cope with her grief because I couldn’t digest what others say.” (D12)

Some social issues can positively or negatively influence families’ decisions to donate organs. For example, the importance of family social support after organ donation can serve as opportunities to promote donations, such as providing free burial plots or support sessions for grieving families.

“Grief sessions are held for families, but only for women. What about us—don’t we grieve?” (Laughs). (D1)

“Your social worker has a phone call and that’s important. Asked how I was doing, and said if I had any problems or anything I needed, I should let them know. I was very happy, and it meant a lot to me.” (D3)

“It’s great that there’s an annual celebration to honor donor families; I’ve made many friends and acquaintances. Here, they even gave our children a separate plot for burial. It’s wonderful. We come together, get to know each other, talk, and feel good about ourselves. We share each other’s pain. . . we help each other. I’ve heard that women go to parks, and parties together. It’s great to think there are other people like us. We donor families keep our hope for everyone. I remember one time they asked for help in getting consent from a donor family. This helps us feel valued and know that our actions are not without reward. . .” (D7)

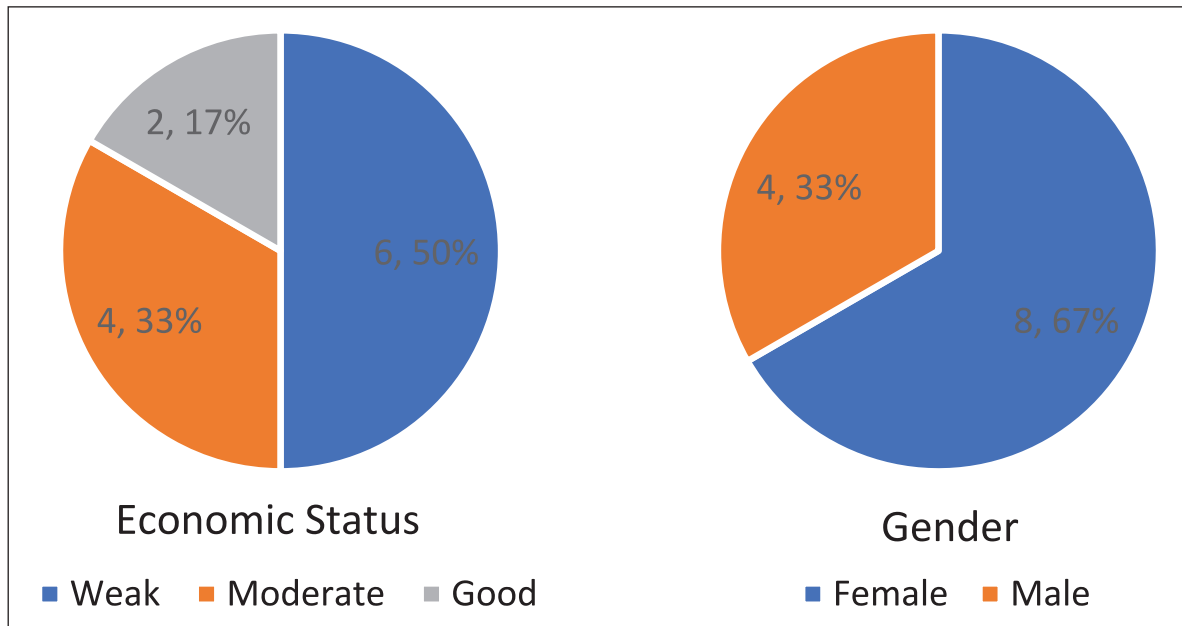
“I just want one thing from you: come to our neighborhood and say that we donated our son’s organs and didn’t sell them. Some people ask me how much money we got for it. . . You, who are in this field, know we didn’t receive any money.” “My daughter hasn’t talked to us since her brother donated a year ago. . . She says, ‘Why didn’t you ask for my opinion? Why didn’t they ask for my consent?’ We weren’t in a good place then, but you, who are in this work, why didn’t you consider her? It hurts her that we didn’t regard her as important. It took me about 8 days to agree to the donation. I wasn’t well at that time, and I’m still not okay.” (D8)

Some families have spontaneously learned to use a series of strategies to cope with the grief over their loved ones. For example, participating in spiritual classes to change their beliefs (D7).

*Coping strategy:* The four subthemes within *coping strategy* were communication with others, social support, meaning-making, and coping with their grief.

Open communication with others and coping with grief allows individuals to share their experiences and emotions, which can help them feel understood and validated. Sharing stories and memories can facilitate healing and reduce feelings of isolation. The strategies and methods individuals use to process their grief and manage their emotional responses can include both healthy coping mechanisms (e.g., therapy and journaling) and unhealthy ones (e.g., avoidance and substance use). Effective coping strategies are essential for navigating the grief process. They provide individuals with the





**Figure 1.** The distribution of economic status and gender of the interviewees ( $n = 12$ ).

tools to deal with the intense emotions and changes that come with loss and help them gradually adjust to life after their bereavement.

“At first, it was hard for us, but as the families gradually got to know each other, we realized how to commemorate our loved ones. Suddenly, we decide to cook a big pot of food to donate for them, or we lit candles as offerings; or when one of us is under stress, we gather together to help. This is one of the good things about having various groups on social media, where we talk about our sorrows and joys together. I know that in that world, just as we are friends, our loved ones are together and not alone. Now, our children are together in this cemetery plot and are not alone.” (D11)

Social support refers to the assistance, comfort, and care provided by others. This can be emotional support from loved ones, practical help with duties, or companionship during difficult times. Having a strong social support network is crucial for coping with loss. It can provide a sense of safety and belonging, help individuals regain a sense of normalcy, and encourage resilience in the face of grief.

Resilience is a positive construct that enables individuals to “overcome stressors or withstand negative life events and not only recover from such experiences, but also find personal meaning in them.”

Support from the system was one of the most important requests from families. When support was lacking, participants described disappointment, and when support was provided, they described a healing effect. “. . . It seemed like they had just come to take the organs and left us after getting our consent.” (D6, D3, D8)

“But our work has meaning; it has had and continues to have a purpose. Our goal has been to give life. The doctor who obtained my consent still calls me now and then to ask

about how I’m doing. Wherever I go for pilgrimage, I pray for him. He has become a part of my family. When I’m feeling sad, not just about my daughter whom we donated, but about anything, I call him to consult. He always gives me a sense of pride and tells me what a valuable thing I’ve done. He taught me how to cope with my problems and has shown me spirituality.” (D5)

Meaning-making is a bridge from negative emotions caused by negative life events to positive emotions through cognitive restructuring. It includes finding personal significance in the experience or reflecting on what the loss means for one’s life. This process can help individuals reconcile their emotions and experiences, leading to personal growth and new perspectives. Finding meaning can transform the grief experience and assist individuals in adapting to life without their loved ones.

. . . ohhhh. . . I am sure that his soul is happy and living with us. The positive energies of the receiving family have definitely reached and will continue to reach our lives. I donated for the sake of God, and nothing else matters to me. . . (D7)

## Discussion

This qualitative study sought to investigate the experiences and outcomes of organ donation for the families of brain-dead individuals. Participants reported a range of emotional responses following their decision to donate. The primary finding of the study suggested that the decision to donate organs can be a complex journey for families, encompassing experiences that span from conflict and uncertainty to feelings of confidence, satisfaction, and even transcendence.

**Table 2.** Themes and subthemes derived from the participants' perspectives.

Themes	Subthemes	Categories and subcategories
Supporting system	Psychological issues	<p>Grief processing</p> <ul style="list-style-type: none"> <li>- Doubt about decisions</li> <li>- Regret</li> <li>- Fear of people's judgment</li> <li>- Loneliness and introspection</li> <li>- Feeling of detachment from the system</li> <li>- Complicated grief</li> </ul> <p>Emotional resilience</p> <ul style="list-style-type: none"> <li>- Revitalizing others</li> <li>- Spirituality</li> <li>- Feeling useful</li> <li>- Sense of pride in decision-making</li> <li>- Hope</li> </ul> <p>Understanding mixed emotion</p> <ul style="list-style-type: none"> <li>- Fear of others' judgment</li> <li>- Fear of losing the breadwinner of the family</li> <li>- Ambivalent feelings of forgiveness and holding on</li> <li>- Ambivalent feelings of pride and dignity</li> <li>- Judgment of others</li> </ul>
	Social issues	<p>Social support networks</p> <ul style="list-style-type: none"> <li>- Understanding the importance of social support systems</li> <li>- The impact of support on emotional healing</li> <li>- The role of peer support groups</li> </ul> <p>Stigma and social interaction</p> <ul style="list-style-type: none"> <li>- Stigma</li> <li>- The need for societal validation</li> <li>- Isolation</li> <li>- Feeling misunderstood</li> </ul> <p>Communal narratives</p> <ul style="list-style-type: none"> <li>- Formation of family groups with families who have donated organs</li> <li>- Sharing grief experiences with other donor families</li> <li>- Collective mourning</li> <li>- Connecting with other families</li> <li>- Investigating how families reconcile the joy of saving lives through donation with the pain of loss</li> </ul> <p>Narrative therapy approaches</p> <ul style="list-style-type: none"> <li>- Grief therapy</li> <li>- Story-telling as a coping mechanism</li> <li>- Redefining identity after loss</li> </ul>
Coping strategy	Communication with others	<p>Open communication</p> <ul style="list-style-type: none"> <li>- Encourage family members to share their feelings openly</li> <li>- Create a safe space where everyone can express their emotions without fear of judgment</li> <li>- Talking about a loved one can help in processing grief</li> <li>- Remind family members to support one another and to check in regularly</li> </ul> <p>Coping strategies</p> <ul style="list-style-type: none"> <li>- Identifying adaptive versus maladaptive coping strategies used by donor families in response to their grief</li> <li>- Avoidance and denial of proactive engagement in advocacy for organ donation</li> </ul>
	Social support	<p>Professional support</p> <ul style="list-style-type: none"> <li>- Consider seeking help from a grief counselor or therapist who specializes in loss and trauma</li> <li>- Provide coping strategies and support tailored to the family's needs</li> <li>- Understanding the process and the positive impact of organ donation can sometimes help alleviate feelings of conflict or guilt</li> <li>- Attending educational sessions or workshops about organ donation</li> </ul>

(Continued)

**Table 2.** (Continued)

Themes	Subthemes	Categories and subcategories
		Support groups <ul style="list-style-type: none"> <li>- Joining a support group for families affected by organ donation can provide a sense of community</li> <li>- Sharing experiences with others who understand the unique aspects of grief related to loss and donation can be comforting</li> </ul>
	Meaning-making	Honor their memory <ul style="list-style-type: none"> <li>- To honor the loved one who passed away</li> <li>- Creating a memory book</li> <li>- Planting a tree</li> <li>- Establishing a scholarship in their name.</li> <li>- Acts of remembrance can help family members feel connected to their loved ones</li> </ul> Practice self-care <ul style="list-style-type: none"> <li>- Encourage each family member to take care of their mental and physical health</li> <li>- Engaging in regular exercise</li> <li>- Maintaining a healthy diet</li> <li>- Ensuring adequate rest</li> </ul>
	Coping with their grief	Seek spiritual support <ul style="list-style-type: none"> <li>- Speaking to a spiritual leader or participating in religious</li> <li>- Spiritual practices that may offer comfort and support during this time</li> </ul> Create rituals <ul style="list-style-type: none"> <li>- Establish family rituals to remember the loved one</li> <li>- Visiting their grave on anniversaries</li> <li>- Sharing stories during family gatherings</li> </ul> Be patient with grief <ul style="list-style-type: none"> <li>- Acknowledge that grief does not follow a specific timeline</li> <li>- Encourage family members to be</li> <li>- Patient with themselves and each other as they navigate their feelings</li> <li>- Recognizing that it's okay to grieve at different paces</li> </ul> Limit stressors <ul style="list-style-type: none"> <li>- Try to minimize unnecessary stressors in daily life</li> <li>- Simplifying routines</li> <li>- Delegating responsibilities</li> <li>- Taking breaks to focus on self-care</li> </ul>

The study identified two themes (*support systems* and *coping strategy*) and six key subthemes (psychological issues, social issues, communication with others, social support, meaning-making, and coping with grief).

*Support systems:* The organ transplantation process involves multiple stages that can evoke significant distress and may lead to adverse psychological effects for both recipients and donors.<sup>22</sup>

While voluntary organ donation is a profound act of altruism and carries the expectation that organ donors will be honored and supported across all nations, it is often the families of organ donors who experience the greatest psychological strain and stress during the donation process. Our study showed that although almost all the families who participated in this study were satisfied with their decision and would agree to donate organs if faced with the same situation again, they all experienced a loss that they have not been able to cope with, and many mothers are suffering from post-traumatic stress. These families frequently confront intense

emotions, complex psychological dynamics, and anticipatory grief.

Based on findings by Dicks et al.,<sup>7</sup> insufficient clarity can also result in family uncertainty, regret, intrusive thoughts, depression, complications in mourning, and post-traumatic stress disorder.

The results of this study align with those of the study by Luo et al.<sup>23</sup> They showed that even after the act of donation, donor families may face ongoing challenges such as bereavement, post-traumatic stress disorder, and depression.

We identified shortcomings in the support provided to some of the participating families during end-of-life and organ donation care. Families require improved assistance during critical moments of the donation process. For example, participants expressed feelings of abandonment and reported inadequate support after their family member's organ donation.

*Coping strategies:* Martínez et al.<sup>24</sup> revealed that connecting with a family member and providing explanations about

the donation process can help facilitate a better acceptance of organ donation. Berntzen and Bjørk<sup>6</sup> discovered that families often lacked a full understanding of the donation process, indicating that healthcare staff should provide ongoing information even after consent is obtained, underscoring the significance of follow-up. Evidence from other healthcare areas, such as oncology or spinal cord injury care, demonstrates that a more individualized approach to family support and communication is effective; therefore, there should be minimal resistance to promoting and implementing such practices in the context of organ transplantation.<sup>25</sup>

Acknowledging the social support needs of donor families can empower coordinators to alleviate their psychological distress effectively. Understanding the specific support requirements of family members is essential for helping them navigate this challenging period.<sup>23</sup> Donor families may receive minimal social support. Many families encounter difficulties when seeking assistance during trying times.<sup>26</sup> Living kidney donors have reported that their recovery from nephrectomy was aided significantly by support from their close social circles, including family and friends. This underscores the crucial impact of social support on improving the recovery experiences of donors.<sup>27,28</sup>

We highlight the need for enhanced support systems, improved dialogue from healthcare professionals, and continuous assistance throughout the donation process. By tackling the shortcomings identified in our study, we aim to advocate for a more empathetic and informed approach to organ donation that focuses on the needs of donor families.

## Limitations

This study has a limitation: We only interviewed parents and spouses and excluded children or siblings. Involving children on such a sensitive topic raises ethical concerns about informed consent and the emotional effect of discussing grief. Regarding the exclusion of siblings, we aimed to focus specifically on the immediate family members (parents and spouses) who often bear the decision-making responsibilities at the time of organ donation. In addition, the results are based on family experiences that may not apply to other types of situations.

## Conclusion

Family members of brain death patients find themselves in a challenging and vulnerable situation, often faced with the need to make crucial decisions, like those regarding organ donation, within a limited timeframe, taking place during a period of shock and loss. In fact, many families become confused and stressed during the announcement of brain death, especially since they are often unfamiliar with this concept beforehand. This highlights the need for education, support, and cultural awareness regarding the concept of brain death.

Health professionals and organ donation coordinators play a pivotal role in the organ donation ecosystem. Having a knowledgeable and skilled coordinator present can help facilitate discussions and enhance the likelihood of obtaining family consent.<sup>5</sup>

To improve the organ donation process and support donor families, it is suggested that appropriate infrastructures and counseling groups for families be considered. In addition, providing opportunities for empowering the spouses and family members of donors to enter the job market could help reduce the psychological and social issues arising from the loss of their loved ones.

Furthermore, clear explanations regarding the allocation of organs and avoiding unrealistic promises in the consent process could build trust among families and enhance the relationship between medical institutions and families. Establishing communication networks among donor families could also facilitate the sharing of experiences and mutual support.

Overall, creating a cohesive support and educational system can help donor families gain a better understanding of the circumstances and processes while also giving special attention to their feelings and experiences. In addition, public awareness could emphasize the generosity of families of organ donors and highlight the difference made to the lives of recipients.

To make future research more inclusive, it would be beneficial to involve a diverse group of participants, including close families, friends, and members of organ donation and transplant coordinator teams. This approach would offer a richer understanding of family dynamics and experiences by capturing a broader spectrum of views that can deepen our insights into the topic. Engaging focus groups or conducting structured interviews with transplant team members can reveal varying opinions and shared experiences, ultimately enhancing the richness of the data gathered. Future research would benefit from follow-up interviews, which could provide further insights into the differences between families.

The interplay between the themes of Supporting System and Coping Strategies is critical in understanding the experiences of families of deceased organ donors. By fostering strong support networks and promoting effective coping mechanisms, families are better equipped to process their grief and endorse the organ donation process, thereby influencing not only their healing journey but also the broader societal perceptions of organ donation. This understanding highlights the need for integrated approaches that address both emotional support and practical coping strategies in the context of organ donation discussions, ultimately aiming to enhance the experiences of grieving families. Continuous assessment and adaptation of these practices will ensure that we meet the evolving needs of families and the broader community effectively.

Participants came from diverse social and cultural backgrounds and ethnic groups. So, the findings can be generalized



to other families from diverse cultural or religious backgrounds by emphasizing the universal aspects of grief, the importance of culturally sensitive education, effective communication, and the incorporation of spiritual and community support.

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## Ethical considerations

Ethical approval to report this case was obtained from the Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences (Ethical Code: IR.SBMU.RETECH.REC.1403.353).

## Consent to participate

The informed consent was obtained from all participants who were included in the study to publish their data. Written informed consent was obtained from all subjects before the study.

## Author contributions

ML: Conceptualization and Reviewing; EP: Writing the draft and Conducting interviews; HR and FE: Data analysis and Conducting revisions; MP: Conducting interviews; SD: Supervision and Writing the final draft.

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## Declaration of conflicting interests

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## Supplemental material

Supplemental material for this article is available online.

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