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# Impact of organ donation on grief symptoms in donor families

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## Abstract

**Introduction** The aim of the study was to identify the factors that influence grief among donor families regarding organ donation.

**Methods** This cross-sectional study, utilizing an analytical approach, employed a convenience sampling method to gather data from family members. Over the three years, all families who consented to organ donation were invited to participate, from all, 222 questionnaires were completed by donor family members who had given consent and successfully proceeded with the donation. We collected data using the Grief Experience Questionnaire (GEQ-34). Descriptive and analytic statistics were utilized to determine the factors influencing grief using SPSS 18 software. A significance level of $P < 0.05$ was considered statistically significant for all analyses.

**Results** The donor gender was mostly male (153, 68.9%) with a mean age of 35.96 ± 17.05 (range: 2–68) years at the time of death. The mean score of GEQ was 93.3 ± 22.4 (ranging from 39 to 141) from a theoretical range of 34 to 170 with the higher the score indicating a more intensive grief experience. 23(10.4%), 100 (45%), and 99 (44.6%) of participants suffered from low (GEQ 34–68), moderate (GEQ 69–102), and high levels of grief (GEQ higher than 103), respectively. Guilt had the highest mean score among different aspects of the GEQ component. A significant negative relationship between guilt, age of the donor ($r$=- 0.10, $P < 0.011$), and time interval from donation ($r$=-0.17, $P < 0.001$), showed that guilt may be more pronounced in cases involving younger donors or more recent losses. Families of suicide-related brain death cases, and those who lost their children rather than their spouses, experienced more grief compared to other families. Additionally, families with prior knowledge of the concept of brain death experienced lower grief compared to those without such knowledge.

**Conclusion** The results reveal that the average grief score among the donors' families was higher than normal, with 89.1% experiencing moderate to severe levels of grief. While the results may seem challenging due to the high prevalence of grief, they offer valuable insights into how support systems and education can be tailored to better assist families in coping with their loss.

**Clinical trial number** Not applicable.

**Keywords** Organ donation, Grief symptoms, Organ donation

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## Introduction

Organ transplantation is the globally accepted and preferred treatment for patients suffering from end-stage organ failure [1].

In recent decades, the field of organ transplantation has achieved significant milestones, enhancing the lives of numerous individuals. The demand for organs continues to rise, creating a widening gap between patients requiring organs and the availability of donors [2]. According to the World Health Organization (WHO), less than 10% of candidates are able to benefit from transplantation. Consequently, while awaiting the necessary organ transplantations, thousands of patients either perish or suffer a diminished quality of life [3].

In Iran, the opt-in approach is utilized for organ retrieval, ensuring that informed consent is acquired from the first-degree relatives of individuals declared brain-dead. Based on the Organ Donation Act, family consent remains crucial for organ donation, even if the brain-dead individual had expressed their desire to donate through a pre-death will [4]. In Iran, organ donation requires consent primarily from the deceased (or their legal guardian), but the process mandates consultation with all immediate family members to secure collective agreement.

The cultural framework of Iran strongly emphasizes altruism, sacrifice, and collective support [5]. Discussion of family members with each another influences their decisions, including during brain death scenarios [6].

The rate of consent for organ donation by next of kin plays a significant role in the shortage of transplantable solid organs. Increasing the rate of consent remains a highly promising approach to increasing the number of donated and received organs in the country with the opt-in system [7].

Families often become the key decision-makers in determining who receives scarce, life-saving organs, especially when patients have not expressed their wishes. These decisions, made in moments of trauma and profound sadness, can ultimately determine the fate of individuals waiting for organ transplants [8].

Research conducted in various countries has revealed that families refuse organ donation in approximately half of cases where suitable organs are available for transplantation [9–11]. The process of deciding whether or not to donate the organs of a loved one who is brain dead often comes unexpectedly and in a sensitive situation [12].

It is crucial to provide nationwide training for coordinators to enhance their skills in approaching families and medical management of brain-dead, taking into account the family's views and beliefs. Furthermore, once consent has been obtained, coordinators should make sure that families receive continuing support and offer psychological aid as needed [13]. If not, this raises the possibility of developing posttraumatic stress disorder in addition to exacerbating the emotional pain brought on by the loss of a loved one [14].

Even after the initial period of grief, families of organ donors remain vulnerable to developing Intensive Care Unit (ICU) syndrome, including grief, depression, and post-traumatic stress, which can manifest months after the crisis has passed [8]. The potential distress that organ donation can evoke in grieving families is a legitimate concern [15]. However, subsequent studies have suggested that donation can alleviate suffering [16], provide positive dealing to grieving families [17], and have a beneficial impact on the bereavement journey [18].

There have been conflicting conclusions regarding whether the decision to donate organs causes significant stress for donor families [18].

Among limited research having been conducted in the context of the psychological experiences of organ donor families in Iran, primary attention has been devoted to identifying the rate of grief among donor families post organ donation. Furthermore, the variety of factors that may influence family grief remains poorly understood. The second aim is to identify the factors affecting grief in donor families regarding organ donation.

## Methods

### Participants and setting

This cross-sectional study, utilizing an analytical approach, employed a convenience sampling method to gather data from family members, including parents, spouses, siblings, and children, who had lost loved ones through organ donation at the Sina Organ Procurement Unit (OPU) of Tehran University of Medical Sciences (TUMS), Tehran, Iran. Data were collected from Aug to Sep 2023.

The study's inclusion criteria required participants to be the legal next of kin of the donor, to have had the organ donation occur at least three months prior to the study, and to have the ability to speak and write in Farsi, not having any psychological disorders, not have participated in grief therapy.

Over the past three years, out of 326 families of deceased donors at the Sina OPU, 287 families met the study's inclusion criteria. Then, all families were contacted to explain the study's aims.

A total of 243 families agreed to participate in the study. If they were willing to participate in the study, a text message with a link of the questionnaire was sent to them. They first fill out an informed consent form and then completed the questions. If they did not complete the informed consent form, they were not allowed to proceed to the second part, which contained the questionnaire questions. For non-responders, weekly reminder

message was sent over a four-week period. Of all families, 222 donor family members completed the questionnaire.

The Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences approved the study protocol (Ethical Code: IR.SBMU.RETECH.REC.1403.535).

### Measures

#### *Demographic and clinical characteristics questionnaire*

The donor's family provided information regarding the donor's age, gender, cause of brain death, education level, marital status, number of children, knowledge about brain death, and the most important person for family consent.

#### *Grief experience questionnaire (GEQ), Persian version*

Barrett and Scott (1998) to assess the level of grief developed the GEQ. This self-report questionnaire was specifically designed to measure grief [19]. Initially, the questionnaire comprised 55 items. However, the Persian version, which underwent factor analysis, consists of 34 items and is divided into seven factors: feelings of guilt (8 items), finding an explanation (6 items), somatic reactions (5 items), feelings of abandonment or rejection (4 items), personal or other people's judgment in relation to the reason for death (4 items), shame (4 items), and stigmatization. (3 items) [20]. Participants rated each item on a 5-point Likert scale ranging from 1 (never) to 5 (always).

The scores obtained ranged from a minimum of 34 to a maximum of 170, and obtaining a higher score in this tool signifies a more intense grief experience. A score of 34–68 is considered a low grief experience, a score of 69–102 is considered an average grief experience, and a score above 103 is considered a high grief experience.

### Data analysis

We analyzed the data using descriptive statistics (frequency, percentage, mean ± standard deviation).

To compare the distributions of categorical variables (analyzing knowledge about brain death, gender, marital status, and level of grief) Chi-square tests were applied as appropriate. Furthermore, The one-Way ANOVA test to determine the difference in the moderate levels of GHQ and the various causes of brain death, and the consent of the donor before brain death (having a donor card, registering to get a donor card, donor verbal consent) followed by Tukey HSD post hoc test. Statistical analyses were performed using SPSS18. A significance level of $P < 0.05$ was considered statistically significant for all analyses.

**Table 1** Demographic data of donors

| Variable | | Number | Frequency |
|---|---|---|---|
| Age | Lower than 10 | 16 | 7.3 |
| | 10–20 | 28 | 12.7 |
| | 20–30 | 48 | 21.8 |
| | 30–40 | 37 | 16.8 |
| | 40–50 | 38 | 17.3 |
| | 50–60 | 33 | 15 |
| | Higher than 60 | 9 | 9.1 |
| Gender | Male | 153 | 68.9 |
| | Female | 69 | 31.1 |
| Marital status | Married | 103 | 46.4 |
| | Unmarried | 117 | 52.7 |
| | Others | 2 | 0.9 |
| Donors' level of education | Illiterate | 49 | 22.1 |
| | Under Diploma | 61 | 27.5 |
| | Diploma | 57 | 25.7 |
| | Bachelor's degree | 47 | 21.2 |
| | Master degree | 7 | 3.2 |
| | Doctorate | 1 | 0.5 |
| No. of children | None | 83 | 40.8 |
| | 1–2 | 81 | 39.9 |
| | 3–4 | 28 | 13.8 |
| | >=5 | 11 | 5.5 |
| Cause of brain death | Trauma | 77 | 36.3 |
| | CVA | 83 | 39.2 |
| | Poisoning | 12 | 5.7 |
| | Suicide | 5 | 2.4 |
| | Cardio arrest | 11 | 5.2 |
| | Seizures | 7 | 3.3 |
| | Brain tumor | 4 | 1.9 |
| | Respiratory arrest | 11 | 5.2 |
| | Others | 2 | 0.9 |

## Result

### Demographic and clinical characteristics

Most of the respondents were mothers ($n = 69$, 31.1%), followed by children of the deceased ($n = 53$, 23.9%). Other relationships included the sibling ($n = 39$, 17.6%) and wife/husband ($n = 37$, 16.7%) of the deceased. The donor gender was mostly male ($n = 153$, 68.9%) with a

**Table 2** Mean and standard deviation of GEQ scores and its components

| Component | Mean ± SD |
|---|---|
| Guilt | 21.22 ± 5.28 |
| Search for explanation | 19.74 ± 6.28 |
| Somatic reactions | 12.20 ± 4.52 |
| Rejection | 11.41 ± 3.96 |
| Personal or other people's judgment in relation to the reason for death | 11.41 ± 3.96 |
| Shame | 9.5 ± 3.12 |
| Stigmatization | 7.31 ± 3.07 |
| Total | 93.3 ± 22.4 |

mean (SD) age of 35.96 ± 17.05 (range: 2–68) years at the time of death.

The average number of months after organ donation had passed was 27.67 (SD = 11.90). Causes of death included CVA ($n = 83$, 39.2%), and head trauma (77, 36.3%) (Table 1).

The most important person for family consent is the all-nuclear family (44 (19.8%)), then the mother (36 (16.2%)) and the wife or husband (34 (15.3%)).

The mean score of GEQ was 93.3 (SD = 22.4), ranging from 39 to 141. Twenty-three (10.4%), 100 (45%), and 99 (44.6%) of participants suffered from low, moderate, and high levels of grief, respectively.

The subscale of "guilt" had the highest mean score ($M = 21.22$, SD.= 5.28), and the subscale of "stigmatization" had the lowest mean score ($M = 7.31$, SD = 3.07) among different aspects of the GEQ component. Table 2 illustrates the mean scores of GEQ for each subscale.

There was a significant negative relationship between the guilt age of the donor ($r$= -0.10, $P < 0.011$), and time interval from donation ($r = -0.17$, $P < 0.001$). Table 3 illustrates the correlation between the GEQ component and demographic items.

Our findings indicate that guilt is strongly correlated with several components of grief, such as search for explanation ($r = 0.36$, $P < 0$ 0.001), somatic reactions ($r = 0.40$, $P < 0.001$), rejection ($r = 0.46$, $P < 0.001$), judgment ($r = 0.68$, $P < 0.001$), shame ($r = 0.66$, $P < 0.001$), and stigmatization ($r = 0.40$, $P < 0.001$). This suggests that guilt exacerbates these emotional and psychological responses, potentially complicating the grief process. Furthermore, the negative correlations with donor age ($r = -0.10$, $P < 0.011$), and the time since the donation ($r = -0.17$, $P < 0.001$) showed that guilt may be more pronounced in cases involving younger donors or more recent losses.

According to the one-way ANOVA results, there is a significant difference between the cause of brain death and the GEQ level (F = 2.084, $P = 0.032$). Further analysis using Tukey's HSD test reveals that families of suicide-related brain death cases had more grief compared to others.

A significant difference was found between pre-brain death donor consent mechanisms (donor card registration, verbal consent, no documented consent) and GEQ level (F = 1.96, $P = 0.045$). Tukey's HSD test further demonstrated that donor card registration before brain death was associated with the lowest level of grief, as measured by the GEQ scale.

Additionally, there is a significant difference between the donor's familial relationship to respondents and GEQ level (F = 5.63, $P = 0.018$), families experience more grief when they have lost their children than their wives or husband (Table 4).

Based on Chi-square, there is a significant difference between knowledge about the brain death and level of grief ($P = 0.008$), families with prior knowledge about brain death concept showed lower grief levels.

In addition, there are no significant differences between gender ($P = 0.259$), marital status ($P = 0.104$), and level of grief.

## Discussion

Several studies conducted on donor families have focused on identifying factors that impact the decision to donate [21, 22], but few have addressed the post-donation psychological experience of these families [18]. This study's results provide valuable insights into the rate of donor family grief and find the factors related to family grief after consent to donation.

The findings revealed that 199 (89.6%) of participants suffered moderate and high levels of grief.

According to Merchant et al., a significant proportion of donor families suffered from complicated problems such as having taken medication for sleep and emotional difficulties. They highlight the potential positive impact of organ donation on grief for donor families [23].

In contrast, Cleiren and Van Zoelen, reveal that there are no differences in levels of depression or detachment issues from the deceased among bereaved individuals who participated in organ donation and those who refused consent. Based on their findings, consenting to organ donation neither impedes nor facilitates the grieving process [24].

The search for an explanation was the main problem, and feelings of guilt were the second most common source of grief. Donor families were trying to cope with this issue, and some of them were struggling with guilt over their decisions.

In the studies conducted by Sque et al. [25], and Manzari et al. [26] families who had donated organs expressed emotions such as missing their loved ones, pride, grief, family love, and guilt. These findings are consistent with our results.

Losing a loved one can trigger the onset of grief, which is a profound yet common form of sorrow that can manifest in various ways over time. Guilt is directly statistically associated with the other components of grief.

In this regard, the trajectory of grief can vary depending on cultural and familial influences, individual history, the nature of the relationship with the deceased, the circumstances of death, and the support received from loved ones [27].

Conversely, unresolved emotional reactions to the death of a loved one may impede the consideration of organ donation, as indicated by various studies [25, 28].

In addition, the age of the deceased and being an effective person on consent had significant effects on the grief

**Table 3** Correlation between GEQ component and demographic items

| Component | (1) | (2) | (3) | (4) | (5) | (6) | (7) | (8) | (9) | (10) |
|---|---|---|---|---|---|---|---|---|---|---|
| Guilt (1) | 1 | $r=0.36$ $P<0.001$ | $r=0.40$ $P<0.001$ | $r=0.46$ $P<0.001$ | $r=0.68$ $P<0.001$ | $r=0.66$ $P<0.001$ | $r=0.39$ $P<0.001$ | $r=0.10$ $P=0.12$ | $r=-0.17$ $P<0.001$ | $r=-0.10$ $P=0.011$ |
| Search for explanation (2) | | 1 | $r=0.33$ $P<0.001$ | $r=0.26$ $P<0.001$ | $r=0.41$ $P<0.001$ | $r=0.29$ $P<0.001$ | $r=0.43$ $P<0.001$ | $r=0.01$ $P=0.78$ | $r=-0.15$ $P=0.01$ | $r=-0.07$ $P=0.29$ |
| Somatic reactions (3) | | | 1 | $r=0.42$ $P<0.001$ | $r=0.34$ $P<0.001$ | $r=0.36$ $P<0.001$ | $r=0.46$ $P<0.001$ | $r=-0.07$ $P=0.26$ | $r=-0.25$ $P<0.001$ | $r=-0.02$ $P=0.69$ |
| Rejection (4) | | | | 1 | $r=0.47$ $P<0.001$ | $r=0.39$ $P<0.001$ | $r=0.55$ $P<0.001$ | $r=-0.05$ $P=0.39$ | $r=-0.04$ $P=0.48$ | $r=-0.06$ $P=0.33$ |
| Judgment (5) | | | | | 1 | $r=0.57$ $P<0.001$ | $r=0.39$ $P<0.001$ | $r=0.009$ $P=0.89$ | $r=-0.06$ $P=0.34$ | $r=-0.08$ $P=0.23$ |
| Shame (6) | | | | | | 1 | $r=0.32$ $P<0.001$ | $r=0.08$ $P=0.23$ | $r=-0.16$ $P=0.01$ | $r=-0.05$ $P=0.43$ |
| Stigmatization (7) | | | | | | | 1 | $r=-0.04$ $P=0.55$ | $r=-0.23$ $P<0.001$ | $r=-0.03$ $P=0.62$ |
| Cause of brain death (8) | | | | | | | | 1 | $r=-0.33$ $P<0.001$ | $r=-0.09$ $P=0.16$ |
| Age (9) | | | | | | | | | 1 | $r=-0.13$ $P=0.04$ |
| Time interval from Donation (10) | | | | | | | | | | 1 |
| Consent to donation (10) | | | | | | | | | | 1 |

$P<0.05$

score of bereaved family members. Ralph et al. showed that while age may generally impact family consent for donation, unique circumstances arise when the deceased is a child, with the grieving process highlighting the emotional weight and potentially influencing family decisions toward donation [29]. In our view, the emotional impact can vary widely depending on the circumstances, perhaps older individuals may have a more established social and familial network, which can influence how their passing is perceived by family members.

Our results showed that families with prior knowledge about brain death concept exhibited lower grief levels, Based on the McEvoy et al., pertain specifically to individuals with intellectual disabilities, they provide a wide framework for understanding how cognitive factors (such as comprehension of death) can impact experiences of grief among different populations [30].

Our data show that the prevalence of grief 9 months after the patient's death was significantly higher in relatives who lacked such an understanding.

This finding aligns with prior research, such as Kentish-Barnes et al. [31], which similarly revealed that relatives who did not have an understanding of the situation had a significantly higher prevalence of complicated grief 9 months after the patient's death. The results highlight how providing families with information about the medical context, prognosis, and brain death concept plays a crucial role in mitigating grief.

**Table 4** The relation between GEQ level and demographic items

| | Sum of squares | df | Mean square | F | *P* value |
|---|---|---|---|---|---|
| Cause of brain death | 8059.23 | 9 | 895.47 | 2.084 | 0.032 |
| Level of education | 788.92 | 5 | 157.78 | 0.34 | 0.88 |
| Number of children | 491.95 | 8 | 614.49 | 1.38 | 0.203 |
| having card* | 7618.573 | 9 | 846.508 | 1.96 | 0.045 |
| Relation with donor | 2501.26 | 1 | 2501.26 | 5.63 | 0.018 |

*: Printed card, register to getting card, or donor verbal consent, $P<0.05$

Our results showed no significant differences in grief levels among gender and marital status of donors. Based on our results gender and marital status may not directly predict grief intensity in donor families, their interplay with contextual factors warrants deeper exploration.

This aligns with the results of Amini et al. [32], which showed that there is a high prevalence of depression among relatives of men aged 30–50 who have died due to brain death. It is important to take this into consideration when planning care for these relatives, particularly those who are low-educated, unemployed, or experiencing the first year after the death of a loved one due to brain death.

It shows that knowledge of the donor's wishes had significant effects on the grief score of bereaved family members.

Consistent with our findings, Kentish-Barnes et al. report that non-donor families had significantly less knowledge of the patient's wishes regarding organ donation and more frequently found the decision-making process challenging. In contrast, donor families often felt supported in their decisions by knowing the patient's preferences [33].

Our result showed that families experience more grief when they have lost their children than their wives or husbands. According to Glatt, the loss of a child has profound repercussions on the family structure, significantly

impacting both the parents and siblings. The effects of a loss remain for years, fundamentally altering the family dynamics and structure [34].

According to our results, having donor consent before brain death was associated with the lowest level of grief, as measured by the GEQ scale. Families found it simpler to make the decision when organ donation was discussed before brain death and the donor provided vocal agreement [18], which may have helped family members stop worrying about this obligation. Burroughs et al. also reported that discussions with brain-dead families were of utmost importance and that this resulted in donor families subsequently feeling satisfied with their decision [35].

The study has several limitations. The data were collected over a specific time period, and the cross-sectional design prevents the evaluation of changes in findings over time. Another limitation is that it was a single-center study, which restricts the generalizability of the results and may yield different outcomes in other centers. The study features donors who are young by international standards, with all donations being from donors after brain death (DBD) and none from donors after circulatory death (DCD). A further limitation is that the evidence was gathered through questionnaires, which were predominantly completed by mothers, followed by children, while responses from spouses were relatively low. Additionally, the study was conducted 27 months after the loss, which could also be seen as a strength as it highlights the prolonged nature of grief. However, a significant limitation is that the survey only included donors and did not account for those who did not donate.

This study was also conducted for the first time in Iran, and according to researchers' searches worldwide, its results can be helpful for future decision-making and policies regarding support and care for donor families. Due to varying timelines following a loss, it is challenging to determine whether feelings of guilt are related to prior events. Future research should focus on conducting qualitative studies to explore these complex emotions further.

## Conclusion

Nearly half of the families experienced grief at high levels, while guilt emerged as a significant component strongly correlated with other emotional and psychological factors. It is crucial to develop proactive strategies to support donor families after the donation.

Knowledge about brain death was associated with lower grief levels, suggesting the importance of education in mitigating the emotional burden on donor families. These insights underscore the need for comprehensive support systems and educational initiatives to address the multifaceted challenges faced by donor families.

Offering access to counseling and grief therapy may help to ensure the well-being of donor families during this difficult time.

Moreover, these results suggest that improving awareness and understanding of organ donation processes may help mitigate grief among families. To better support donor families, the organ donation team should develop standardized protocols for assessing psychological needs. Future research should focus on evaluating the effectiveness of psychological support programs for these families. Support mechanisms should be developed through group therapies, and organ transplant coordinators and health professionals, especially those in intensive care should be trained on the psychological dimensions of the organ donation process. In addition, relationships between grief level and factors like understanding of brain death, these associations require confirmation in studies that directly compare donor/non-donor families and death circumstances.

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#### Author contributions

M.L. Conceptualization and Writing original draft; E.P. Supervision, Review, and Editing of the manuscript; MT.T. & I.S. Analyze the data; E.A. & M.S. Data collecting.; S.D. Project administration and Writing final draft. All authors have read and agreed to the published version of the manuscript.

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#### Data availability

The datasets used and/or analyzed during this research study are available from the corresponding authors [Dr. Sanaz Dehghani with email: sanaz_dehghani2002@yahoo.com and Ms. Elahe Pourhosein with email: elahepoorhosein1990@gmail.com] on reasonable request.

## Declarations

#### Ethics approval and consent to participate

This research was conducted on humans are in accordance with the Helsinki Declaration of 1975, as revised in 2013 (http://ethics.iit.edu/ecodes/node/3931). Ethical approval to report this case was obtained from Medical Ethics and Law Research Center, Shahid Beheshti University of Medical Sciences (Ethical Code: IR.SBMU.RETECH.REC.1403.353). The informed consent was obtained from all participants who were included in the study to publish their data.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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