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# Exploring family attitudes toward organ donation among donor and nondonor families

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## Abstract

**Background** To increase organ donation, understanding the factors that influence a family's decision to donate or not is essential to developing effective strategies to alleviate the current donor shortage. By concentrating on the lived experiences and perspectives of both donors' and non-donors' families, this study aims to uncover the intricate interactions that shape these critical decisions. The goal of this study was to investigate the factors that affect families' decisions regarding organ donation, particularly through the experiences of both donors' and non-donors' families.

**Methods** The present study was conducted using a qualitative method and conventional content analysis approach (CCA) following Graneheim and Lundman's approach. Sixteen family members of donors and non-donors were included in the study through a purposive sampling method. Data were gathered by using semi structured interviews.

**Results** Participants were 10 females and 6 males; the mean age of families was 54.73 ± 21.49 years. Data analysis led to the emergence of two themes: Organ Donation Coordinators' Characters including coordinator's communication competence, expertise, and empathetic demeanor, comprehension of the concept of brain death, clinical and psychological expertise, sufficient information about the patient's record, timing of the request, setting in which the request is made, type of medical staff behavior towards family; and personal values, including trust in healthcare systems, cultural issues, emotional distress, religious belief, along with 37 categories.

**Conclusion** The characteristics and behavior of coordinators shape the families' beliefs about the organ donation process, the circumstances under which requests are made, and their personal and cultural values. Effective communication, a respectful environment, and cultural sensitivity are crucial for facilitating acceptance and informed decision-making regarding organ donation.

**Keywords** Qualitative investigation · Non-donor families · Organ donor families

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## 1 Introduction

Many people die on transplant waiting lists because the demand for organs outstrips supply [1]. Despite efforts, the number of available organs remains below the required level. Medical professionals have indicated that the plausible reasons for this shortage include the public's insufficient awareness of, and motivation for, organ donation [2].

According to latest report of the International Registry in Organ Donation and Transplantation, the rate of actual deceased organ donors in Iran in 2025 was 14.69.

per million population (PMP) [3]. Despite this slight improvement, the donation rate in Iran remains below the worldwide average, with a donation rate of 51.9 PMP in Spain [3].

While advancements in medical technology and increased awareness have improved the processes surrounding organ donation [4], societal attitudes and familial perspectives continue to play a crucial role in influencing donation rates [5].

Substitute decision-makers faced with consent decisions often do so in emotionally charged circumstances and many do not know the explicit wishes of the patient. The causes of this shortage are intricate and varied, encompassing a lack of awareness and misunderstandings about organ donation, as well as cultural, religious, and psychological obstacles. Furthermore, systemic problems, including ineffective organ donation and transplantation policies, can intensify the shortage [6].

Given this context, the process of obtaining consent and the support provided may have a substantial impact on the decision [7]. Practices have been identified that improve consent rates from substitute decision-makers, and these are routinely performed by large, high-performing organ donation organizations [8]. An epidemiological study has identified no modifiable factors associated with donation consent (e.g., race, age, socioeconomic status, and education) [1].

Though donation practices prioritize the wishes and consent of the potential donor over the relatives, it is almost inconceivable that organs would be retrieved from a brain-dead patient against the wishes of his or her family. Thus, requests to relatives for organ donation are likely to remain an important step in organ procurement [9].

In Iran, the process of approaching families for organ donation is primarily the responsibility of the organ donation coordinator, who plays a central role in the multidisciplinary transplant team. Coordinators come from various healthcare backgrounds, and their effectiveness has been linked to training, experience, and dedication [10]. Before any discussion of organ donation, Iranian protocols emphasize that families must first accept the reality of brain death. A "three-step method" is used to break the news gradually, providing time for acceptance and trust-building. Confirmation of brain death involves independent examinations by specialists in surgery, neurology, internal medicine, and anesthesiology, as well as a forensic medicine specialist, all appointed by the Ministry of Health.

Two principal policy regulate the consent process for organ donation: opt-in policy, based on explicit informed consent, and opt-out policy, which rely on presumed or deemed consent [11]. In Iran, organ donation operates under an opt-in policy, meaning that donation does not proceed without explicit family consent, regardless of the deceased individual's known wishes [12].

A complex interplay informs family consent of organ donation of demographic, cultural beliefs, psychological and emotional responses, and informational factors related to both the family and the deceased [13]. While some barriers are deeply rooted and resistant to change, others, especially those stemming from misinformation, can be addressed through effective, compassionate communication, and all contribute to the decision-making process surrounding organ donation [14]. Recognizing the factors contributing to the refusal of consent, which is part of the current donor shortage, is essential for developing effective strategies to promote organ donation [15]. By focusing on the lived experiences and perspectives of both donor and non-donor families, this exploratory study aims to uncover the nuanced dynamics that shape critical decisions about organ donation. Qualitative research

was chosen for this study to explore the emotional and contextual factors influencing families' ideas about organ donation, making it an apt approach for understanding this complex issue. The goal of this study was to investigate the various factors that affect families' decisions in the Sina Organ Procurement Unit (OPU) regarding organ donation, particularly through the experiences of both donors' and non-donors' families.

## 2 Methods and materials

### 2.1 Study design

This qualitative study focused on families of brain-dead cases, including both organ donors and non-donors, with a mix of family relationships (e.g., spouses, parents, children, and siblings). Participants were families of patients diagnosed with brain death and referred to the Sina Organ Procurement Unit (OPU) between January 2022 and January 2025. During this period, approximately 600 brain-dead cases were registered, of which more than 70 families were contacted for this study.

The authors contacted potential participants by phone after explaining the study aims and their eligibility. If they met the inclusion criterion and signed informed consent, a face-to-face interview was scheduled. Maximum variation sampling was employed.

Participants were selected using maximum variation purposive sampling to ensure diversity in terms of age, relation with the donor, and social and cultural background. This strategy was conducted to ensure a diverse range of perspectives on the study's focus. Interviews continued until data saturation was achieved across all categories. Data collection ceased when responses became repetitive [16]. In this case, the authors prepared a list of eligible families in Sina OPU.

A preliminary analysis after 14 interviews indicated that no new codes were extracted; two additional interviews were conducted to ensure that the data had indeed reached saturation. These final interviews also yielded no new codes, confirming that data saturation had been achieved across all categories. Therefore, data collection ceased after 16 interviews.

Sixteen close families, with participants aged 18 years and older, participated in the study.

### 2.2 Data collection

To determine experiences and expectations influencing families' decisions regarding organ donation, in-depth, face-to-face interviews were conducted with each participant. The interviews took place in the family waiting room in Sina OPU, approximately 6 months to 3 years after the death of the family member. Each interview lasted 35–45 min and was conducted by a researcher, with an observer present. The interviews were recorded using a voice recorder.

The checklist used during the semi-structured interviews was developed by the researchers following a review of reputable literature, ensuring it captured comprehensive insights from participants' accounts regarding the study's focus [17].

The initial draft of the interview guide was prepared by the research team and reviewed by two organ donation coordinators. The final version of the interview checklist was developed after conducting one pilot interview with an eligible family who were not part of the main participation.

During the interviews, the researchers employed probing questions, allowing participants to narrate their own experiences and share any additional information that arose. This flexible interview format fostered an open dialogue, enabling participants to express their feelings and thoughts in their own words. By encouraging rich, narrative responses, the researchers aimed to gain a deeper understanding of the emotional and contextual factors influencing families' perspectives on organ donation.

#### 2.2.1 Data analysis

Each interview was transcribed verbatim immediately after completion to obtain a holistic understanding of the content. The research team read each transcript several times.

To analyze the data, the conventional content analysis approach described by Graneheim and Lundman [18] was used.

The steps include: [1] Familiarization, with data by thoroughly reading all transcripts followed by initial broad coding to categorize the content; [2] Initial Coding, where the data was categorized; [3] Developing more detailed subcategories through line-by-line analysis to create more refined categories; finally [4] Synthesizing and interpreting the organized data to gain a nuanced understanding of the participants' experiences. Throughout the process, categories and codes were continually refined to reflect the data's depth [18] accurately.

To enhance the analytical rigor, two members of the research team independently coded the first three transcripts using MAXQDA 2020. They then convened to compare their coding schemes, resolve any discrepancies through discussion, and establish a preliminary codebook. This codebook was then applied to the remaining transcripts. Research team sessions were held throughout the analysis process to discuss evolving codes and categories, resolve coding disagreements through consensus, and ensure a consistent, hermeneutic interpretative approach.

#### 2.2.2 Trustworthiness

Trustworthiness was established according to Lincoln and Guba, four criteria: credibility, dependability, confirmability, and transferability [19].

Credibility was established through member checking; the extracted codes were returned to three participants to provide feedback on the researchers' interpretations of their statement.

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Dependability was ensured through a clear audit trail, achieved by meticulously documenting all steps and procedures of the study, from the development of the interview guide to the step-by-step ICA procedure. Two researchers independently coded a subset of the data, then discussed any discrepancies. A progressively developed codebook was refined throughout the analysis process during regular research team sessions, ensuring consistency with emerging themes.

Confirmability was supported through external review. The authors engaged in regular discussions to critically examine their own biases and assumptions, ensuring that the findings were grounded in participants' data rather than the researchers' preconceptions.

Transferability was addressed by providing detailed descriptions of the thematic categories [20], the Sina OPU context, the decision-making process, the data collection and analysis procedures, and direct participant quotations.

## 3 Results

Sixteen subjects participated as family members of both groups: mothers, fathers, sisters, and spouses. The average number of months after organ donation had passed was $11.42 \pm 2.31$.

Of the 16 participants, 10 were female and 6 were male, with a mean age of $54.73 \pm 21.49$ years. The mean age of brain-dead patients was $36.06 \pm 17.86$ years among donors and $34.48 \pm 15.76$ years among non-donors.

The general demographic data of the participants are shown in Table 1.

Data analysis led to the emergence of two themes, 11 Subthemes, and 37 categories (Table 2).

**Table 1** General demographic data of the interviewees ($N = 16$)

| | | Donor | Non-donor | Number |
|---|---|---|---|---|
| Relationship with brain death cases | *Child* | 1 | 0 | 1 |
| | *Brother* | 1 | 0 | 1 |
| | *Sister* | 0 | 1 | 1 |
| | *Husband* | 2 | 1 | 3 |
| | *Father* | 1 | 1 | 2 |
| | *Wife* | 3 | 1 | 4 |
| | *Mother* | 2 | 2 | 4 |
| Economic Status | *Low* | **4** | **2** | **6** |
| | *Moderate* | **2** | **3** | **5** |
| | *Good* | **2** | **2** | **4** |
| Information related to brain death cases | | | | |
| Having donor card /Verbal willing | *Yes* | **5** | **1** | **6** |
| | *No* | **3** | **7** | **10** |
| Brain death cases marital status | *Married* | **4** | **5** | **9** |
| | *Single* | **2** | **3** | **5** |
| | *Other* | **2** | **0** | **2** |
| Level of education | *Lower than diploma* | **2** | **3** | **5** |
| | *Diploma* | **1** | **4** | **5** |
| | *Academic* | **1** | **1** | **2** |
| | *Student* | **1** | **3** | **4** |

## 3.1 Organ donation coordinators' characters

The coordinators' character theme included seven subthemes. Subthemes derived from the donor and non-donor families' perspectives are described as follows:

### 3.1.1 Coordinator's communication competence, expertise, and empathetic demeanor

This was the most frequently cited overarching theme regarding the coordinator's role. Families' perceptions were shaped by two interrelated yet distinct dimensions of the coordinator's performance: basic communication competence and demeanor, and advanced clinical and psychological expertise.

Families, particularly non-donors, emphasized that consistency of information and the use of simple, non-technical language were non-negotiable for building trust. Inconsistency severely undermined their confidence in the medical diagnosis and the coordinator's integrity.

> *Their statements were inconsistent; the nurse contradicted the doctor, and the doctor kept undermining what the man from the donation had said. They themselves did not know what had happened to our son. If they were not sure about the condition of their own patient, how could I even think about donation? What if he was alive? If I woke up to a situation like that, I would not give my consent* **(Non-donor Father).**

Beyond consistency, the team's failure to translate complex medical realities into simple, digestible language left families feeling intellectually paralyzed and emotionally unprepared. In their heightened state of grief, families could not grasp abstract medical terms, which directly hindered their ability to understand the finality of brain death—a prerequisite for considering donation.

> *In our critical situation, we struggled to understand even the simplest things. The medical team spoke very specifically, and we did not grasp the medical terminology well at all* (Non-donor Husband 1).

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

| Themes | Subthemes | Categories and Subcategories |
|---|---|---|
| Organ Donation Coordinators' Characters | **Coordinator's Communication Competence, Expertise, and Empathetic Demeanor** | *- Sufficient information given regarding the process of donation and allocation*<br>*- A complete and clear explanation of brain death, which equates to definitive death*<br>*- Use of complex and intricate medical terminology*<br>*- Appearance as a respectable person.*<br>*- Alignment of beliefs with the families.*<br>*- Physician with a strong command of their profession.*<br>*- Possessing a deep understanding of parental emotions.* |
| | **Comprehension of the Concept of Brain Death** | *- Attention to the understanding or misunderstanding of the concept of brain death by families*<br>*- Haste in concluding the meeting* |
| | **Clinical and Psychological Expertise** | *- Experience level of the coordinator managing the meeting*<br>*- Feeling saddened by the family's loss*<br>*- Ability to make eye contact and communicate effectively with families*<br>*- Having an organ donation card from the coordinator*<br>*- Sufficient information regarding the process and avoiding contradictions when discussing the timing of donation and allocation methods*<br>*- Being confident in one's responsibilities*<br>*- Gathering all family members in initial meetings* |
| | **Sufficient Information about the Patient's Record** | *- Reviewing the brain-dead record before entering the meeting*<br>*- Complete familiarity with the donor's profile* |
| | **Timing of the Request** | *- Quick approach to the family before accepting death.* |
| | **Setting in Which the Request is Made** | *- The meeting time for donation was requested.*<br>*- Inappropriateness of the consent location.*<br>*- High traffic and lack of focus regarding donation or non-donation.*<br>*- A donation request was made in the ICU corridor.*<br>*- Telephone consent is not appropriate.* |
| | **Type of Medical Staff Behavior Towards Family** | *- Complaints about hospital practices.*<br>*- Complaints about the attending physician.*<br>*- Nurses not providing adequate care.* |
| Personal Values | **Trust in Healthcare Systems** | *- Uncertainty regarding organ allocation.*<br>*- Concerns about organ trafficking.*<br>*- The patient is still alive, and there was a desire to withdraw care.* |
| | **Cultural Issues** | *- The family refuses to allow the donation.*<br>*- Fear of societal rejection.* |
| | **Emotional Distress** | *- Fear of separation.*<br>*- Having a small child.* |
| | **Religious Belief** | *- Religious beliefs regarding the sanctity of the body to be buried intact.*<br>*- Uncertainty about the action.*<br>*- Miracle* |

### 3.1.2 Clinical and psychological expertise

This subtheme was cited almost exclusively by donor families, who credited a single skilled coordinator with changing their decision. This was the most impactful positive subtheme.

*I was initially not at all satisfied with the idea of donation; I was upset with the hospital. However, Dr. ... came in as a consent seeker and changed everything that was on my mind. He was very skilled in*

*communication, a complete psychologist. He briefly explained my daughter's condition to me and then told me that she had passed away and would not come back. He provided such determined and precise information and showed such empathy towards us that my opinion changed right then and there. Now I have become an advocate for organ donation, and I am not at all dissatisfied with my decision* **(Donor Mother 1).**

The demeanor and expertise of the individual making the request can significantly influence the family's response. A calm, knowledgeable approach that demonstrates empathy can foster trust.

Including all relevant family members in initial discussions ensures everyone has the same information, reducing misunderstandings and promoting a unified stance on organ donation.

#### 3.1.3 Comprehension of the concept of brain death

A recurring concern among non-donor families was the timing and clarity of brain-death explanations. Most of families declared that prolonged or confusing discussions occurred before they had accepted the diagnosis.

*The consent meeting was very time-consuming. For someone like me, whose attention was completely focused on the ICU, this meeting felt prolonged and, in my opinion, quite unpleasant* **(Non-donor Mother 1).**

Families must have a clear understanding of brain stem death, as misconceptions can lead to resistance or confusion regarding organ donation. Educators and coordinators should be prepared to thoroughly explain this medical condition.

#### 3.1.4 Sufficient information about the patient's record

Families valued coordinators who appeared fully briefed on the patient's case. Inconsistencies in this area led to suspicions about the coordinator's motives.

*I think they should have full access to the patient's file so that they can explain the situation to us completely. I've mentioned before that they were speaking so inconsistently that I was sure they didn't want a negative vote; they just wanted to fulfill their job responsibilities, and they were doing it completely incorrectly* **(Donor Brother).**

Coordinators must have a detailed understanding of the patient's medical history and current status to answer any questions the family might have, enhancing their confidence in the decision-making process.

#### 3.1.5 Coordinator's personal maturity and emotional demeanor

A few participants mentioned the coordinator's personal characteristics beyond their professional demeanor, though those who did linked calmness and maturity to success. A non-donor sister articulated this clearly: *"I think that if a person is established and has a calm personality, it can significantly impact their ability to achieve satisfaction. People who are impatient and only focus on the end of the session are not, in my opinion, successful individuals"* ***(Non-donor Sister).***

This suggests that the family's receptiveness is less about the coordinator's chronological age or demographic background and more about their perceived emotional stability and ability to remain patient under highly charged circumstances. Coordinators who project calmness and maturity may be better equipped to de-escalate family distress and foster a therapeutic rapport.

#### 3.1.6 Timing of the request

This was one of the most emotionally charged subthemes, particularly among non-donors. The perception of being asked "too soon" was a near-universal complaint in refusal cases.

> *I was still struggling to understand the concept of brain death when the donor [coordinator] insisted on the donation. It was really insulting to me that I had not yet accepted that my spouse was dead, and they were telling me to give their organs to someone else. The timing was awful, and they should have given me time and space to come to terms with this issue* **(Non-donor Wife).**

The timing of when the organ donation request is made can influence family decisions. Making the request too soon after a traumatic event may not be conducive to an open discussion, while waiting too long may cause emotional fatigue.

#### 3.1.7 Setting in which the request is made

While less frequently discussed, when mentioned, this subtheme was associated with traumatic experiences, highlighting the need for private, compassionate spaces for conducting donation discussions.

> *I was waiting for the doctor outside the ICU to find out how my daughter situation. Two doctors, or maybe nurses, came out of the ICU and were talking about patients in ICU. They mentioned that my daughter had died, and I followed them to the elevator, but they didn't even notice my presence and continued their conversation. The world had collapsed around me after hearing conversation. It was the worst way to hear about my daughter death (***Donor Father).**

The environment in which the discussion takes place can affect the family's receptiveness. A private, compassionate setting free from distractions is often more appropriate for these sensitive conversations.

Notably, this participant ultimately did consent to donation, despite this profoundly unprofessional disclosure. At first glance, this appears to challenge the importance of the setting. However, we interpret this paradox not as evidence that the setting is irrelevant, but rather as an indication that its influence is not deterministic. In this case, other powerful factors—likely the subsequent intervention of a highly skilled coordinator (as described in the previous theme) or the family's pre-existing altruistic inclinations—appear to have overridden the negative impact of the traumatic setting. This finding underscores two critical points: (a) the setting remains an important modifiable factor, as such traumatic disclosures are ethically unacceptable and cause unnecessary suffering; and (b) decision-making in organ donation is complex and multifactorial, where a single negative element can be counterbalanced by exceptionally positive interpersonal interactions elsewhere in the process. Therefore, while coordinators should always ensure private, compassionate settings, they should also recognize that families may still choose donation if other elements of the request process are executed with exceptional skill and empathy.

#### 3.1.8 Type of medical staff behavior towards family

Compassionate behavior from the broader medical team was strongly correlated with positive donation decisions, acting as a precursor to the coordinator's request.

> *The nurses treated us well, allowing us to see our mother through the glass. They kept comforting us during those agonizing moments. The way everyone at the hospital, especially the transplant and donation team, interacted with us was truly wonderful; they cried with us. May God bless them. Perhaps it was their selfless behavior that encouraged us to donate* **(Donor Child).**

Healthcare providers' behavior towards the family during this difficult time should be respectful and supportive. This can help establish a positive rapport, making the family more open to considering organ donation.

As the families said, the coordinator's character, such as sensitivity and ability to communicate clearly, can make a significant difference.

## 3.2 Personal values

The personal values theme included four subthemes. Themes and subthemes derived from the participants' perspectives and experiences are described as follows.

### 3.2.1 Trust in the healthcare system

A lack of transparency regarding the organ allocation process was a significant barrier for several non-donors.

> *I've never heard of the topic of organ donation before, and no one explained it well to me. They didn't say how these organs eventually reach someone or what the process is. Transparency is the most important principle that I didn't understand. I was afraid that my dear organs would be sold or that they wouldn't be given to those in need* **(Non-donor Mother 1).**

### 3.2.2 Cultural issues

Fear of community judgment was mentioned occasionally, but for those who raised it, it was a powerful deterrent that required active overcoming.

> *Someone in our city had donated, and everyone said that the organs were sold. I was afraid of being ostracized by society, but in the end, I made my own decision and donated. I just asked Ms. … not to post the photo on the website so that people wouldn't find out that we donated* **(Donor Sister).**

### 3.2.3 Emotional distress

For non-donors, emotional and financial vulnerability often outweighed altruistic considerations. This subtheme appeared frequently alongside the "timing" subtheme.

> *With two small children, without guardianship, without a salary… I couldn't bring myself to donate. I had a small percentage of hope for a comeback, both for him and for ourselves, wondering what we would do afterward* **(Non-donor Wife).**

### 3.2.4 Religious belief

This was the most cited subtheme within the Personal Values theme. Notably, many donor families described a shift from a miracle-based belief system to an acceptance of medical reality, often facilitated by the coordinator's clarity.

> *I believed in miracles. I prayed for him and read the Quran. Even the night before his death, I had a Quran recitation in his honor, and I was sure a miracle would happen, but it didn't… Now I've come to believe that brain death equals death*. **(Donor Wife 2).**

## 4 Discussion

This study was conducted to uncover any modifiable factors in the request for organ donation that might affect a family's willingness to consent to organ donation.

The process of requesting organ donation plays a crucial role in whether individuals accept or refuse donation. According to Siminoff et al., incomplete or inaccurate information can hinder consent. The psychological literature highlights that addressing individuals' fears about the donation process can enhance their willingness to consent [21].

Consistent with our results, Lopez et al. reveal that it is crucial to approach the request with confidence and positivity, allowing families the space to express their feelings and discuss their loved one. Above all, it is vital that families feel neither rushed nor pressured and are given ample time to make their decision [22]. Our findings indicate that "ample time" is subjectively defined by families and encompasses: (a) sufficient time to process the diagnosis of brain death before the donation discussion begins, (b) opportunity for private family deliberation, and (c) the absence of perceived pressure from the coordinator. Notably, families in our study reported feeling rushed not necessarily when meetings were short, but when coordinators appeared impatient or focused solely on obtaining consent rather than attending to their emotional needs. This suggests that duration alone is insufficient; rather, the quality and timing of the interaction are paramount.

Uzuntarla (2018) reported that half of Turkish health staff favored public education, informing families, and legislation for donation without family consent to boost organ donation [22].

Other issues such as the approach of organ donation coordinator, especially when done sensitively and at a suitable time for the next-of-kin, is crucial in influencing their decisions about organ donation [23].

When families face the loss of a loved one, the way they are supported can make all the difference. Approaching them with kindness and understanding, and having honest conversations from the start, can greatly influence their decision about organ donation. Similar to our result, research by Miller and Brealwell highlights that families who chose not to donate often felt let down by insensitive communication [24].

It is suggested for professionals to approach these families with sensitivity and compassion. Even small details, like how they present themselves, can influence how families perceive them. Understanding the emotional context after a loved one's neurological death is vital. This empathetic approach can help families make difficult decisions, such as those related to organ donation, during an emotionally challenging time [24].

Knowing about organ donation and transplantation, or having personal experience with it, positively influences family members in making a decision. When family members have positive attitudes and beliefs, they are more likely to decide in favor of donation. However, if family members disagree about donating, it can create tension and bring up difficult emotions, which might ultimately make it harder to decide to donate [25].

Our findings, as supported by Lopez et al. and Shemie et al., emphasize the importance of creating a supportive environment such as preparing a private location for families when discussing organ donation [9, 26].

Another factor is the situation in which donation is requested, including the type of organ donation coordinator behavior towards the family, and the setting in which the request is made is another factor that affects a family's consent. These results are also reflected in research by Roza et al. [27].

The majority of families spoke about religious belief. As reflected in de Groot et al., spiritual beliefs are often mentioned by families as an explanation for the differences in willingness to donate organs, but they are less frequently mentioned as a bedside explanation [28]. Although most religions are in favor of organ donation [29], some families have a belief in miracles. Religious faith encouraged donation if it fits within the altruistic belief system provided by the religion [30].

Through the interviews, it was found that the majority of participants expressed the need for spiritual comfort and emotional support. Family members mostly needed the emotional support of their relatives. The support and help provided by the family in physical, emotional, and social aspects are essential [31].

From the interviews, it could be seen that many family members had different degrees of psychological stress due to traditional beliefs and the pressure of public opinion [32].

Some families expressed misgivings about the healthcare system and a mistrust of organ allocation in our study. According to Siminoff et al. and Ralph et al., participants felt reassured if healthcare providers explained the high degree of medical care they were providing to their relative [33, 34].

The prior consent to donation of the deceased is also an important factor. Families were more likely to consent to donation when their relative had already formally expressed his or her wish [35]. Walker et al., Lopez, Miller and Breakwell, and Traino and Siminoff showed that awareness of their loved ones' donation wishes is strongly associated with honoring those wishes [13, 24, 36, 37]. Bramstedt et al. reported that when the wish of the deceased is known, families feel themselves ethically obliged to make a decision that represents the values and preferences of those whom they represent [38]. Within our study, only one family whose loved one had signed a donor card refused consent to the donation. Consistent with our result, the majority of non-donor families did not know the loved one's wishes about donation [39].

According to Rodrigue, when the deceased's intentions were unclear, the likelihood of consent dropped significantly, with only 26.7% agreeing to donation compared to 73.3% when intentions were known. This indicates that uncertainty about donation wishes can lead families to make decisions based on different factors, often resulting in a lack of consent [23]. Some non-donor families refused consent for donation, when forced to make a surrogate decision, because their deceased had not given any directive. That confirms research findings that state that families feel "left in the dark" when they have to decide on behalf of the deceased person [40].

## 5 Limitations

This study has several limitations such as the potential emotional distress by participants when recalling traumatic memories associated with organ donation. Such distress may have influenced their willingness to share or fully articulate their perspective and experiences during the interviews. In addition, this study was conducted in a single OPU and within one national and cultural setting, which limits transferability to other contexts. Only families who agreed to participate are represented, and families declining participation might have different or more negative experiences.

The researchers also recognize the possibility of bias in participant responses, as individuals may have felt pressure to conform to perceived societal expectations regarding organ donation. Future research could address these limitations by employing larger, more diverse samples and utilizing additional methods, such as longitudinal studies or mixed-method approaches, to gain a more comprehensive understanding of the factors influencing families' decisions regarding organ donation.

## 6 Conclusion

The results highlight valuable insights into the complex relation between organ donation coordinators' characteristics, the contextual factors of the request, and the families' personal values. In summary, families of potential donors perceive the organ donation process as most supportive and conducive to informed decision-making when coordinators combine professional expertise with compassionate communication, approach families at the right moment and in the right setting, and demonstrate genuine respect for the complex personal, cultural, and religious values that shape family decisions. Importantly, families consistently expressed a clear preference for this empathetic and family-centered approach, describing it as essential for their emotional well-being and their ability to make a confident decision. However, we acknowledge that our qualitative design does not permit causal claims regarding the direct impact of these factors on donation consent rates. Rather, this study identifies modifiable factors that families themselves perceive as critical to their decision-making experience. Future research employing

quantitative or mixed-methods designs is needed to establish whether implementing these approaches reliably translates into increased donation rates.

Despite this limitation, our findings provide evidence-based guidance for coordinators and healthcare institutions seeking to improve the quality of donation conversations. By adopting a holistic approach that prioritizes the family's emotional and informational needs, coordinators can ensure that organ donation is requested not only effectively but also ethically and empathetically.

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**Author contributions** SN Conceptualization, and drafting of the manuscript, HR Methodological guidance, data interpretation, and English revise, FE Supervision of data analysis, review of qualitative methodology, and Coding, ML Study design, project supervision, data validation, and final approval of the manuscript, EP, MK Contribution to data collection, coding, and literature review. All authors reviewed and approved the final version of the manuscript.

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## Declarations

**Ethical approval** The study was conducted in accordance with the principles of the Declaration of Helsinki and was approved by the Medical Ethics and Law Research Center of Shahid Beheshti University of Medical Sciences and received the ethics code from the Research and Technology Deputy of Shahid Beheshti University of Medical Sciences. (Ethic Approval number: IR.SBMU.RETECH.REC.1404.210).

**Consent to participate** All participants provided informed consent after being given oral information about the study. They were informed that participation was voluntary and that they could withdraw at any time.

**Consent to publish** Not applicable.

**Competing interests** The authors declare no competing interests.

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