

## Concerns and Challenges of Living Donors When Making Decisions on Organ Donation: A Qualitative Study

### Abstract

**Background:** Mental concerns of living donors can be a solid barrier to logical and informed decision-making for organ donation. The present study explores living donors' mental concerns and problems during the process of decision-making for organ donation. **Materials and Methods:** The present study was performed using qualitative content analysis. Twenty-one participants were selected by purposive sampling. The data were collected and recorded through semistructured interviews and analyzed by MAX Qualitative Data Analysis software 12, based on Graneheim and Lundman's contractual content analysis method. **Results:** Data analysis extracted 425 codes, 13 subcategories, 3 main categories, and 1 core theme (conflict between doubt and certainty). The three main categories were individual barriers and concerns (faced by the donor), interpersonal concerns and barriers (experienced by the family), and socio-organizational concerns and barriers (at the community). **Conclusions:** Based on the results, donors have significant concerns and face major problems when deciding on organ donation. Therefore, health-care professionals should take into account organ donors' concerns, raise awareness of donor associations, and formulate policies to increase living donors' satisfaction.

**Keywords:** Decision making, living donors, organ transplantation, qualitative research

### Introduction

Studies have shown that deceased donors cannot meet the growing demand for organs such as the kidneys, liver, etc. Sometimes cultural, religious, and legal considerations may even be reluctant to donate organs after death.<sup>[1]</sup> Thus, because of the high demand for organ transplantation and the increased wait time for transplantation, receiving organs from living donors is a primary strategy to meet patients' needs and overcome their problems.<sup>[2]</sup> Popoola *et al.*<sup>[3]</sup> reported that the low number of living donors had been identified as a significant challenge worldwide. Furthermore, donors go through a tough decision-making process for organ donation. They may encounter problems, worries, and concerns. Recent studies have shown that the decision to donate an organ is influenced by issues related to personal life, family status, and the relationship with the recipient, leading to a wide range of problems during the decision-making process.<sup>[4]</sup> The decision-making process has been significantly influenced by

various concerns such as medical uncertainty, post-donation recovery, family responsibilities, recipient health-related concerns, and donors' health in the future.<sup>[5]</sup> According to Kim *et al.*,<sup>[6]</sup> barriers to the proliferation of live donors are multifactorial and need to be addressed using extensive nationwide studies. They stated that common concerns of living kidney donors include the impact of donation on future health, increased risk of chronic medical conditions with future weight gain or return to unhealthy lifestyles, and the inability to return to previous activities. Other studies have shown that obesity<sup>[7-9]</sup> and social factors may also prevent many potential donors from becoming donor candidates.<sup>[6,10]</sup>

Other studies have shown that despite unique liver transplant needs, many transplant programs and transplant-related activities have been suspended or severely restricted due to the rapid growth of the COVID-19 pandemic.<sup>[11]</sup> Another study showed that the prevalence of COVID-19 was one of the concerns that led to a significant reduction in the number of living

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and deceased liver transplant donors and the inactivation of the waiting list.<sup>[12]</sup>

In addition to the issues mentioned above, the acceptance of organ donation depends on cultural, ethnic, and religious factors in the community. For instance, Farid and Mou<sup>[1]</sup> stated that although organ donation and transplantation can be hopeful for dying patients, attitudes toward organ donation and transplantation can be different depending on religious, cultural, and legal issues in the community. Thus, community-related issues are some challenges beyond the individual decision to transplant an organ. Living donors' concerns always hinder making logical decisions. Thus, some strategies need to be adopted to educate donors and empower them to make informed decisions about donation. It is believed that as national policies require centers to inform potential donors of the specific risks associated with organ donation, comprehensive donor training is needed to address living donors' other concerns and possible misconceptions.<sup>[13]</sup>

Many studies have addressed barriers, challenges, and concerns of organ donation in brain-dead patients. However, problems faced by living donors have been less qualitatively examined. The present study used a qualitative approach and provided an in-depth analysis of barriers and problems faced by living donors. It tried to explore their mental concerns about the decision to donate organs to direct policies governing the community toward accurate assessment of possible risks and problems encountered by potential donors when making informed decisions and managing these mental concerns. It is not reasonable to encourage living people to give their organs to others for any reason, for example, in exchange for money. Thus, given the high demand for organ donation and the low number of donors, more investigations are needed to identify factors affecting donors' decisions for organ donation. To this end, the study explores the mental living donors' concerns and problems faced by them during the process of decision-making for organ donation.

## Materials and Methods

This study was part of a larger research project that aimed to provide solutions to advance the decision-making on organ donation and was conducted from August 2019 to December 2020. A qualitative approach following contractual content analysis was adopted to explain the impact of organ donation on living donors. The participants were selected using purposive sampling from living organ donors, their family members, organ recipients, and medical staff in the Organ Donation Center, Kidney, and Bone Marrow Donation Commission in Afzalipour Hospital, and Kidney Donation Association in southeastern Iran. The interviews with the participants were conducted in places preferred by participants (hospital, private home, park, nursing school, etc.) so that they felt relaxed and unstressed during the interview since this study was conducted during

the COVID-19 outbreak and given its possible risks for the participants, the research procedures were conducted with strict adherence to health and social protocols.

The data were collected through the interviews with 21 participants, including 16 organ donors, 1 member from the family of the donor, 1 organ recipient, 1 surgeon from the organ donation commission, 1 person who had given up to donate an organ, and 1 psychologist. Nine of the donors participating in the study were kidney donors, five were nonrelated (for sale), and four were related (not for sale). Four of them had bone-marrow donations, one nonrelated (for sale) and three related (not for sale), and the remaining three donors, who were related (not for sale), donated a portion of the liver.

Data analysis was performed simultaneously with data collection. Sampling continued without any restrictions until the data were saturated. Proper links were established between the identified categories. The first author conducted interviews. However, all the researchers reviewed the interviews like outside observers. After each interview, the researchers studied the interviews, identified the interview's strengths and weaknesses, and reviewed the items to be considered in the subsequent interview. According to the written reminders, the proposed questions required researchers to conduct additional interviews with two participants during the analysis of the data. Two interviews were conducted with participants 2 and 1. The researchers conducted a total of 22 interviews with 20 participants. The interview questions focused on the implications of organ donation in living donors. First, each interview started with warm-up questions followed by open-ended questions like "Would you mind sharing your experience of the organ donation you did?", and probing questions for further clarification of the interviewee's statements. Each interview took 45–90 min. At the end of the interview, the participants were given the interviewer's mobile phone number and asked to discuss any issues with the interviewer if they remembered any of the implications of organ donation and the possibility of further interviews. Finally, the participants were appreciated with a small gift.

Data collection and analysis were performed simultaneously. The MAX Qualitative Data Analysis 12 was used to facilitate the organization and comparison of the data. The transcript of each interview was reviewed several times. The qualitative data content analysis process was performed according to the method proposed by Graneheim and Lundman, including transcribing the interview, reading the transcripts several times to come up with a general understanding of their content and get immersed in the data, determining semantic units, and summarizing them, extracting the primary codes, classifying the similar primary codes under the same subcategories, classifying similar codes under more comprehensive categories,

extracting latent and manifest concepts from the data, and formulating the final themes.<sup>[14]</sup> To this end, after preparing the transcripts, each text was reviewed several times. Later, the semantic units were identified based on the research questions, and appropriate codes were assigned to each semantic unit. As shown in Table 1, the preliminary codes were placed into subcategories and labeled based on their conceptual similarity. The subcategories were compared and placed under the more abstract categories (main categories). The main categories were further categorized under a more abstract concept (theme). All extracted codes and categories were reviewed and approved by the second and fifth authors of this study. The initially extracted codes were reduced by continuous data analysis and comparisons. Finally, the categories and subcategories were abstracted. The criteria proposed by Lincoln and Guba (credibility, dependability, confirmability, and transferability) were used to ensure the trustworthiness of the data.<sup>[15]</sup> To ensure the credibility of the results, the participants were asked to review and confirm the codes extracted from the interview and revise the contents on demand (member check). Collecting the data from interviews with family caregivers with great diversity in terms of the relationship with the patient, ethnicity, and religion established credibility. To enhance the confirmability of the findings, all texts

of the interviews, codes, and categories were reviewed and confirmed by the second, third, and fifth authors of this study (peer check) as well as a faculty member that was not a member of the research team (faculty check). To ensure the dependability of the results, all stages of the study were recorded. The participants were selected by maximum variation in terms of ethnicity, education, religion, economic status, relation to the patient, and social class, which enhanced the transferability of the findings of the study.

### Ethical considerations

To observe ethical considerations, the researcher asked the participants to complete the informed consent form. Moreover, before starting the interview, the participants' permission was obtained for recording the interviews and taking notes. They were also assured their demographic information would remain confidential. After the final report, the audio files would be removed, and, if desired, they could receive the audio file of the interview and be informed of the overall results. The participants were reassured that they were free to leave the study at any stage of the study. The Ethics Committee of Kerman University of Medical Sciences approved this study with the code of IR.KMU.REC.1398.222.

**Table 1: The participants' demographic characteristics**

Row	Gender	Age	Education	Economic state	Marital status	Donation	Period	Donation state	Relation with recipient
1	Female	30	Bachelor's degree	Average	Single	Kidney	1 year	Not for sale (related)	Sister
2	Male	35	Master's	Poor	Single	Kidney	1 year	Not for sale (related)	Brother
3	Female	33	Diploma	Poor	Others	Kidney	5 years	For sale (nonrelated)	Nonrelated
4	Female	27	Bachelor's degree	Good	Single	Kidney	5 months	Not for sale (related)	Sister
5	Female	43	Master's	Good	Others	Bone marrow	8 months	Not for sale (humanitarian aids)	Nonrelated
6	Male	45	Diploma	Good	Married	Bone marrow	4 months	Not for sale (related)	Father
7	Male	28	Diploma	Poor	Single	Bone marrow	2 years	For sale ads (nonrelated)	Nonrelated
8	Male	36	Bachelor's degree	Poor	Married	Kidney	6 years	For sale by organ donation association (nonrelated)	Nonrelated
9	Female	35	Illiterate	Poor	Married	Kidney	10 years	Not for sale (related)	Mother
10	Male	38	Bachelor's degree	Average	Married	Liver	2 years	Not for sale (related)	Father
11	Male	32	Diploma	Good	Others	Liver	1 year	Not for sale (related)	Mother
12	Male	40	Diploma	Average	Single	Kidney	5 years	For sale by organ donation association (nonrelated)	Nonrelated
13	Male	56	Bachelor's degree	Average	Married	Kidney	15 years	For sale by organ donation association (nonrelated)	Nonrelated
14	Female	29	Master's	Good	Single	Liver	11 months	Not for sale (related)	Sister
15	Male	40	Diploma	Average	Others	Kidney	7 years	For sale by organ donation association (nonrelated)	Nonrelated
16	Female	46	Diploma	Good	Married	Bone marrow	1 year	Not for sale (related)	Mother
17	Male	56	Superspecialized	Good	Married	–	–	–	Surgeon
18	Female	38	PhD	Good	Married	–	–	–	Psychologist
19	Female	34	Diploma	Poor	Married	–	–	–	Donor's family member
20	Male	26	Bachelor's degree	Average	Single	–	–	–	Recipient
21	Male	29	Bachelor's degree	Average	Single	–	–	One person who has given up to donate an organ	Nonrelated

## Results

The participants were 21 persons including 16 organ donors, 1 donor family member, 1 organ recipient, a surgeon member of the donation commission, 1 person who has given up to donate an organ, and a psychologist. The participants were in the 26–58 age range. Table 1 displays participants’ characteristics including gender, marital status, education level, age, etc.,. Following the analysis of the participants’ statements about organ donation implications, 425 codes, 13 subcategories, 3 main categories, and 1 theme were extracted [Table 2].

The theme emerging from all categories was the conflict between doubt and certainty, which covered three main categories: “individual concerns and barriers (perceived by the donor),” “interpersonal concerns and barriers (experienced by the family),” and “socio-organizational barriers and concerns (apparent in the community).”

### Individual concerns and barriers

This main category accounts for the mental concerns of the donor that disrupt the process of decision-making for organ donation and is the most critical category. It consists of five subcategories: “Fear of negative implications in the future,” “Fear of having Covid-19,” “Doubtfulness due to lack of knowledge,” “Lack of independence,” and “Fear of surgery and anesthesia.”

#### *Fear of negative implications in the future*

Sometimes, thinking about possible problems causes anxiety. Each decision may have positive and negative

consequences that the donor must consider logically before making a decision. The donors expressed concerns such as fear of disability and the possibility of regret in the future, the possibility of rejection by others, fear of the unknown, etc., when making decisions on organ donation. Accordingly, one of the participants said: *“One of the fears that preoccupied my mind is what should I do in case of my kidney dysfunctions? What happens if I cannot find a kidney on time? If so, I may blame myself, but as soon as I leave everything to God, I will calm down”* (P3).

#### *Fear of getting COVID-19*

Fear and anxiety about having COVID-19 raised some concerns for organ donors. Fear and anxiety weaken the immune system and raised shared concerns in donors in the current state of society. The participants pointed out to the possibility of developing COVID-19 during hospitalization, the impact of COVID-19 on the recovery process, and the possibility of deterioration due to having one kidney as the leading causes of concerns. One of the participants said: *“My only concern was the risk of getting Covid-19 during hospitalization. I was terrified of it; otherwise, I had made this decision, and I would rest assured If they made me ascertained”* (P4).

#### *Lack of knowledge and awareness*

Having sufficient and up-to-date information leads to making rational and prudent decisions. A critical issue to consider in decision-making is collecting reliable information. Sharing information increases trust. The participants believed that the lack of knowledge and awareness could be due to the donor’s unwillingness to obtain information, the time limit to get information, unavailability of a reliable source of information, obsession with acquiring more information, etc. One of the participants said: *“Although I inquired a lot, I was worried that I had not got enough information or my information was wrong, as if I was obsessed. I also feared that I did not have access to reliable information (physicians)”* (P15).

#### *Lack of independence*

Some people constantly ask others for advice when faced with challenging life situations instead of making decisions based on their inner and personal needs. Fearing from the consequences of their choices, these people either constantly delay decisions or completely submit to the opinions of others. Making decisions to donate an organ depends on individual will and independence. The decision-maker must have an intention to decide and accept the responsibility. However, some participants pointed to some issues such as dependence on others in decision-making, fear of individual decision-making, and inability to take responsibility for decision-making. A participant said: *“I left it to my family to decide so that if something went wrong, they wouldn’t blame me for making the wrong decision alone. Because I was afraid the transplant would be rejected, then my family*

**Table 2: Themes, categories, and subcategories extracted from the data**

Subcategory	Main category	Theme
The conflict between doubt and certainty	Individual concerns and barriers	Fear of negative implications in the future
		Fear of having COVID-19
		Lack of knowledge and awareness
		Lack of independence
	Interpersonal concerns and barriers	Fear of surgery and anesthesia
		Variety of opinions
		Opposition from family members
		History of chronic disease in the family
	Socio-organizational barriers and concerns	Family beliefs and misconceptions
		Distrust of the medical system
Lack of community welfare facilities for donors		
Fear of losing reputation and being stained		
		Unacceptable working conditions

would blame me for the uselessness of my transplanted organ” (P12).

### *Fear of surgery and anesthesia*

Anesthesia, where general or local, is an integral part of the surgery. Anesthesia-related death news has left many people fearful of anesthesia during surgery. Fear and anxiety resulting from anesthesia are normal, but unfortunately, they may appear in the form of phobia. An influx of negative thoughts, not waking up after anesthesia, following similar bad news, and inability to overcome fear were some of the issues extracted from the participants' statements. One participant said: *“I am terrified of being anesthetized and not awakening then. I also feel horrible imagining myself in the waiting and operating room as I am intensively stressful”* (P11).

### *Interpersonal concerns and barriers*

This main category accounted for the concerns of family members for the donor. It had the subcategories such as “diversity of opinions,” “family opposition,” “history of chronic family diseases,” and “family beliefs and misconceptions.”

#### *Variety of opinions*

It is advisable to consult knowledgeable and educated people who are aware of the ups and downs of the path, but sometimes asking for views of ordinary people may confuse the donor. Diversity of opinions raises doubts in decision-making. One of the participants, who had a large family, said: *“It was confusing. Everyone had an idea. I was baffled about what the right decision was. But I think one should first think deeply to decide what to do and get advice from his family or friends”* (P14).

#### *Opposition from family members*

Strong opposition from family members was another problem especially for unrelated donors. Some participants found it a reason to conceal the decision from the family. Related donors faced objections due to their age and education. In some cases, the recipient firmly refuses to accept organs for fear of harming the donor and feeling indebted to the donor. *“I really could not accept any organ of my family members because I was afraid something bad would happen to them or the organ would be rejected. Then, I could not forgive myself”* said one recipient.

Another donor said: *“My sister, who had dialysis every week, disagreed. She said she never got an organ from me.” She did not want to get me into the same trouble she had. My mother disagreed initially”* (P1).

A member of the donor family said: *“As a woman, it is tough to hear that your husband sold his kidney because he couldn't make a living. I told him right before the donation that I would leave you forever if he did this”* (P13).

### *History of chronic diseases in the family*

Currently, diseases such as diabetes and hypertension have affected many people. Although the history of these diseases in the family's medical records is not an absolute contraindication of organ donation, some donors have difficulty making decisions because of congenital diseases of donors and recipients. Having a history of kidney and liver disorders in the family, improper family lifestyles such as inactivity, an unhealthy diet, etc., are factors that make donors doubtful in decisions. *“I had made up my mind and even had a kidney test, but my doctor said my blood creatine was high, and it may be congenital in my family, so I gave up donating. The association introduced another donor”* (P21), said one participant who gave up donating and was a recipient family member.

Another participant stated: *“My mother had a history of high blood pressure and diabetes. I was afraid that it would be congenital and I have the same problem later. These thoughts preoccupied my mind a lot”* (P2).

### *Family beliefs and misconceptions*

Misconceptions in the family were mentioned by the donors as issues that cast doubt on donation. The participants pointed to consequences such as the shortening of life span, the weakening of the body, and not returning to everyday life after donation until the end of life. *“One of the main concerns of donors and their families is their concern if they can have a normal life after donation. I have always told their families that donating a kidney will never cause disorders in their health and well-being, and the life expectancy of kidney donors is not shorter than non-donors. The kidney failure is not also associated with previous donations”* (P17), said a surgeon who participated in our study.

### *Socio-organizational concerns and barriers*

Socio-organizational concerns were the issues in the community that caused concern for the donor. These concerns were subcategorized into “distrust in the medical system,” “lack of welfare facilities in the community for the donor,” “fear of losing reputation,” and “inappropriate working conditions.”

#### *Distrust in the medical system*

Organ donation candidates need to trust the health-care system. Some donors misconceive that the medical team may not be skilled at performing the transplant. Donors' concerns include mistakes made during the operation, refusing a transplant and returning the patient to dialysis, the disclosure of private information by treatment staff, and the possibility of transmitting the disease from the donor to the recipient. *“I did not want anyone to find out that I donated, but I was unsure whether this information would remain confidential. I had never been in such a stressful situation during hospitalization. Because if someone spotted*

*me in the hospital, he would find that I was a donor. There was no privacy in the hospital at all” (P7).*

Another participant stated: *“I was always afraid that something bad would happen to me during the surgery. Honestly, I was not sure, but I had no other choice” (P10).*

#### *Lack of community welfare facilities for donors*

The organ donors complained about the nonsupportive government. Lack of medical insurance coverage including life insurance, non-prioritization in government-supporting schemes, lack of post-donation support due to the prolonged recovery process, and unavailability of caregivers during the recovery process were among the points mentioned by the donors. One of the donors said: *“I underwent liver surgery willingly, but I had no other choice. They did the operation and tests for me at a lower price. But as my recovery process took a long time, there was no financial, professional, or educational support. I lost my job during this time” (P8).*

#### *Fear of losing reputation and being stigmatized*

Undoubtedly, there is a negative social attitude toward specific groups of people in society. Some people label donors and their families as dealers. This issue is more commonly found in unrelated donors who receive money from the recipient’s family. A member of the donors’ family said: *“We were more afraid of losing our reputation, so we were against it. They did not know we did it to pay for our child’s operation, but unfortunately, we were misjudged” (P15).*

#### *Unfavorable working conditions*

Organ donors need good working conditions and a lively social life after organ donation. Some people are doubtful about deciding to donate due to their working conditions. Occupations involving hard and tedious work, especially in hot weather, heavy sports, constant exposure to radiation and pathogens, etc., were among the concerns of the donors. One participant said: *“I was just worried after the transplant. I was wondering if I could do a lot of work with this medical condition or not. I am a worker. I work hard. I was worried about the future because I had hard days before the donation” (P9).*

## **Discussion**

The present study explored the concerns and problems of living donors when deciding to donate an organ. The core theme identified in this study was “Conflict between doubt and certainty,” which included three main categories: “individual concerns and barriers,” “interpersonal concerns and barriers,” and “socio-organizational concerns and barriers.” Liver donors reported the most server concerns and problems. In contrast, people with bone marrow transplantation reported fewer challenges and problems. The severity of these problems was the same in related

and nonrelated donors but was more severe for donors who decided urgently or coercively.

The donors reported some personal concerns and challenges. They typically believed that organ donation would have severe health-related complications. Half of the people who were to decide to donate organs to their loved ones did not do so due to health and safety concerns.<sup>[16]</sup> Studies have shown that fear is a significant barrier to living organ donation. Interestingly, this fear may be strongly associated with a lack of knowledge about living organ donation processes and outcomes.<sup>[17]</sup> This fear is caused by side effects such as kidney failure,<sup>[13]</sup> risk of hypertension, proteinuria, and cardiovascular events,<sup>[18]</sup> and fear of surgery and death.<sup>[13,19]</sup> Fear of rejection<sup>[20]</sup> was another concern for the health and well-being of the recipient.<sup>[13]</sup> In the present study, most of these fears were associated with the possibility of getting COVID-19 during the organ donation process or during the recovery period, which could significantly reduce organ donation in the community.<sup>[11,12]</sup>

Lack of knowledge about living organ donation was another challenge found in many previous studies. Alvaro *et al.*<sup>[17]</sup> stated that the lack of knowledge about organ donation is due to the difficulty in obtaining such knowledge. Many participants reported that learning more about donation helped them overcome fears or worries about organ donation.<sup>[13]</sup> The results of the present study, as in recent studies, suggested that potential living donors support more effective and more explicit educational content as well as more explicit discussions with health-care professionals.<sup>[17,20]</sup> In the present study, the donors reported more concern about reliable information about the organ donation process and were more likely to seek information obsessively.

On the contrary, the recipients played a passive role in this regard. Donors have other options to choose from, while recipients have to wait for their decision. Other data, however, indicate that potential recipients requested information about the living donor.<sup>[20]</sup>

Regarding barriers and interpersonal concerns, Ruck *et al.*<sup>[13]</sup> believe that donors have personal concerns about donation and hear concerns about organ donation from family and friends. The decision-making process is dramatically influenced by post-donation recovery concerns, family responsibilities, recipient health-related concerns, and the donor’s health in the future.<sup>[5]</sup> Irving *et al.*<sup>[21]</sup> stated that the opinions of participants’ families often shape viewpoints about organ donation. Such influences can positively or often negatively affect individuals’ decisions, with some feeling that they have to ask permission from family members. There is a general consensus on respect for autonomy in decision-making by potential donors about transplants.<sup>[22]</sup> However, another study found that a series of intra- and interpersonal negotiations were involved in

the decisions on the transplant to be made by both the donor and recipient.<sup>[23]</sup>

Some evidence from the recipient's refusal to receive an organ from a family member indicated that patients are unlikely to ask their family members to be evaluated for a living organ donation.<sup>[24]</sup> They were not happy with this request.<sup>[17,20]</sup> Potential recipients raised concerns about the impact of kidney donation on the donor's health. They were concerned about the negative implications of surgery, including fear of rejection by the recipient and uncertainty about possible donor reactions,<sup>[17]</sup> loss of the donor's kidney, and the possibility that he or she may need his or her donated kidney in the future.<sup>[17,25-27]</sup> In addition to concerns about physical harm to donors, recipients expressed moral concerns. The patients stated that they may feel indebted to their donors.<sup>[19]</sup> Some are concerned that younger family members may later need all of their potential donors.<sup>[28]</sup> The present study showed that the recipients who received an organ from a related donor felt obliged and owed, and the severity of this feeling depended on the intimacy between the donor and the recipient. It is more prominent in Iran due to the expansion of families and closeness between family members. Accordingly, Asian studies have shown that living donation can impose an unsatisfactory commitment.<sup>[20]</sup> Another study found that feeling owed varies significantly across cultures, with more substantial interpersonal commitments seen in collectivist cultures.<sup>[17]</sup>

In the present study, the families of unrelated donors disagree strongly with the donation. Related donor families were less likely to oppose the donor due to the patient's presence in the family. The reasons for the objections were the fear of endangering the donor, devaluing the effort in case of transplant rejection, the possibility of blaming the patient for doubling family problems, and feeling indebtedness to the donor till the end of life. However, the opposition in nonrelated families was primarily due to the misconceptions of the family.

Gan Kim Soon *et al.*<sup>[16]</sup> believed that participants' occupational discomfort results from a nonsupportive system and workplace restrictions. For instance, employers did not approve medical certificates, so donors were forced to take unpaid sick leave during surgery. Other studies indicated that the decision-making process was significantly influenced by other concerns, including uncertainty about the medical system.<sup>[19,21]</sup> The participants attributed this concern to the distrust in the health system and organ donation process, previous negative experiences with the health system, and lack of proper care.<sup>[21]</sup> However, in the present study, these fears and worries were mainly related to the surgical process and the fear of the disclosure of organ transplantation. The present study showed that the most common social concern in relative donors was the distrust in the medical system. Unrelated donors complained about

the fear of being stigmatized, not receiving government support, and unacceptable working conditions. This study also showed that people who belonged to minority groups were more likely to have social concerns in society. They often expressed fears of a lack of support from the government and insurance organizations. Therefore, health officials are recommended to provide medical, care-support, educational, and insurance facilities for these people in the community. In their recent study, Fernández-Alonso *et al.*<sup>[29]</sup> stated that the organ donation process requires specialized training to avoid organizational problems. Accordingly, Allahverdi *et al.*<sup>[30]</sup> suggested the necessity to start nurses university education in this regard. Attitudes toward organ donation and transplantation can differ according to religious, cultural, and legal issues at the community. Since this issue has been accepted in Iran, the participants did not express any concerns. However, in other cultures, this can be a deterrent beyond the individual decision to transplant.<sup>[1]</sup>

Since this study was conducted in southeastern Iran, so cultural beliefs, economic, and even educational problems in this region may restrict the generalizability of the results to the other areas. However, it was attempted to include participants with maximum diversity in terms of socio-cultural background, work experience, and educations to make the results more applicable to similar populations. In addition, this study was retrospective in nature, so its findings may be subjected to misreporting and memory biases.

## Conclusion

Following the results of the present study, the worries and concerns of living donors act as barriers to logical and informed decision-making for organ donation. After deciding to donate an organ, the donor may struggle with its implications for the rest of his life. Given the growing number of living donors, it is essential to understand the concerns of living donors in the organ donation decision-making process. It is recommended to manage these concerns and prohibit donors who experience more significant challenges from donating organs. Health-care professionals also need to use these experiences to raise awareness of donation associations, develop health policies at higher levels, and most importantly, increase the satisfaction of living donors.

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## Conflicts of interest

Nothing to declare.

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