

# Challenges and Motivators to Organ Donation: A Qualitative Exploratory Study in Gujarat, India

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**Purpose:** Despite the global efforts to improve organ donation, there is a demand-supply gap for organs in India. The only solution to meet this disparity is to improve deceased donor transplants in the country through victims of road accidents. The government has instituted several initiatives to achieve this goal. However, challenges and barriers continue to affect the organ donation process. The present study aims to document the motivating factors and obstacles in the decision of families to donate organs in Ahmedabad, Gujarat and their suggestions to improve the processes involved in organ donation.

**Patients and Methods:** A qualitative exploratory study (in-depth interview) of ten relatives of deceased organ donors was conducted from Oct 2021 to Feb 2022. Interviews were audio recorded, and detailed notes were taken during the interview. Thematic analysis was done using ATLAS.ti version 8 software.

**Results:** The significant motivators identified were family members' belief or conviction that it would help save the lives of others; a sense of moral obligation to do so as bodies of brain-dead persons can contribute to this noble goal, no use of the body after death, an extension of life, and being a role model for others. The challenges were mistrusting the organ donation process, fear of being responsible for any mishappening, and feeling of shock. The suggestions to improve organ donation included awareness creation, simplifying the legal process for accidental deaths, providing benefits to the donor family, and a system for identifying potential donors and their counselling.

**Conclusion:** The present study reflects the need for a more comprehensive awareness campaign to generate awareness and remove the misconception about organ donation in India. The findings of the study can be helpful for policymakers to amend the current organ donation process in India and improve the disequilibrium of demand and supply of deceased donations in India.

**Keywords:** organ donation, factors, motivators, barriers

## Introduction

Worldwide, organ transplantation has saved and improved the lives of thousands of recipients over the past five decades.<sup>1</sup> Still, deceased donor organ donation has not seen such growth. According to the Organ procurement of Transplant Network (OPTN, 2015), the organs donated by one deceased donor can give life to eight people.<sup>2</sup> Despite this and the general recognition of organ donation as a global priority, demand for organs exceeds supply in every country globally, including India, with an organ donation rate of just 0.80 per million population.<sup>3</sup> There is a need for 258,000 organs every year, i.e., 185,000 kidneys, 33,000 livers, and 50,000 hearts in India. Still, according to the National Organ Transplant Program, only 6000 kidneys, 1200 livers, and 15 hearts are transplanted annually.<sup>4</sup> The demand for organs in India remains unmet. The only sustainable solution for reducing this gap is deceased organ donation. The government of India promulgated the Transplantation of Human Organ and Tissues Act (THOA) in 1994, as per the act, one can pledge to donate one's organs after death. Promoting deceased organ donation has brought amendments to legislation (2011) and notification of rules (2014)<sup>2,5</sup> which enable the public to pledge to

donate various tissues. Although an opt-in system is in place, individuals can make their wish to donate independently. In the event of brain stem death of an individual, the organ donation decision rests with the family.<sup>6,7</sup> Despite a well-established program for the donation and transplantation of cornea, donation after brain death has been relatively slow.<sup>2</sup>

Several factors account for this slow growth of deceased organ donation, including cultural, ethical and religion-related problems.<sup>8,9</sup> The interplay of sociocultural factors, beliefs and superstitions, lack of communication and organizational support, and negative media views also play important roles.<sup>10</sup> Other possible barrier to the low number of donations from brain-dead patients is that the families of these patients are in a complex decision-making situation for accepting the idea of donation. Social, educational, and spiritual factors impact this process and make family decisions difficult.<sup>11</sup> The main barrier to organ donation is disagreement amongst family members about giving consent; despite many brain-dead patients, the ultimate aim of donation is not achieved.<sup>12</sup> Families must consent to donate their deceased relative's organs or tissues. It is important for both well-being of the family and the potential transplant recipients that the request for family consent is conducted well.<sup>13,14</sup> Healthcare professionals also play a vital role in organ donation. They are strategically positioned as the primary mediators between organ donors and transplant recipients and implement organ donation and transplantation processes. Hence they are often criticized for organ shortage.<sup>15,16</sup>

There are many studies conducted among different people on the awareness about organ donation;<sup>17-19</sup> however, the literature on experiences of deceased donor family members' challenges and barriers is scant in India. Understanding why people donate and the factors influencing decision-making and the process could help inform policies addressing this undersupply and improving India's current organ donation system. The present study aims to understand what influences the decision of families to donate organs in Gujarat, India, and to document the issues/challenges in the organ donation process and suggestions to improve organ donation in the western state of India.

## Materials and Methods

A qualitative exploratory study was designed to fulfil the above objective, implemented between Oct 2021 and Feb 2022. The study was conducted in the Ahmedabad district of Gujarat among the relatives of organ donors. The city documented 29 voluntary organ donations in the year 2021. The list was procured retrospectively from the daily newspapers published in Ahmedabad city, mainly vernacular and English and the Institute of Kidney Disease and Research Centre (IKDRC) was the source of index cases for this study. The semi-structured interview guide was prepared based on the literature review. The relatives of organ donors (deceased donor transplants) in 2021 were identified and approached to explore their willingness to participate in the study. Participants from both upper and low socioeconomic backgrounds (The presence of a Below Poverty Line (BPL) card or not) were included in the study.

An in-depth interview (IDI) of relatives of donors who were present during the entire event was conducted at a mutually convenient place (mostly in their resident settings) after obtaining written informed consent from the participants. Six researchers (three male and three female) trained in qualitative research with technical public health knowledge conducted IDIs. Half of the investigators who conducted interviews hold a doctoral degree and are proficient in conducting qualitative interviews. An interview guide ([Appendix](#)) with broad, open-ended questions was prepared. The interview was conducted on major themes like details of the event, the barriers and facilitators in the decision-making process and what can be done to improve organ donation in India. Initially, the interviewers built a preliminary discussion with the interviewee and briefly explained the study's need. Those who provided consent were included in the study. Out of 29 eligible donors, the study could only document ten cases considering consent. Audio recording (after consent) and verbatim notes were taken during the interview. Only two at a time interviewers with interviewees were allowed at the place of the interview. The duration of the interview was recorded, and the assistants took field notes. After the interview was over, the interview summary was read back to the participants to ensure participant validation. The transcripts were prepared from the recorded interviews and coded. The codes were clustered for a code family, and the themes were generated. The themes were pre-decided based on the literature review; however, a small window was kept including newer themes generated from the synthesis. Thematic analysis was performed using ATLAS.ti version 8<sup>20</sup> software.

The study has obtained the Institutional Ethical Committee (IEC) clearance from the Indian Institute of Public Health Gandhinagar, India (TRC/2020-21/28). All the details were kept confidential and complies with the Declaration of Helsinki. Written consent was sought for the interview and recording, and anonymized responses were included in the publication. There was a provision for note-taking by two researchers in case permission for audio recording was not given.

## Results

Out of the ten IDIs, all the deceased have donated livers except in one case (Table 1). Most organ donors were males, except one female. The age of the donors ranges from 32 to 78 years. All donors had completed primary or secondary education except one illiterate. Out of ten donors, three were retired, two were occupied in private jobs, two were labourers, two were self-employed, and one female donor was a housewife. Through organ donation by these ten donors, 28 organs were donated. The kidney was the next organ frequently extracted, followed by the liver. The heart, eye, lungs, and pancreas were also donated, among other organs. The characteristics of participants is presented in Table 2. The relatives interviewed for the deceased organ donation varied from son, father, brother, sister, husband, uncle, brother-in-law, and sister-in-law. The majority of participants were male, and half have completed their Bachelor's and higher education, whereas the rest of the participants completed primary or secondary education. Out of ten, the majority were engaged in private jobs, and the remaining were self-employed, homemakers, labourers and retired, respectively.

## Exploring What Motivated Them to Donate Organs?

The primary motivators were saving the lives of others, moral obligation, no use of the body after death, an extension of life, and being a role model for others. Each finding is discussed below in detail.

### Saving the Lives of Others

Most respondents opined that giving life to many people by donating organs was the biggest motivator. After the person's death, if the body is cremated or buried, it is of no use. Instead, if it is donated, many lives of needy people can be saved.

We will take him straight to the crematorium after taking him home. We don't have any use; now, we don't have any use of his body; if someone's life is saved, why should we care? That's why we decided to donate. (Father)

Look, he is dead, so will be burned and of no use. But if we donate organs, one or two people will get a new life because of him, and this is enough for us. (Son)

At the end, the body is going to be ash. It would be better if useful for someone. (Brother-in-law)

**Table 1** Profile of Donors Recruited in the Study for Challenges and Motivators to Organ Donation in Gujarat, India

| Sr. No | Age | Gender | Education           | Occupation    | Organs Donated                 |
|--------|-----|--------|---------------------|---------------|--------------------------------|
| 1.     | 41  | M      | Illiterate          | Labourer      | Liver, Kidney, Heart           |
| 2.     | 35  | M      | Secondary           | Private Job   | Liver, Kidney                  |
| 3.     | 47  | M      | Secondary           | Self Employed | Liver, kidney, eye             |
| 4.     | 42  | M      | Diploma/Certificate | Private Job   | Liver, kidney, eye             |
| 5.     | 78  | M      | Primary             | Retired       | Liver                          |
| 6.     | 69  | M      | Secondary           | Retired       | Liver, Kidney                  |
| 7.     | 35  | F      | Primary             | Housewife     | Liver, Kidney, Heart, pancreas |
| 8.     | 55  | M      | Bachelors or Higher | Self Employed | Liver, Kidney, Heart, Lungs    |
| 9.     | 62  | M      | Secondary           | Retired       | Heart, Lungs                   |
| 10.    | 32  | M      | Higher Secondary    | Labourer      | Liver, Kidney, Heart, pancreas |

**Table 2** Participants' Characteristics Recruited in the Study for Challenges and Motivators to Organ Donation in Gujarat, India

| Sr. No | Age | Gender | Education            | Occupation    | Socio Economic Status |
|--------|-----|--------|----------------------|---------------|-----------------------|
| 1.     | 18  | M      | Primary education    | Labourer      | BPL                   |
| 2.     | 70  | M      | Secondary education  | Retired       | APL                   |
| 3.     | 35  | F      | Bachelor's or Higher | Housewife     | APL                   |
| 4.     | 50  | M      | Bachelors or Higher  | Private Job   | APL                   |
| 5.     | 40  | M      | Secondary education  | Self-employed | BPL                   |
| 6.     | 42  | M      | Bachelor's or Higher | Private Job   | APL                   |
| 7.     | 40  | M      | Bachelor's or Higher | Private Job   | APL                   |
| 8.     | 38  | M      | Bachelor's or Higher | Private Job   | APL                   |
| 9.     | 37  | M      | Secondary education  | Self-employed | APL                   |
| 10.    | 40  | F      | Primary education    | Housewife     | BPL                   |

**Abbreviations:** BPL, Below Poverty Line; APL, Above Poverty Line.

### Moral Obligation: Giving Back to the Society

The respondents believed that their moral obligation was to donate organs after death. As narrated in the quote below, giving back to society is a holy work and the best donation.

We have not donated anything in our entire life. But if we donate organs, somebody with our help can see, if somebody gets a kidney then can live so, with this idea, we decided to donate the organs. (Sister-in-law)

Our brother's life has come to an end, but what good can we do through his life and benefit others is just like we are losing one boy, one boy of another survives death and gets new life. Our boy's organs will be implanted inside someone else's body, they can see if they get eyes, if they get a liver, the light will shine in their life, and their life will be good, and that is the happiest thing, and that is why we could do this in such a good way. (Brother in law)

Humanity approach. We have gone bad, But it will be better for someone else. We will get his blessings. (Brother)

As a responsible citizen, I know about the donation. Some time ago, one of our relatives died. We told the doctor we wanted to donate, but the doctor said it was not possible in the case of on-the-spot death. That's why I am ready for it. (Brother)

### Extension of Life

For a few participants donating an organ means their loved ones would continue their life through another person's body, which was the motivator or influencing factor for the decision to organ donation. It was also narrated that knowing that the deceased's organ is successfully transplanted and giving a new life to the needy relieves their grief.

After burning the fire, it will become ashes; no one will use it. That's why all of us family members together took the decision. With our wish, we donated the liver. If donating this saves someone's life, then even though our father is not here with us, he will stay somewhere. (Son)

Then we thought that now brother is not in this world. But if his organs go into someone and he is alive, then we will believe that our brother is alive. (Sister)

Anyway, he will go into the woods, and everything will go in vain. It's better if it saves someone's life. After a month, when we learned that one young boy received one of his organs at that time, we all were pleased. (Son)

We thought that what we had has already gone. But if because of such something good happens to others, then why we should have any problem. (Husband)

So I also thought, that let's do it. The thing is that we know nothing is going to happen and possible so that someone else can get a life. (Son)

### Role Model

One respondent opined that one could become a role model for others and inspire many people to donate through organ donation. It was also shared that many people have donated organs after hearing the success stories of others, which gives satisfaction and happiness.

We did it today. Someone else will do it tomorrow; with that in mind, we did. (Sister)

## Confronting Challenges During the Organ Donation Process

When a person is declared braindead initially, it is tough for the family to accept reality. It is even harder to make such a valuable decision as many feelings are attached to the person.

In the present study, the participants shared many challenges faced during the decision-making process, like mistrust about the organ donation process, fear of being responsible for any mishappening, and feeling of shock.

### Mistrust About the Organ Donation Process

The present study reflects that mistrust of organ donation is the biggest challenge for the decision-making process. Out of ten participants, three shared that initially, they were skeptical and mistrusted the medical system and the organ donation process, leading to delays in the decision-making process. However, after counselling by doctors, they decided to donate.

We all had doubts, so we told doctors that they do not sell it. Then they showed us the list of individuals who require the organs in their system and made sure that they would give it according to this list. And this list comes from the government itself. (Sister-in-law)

Like it is seen in the movie, they sell the organs for money. So, there was such a fear, but then when the doctor explained everything and showed the list in the system, it seemed that all is good. (Son)

Initially, we were a little bit confused and hesitated to donate organs as there were so many thoughts in our mind like what they will do with the organs, they will use these organs or not, etc. (Uncle)

As we used to hear, they do wrong business with the organs. But now the generation is so advanced, and the govt. The system is so good that they made us believe the system, and then we also felt that we should go for this. (Son)

### Fear of Being Responsible

The participants believed the senior family member or spouse should decide on organ donation. As narrated in the quotes, the consensus is essential because of the fear of being responsible for any mishappening.

He is my father, but we did not take any decision without involving my uncle so he or other family members will not say anything or scold us in future. (Son)

I was already ready to donate the organ, but I was not in a situation to decide because his wife is alive, so she should decide. (Brother)

### The Feeling of Shock and Grief

All participants recalled shock or disbelief upon learning of the unexpected or impending death. These feelings impaired their ability to absorb any information or make decisions for the donation, which is reflected in the following quote:

My life was on this boy. Even though his mother is not alive, I thought there would be no problem in my later life because my son is with me. It felt bad for that Thirty-four-year-old boy who has no disease and if he dies this way. The heart will not work (here he meant it is tough to make a decision). (Father)

Didn't know anything like this before, so first of all, we were engrossed. (Daughter in law)

### Difficulty in Convincing the Family Member

Convincing the family to organ donation was the most challenging task, narrated by the respondents, because the family was already in shock. As narrated in the quotes, informing the immediate family members about the brain death and convincing them to donate was the most challenging situation.

Initially, she (wife of the donor) was not ready and agreed to the donation as she doesn't understand all these things as she is illiterate. But then we all explained everything and convinced her. (Sister-in-law)

At that time donor's wife was admitted to the covid ward, So who goes to the ward? Again, everyone hesitated to inform her of this situation. (Brother)

One day passed in to explain things to mother. Even I can't tell my mother directly that now such a situation has taken place, and this is it. (Brother)

### The Appearance of the Body and Religious Belief

The present study also identified the traditional and religious challenges. One of the respondents shared that the relatives commented on the body's appearance after donation. Another respondent narrated that the donation will disrupt the afterlife of the donor (will not get moksha).

Many of our relatives said bad things. When we brought the body of the brother home, relatives saw that the eyes were filled with cotton, and the body had become tiny in size. So they told us what you have done, and you did not take the advice of anybody. His wife is illiterate, so you fooled her and made her do this. (Sister-in-law)

There are people who told that you went for donation and it took the whole day. (Brother in law)

In the group of people (here he is talking about relatives), many think that it is better not to cut the body like this, even though we have taken the body there and have to spend the whole day there. (Brother-in-law)

Relatives' response was not positive that what we did was wrong. If all the organs are not present in the body, they will not get sadgati and moksha... (Brother)

## Simplifying the Organ Donation Process

### Awareness Creation

Most respondents opined that people should be aware of organ donation and its importance. There are also many misconceptions about organ donation (eg, the criteria for organ donation and the place where the organ donation is performed) among people, which can be removed through awareness. It was also suggested to include organ donation in the school curriculum. So that children also know about the process and can influence people to donate.

Still, many do not know what organ donation is. And in what circumstances and how people should be aware of this? But govt. / organization should inform the community in what circumstances organ donation is possible and not in which circumstances. Then the community will be more aware of this, and this can inspire them (Son)

We need to make people aware of organ donation and understand that if we bury or burn them, they will become soil or ash, but if we donate their organ, then people who need it get new life. (Son)

Awareness should be spread across the community using the various medium like television, social media, newspaper or street play. (Brother-in-law)

Elderly people have negative thoughts about organ donation. They think that doctors will do this or that or do business with the organs, But it is not true. They were not given the right idea, and no one drew their attention to this. Such people should be taken to the hospital and shown live organ donation. I am sure they will also donate their organs after this.... (Brother)

More and more people should know the name of the one who has donated. It should be given in the newspaper. (Son)

Organ donation should be part of education syllabus in schools. (Brother-in-law)

### Knowledge About the Recipient's Outcome

There was also a suggestion to disclose the information that the transplant was successful and that new life is given to the needy person. This information will be enabling factor and will inspire others to donate.

They should provide the details of the actual recipient to the family members, so that family members and others are inspired to donate the organs. (Son)

### Benefits to the Donor's Family

As narrated in the quote, providing benefits to the donor's family through the organ donation program was also suggested to inspire the family members to donate organs.

Government should provide some benefits to the family of the donor, like free education for the child of that family so that child also inspired to do the same in future. (Brother in law)

### Changes in the Current System

There was also a suggestion to have a system to identify potential donors from the village level for further counselling and organ donation. Simplifying the legal process of accidents was also one of the suggestions from the participants.

Every village has a hospital where a doctor or an officer has to be appointed. If a person is in such a critical situation, they check, explain, and take them for organ donation. (Brother-in-law)

In case of an accident, if one does not go for it due to frequent police department visits, then legal simplification should be brought so that the individual can be shifted to the hospital quickly. (Brother-in-law)

If possible, everyone should get their name registered for the donation. (Father)

To generate awareness among the community survey should be conducted when collecting a death certificate like that person was in the condition to donate the organ or not, whether they have been informed regarding donation if they have not donated then why....

Everyone should get their name registered for the donation. (Brother-in-law)

Those who crossed 50 or 60 years and healthy, then they should decide to donate by themselves after their death, and there should be a such system at govt. system to register. (Son)

The organizations working on this worthy cause should come in front and communicate what they are doing to the community to generate awareness among the community. (Son)

## Discussion

The present study highlighted that there are multiple reasons why people donate organs. The major motivators for organ donation identified are saving the life of others, moral obligation, an extension of life, relief of grief, and being a role model for others. In the present research, organ donation is seen as an opportunity to extend life. The relative's decision was motivated by a belief that donation would give life to others. This finding is congruent with the previous research on family members' organ donation experiences in the USA.<sup>21</sup> Another study of registered participants concluded that

helping others/with altruism is the essential motivation for organ donation. A study conducted amongst the volunteers also confirmed this finding.<sup>19</sup>

Similarly, a review of factors influencing organ donation decisions in brain death patients identified humanitarian motivators, such as allowing living by donating organs and helping patients in need of organ donation in their study.<sup>11</sup> A thematic synthesis of 34 qualitative studies conducted in Australia also concluded that the participants believed their loved ones would continue to live in another person's body, which is one reason for consenting to donate the organs.<sup>22</sup> The perception of giving back to society is consistent with previous research. Previous studies reported that donors would like to donate organs to give back to the community and others.<sup>12,17,18</sup>

The decision-making process challenges were mistrust about organ donation, fear of being responsible for any mishap, feeling of shock, body appearance after donation, and traditional values. The findings of mistrust of the organ donation process and fear of being accountable for mishappening are consistent with the thematic review of Ralph et al.<sup>22</sup> The feeling of shock and grief was indicated as one of the challenges consistent with previous research. The donor's relative was in shock and chaos and had disbelief upon learning of impending death.<sup>21</sup> The belief about the disruption of the afterlife was also consistent with previous research. In their thematic analysis, Ralph et al; reported that the respondents refused consent because they believed organ donation would prevent successful "re-birth".<sup>22</sup> A recent qualitative study conducted in India also reported the adverse comment by society on the decision to organ donation.

The present study also documented the suggestion to improve India's organ donation process. Most participants expressed the need for awareness creation to remove the misbeliefs in the community and society. Evidence also indicates the role of religion in organ donation. A study conducted by Randhawa et al highlighted the role of religion in organ donation. The study suggested faith leaders' engagement in organ donation process, However; in this study we did not observe such incidences because of our limited sample and all the donors were from the same religion.<sup>23</sup> There was also a suggestion to include organ donation in the school curriculum for broader awareness. A study by Vincent et al<sup>3</sup> also found that education through school curricula and more awareness campaigns can improve organ donation. There was also a suggestion to simplify the legal processes related to accidents. Another study<sup>3</sup> also reported that support from the police department is a crucial factor in the process of organ donation. The need for a system to identify potential donors (brain dead) was also reported. The benefits to the family are essential to encourage the family members to donate in the future and were also narrated as one of the solutions to improve organ donation in India. The present study offers an essential contribution to the literature; however, the study has few limitations. First, the potential donor's relatives who refused organ donation and community members have not been interviewed in the present study. Second, we have captured only one key family member who has prime role during the organ donation, it might have been a better case to consider all the actors who were part of the event. Third, the sampled donors were not stratified based on the socio-economic status or the education levels, it might have been an ideal case to get the representation, however, it was such a difficult situation to do the same. Although the present study analysed a limited number of cases, the findings of the study may set the ground for future broader studies on this issue and inform the development of a questionnaire to examine which factors (perhaps quantitatively) mostly challenge and motivate the willingness to be an organ donor in the broader community.

## Conclusion

The present study highlights essential insights into the motivators and challenges of deceased donor families. The study reflects a need to remove the misconceptions and mistrust of the organ donation system, which can be addressed through a more comprehensive awareness campaign. There were also challenges related to the tradition, which can be tackled by involving religious leaders in the awareness generation process. The present study also highlights the various motivators for organ donor families that can be considered during the counselling of the families to donate the organ. The recommendations provided by the family members can be helpful for policymakers to improve the current organ donation in India and improve the disequilibrium of demand and supply of deceased donations in India. Although, the present study addresses the crucial issues in deceased donation, further broader studies are required. There is a need to develop the evidence on similar kinds of studies to understand the multiple societal barriers and challenges in organ donation in countries like India and other parts of the globe. A strong research impetus is needed to develop the grounded theory on the dynamics of organ donation and its barriers. Therefore, future studies are urged to focus on similar lines.

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## Disclosure

The authors report no conflicts of interest in this work.

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