

THE DECISION-MAKING PROCESS OF RENAL DONORS: A QUALITATIVE STUDY FROM INDIA

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DOI: <http://doi.org/10.47211/idcij.2024.v11i04.004>

ABSTRACT

The study explores the decision-making process of renal donors in India, aiming to understand the motivations, emotions, and contextual factors that influence their choices. Through in-depth interviews with a diverse group of kidney donors, the research delves into their personal experiences and the societal pressures that shape their decisions. The findings reveal that altruism, a sense of duty towards family or community, and personal health experiences significantly drive individuals to donate a kidney. Results: Researcher conducted semi-structured interviews with 20 donors the day before their scheduled donation. Data collection involved open-ended questionnaires, which were voice recorded and analysed using a grounded theory and interpretative approach. The findings indicated that the primary motivation for donation stemmed from the suffering of the recipient. Notably, many mothers chose to donate despite the presence of other potential living donors. All participants confirmed that their decision was made voluntarily, without any external pressure. Throughout the interviews, donors consistently expressed that the recipient's recovery was more important than their own health, a sentiment driven by deep emotional connections. Conclusion: The study found no evidence of coercion among donors, who exhibited a strong awareness of their choices and made voluntary decisions driven by emotional motivations. The primary factors influencing their decision to donate were emotional attachments and concerns for the recipient's well-being, highlighting the profound impact of personal connections in the organ donation process.

Keywords: Decision-making process, Gender disparity, Kidney donors, Qualitative research, Renal donors, India

INTRODUCTION

Renal transplantation remains the most definitive treatment for End Stage Renal Disease (ESRD), with living related donor programmes playing a pivotal role in India. Due to the slow progress of the deceased donor programme, the living donor system has been pushed to its limits to ensure positive outcomes. The psycho-social evaluation of potential donors, however, remains highly subjective and varies from programme to programme. The global shortage of organs, particularly in India, continues to rise, with a growing disparity between supply and demand. Research has consistently shown a significant gender disparity in organ donation within India (Nautiyal A, 2024; Sameer Bhuwania, 2020; Bal MM, 2007). A study from Kerala highlights that most living related donors are family members of the recipient, with a marked overrepresentation of female donors (Malattiri, R, 2014).

While voluntary consent is a cornerstone of renal donation guidelines, limited research has examined the decision-making process of these donors. Given that kidney donation involves a major surgical procedure, understanding the factors influencing donors' decisions is crucial. Donors often face a range of emotional, physical, financial, and social challenges throughout this journey. This study aims to explore these complex dynamics through qualitative research, delving into the lived experiences of renal donors in Kerala—a state where no similar studies have been conducted.



METHODS

This study employed a qualitative descriptive design, focusing on renal donors from the author's institution. Participants were selected purposively from among the living donors, and data were collected through in-depth, semi-structured interviews using an open-ended questionnaire. All interviews were conducted one day prior to the donation procedure and were voice-recorded for accuracy. Informed consent was obtained from each participant, and approval for the study was secured from the Institutional Ethics Committee.

A total of 20 donors participated in the study. Grounded theory, interpretative approaches, and thematic analysis were employed to analyse the data. The interview process centred upon exploring the decision-making process of the donors. Key themes examined are illustrated in Figure-1 given below —

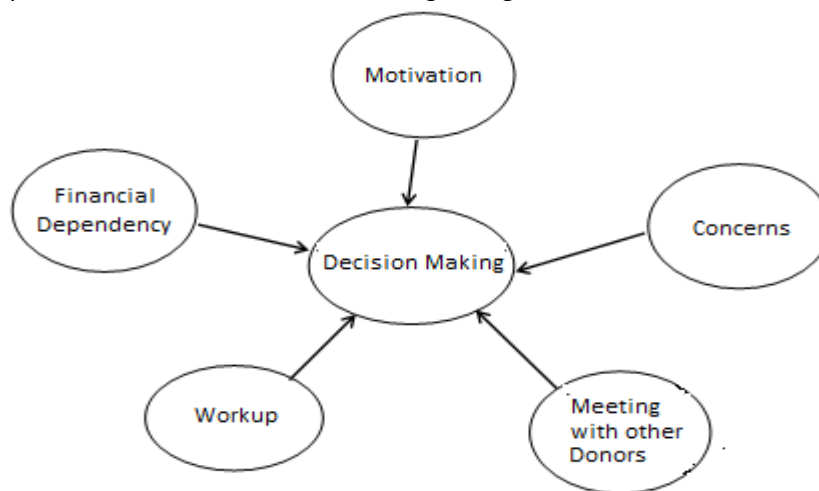


Figure - 1

Participants were interviewed at the hospital after completing the necessary pre-donation evaluations. The interviews included both open-ended and specific questions designed to capture personal details, their relationship to the recipient, financial situation, and future concerns. Recordings were transcribed verbatim and transferred to an Excel file, where labels were assigned. Transcripts were reviewed twice by the lead researcher to ensure accuracy. All transcripts were coded by the author and independently evaluated by another researcher. Donor quotations are presented with their consent, ensuring anonymity.

RESULTS

Of the 20 donors interviewed, 18 were females. A summary of the participants' gender and relationship to the recipient is provided in Figures- 1 and 2. At the time of the interview, all donors exhibited resilience in their decision to donate. Notably, 60% of the mothers in the study had voluntarily chosen to donate despite the availability of other potential donors. In contrast, other donors, including the remaining mothers, chose to donate because no other volunteers were available.

The study revealed that the primary motivation for all donors was to alleviate the suffering of the recipient, most of whom were undergoing dialysis. Financially, 60% of the donors relied on public funding for the transplantation process, with only two female donors being financially independent. The donors' main concern was the well-being of the recipient, with only one donor expressing concerns about their own health alongside the recipient's.

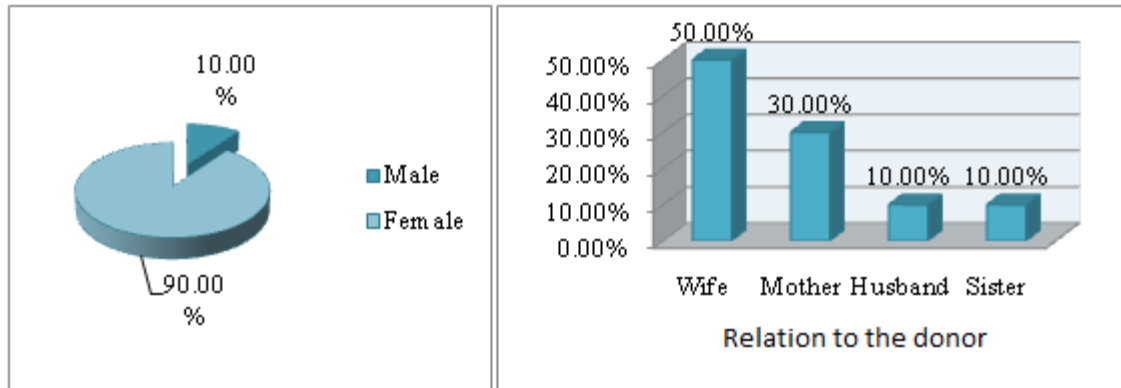


Figure – 2 & 3

The pre-donation work-up posed challenges for 50% of the donors, particularly during tests like CT scans and TMT (Treadmill Test). However, despite the physical and emotional strain, many expressed that they endured these hardships for the sake of the recipient's survival.

As one donor shared —

"I don't know how I got the courage to undergo all these tests. I was feared even for taking an injection. Nobody to my children hence decided rest is with God".

Interestingly, half of the donors did not consult with other previous donors before making their decision. Their focus remained solely on ensuring the recipient's survival, often disregarding their own well-being. Several quotes from the donors underscore this selflessness:

"He must live, if anything happens to me, doesn't matter. I have no fear, I am ready to suffer the consequences."

"Don't need to know more, if knows will feel sad".

"Heard that one kidney is enough."

"One is enough for living, the rest is with God".

"No problem in giving one, everybody is doing hence not feeling anything".

While donors were not coerced into the decision, many reported significant mental stress. Despite the voluntary nature of their choice, the emotional toll was evident in their narratives. Here are some of their responses —

"My son needs his father. From the beginning, I had a feeling that I must donate."

"I was afraid of the outcome of each test—I prayed for a match. He's in a difficult situation, I have to help him, but I also have to survive."

"His relatives only came after I made my decision—I can't blame them."

"I asked everyone, but nobody was willing. This isn't something you can demand from others."

"I'm fed up with dialysis. I have no fear about my surgery."

"I made the decision knowing how serious it was. There was no other option."

"One kidney is enough; nothing will happen. I'm donating even with a one-and-a-half-year-old child at home. Since there's no other option, I agreed."

Low awareness about the risks and complications of kidney donation was highlighted by one donor: "Awareness about donation was low. Even though we came to know about the risks and complications, we still agreed, as we had no other option, and I am prepared for it."

A male donor shared his perspective on the lack of available alternatives —

"There was no chance of anyone else coming forward, so there was no other way to save my small daughter. After seeing other donors, I got the courage. I'm happy to donate."

Finally, one donor's statement encapsulates the reality of the current scenario: "Everybody shows sympathy, but nobody is willing to donate."

**DISCUSSION**

Previous studies indicate that renal donors are often deprived of relevant information during the decision-making process, and that healthcare professionals may not provide adequate support (Agerskov et al., 2018; Sandal et al., 2019). However, in this study, only one participant expressed dissatisfaction with the information provided. Most of the donors, particularly mothers, were not concerned about the details of the donation process.

A key challenge faced by both donors and recipients, as noted in earlier research, is the long and arduous work-up process required before transplantation (Julian, 2024). In our study, 50% of the donors reported difficulties during this phase, particularly with tests such as CT and TMT. However, they emphasised that they endured these hardships for the recipient, further reinforcing the selfless nature of their decision-making.

Motivation for donation in this cohort was driven largely by the donors' desire to alleviate the suffering of their loved ones, especially in response to the ongoing burden of dialysis. Many donors did not consult with others who had undergone donation, indicating a personal, often solitary, decision-making process, where the welfare of the recipient took precedence over concerns for their own health. This selflessness, coupled with strong familial bonds, appears to be the dominant factor guiding the decision, rather than a thorough understanding of the medical risks or long-term consequences for themselves.

Financial stress was a significant factor for many donors, with 60% depending on public funding for the transplantation process. This underscores the socio-economic challenges that accompany living organ donation, particularly in regions where healthcare funding is limited. While financial concerns did not deter the decision to donate, they add an additional layer of stress for donors, especially in cases where only one household income is supporting the family.

Mental stress was evident in most donors, even though they voluntarily chose to donate. The uncertainty of medical outcomes, fear of the tests, and concerns for their own future health were common, yet these were often minimised or set aside in favour of ensuring the survival of the recipient. The finding, that only one donor explicitly expressed concern for her own well-being, suggests a cultural or emotional prioritisation of the recipient's life over the donor's health, further highlighting the complexities in decision-making within family dynamics.

CONCLUSION

This study revealed several key insights into the decision-making process of renal donors. Contrary to concerns about coercion, all participants affirmed that their decision to donate was voluntary and well-informed. The primary motivations for donation were emotional attachment to the recipient and a deep sense of responsibility to alleviate the suffering of their loved one. Mothers, in particular, displayed an overwhelming determination to save their children, often disregarding personal concerns or the medical risks involved.

While donors reported being aware of the donation process, many stated they felt they had no alternative but to donate due to the lack of available cadaveric organs and the strong familial obligation to help their loved ones. The emotional weight of the decision was palpable, especially among wives and mothers, who expressed a sense of helplessness in the face of their family members' suffering. In these cases, the donors prioritised the recipient's well-being, with little regard for their own future health or financial situation.

This study highlights the complex interplay of family bonds, emotional attachment, and socio-economic factors in the decision to donate. The fact that only two donors in this study were the primary earners in their families further suggests that economic dependency may also influence the decision-making process.

In conclusion, the decision to donate a kidney in Kerala is largely driven by strong family ties and emotional considerations. The findings underscore the need for improved awareness campaigns and support systems to ensure that donors are fully informed and adequately supported throughout the donation process. Nonetheless, this study demonstrates that familial loyalty and emotional bonds remain the most compelling factors in renal donation decisions.



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