

Perception of living kidney donors after taking a decision of kidney donation and their perception of the quality of life after kidney donation

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ABSTRACT

Background: With increasing renal transplantation surgeries, the living donor renal transplant is being promoted, majorly due to the shortage of renal graft from deceased persons and potential benefits of living kidney donation itself. It is a complex phenomenon, better studied by the qualitative analysis which allows a complementary in-depth exploration of complex human experiences in such cases. This study adds to the existing literature of qualitative research covering the analysis of decision-making, perioperative, and post-operative period. **Objectives:** Our aim was to explore the donation process of a heterogeneous group of genetically and non-genetically related living kidney donors, to know their perception during the decision and quality of life after kidney donation. The objectives were to know the factors involved in decision-making process, the psychological status after committing for donation and to explore the changes in individual's life post-donation. **Materials and Methods:** It is a thematic study with descriptive approach, with non-probability, purposive sampling of participants. In-depth interviews were analyzed by interpretative phenomenological analysis. Results were created through a comprehensive range of constituent themes and master themes after analysis of transcripts. **Results:** The decision-making is a rapid, rational, and altruist process. Reassurance and better management of psychological experience during the pre-operation period is helpful to a great extent. The increase in self-esteem is almost universal except a few cases of negative impact after donation. **Conclusion:** This study will not only help in better understanding of pre-surgical preparation but also for the better management of post-operative and follow-up period.


KEY WORDS: Living Donors; Quality of Life; Decision-Making; Self-Concept; Interpersonal Relations

INTRODUCTION

Chronic kidney disease is a significant health hazard for any patient. The kidney transplant remains to be the best option considering the better physical and mental outcomes for the patient.^[1] The kidneys can be harvested from cadaveric donors or live donors. As the procedures are on rise, there

is worldwide shortage of organs from cadaveric donors.^[2] Hence, there is an increased interest in living kidney donation. Living kidney donation has plenty of advantages: Improved patient and graft survival, a synchronized surgery schedule for donors and recipients, and shorter waiting time for kidney transplantation.^[3] The process itself is a complex phenomenon which includes external pressure to donate, dilemma about decision-making, significant stress of the life-threatening procedure and irreversible, post-operative discomfort, a fear of being ignored by the health-care team, and conflicts with the recipient.^[4,5]

That is why it becomes important to explore the process of donation including the decision-making to post-donation phase considering the psychosocial perspectives. According

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to the existing studies, after live renal transplantation, the donors are found to have positive results with a higher or equal quality of life compared to average population.^[6] Our aim is to add to this existing literature with qualitative research. We have explored the experience of 22 living kidney donors from Eastern India, covering decision-making, perioperative, and post-donation period, encompassing various aspects such as motivation for donation to psychological state and quality of life for each patient.

MATERIALS AND METHODS

The study was conducted in the Department of Urology of SSKM and IPGMER hospital, Kolkata. It is tertiary care hospital and research center in Kolkata with a high patient turnover. Proper ethical approval was taken from the Institutional Review Board before starting the research.

Data Analysis

Interpretative phenomenological analysis.

Type

Thematic.

Approach

Descriptive.

Data Collection

In-depth interview (IDI), semi-structured, and audio recorded.

IDI Respondents

The participants were live renal donors after donor nephrectomy, either related or unrelated to kidney recipients.

IDIs were pilot tested for getting basic structure of questionnaire. The duration of the interviews was not fixed beforehand. Interview conducted in a private room according to convenience of participants. Field notes were taken by the interviewer at the time of the interview. A follow-up interview planned if there is lack of clarity in responses after the interview. Audio recordings were later transcribed into English followed by analysis with master and constituent themes. Transcriptions were returned to participants on a later date for any objection in transcription.

Sampling Method

This was a non-probability and purposive sampling.

Sample size was fixed beforehand and it was guided by data saturation.

Primary Interviewer

Dr. Ankit Vaishnav, Post-doctoral trainee, M.Ch. urology who is working in the same institute.

Data analysis was done by a different team, experienced in the analysis of qualitative data, also to eliminate any observer bias.

RESULTS

A total of 22 randomly selected living kidney donors were interviewed. All were semi-structured, IDIs, 16 taken at office accommodation, and six taken at participant's house. The details of the breakdown about the relationship of recipient to donor are presented in Table 1. Each donor was interviewed once, with each interview lasting between 1 and 1.5 h. These tape-recorded interviews were converted into verbatim transcripts before data analysis. After analyzing the data, a comprehensive range of constituent themes and master themes was generated, and it is presented in Table 2, with examples of extract quotations associated with a selection of the constituent themes.

Results are presented in typical chronology of the living kidney donation process. Which goes in this order: The decision-making phase, followed by results pertaining to the timing of donation, then results in relation to the period after donation.

Decision-making Process

The decision-making starts along before the decision is made, even before the decision for compatibility tests. A universal and powerful motivation and an influential factor in donors' decision was awareness of recipient's suffering: "To me this was the only long-term treatment option, to be good for recipient." For most of them this was a non-pressurized decision: "Decided by self; without any pressure." Family opinion and support is one significant factor during decision-making as described by the donors. The family need: "I am the only non-earning member in the family, and the earning member needs transplant" and opinion "my family members seem happy by my decision" strengthens the feeling of the appropriateness of the original decision. Many candidates used to get involved in deep discussions, mediation, and

Table 1: Relationship of recipient to donor

Relationship of recipient to donor	<i>n</i>
Husband to wife	3
Mother to son	6
Mother to daughter	5
Father to son	4
Father to daughter	3
Mother-in-law to son-in-law	1

Table 2: Master and constituent themes

Constituent theme	Extract (example)
Master theme: Decision-making	
Self-knowledge	“Never have I thought about the decision for long before and after taking it”
Ease/difficulty continuum	“Decided by self; without any pressure”
Illness progression	“To me this was the only long-term treatment option, to be good for recipient”
Cognitive Component	“It was a rational decision... decided as I was the only non-earning member of the family”
Decisiveness	“Did not think about pulling out of it ever”
Time scale	“It was a rapid decision. was just thinking of saving someone’s life”
Failed other attempts to get kidney	“All family members denied, so decided to donate my kidney as a last option”
Personal emotional moment	“Entire pre-surgical period, especially the day of operation”
Previous decision making strategies	“This was unique for me”
Spiritual component	“I was just praying while making the decision that the recipient gets well early”
Master theme: motivation	
Giving	“My daughter asked for donation to save her husband”
Selflessness	“Decided by myself out of my desire to save my loved one’s life”
Personal goal achievement	“To make our family-run”
Self-empowerment	“When I got this opportunity, I just wanted to do something good in my life”
Master theme: Psychological states/processes; pre-surgery	
Anxiety	“Anxiety about the process and regarding life on single kidney, it starts after the decision-making and increases as the day comes nearby”
Frustration	“I just wanted it to get finished as early and smoothly as possible”
Confidence	“My confidence boosted after counseling, I believed in it and just followed doctor’s orders”
Uncertainty	“Too much time to think about things like...What will happen to my children if one of their parents fell ill, should I still go with it?”
Isolation	“It’s all on your own, it’s all in yourself...how you deal with these things”
Master theme: Psychological states/processes; post-surgery	
Reflection on meaning	“Feeling very satisfied and content, both physically and mentally”
Emotional dimension	“Sense of accomplishment and saving someone’s life also inter-family relation has improved”
Elation	“Got more love and respect by others after donation and gets applauded by others for this great work”
Detachment/conflicts	“Sometimes stressed and have poor interpersonal relationship, as the transplant or the post-operative period did not go as expected”
Need for reassurance	“I had to be reminded, What are you supposed to feel like?”
Overall experience	“It was up to the mark, I would like to go for it again, if possible and needed”
Master theme: Professional intervention	
Information giving	“It is always relaxing if you get all the information you want at every step”
Communication	“...In government setup, it is better to have coordinated and sequential communication”
Preparation	“The thing which eased it was the step by step process up to the surgery”
Emotional support	“The doctors and the professional staff was there to talk, whenever I was anxious”
Support for family members	“I would have appreciated if a bit more in-depth conversation was done to my family members regarding the process”
Development of TRUST	“As per my experience, people should listen to their doctor very carefully and with full trust”
Message to the society	“The donors should be determined before taking the decision, and it should be without any pressure, also they should have full trust in their doctor”

negotiation with their family before the decision, specifically when there is more than one candidate for donation. Sometimes the decision is made when they are simply out of options: “All family members denied, so decided to donate my kidney as a last option” or after describing personal goals: “To make our family-run.” The original decision is rather made very swiftly: “Never have I thought about the

decision for long before and after taking it; “It was a rapid decision. I was just thinking of saving someone’s life;” and firmly: “Did not think about pulling out of it ever.” In spite of being rapidly made, an important aspect of the decision was rationality: “It was a thoroughly rational decision.” We also found a strong correlation between donor’s spirituality and decision-making: “I was just praying while making the

decision that the recipient gets well early.” On the motivation part, it is highly characterized by selflessness on the part of donor. Their own desire to help along with self-awareness about being in position to give: “Decided by myself out of my desire to save my loved one’s life.” The donors do feel anxiety and frustration, but it is justified by their concerns about the success of the procedure and post-operative life. This stress increases as the day approaches nearby: “I just wanted it to get finished as early and smoothly as possible.” The most stressful period as described by the candidates was the day of surgery and the previous day: “Entire pre-surgical period, especially the day of operation.” They feel that the social support found at that time helps a lot in reducing the psychological stress.

At the Time of Donation

As previously stated, the most stressful time starts as the day approaches. Few patients take it calmly: “Its all on your own, it’s all in yourself...how you deal with these things;” but some patients feel very anxious: “Anxiety about the process and regarding life on single kidney, it starts after the decision-making and increases as the day comes nearby.” This suggests that each and every candidate’s need are unique in this period. To overcome this most of them just needed support from health-care personnel, specifically the doctor: “My confidence boosted after counseling, I believed in it and just followed doctor’s orders.” The donors also put stress on value of professional information and proactive preparation: “It is always relaxing if you get all the information you want at every step;” “...in government setup, it is better to have coordinated and sequential communication.” They emphasize that there should be a systemic flow of information throughout the pre-operative period and professional support as and when needed: “The thing which eased it was the step by step process up to the surgery;” “The doctors and the professional staff was there to talk, whenever I was anxious.”

After Donation

Majority of the patients expressed satisfaction toward the process and care received, with successful outcome, still few patients found frustrated due to unmet expectations from health-care facilities: “Sometimes stressed and have poor interpersonal relationship, as the transplant or the post-operative period did not go as expected.” Specifically, one donor had developed conflicts with his family as he donated kidney to his son. The outcome was successful, but he could not get proper post-operative medication and health care at a reasonable cost. However, the experiences like “it was up to the mark, I would like to go for it again, if possible and needed” suggests awareness and rationality regarding the process. Most of the donors experienced increase in self-esteem: “Feeling very satisfied and content, both physically and mentally” and also identity in society: “Got more love and respect by others after donation and gets applauded by

others for this great work.” There were also advised for the future donors: “The donors should be determined before taking the decision and it should be without any pressure, also they should have full trust in their doctor.”

Overall Experience of Donating a Kidney

Majority of donors were having experience of benefits such as increased self-esteem, a sense of accomplishment and pride, great level of personal satisfaction, better interpersonal relationship, and a change in their outlook on life. The process of donation was also considered as a selfless act of help toward the betterment of the recipient. In that way, it is considered meaningful.

DISCUSSION

In our study, we found that the process of donation and the experience of the living donor is multifaceted. As seen in our study, the literature shows that awareness of recipient’s suffering plays a huge role in motivation to donate as this finding appeared in 53.3% of studies reviewed.^[7] A decision described as altruistic or selfless, seen as natural and meant to improve recipient’s health, also had a very high-frequency effect size as this finding emerged in 46.7% of the studies reviewed.^[7] The spiritual aspect involved in decision-making is different from straightforward moral decisions, which shows that the donors are aware of the coexistence of spiritual components while making a rational and swift decision. This aspect needs further qualitative research to explore more about the donor’s experience in this domain. The donors had no regrets after the procedure; in fact, they noticed improved self-esteem and self-worth. The donors who have control over their internal beliefs have better psychological outcomes post-donation. This can be utilized and psychological measurement can be included in assessment and testing process itself to identify potential donors. The interpersonal relationship between donor and recipient most often improves or remains normal.

The decision-making process has been most extensively studied in existing literature. The challenging aspects of live renal transplants are mainly pertaining to the decision-making and pre-surgical phase. Hence, these aspects such as experiencing extensive tests, selfless will for surgical intervention, and losing one kidney – are better studied in literature.^[8] Most of the time, the decision making is swift and decisive. Fehrman-Ekholm^[9] also had similar results in their study, which indicate that 86% of their sample of living kidney donors find the decision easy to make. Eggeling’s statement that “the decision-making process for the majority of donors is emotional, uninformed, and not intellectual,”^[10] which can be reviewed as the decision was more than often was found to be completely rationalized. It is also seen as an unfamiliar trajectory by the donor, as it puts a fit person to get surgically traumatized and with conflicting roles, as the donor

was simultaneously a patient, a relative to the recipient, and a family member, this could lead to a stressful convalescence. We reviewed existing studies, out of which 40% indicate that donors would like to repeat the donation, and personal benefits for donors were found in 53.3%.^[11] Some of the challenging aspects of the process are during post-surgical period. Post-surgical pain, nausea, and exhaustion were noted in 46.7% of the reviewed studies.^[12] In literature, 13.3% studies found that risk of deterioration in inter-personal relationship was found in cases of conflict between donor and recipient, strain related to the transplantation or already difficult relationship before the transplantation.^[13] One potential factor to alter relationship was the issue of gift reciprocity and obligation to repay.^[14]

The strength of the present study is the in-depth view of the entire transplantation process for donors. It includes the period after the surgery also, which is not generally explored in the present literature. Some improvements suggested by the donors were: better preparation for the post-surgical period, easily accessible psychological support throughout the process and post-operative period, and continued follow-up by the transplantation health care team. Access to psychological support has also been advocated in prior studies.^[15] A good practice of ethical decision-making involves informing donors not only about all risks and complications that may occur but also about potential benefits of the transplant for both recipients and donors. The limitation of this study is it explores the experience of the candidates treated in the government health setup only, not including all the sections of health-care setups. Further research in the future would be helpful in this regard.

CONCLUSION

Our study is strengthened by the fact that it involves the entire process of transplantation from the donor's perspective right up to the post-surgical period. That is why it gives a complete picture of donors' experience of the process. There already exists literature pertaining to donor experiences; our study adds to the existing literature and also tries to further expand the knowledge of various aspects related to it. It can be useful for new professionals as well as can be utilized to improve the healthcare supply. We are in the time when the live kidney donation is being encouraged; it is better to have understanding of donors' experience of the process.

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