

A Qualitative Study on the Perceptions of Renal Transplantation Patients

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Abstract

Background: The process of transplantation is something more than receiving an organ. It is also possible that the patients proper understanding about reduce the stress and improve the self-care behaviors of the transplanted patients to protect the transplanted organ and also the survival of their life. Although the largest number of transplant operations belongs to the kidney transplantation, yet the unknown issues of life after kidney transplantation are still unclear and very few studies have been conducted on this issue, particularly in India. Therefore, this qualitative study on the perceptions of kidney transplant patients, have been envisaged in this institute which has to its credit in this institute which has to its credit a large number of successful kidney transplantation operations done so far.

Materials and Methods: The study was conducted in the Department of Urology of SSKM hospital, IPGMER in Kolkata, West Bengal. The study was one of a qualitative descriptive pattern involving in-depth interviews (IDI) of 18 patients of end-stage renal disease (ESRD) who were undergone kidney transplant treatment from a living donor. The IDIs were audio recorded and later translated in English and transcribed followed by analysis with categories and codes. Before beginning of the study, formal approval was taken from the Institutional Ethical Committee of the relevant institutes.

Results: In this study, IDI of 18 patients were taken. The analysis of transcripts of those IDIs showed that the IDIs could be grouped into four categories, viz., primary symptoms of the disease, primary reaction of the patients, feelings of the patients during dialysis, and feelings of family and friends and lastly, perceptions of patients after kidney transplant operation. The first category, viz., primary symptoms of the disease includes eight codes, viz., vomiting tendency, physical weakness, poor appetite, sleep disturbances, weight loss, fever, and routine checkup (i.e., there were no symptoms sometimes, yet they needed a routine checkup and blood tests). The second category, viz., primary reactions of the patients included five codes, i.e., depression, apprehension, uneasiness, anxiety, and agitation (e.g., why god has chosen me as the sufferer). The third category feelings of the patients during dialysis included again five codes, viz., pain, respiratory distress, swelling, cost, and loss of work. The fourth category that is, feelings of family and friends included only three codes, such as pathetic (initially they appear helpless and very sad), psychological support, and helping attitudes (all family members and friends tried to help in all aspects). The last (or 50) category which means perceptions of patients after kidney transplant operation consists of six codes, which are, physical weakness, daily activities, social life, occupational work, financial help, and mental health.

Discussion: Our study was unique in that it was the only open-ended qualitative study in which the recipients could speak their mind in full length. It was devoted to several facts of the patients, viz., when they became a patient of ESRD when they started having dialysis, when they had their transplantation operations over and lastly reactions of family and friends during all these phases.

Conclusion: It was perceived from our study that it was the first study of its kind which covers a wide range of facets regarding the patients in question. It was found that like several others, the patients showed gross improvement in all aspects after transplantation operation. However, one unique feature observed was that like other centers none of the patients here expressed extreme concerns on the rejection of the organ transplant.

Keywords: In-depth interview, Renal transplantation, Qualitative research

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INTRODUCTION

The process of transplanting a kidney from a healthy donor to a patient with end-stage renal disease is known as “renal (or kidney) transplantation.” Previously cadaveric transplant or deceased donor transplant was more common, that is, the otherwise healthy kidney

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of a dead person used to be taken for transplantation. However, at present kidney, for the purpose of transplant is almost exclusively taken from a healthy donor. This process is called “living donor transplantation.” Not only that, transplants are usually taken from genetically-related healthy adult person (below 60 years of age) and this is called “living-related transplant.”

The first kidney transplantation from a living donor was performed in 1952 at Necker Hospital in Paris by Jean Hamburger. However, the kidney failed after 3 weeks of good function.¹ Lack of donors used to be a big problem at the beginning. The donor has to match regarding blood group and human leukocyte antigen types to have a successful transplantation.

The formation of kidney chains from altruistic donors changed the situation. Kidney chains are initiated when an altruistic donor donates a kidney to a patient who has a willing but incompatible donor. This incompatible donor then pays it forward and passes on the generosity to another recipient who also had a willing but incompatible donor. Rees *et al.* from the University of Toledo developed the concept of open-ended chains.²

The above was the variation of a concept developed at Johns Hopkins University in 2006 by Montgomery *et al.*³ On July 30, 2008, an altruistic donor kidney was shipped through commercial airlines from Cornell University to the University of California Los Angeles, thus triggering of a chain of transplants.⁴ The shipment of donor kidneys, computer matching software algorithms, and cooperation between transplant centers has enabled long and elaborate chains to be formed. In carefully screened kidney donors the chances of survival up to old age without catching an end-stage renal disease appear to be similar to that of the general population. Therefore, these are no extra risk of healthy kidney donor over and above the healthy people belonging to the general population.⁵

In recent years, a huge number of kidney transplants are taking place in every civilized country. Although this operative procedure is both an effective and efficient treatment, yet the life of a patient before the onset of end-stage renal disease (ESRD) after kidney transplantation is not the same. Furthermore, the patients have various expectations, apprehensions, hearsays and perceptions about their life after transplantation. However, when they meet the reality after the operation actually over, they find something that is far from their visualizations before this major life incidence. The situation of living with a transplanted kidney is far from their expectations before the transplantation. It makes them to face the shock of reality when encountering the new situation and vast difference from pre-operative and feelings.

Thus, the process of transplantation is something more than receiving an organ. It is also possible that the patients proper understanding about reduce the stress and improve the self-care behaviors of the transplanted patients to protect the transplanted organ and also the survival of their life.⁶

Although the largest number of transplant operations belongs to the kidney transplantation, yet the unknown issues of life after kidney transplantation are still unclear and very few studies have been done on this issue, particularly in India. Therefore, this qualitative study on the perceptions of kidney transplant patients, have been envisaged in this institute which has to its credit in this institute which has to its credit a large number of successful kidney transplantation operations done so far.

MATERIALS AND METHODS

The study was conducted in the Department of Urology of SSKM Hospital, IPGMER in Kolkata, West Bengal. IPGMER is a super specialty care leading Government Postgraduate Medical College and Hospital. The catchment area includes the entire population of West Bengal and the neighboring states such as Bihar, Jharkhand, and North-East states and even neighboring countries such as Bangladesh, Nepal, and Bhutan. The study was one of a qualitative descriptive pattern involving in-depth interviews (IDI) of 18 patients of ESRD who were undergone kidney transplant treatment from a living donor.

All the IDI were conducted by the 1st author under the guidance and strict supervision of the third author. Proper consent was taken from all the patients beforehand. Before beginning of the study, the interviewer who summoned the patients and individually and privately performed all the IDIs taking an audio recording of all was trained thoroughly about the interview methods the background and purpose of the qualitative study by the 2nd and 4th author. He was also from time to time monitored and guided by the other authors. The transcript and analysis of the data were performed mainly by the 2nd and 4th author. They also prepared the final script of the paper which was shown to all other authors concerned and finalized before being sent for publication.

In total 18 IDIs were taken by 1st author. Translation and transcription of the recorded interviews were done by 2nd and 4th author who also typed the interviews in English language. The descriptive content analysis was performed manually. At first descriptive codings of the text information was done and categories were formed by merging similar codes together. The consolidated criteria for reporting qualitative research guidelines were followed in this study. The questions in the interview were all open-ended.

Before beginning of the study, formal approval was taken from the Institutional Ethical Committee of the relevant institutes.

RESULTS AND ANALYSIS

All the 18 patients included in the qualitative IDI were in the age group of 34-56 years. They are from different places of West Bengal, Bihar, and other places with diverse of occupations such as music teacher, van puller, social worker, teacher, government employee, and manual laborer (Tables 1-5).

DISCUSSION

In this study, IDI of 18 patients were taken. The analysis of transcripts of those IDIs showed that the IDIs could be grouped into four categories, *viz.*, primary symptoms of the disease, primary reaction of the patients, feelings of the patients during dialysis, and feelings of family and friends and lastly, perceptions of patients after kidney transplant operation.

Table 1: Primary symptoms of the disease

Codes	Comments
Vomiting tendency	There is always desire to vomit, vomiting 2-3 times everyday
Physical weakness	Feeling weak all the time, not getting any energy for work, not able to do any work
Poor appetite	No desire to intake food, not able to take food
Sleep disturbances	Unable to sleep in night, spending sleepless nights, waking up early in the morning
Weight loss	Losing weight, became emaciated
Fever	There was fever for a few days
Routine check up	There was no symptoms disease was during routine blood examinations

Table 2: Primary reactions of the patients

Depression	Initially feeling hopeless, not able to think, life is finished, feeling lonely
Apprehension	I was very much afraid of continuing the treatment of the disease, there was a fear of death
Uneasiness	I was restless and feeling uneasiness
Anxiety	What will do? What will happen to my family?
Agitation	Why I am the sufferer?

Table 3: Feelings of the patients during dialysis

Painful	It was very painful condition, fear of needle pricks
Respiratory distress	Feeling shortness of breath, chest discomfort during respiration
Swelling	Swelling of leg, swelling in the groin
Cost	Regular use - financial burden, it is costly
Loss of work	Longstanding process in regular intervals - loss of work

The first category, *viz.*, primary symptoms of the disease includes eight codes, *viz.*, vomiting tendency, physical weakness, poor appetite, sleep disturbances, weight loss, and fever and routine checkup (*i.e.*, there were no symptoms sometimes, yet they needed a routine checkup and blood tests).

The second category, *viz.*, primary reactions of the patients included five codes, *i.e.*, depression, apprehension, uneasiness, anxiety, and agitation (*e.g.*, why god has chosen me as the sufferer).

The third category feelings of the patients during dialysis included again five codes, *viz.*, pain, respiratory distress, swelling, and cost and loss of work.

The fourth category that is, feelings of family and friends included only three codes, such as pathetic (initially they appear helpless and very sad), psychological support, and helping attitudes (all family members and friends tried to help in all aspects).

The last (or fifth) category which means perceptions of patients after kidney transplant operation consists of six codes, which are, physical weakness, daily activities, social life, occupational work, financial help, and mental health.

Studies by Zare *et al.*⁷ from Iran have revealed the following facts, apart from ours, that is, all kidney transplant recipients have commonly expressed concerns about the fear of transplant rejection. Probably, this is a

Table 4: Feelings of family and friends

Pathetic	Initially feeling of helplessness and sadness
Psychological support	They have given me mental support, consoled me
Helping attitude	My family members and friends helped me in all aspects

Table 5: Perceptions of patients after kidney transplant operation

Physical weakness	Initially, I was very weak, then gradually feeling better. Not getting strength for work
Daily activities	After operation for 3 months I was not able to do any work, now I can do my daily work, I am not able to do any work till now
Social life	Very bad few months back before the operation, now it is not bad. I am in touch with my friends, who helped me during the disease
Occupational work	Not able to do my professional work, doing well my professional life
Financial help	My family was in financial crisis; now I am contributing financial help to my family
Mental health	Now very bad feeling, not feeling good, feeling very well.

big concern for all organ transplant recipients, *viz.*, heart, liver, and bone marrow transplant recipients. Because of approximately 7-12% of recipients have transplant rejection within the 1st year, which increases over time, the fear of transplant rejection is inevitable.

Other causes of stress in their study included high-cost medication, stress of the result, following a strict dietary regime and its tolerance. The latter is a problem as the authors say because of all different types of organ transplant kidney transplant is one of the most important ones in which dietary regimen is a significant aspect of care.

Howell *et al.* in an article in American Journal of Kidney Diseases mentioned that 57 participants identified 47 different points relevant to their post-surgery status. Transplant survival consistently was ranked more highly than any other outcome, followed by other issues such as damage to other organs, survival, and cancer possibility. Only 12% of the participants ranked their own survival as more important than transplant survival. In contrast, the relative importance of side effects differed among participants. Themes underpinning priorities were concern for fatal and serious events, relevance to life circumstances, acceptance, trivialization, tolerance, and future outlook. Participants described a willingness to tolerate side effects. In short, in their study, transplant survival appears to be more important than life itself in kidney transplant recipients.

In another study by Shrestha *et al.*⁸ from Sheffield, UK, which included the Medical outcome survey short form-36 (SF-36) and the kidney transplant questionnaire (KTS) the study tools, the results showed that there was a significant increase in the SF-36 scores for all dimensions compared to their pretransplant scores. However, their scores on physical functions, physical roles, bodily pain, general health, and physical component summary were significantly lower than that of the control group. However, overall improvement in the quality of life (QOL) was observed in 49/58 (85%) of the transplant recipients.

Regarding KTS scoring, the post-transplant scores were significantly higher, both clinically and statistically, compared to pretransplant scores, except for the dimension A (appearance), which was significantly lower in post-transplant patients.

In conclusion, the authors comment that in their study there was a significant improvement of QOL following live donor renal transplant in their center. Therefore, LDRTx should be encouraged to address the issue at hand.

In still another study by Gordon *et al.* from Northwestern University, Chicago, USA, 180 patients participated.

Patients received increased risk (IR) donor kidneys. The IR donor was having poor (44%), advanced age (38%), and poor quality kidney (24%) patients would accept IR donor kidneys first to get of dialysis and then to improved health by receiving a kidney transplantation quickly and felt that the risk of infection was low.

Patients would decline IR donor for fear of infection, perceived that a poor quality kidney would not last long and their health was good enough to wait for an average-risk kidney.

This was a qualitative study but related to a quite different aspect that whether IR kidneys are acceptable by would be kidney recipients to minimize their kidney transplantation operation delays.

Our study was unique in that it was the only open-ended qualitative study in which the recipients could speak their mind in full length. It was devoted to several facts of the patients, *viz.*, when they became a patient of ESRD when they started having dialysis, when they had their transplantation operations over and lastly reactions of family and friends during all these phases.

CONCLUSION

It was perceived from our study that it was the first study of its kind which covers a wide range of facets regarding the patients in question, *viz.*, their perceptions on initial symptoms of the disease, primary reaction of the patients, feelings of the patients during dialysis, feelings of family and friends, and lastly perceptions of the patients after kidney transplant operation.

It was found that like several others, the patients showed gross improvement in all aspects after transplantation operation. However, one unique feature observed was that like other centers none of the patients here expressed extreme concerns on rejection of the organ transplant. Whether this is because less graft rejections occur in this center or because of good counseling by the doctors and staff here or for some other reasons is debatable.

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