

**PATIENT REPORTED OUTCOME MEASURES OF KIDNEY
TRANSPLANT PATIENTS**

Dissertation submitted to



The IIHMR University, Jaipur
for the degree of
Master of Business Administration (MBA)
In

Hospital and Health Management

By

Dr Surbhi Handa

Under the Supervision of

Mr. Jagajeet Prasad Singh

**Patient Reported Outcome Measures of
Kidney Transplant Patients**

Dissertation submitted to



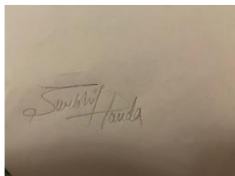
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DECLARATION BY STUDENT

I hereby declare that this dissertation titled '**Patient Reported Outcome Measures of Kidney Transplant Patient**' is the record of my research work. I declare that it has been not submitted to any other university. Information is derived from the Max, Hospital and it was very confidential.

A square image showing a handwritten signature in dark ink on a light-colored background. The signature appears to read 'Surbhi Handa'.

Dr. Surbhi Handa

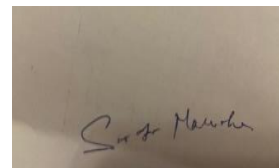
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CERTIFICATION BY ORGANIZATION

This is to certify that Dr. Surbhi Handa in fulfilment of the requirements for the award of the degree of MBA (Hospital and Health Management) from the IIHMR University, Jaipur has successfully completed her internship at MAX HOSPITAL, MOHALI during 23rd february – May 20, 2023

Date: 31/05/2023

Dr Swati Marwaha

A rectangular box containing a handwritten signature in dark ink, which appears to read "Dr. Swati Marwaha".

CERTIFICATION BY INSTITUTION

PLAGIARISM REPORT

This is to certify that the dissertation project report titled “Patient reported outcome measures of kidney transplant patients” submitted by Dr. Surbhi Handa for the fulfilment of the requirements for the award of degree of MBA (Hospital and Health Management) from the IIHMR University.

This thesis has XX% plagiarism on evaluation by Turnitin Software.

ACKNOWLEDGEMENT

I am grateful for the fortunate opportunity and exposure I had at Max Hospital , Mohali and would like to express my sincere gratitude to the individuals who guided, assisted and motivated me throughout this endeavour.

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Dr. Surbhi Handa

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TABLE OF ABBREVIATIONS

Abbreviations	Meaning
PROMs	Patient Reported Outcome Measures
CKD	Chronic Kidney Disease
GFR	Glomerular Filtration Rate
HRQOL	Health-related quality of life
ICU	Intensive care unit
CPRS	Computerized patient record system
PRO	Patient Reported Outcome

ABSTRACT

Proms is a set of questionnaires that tells about the views of patients on their health status. In health sector it is important to know the patient's perspective about the ongoing procedure PROMs helps us to do so.

Over last few years, Patient's perspective plays an important role in proper functioning of any organization.

The main motive of this study was to know how patient felt during and after surgery of kidney transplant. So we collected data for the month of Dec, Jan, Feb and March. Questions were asked from the patients who were suffering from Chronic Kidney Disease. The overall result was good and patient had a good experience in Max Hospital, Mohali.

Patient was able to perform daily activities and no need for hospitalization. It was observed that only 13% of patients had fever before surgery. 55% of patients need occasionally dialysis before surgery. Before surgery only 9% of patients felt anxiety rest all were fine and satisfied with the healthcare services provided by the hospital.

Patients were satisfied with the services provided, food and hygiene of the hospital. PROMs is the direct feedback of the patient so that a patient is able to communicate and tell about their needs and what they expect from the hospital.

So it is great way to communicate about the patients overall health.

KEYWORDS :- PROMs, Kidney Transplant, Questionnaire, Chronic Kidney Disease, Surgery.

1. INTRODUCTION

1.1 ORIGIN OF PROMs

PROMs is a set of questionnaires that tells about the view of patients on their health status. quality of life can be measured by tools such as PROMs.

There are 2 types of PROMs that are used in health services i.e. Generic and Disease specific. PROMs were firstly introduced in England and in some parts of US and were highly useful in Pharmacology and healthcare services.

UK has made PROMs a mandatory tool since 2009 to evaluate health services and quality of care. The main purpose to introduce PROMs in UK was to compare health services before and after using PROMs and to identify whether patient is benefited from PROMs.

By using PROMs, Patient informs us about his overall health experiences during the surgery and questions are asked after the surgery as well to know about the health status of the patients.

Patient is asked about his experience and the changes he wanted to see in the future. It provides valuable information and has proved to play an important role in achieving healthcare goals. (Smith2, 2013)

1.2 PURPOSE OF THE STUDY

The purpose of this study is to find out how patient felt during and after surgery. It helps in assessing a patient's health status at a particular point of time.

The main aim of any surgery is patient's satisfaction and PROMs has been proved to be an important tool for that. It tells us about the experience about the experience of patient with the healthcare services.

PROMs is important to assess quality of any healthcare services.

It is important to know whether Proms is making a difference in health status and quality of life of the patient. It tells us about the effectiveness of the procedure. In healthcare sector it is very important to know the patient's perspective about the ongoing procedure and PROMs helps us to do so. As we know only patient can tell us about the clear picture which will be helpful for the organization in improving the healthcare services. (Andre Chow BSc(Hons), 2009)

Healthcare system can be improved only if patient lets us know about his problem. Responses we get from PROMs helps us to know what patient needs and wants.

Studies has shown that the patients whose proms were monitored has shown improvement in their health than the one whose PROMs were not monitored.

PROMs is helpful in many ways as following:-

- 1 Letting us know what really matters to our patient.
- 2 Patient can understand about his condition in a better way.
- 3 Health services will be improved and moulded according to patients' requirements.
- 4 Helps us to treat the patient in a better way.
- 5 It helps in knowing about the success of the treatment and quality of care.

1.3 RESEARCH QUESTIONS –

What was the clinical outcome of Renal transplant surgery in terms of postoperative recovery, renal functions, and overall patient's well-being?

1.4 AIM AND OBJECTIVE

AIM – The main aim of this study is to take direct feedback from patient so that it would be helpful in improving the health services.

OBJECTIVE –

To measure a person's perception of their own health through questionnaires.

1.5 PATIENT REPORTED OUTCOME IN PATIENTS WITH CHRONIC KIDNEY DISEASE

CKD occurs when the kidneys develop structural or functional abnormalities or when the glomerular filtration rate (GFR) decreases. The treatment of chronic kidney disease is a complex process that requires a complete medical approach. Questionnaires or statements on patients reported outcome measures help in improving quality of life for patients.

PROMs helps in engaging patients and providing them care they want. It helps in improving quality of life . We get direct responses from the patients about changes they need and want. PROMs helps in knowing about the symptoms.

PROMs help in better communication with the patient. It helps in knowing the symptoms that is faced by the patients before and after the surgery.

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REVIEW OF LITERATURE

S. No.	Title	Author(s)/Year	Journal name	Description
1	Patient-reported outcome measures: A review of generic and condition-specific measures and a discussion of trends and issues	Kate Churruca, et. al. Year - 2021	National library of Medicine	PROMs were basically introduced for clinical trials and for knowing the effectiveness of the intervention. It is proven that adequate use of PROMs can help in improving quality of care. There are two types of PROMs Disease specific and Generic. PROMs has been proved to be an important tool in treating patients with cancer. They involve self-reported questionnaires or surveys that capture the patient's subjective experiences, functional status, symptoms and overall quality of life. PROMs is the patient's direct statement or answer that defines Patient Reported Outcomes Measures. Its important to note that specific PROMs instruments can vary in their content and purpose. (Kate Churruca, 2021)
2	Outcomes after kidney	Yiman Wang , et. al. Year - 2021	National Library of Medicine	Over the past 60 years the patients with end stage kidney disease, preferred kidney transplantation.

	transplantation, let's focus on the patients' perspectives			It is noted that in some cases PROMs helps in improving the quality of care such as :- • Patients with stage 4 and 5 and not on Dialysis. In this case PROMs helps in communication between patient and health professionals. • Patient on dialysis :- PROMs allows intervention for identified problems. PROMS helps in Patient participation as patient tells about their condition. It is important for patient to communicate and share his views and what he expects from the healthcare professionals. (J., 2021)
3.	Patient-Reported Outcomes as Endpoints in Clinical Trials of Kidney Transplantation Interventions	lison Tong, et. al. Year- 2022	Research Gate	PROMs are tools used to assess the patient's perspective on their treatment outcomes. They involve self-reported questionnaires or surveys that capture the patient's subjective experiences, functional status, symptoms. In the context of kidney transplant patients, PROMs can help evaluate various aspects of the transplant process, including pre-transplant assessment, perioperative care, and long-term outcomes. These measures can provide insights into the patient's physical and psychological well-being, medication adherence, treatment satisfaction and potential complications. Common areas assessed by PROMs in Kidney transplant patients include:- 1. Health-related quality of life PROMs can capture the patient's perception of their overall well-being , physical function ,

				mental health and social functioning. These measures can help identify areas of impairment or improvement following a Kidney Transplant. (Allison Tong, 2022)
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3. METHODOLOGY

3.1 AIM-

The main aim of this study was to take direct feedback from the patient so that it would be helpful in improving the healthcare services.

3.2 MATERIAL AND METHODS-

Study Design- Observational cross sectional study

Setting – MAX Hospital, Mohali.

Study sample-

Patients undergoing Kidney Transplant Surgery for the month of December, January , February and March.

Study Tools – Data was taken primarily through the questionnaires which constitutes of the questions that fulfil the requirements of the objectives.

Study duration–

20th feb , 2023 – 20th May, 2023

Sample Size-

Total 31 patients reported from December 2022 to March 2023.

3.3 DATA COLLECTION PROCEDURE –

Data was collected from Nephrology Department in which patients and donor's information was given. Total number of patients were 31 from the month Dec to Feb.

Questionnaire was prepared, questions were asked from the patient Before surgery, one month after surgery and three months after surgery.

So data was collected for the month of Dec, Jan and Feb. patient were called questions were asked from them. Different patients have different answers according to which result was made.

Total number of questions were nine which were about dialysis, surgical site infection, fever, pain, anxiety, depression and overall experience of the patient. According to which scoring was given. Based on the scoring results were formed.

So, we prepared questionnaire. These are the nine questions that were asked from the patients. Five options were given to the patients according to which they had to choose the most.

appropriate option.

1. Do you need to undergo Dialysis?

- No need
- Occasionally
- Regular and weekly
- Same as before surgery
- Worse than pre surgical status

2. Do you face problem of infection of Surgical Site?

- No
- Slightly infection
- Infection was treated with oral antibiotics.
- Infection needed admission for treatment
- State worse than pre-surgical status

3. Do you face problem of generalized infection/fever?

- No
- Slightly infection
- Moderate
- Severe
- Extreme

4. Are you able to do your daily routine activities?

- Perfectly
- Little discomfort
- Able to do few activities
- Not able to do anything
- Worse than pre surgical status

5. Do you have pain?

- No
- Slightly
- Moderate

- Severe
- Extreme

6. Do you have fatigue?

- No
- Slightly
- Moderate
- Severe
- Extreme

7. Do you have anxiety/depression?

- No
- Slightly
- Moderate
- Severe
- Extreme

8. Need for Hospitalization?

- No need
- Very rarely
- Sometimes
- Frequent
- Many hospitalization with ICU stay

9. How would you rate your experience?

- Poor
- Fair
- Good
- Very good
- Excellent

3.4 DATA ANALYSIS PLAN :

Computerized Patient Record System (CPRS)

3.5 IMPLICATIONS OF RESEARCH

To help healthcare workers and the patients to communicate properly and know about the symptoms that is faced by the patients. It improves Patients satisfaction.

ETHICAL CONSIDERATION

Following consideration concerning ethics will be strictly followed:

- All the classified data is kept confidential.
- All the information about the patients is kept confidential.
- Any discussion planned will not be recorded to maintain the confidentiality of the organisation.

4. RESULT :-

Though the analysis of the data collected, the following objectives were accomplished: -

1. Communication between the patient and physician.
2. Direct review of patient.
3. Improved quality of care and healthcare services.
4. Benefits of doing PROMs routinely.

Total number of questions were nine :-

Table 1. These were the following questions asked from the patients.

Sno	Question
1	Do you need to undergo Dialysis now?
2	Do you face problem of infection of Surgical Site?
3	Do you face problem of generalized infection/fever?
4	Are you able to do your daily routine activities?
5	Do you have pain?
6	Do you have fatigue?
7	Do you have Anxiety/Depression?
8	Need for hospitalization?
9	How would you rate your experience?

Total number of patients were 31. These are the result of PROMs of patients of kidney transplant. The result here is given in percentages:-

	(n)%		
	Before surgery	After 1 month	After 3 months
No need	42	100	100
Occasionally	17	0	0

Regular ad weekly	1	0	0
Same as before surgery	0	0	0
Worse than pre-surgical status	0	0	0

Table 2. Do you need to undergo Dialysis now?

It was observed that 17% of patients feels need to undergo dialysis occasionally on the other hand 42% of patients does not want to undergo dialysis before surgery. After 1 month of surgery no patient had undergone dialysis. After 3 months of surgery % of no need for dialysis was still 100%. That means patients needed the dialysis before surgery but after surgery results were good.

Table 3. Do you face problem of infection of surgical site?

	(n)%		
	Before surgery	After 1 month	After 3 months
No Infection	90	97	100
Slightly infection	3	0	0
Infection was treated with oral antibiotics	6	0	0
Infection needed admission for treatment	0	0	0
State worse than pre-surgical status	0	0	0

It was observed that before surgery 90% of patients dosenot face any surgical site infection but 3% of patients had infections. After 1 month 97% of patients were non-infected. After 3 months of surgery 100% of patients were not having any kind of infection. It shows that good hygiene was maintained in the hospital and patients were not infected after the surgery. Post operative results were good.

Table 4. Do you face problems of generalized infection/fever?

	(n)%
--	------

	Before surgery	After 1 month	After 3 months
No	87	100	100
Slightly	13	0	0
Moderate	0	0	0
Severe	0	0	0
Extreme	0	0	0

From the above result it was observed that 87% of patients were not facing problems of generalized infection/fever whereas 13% were facing fever slightly. After 1 month and 3 months no fever was observed in any patient.

Table 5. Are you able to do your daily routine activities?

	(n)%		
	Before surgery	After 1 month	After 3 months
Perfectly	61	84	100
Little discomfort	39	10	0
Able to do few activities	0	6	0
Not able to do anything	0	0	0
Worse than pre-surgical status	0	0	0

- It was observed that before surgery 61% of patients were perfectly doing their daily activities and 39% were facing a little discomfort whereas after 1 month 84% of patients were perfectly doing their work and 10% were facing little discomfort and 6% were able to do few activities. After 3 months 100% patients were perfectly fine. It was observed that surgery was performed well and post operative symptoms were not there. Patients were told to do their daily routine work after one week of surgery and almost all the patients were fine after 3 months of surgery.

Table 6. Do you have pain?

	(n)%
--	------

	Before surgery	After 1 month	After 3 months
No	65	100	100
Slightly	35	0	0
Moderate	0	0	0
Severe	0	0	0
Extreme	0	0	0

From the above information it is seen that 65% of patients felt no pain before surgery whereas 35% of patients faced slight pain. After 1 month of surgery patients felt no pain and after 3 months results were same. It is because patients were given medicines for the pain management and success rate of kidney transplant was good as patients were healthy after the surgery.

Table 7. Do you have fatigue?

	(n)%		
	Before surgery	After 1 month	After 3 months
No	61	77	94
Slightly	35	19	3
Moderate	3	3	3
Severe	0	0	0
Extreme	0	0	0

From the above result it was observed that before surgery 60% of patients were fine but 35% of patients had fatigue issues. After 1 month of surgery 77% of patients were fine and were able to do work. After 3 months of surgery 94% of patients were fine and only 6% of patients had fatigue. After surgery the rate of patients that were fine increased as compared to before.

Table 8. Do you have Anxiety/Depression?

It was observed that before surgery 90% of patients were not facing any anxiety/depression where as 9% of patients were facing slightly or moderate anxiety/depression. After 1 month 97% of patients were not facing any anxiety whereas remaining 3% were facing a slight

anxiety. Certain exercises and yoga were suggested to the patients. But after 3 months all the patients were free from depression.

	(n)%		
	Before surgery	After 1 month	After 3 months
No	90	97	100
Slightly	6	3	0
Moderate	3	0	0
Severe	0	0	0
Extreme	0	0	0

Table 9. Need for hospitalization?

	(n)%		
	Before surgery	After 1 month	After 3 months
No	71	100	100
Very rarely	29	0	0
Sometimes	0	0	0
Frequent	0	0	0
Hospitalization with ICU stay	0	0	0

It was observed that 29% of patients needed hospitalization very rarely whereas rest were fine. After one month results were different as no patient needed hospitalization and results were same after 3 months of surgery. It was observed that after surgery patients were satisfied with the surgery and patients visited hospital only for follow ups.

Table 10. How would you rate your experience?

	(n)%		
	Before surgery	After 1 month	After 3 months
Poor	84	0	0

Fair	13	74	29
Good	3	25	58
Very good	0	0	6
Excellent	0	0	0

Before surgery patients were facing many problems of pain, fatigue or they have to undergo dialysis. But after surgery their experience changed and they were happy with the treatment and the services provided by the hospital. As mentioned above 84% of patients were in a bad state before surgery but after 1 month of surgery 74% of patients were happy with the services of the hospital and 25% were feeling good. Patients were satisfied with the treatment and proper follow ups were taken by the Doctor.

Post operative care was eventually better as patients were happy with the overall stay and after 3 months also patients were satisfied and faced less problems as compared to before. After Kidney transplant the main danger to the patient is from infections so proper care was provided by the doctor as well as from the staff as infection rate was very low and eventually after 3 months patients were facing no infection.

Overall result was good. Patient was satisfied with services provided by Max hospital, Mohali. Patient was able to perform daily routine activities after few days of surgery.

Need for hospitalization is decreased after the surgery.

PROMs helped us to know our patients better and what they need.

5. DISCUSSION

Main motive of this study was to observe that how patient felt before and after surgery. So we collected data for the month of Dec 2022, Jan , Feb , March .We observed many benefits of PROMs in Kidney transplant patients.

It helped in capturing the patient's subjective experience, including physical symptoms, emotional well-being and social functioning.

Patients were satisfied with the services provided, food and hygiene so that a patient is able to communicate and tell about their needs and what they expect from the hospital. It was observed that many patients were able to do their daily routine activities. After surgery need for dialysis decreased. Less surgical site infection was seen. It was observed that only 55% of patients need occasionally dialysis before surgery. Before surgery only 9% of patients felt anxiety rest all were fine and satisfied with the healthcare services provided by the hospital.

PROMs also helped in decision making and communication between healthcare professionals and the patient. Before surgery patients were facing many problems of pain, fatigue or they have to undergo dialysis. But after surgery their experience changed and they were happy with the treatment. PROMs helped us to know our patients better and what they need.

SUGGESTIONS :-

Following are the suggestions to enhance the benefits of PROMs in any organization :-

- PROMs should be used in intervals such as pre-transplant , post -transplant , follow-ups etc.
- Questionnaire of PROMs should be prepared according to the needs of the patients.
- Protocols should be developed in the communication of healthcare professionals and the patient.
- PROMs data should be collected beyond the post-transplantation to ensure that the patient is well and is not facing any sort of problem.

If these suggestions are implemented then we can improve quality of care. It will help in better communication between a healthcare provider and the patient. PROMs when done in intervals can really help in the intervention and in post transplant complications.

5. CONCLUSION

Patient-reported outcome measures (PROMs) plays a crucial role in evaluating the quality of life and overall well-being of patients. By capturing the patient's perspective, PROMs provide valuable insights that can help healthcare professionals assess transplant outcomes, identify areas of concern, and tailor interventions to improve patient care and satisfaction.

After collecting data for the months of dec , jan and feb. It was observed that most of the patients were satisfied after the surgery. Over all result was good. It was observed that patients were able to do their daily routine activities.

A key challenge was selecting a suitable tool for the PROMs.

Patients were satisfied with the services provided, food and hygiene so that a patient is able to communicate and tell about their needs and what they expect from the hospital.

It a great way to communicate about the patient's overall health. Patients were more comfortable about telling their problems.

It is observed that Patient reported outcome is an evolving field. It helps in changing quality of care.

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ANNEXURE – A

Questionnaire for collection of data

Name of patient..... UHID/IPD..... Age/Sex.....
Consultant..... Date of KTP.....

Patient reported outcome measures (Kidney Transplant Patients) Form

Under each heading, please tick the ONE box that best describes your answer

1. Do you need to undergo dialysis now?

OPTIONS	Before surgery	After 1 month	After 3 months
No need for dialysis			
occasionally			
On regular weekly dialysis			
Status is same before surgery			
Status is worst than pre-surgical status			

2. Do you face problem of infection of surgical site?

OPTIONS	Before surgery	After 1 month	After 3 months
No			
Slightly infection			
Moderate infection was treated with oral antibiotics			
Severe infection			
Worse than pre-surgical status			

3. Do you face problem of generalized infection/fever?

OPTIONS	Before surgery	After 1 month	After 3 months
No			
Slightly			
Moderate			
Severe			
Extreme			

4. Are you able to do your daily routine activities?

OPTIONS	Before surgery	After 1 month	After 3 months
Perfectly			
Able to do with little discomfort			
Able to do few activities			
Not able to do anything			
The status is worst than presurgical status			

5. Do you have pain?

OPTIONS	Before surgery	After 1 month	After 3 months
No			
Slightly			
Moderate			
Severe			
Extreme			

6. Do you have fatigue?

OPTIONS	Before surgery	After 1 month	After 3 months
No			
Slightly			
Moderate			
Severe			
Extreme			

7. Do you have Anxiety/Depression ?

OPTIONS	Before surgery	After 1 month	After 3 months
No			
Slightly			
Moderate			
Severe			
Extreme			

8. Need for hospitalization?

OPTIONS	Before surgery	After 1 month	After 3 months
No need			
Very rarely			
Sometimes			
Frequent			
Hospitalization with ICU stay			

9. How would you rate your experience ?

OPTIONS	Before surgery	After 1 month	After 3 months
Poor			
Fair			
Good			
Very good			
Excellent			

