

Annexure A-1

	Permuted Block randomization list			
	List created on August 27 2019 11:51:58			
	Random seed: 1568886918			
	Total sample size: 120			
	Groups	Ratio		
	A	1		
	B	1		
StratID	study_ID	block	size	Groups
1	116	1	10	B
1	94	1	10	A
1	92	1	10	B
1	101	1	10	B
1	136	1	10	A
1	131	1	10	B
1	155	1	10	A
1	99	1	10	A
1	134	1	10	B
1	104	1	10	A
1	112	2	6	B
1	126	2	6	B
1	150	2	6	B
1	151	2	6	A
1	164	2	6	A
1	120	3	8	B
1	143	3	8	A
1	90	3	8	B
1	128	3	8	A
1	110	3	8	A
1	97	3	8	B
1	127	3	8	A
1	167	3	8	B
1	168	4	10	A
1	153	4	10	B
1	133	4	10	B
1	130	4	10	A
1	100	4	10	B
1	93	4	10	A
1	138	4	10	B
1	161	4	10	A
1	114	4	10	B
1	165	4	10	A
1	152	5	8	A
1	144	5	8	A
1	102	5	8	B
1	113	5	8	A
1	146	5	8	B
1	91	5	8	A
1	141	5	8	B
1	154	5	8	B
1	158	6	4	A

1	129	6	4	B
1	108	6	4	B
1	159	6	4	A
1	139	7	6	A
1	156	7	6	B
1	145	7	6	A
1	148	7	6	A
1	169	7	6	B
1	124	7	6	B
1	95	8	4	A
1	163	8	4	A
1	123	8	4	B
1	106	8	4	B
1	98	9	2	B
1	157	9	2	A
1	111	10	8	B
1	118	10	8	A
1	147	10	8	A
1	107	10	8	B
1	121	10	8	B
1	132	10	8	B
1	149	10	8	A
1	166	10	8	A
1	103	11	8	B
1	115	11	8	B
1	142	11	8	A
1	125	11	8	A
1	160	11	8	B
1	140	11	8	B
1	109	11	8	A
1	122	11	8	A
1	105	12	6	B
1	137	12	6	B
1	96	12	6	B
1	119	12	6	A
1	117	12	6	A
1	162	12	6	A
1	172	13	4	A
1	135	13	4	B
1	186	13	4	B
1	170	13	4	A
1	184	14	10	A
1	193	14	10	B
1	191	14	10	B
1	171	14	10	A
1	185	14	10	B
1	192	14	10	A
1	175	14	10	B
1	187	14	10	A
1	173	14	10	B

1	189	14	10	A
1	178	15	8	B
1	190	15	8	A
1	174	15	8	A
1	188	15	8	B
1	196	15	8	B
1	176	15	8	B
1	195	15	8	A
1	201	15	8	A
1	177	16	4	A
1	194	16	4	B
1	200	16	4	B
1	181	16	4	A
1	202	17	6	A
1	179	17	6	B
1	205	17	6	B
1	208	17	6	B
1	180	17	6	A
1	198	17	6	A
1	209	18	2	B
1	207	18	2	A
1	182	19	6	A
1	199	19	6	B
1	206	19	6	A
1	183	19	6	A
1	203	19	6	B
1	204	19	6	B

Annexure A-2

A. Socio Demographic Sheet

1. Age(years)
 - a. 18-35
 - b. 36-45
 - c. 46- 55
 - d. >55
2. Gender
 - a. Male
 - b. Female
 - c. Any other
3. Education
 - a. Illiterate
 - b. Primary
 - c. Secondary
 - d. Higher Secondary
 - e. Graduation
 - f. Post graduation and Higher
4. Marital status
 - a. Single
 - b. Married
5. Occupation _____
6. Residence
 - a. Rural
 - b. Urban
7. Type of family
 - a. Nuclear
 - b. Joint
8. Family income per month (in Rs.)
 - a. Below poverty line
 - b. 5000-10000
 - c. 10000-20000
 - d. 20000-30000
 - e. 30000-40000
 - f. >40000
9. Source of Reimbursement, if any_____
10. Donor type
 - a. Relative
 - b. Non relative
 - c. Cadaver

B. Clinical profile sheet

1. Previous history of medical illness
 - a. Pulmonary Koch's
 - b. Hepatitis B
 - c. Hepatitis C
 - d. Any other
2. Co- morbidities
 - a. Diabetes Mellitus
 - b. Hypertension
 - c. Peripheral Vascular Disease
 - d. Any other
3. Do you Smoke? Yes _____ No _____
4. Do you take Alcohol? Yes _____ No _____
5. Do you take Tobacco? Yes _____ No _____
6. Post Transplantation Complications, if any:
 - a. Infection
 - b. Rejection
 - c. NODAT(New Onset Diabetes after Transplantation)
7. Current Serum creatinine_____

Annexure A-3

SELF CARE PRACTICE SCALE FOR KIDNEY TRANSPLANT RECIPIENTS

Instructions: This performa assesses your self care practices. Kindly tick the most appropriate option in the column. Also answer all the items provided in this performa.

S.No.	Items	Never 0	Rarely 1	Sometim es 2	Often 3	Always 4
	Nutrition and Diet					
1.	I avoid sweets, high-calorie foods and fried foods					
2.	I eat low-fat food and low fat dairy products.					
3.	I take low salt diet.					
4.	I avoid intake of raw fruits, vegetables and salads.					
5.	I eat healthy and well balanced diet.					
	Medication management					
6.	I take my medicine as prescribed by the doctor.					
7.	I use alarms in the phone to remember medication time.					
8.	I discuss my concerns related to medication during my visit to doctor					
9.	I decrease the dose of the medication on my own					
	Lifestyle modification					
10.	I exercise for at least 20-30 minutes 5 times per week.					

11.	I limit alcoholic drinks to not more than one drink per day.					
12.	I refrain from taking tobacco.					
13.	I refrain from smoking.					
	Self monitoring					
14.	I check my blood pressure and record everyday.					
15.	I check my blood sugar as advised.					
16.	I check my feet or ankles for swelling as instructed by my doctor.					
17.	I visit my doctor if I gain more than around 2 kg weight in one day.					
18.	I call my transplant doctor if I urinate less than usual.					
	Avoidance of Infection					
19.	I check my body temperature everyday.					
20.	I avoid close contact with people who are sick with cold or fever.					
21.	I wash my hands with soap and water after using the toilet.					
22.	I wash my hands with soap and water before meals.					

23.	I use face mask while going outside the house.					
	Follow up					
24.	I keep appointment with my transplant doctor.					
25.	I get my blood (lab) investigations done as prescribed.					
26.	I visit my doctor when I have any of the symptoms of an infection like fever, flu-like symptoms, pain on urinating, or cough.					
	Psychological care					
27.	I have sufficient rest and sleep.					
28.	I practice yoga/relaxation.					
29.	I receive sufficient support from my family.					
30.	I consult my doctor when feeling sad/depressed.					

किडनी ट्रांसप्लेंट प्राप्तकर्ता के लिए स्वयं की देखभाल अभ्यास पैमाना

निर्देश: यह प्रदर्शन आपके स्वयं की देखभाल का आकलन करता है। कृपया कॉलम में सबसे उपयुक्त विकल्प पर सही का निशान लगायें। इस प्रदर्शन में प्रदान की गई सभी वस्तुओं का भी उत्तर दें।

क्रम संख्या	वस्तु	कभी नहीं 0	शायद ही कभी 1	कभी कभी 2	बार-बार 3	हमेशा 4
	पोषण और आहार					
1.	मैं मिठाई, ज्यादा कैलोरी युक्त और तले हुए खाद्य पदार्थों को खाने से बचता हूँ / बचती हूँ।					
2.	मैं कम वसा युक्त भोजन और कम वसा युक्त डेयरी उत्पाद खाता हूँ / खाती हूँ।					
3.	मैं कम नमक वाला भोजन लेता हूँ / लेती हूँ।					
4.	मैं कच्चे फलों, सब्जियों और सलाद के सेवन से बचता हूँ / बचती हूँ।					
5.	मैं स्वस्थ और अच्छा संतुलित आहार खाता हूँ / खाती हूँ।					
	दवा प्रबंधन					
6.	मैं डॉक्टर द्वारा बताई गई दवा लेता हूँ / लेती हूँ।					
7.	मैं दवा का समय याद रखने के लिए फोन में अलार्म का उपयोग करता हूँ / करती हूँ।					

क्रम संख्या	वस्तु	कभी नहीं 0	शायद ही कभी 1	कभी कभी 2	बार-बार 3	हमेशा 4
8.	मैं डॉक्टर से मिलने के दौरान दवा से संबंधित अपनी चिंताओं पर चर्चा करता हूँ / करती हूँ।					
9.	मैं स्वयं दवा की खुराक को कम करता हूँ / करती हूँ।					
	जीवन शैली संशोधन					
10.	मैं सप्ताह में पाँच दिन कम से कम 20-30 मिनट प्रतिदिन व्यायाम करता हूँ / करती हूँ।					
11.	मैं शराब का सेवन नहीं करता हूँ / करती हूँ।					
12.	मैं तंबाकू लेने से परहेज करता हूँ / करती हूँ।					
13.	मैं धूम्रपान से परहेज करता हूँ / करती हूँ।					
	स्वयं निगरानी					
14.	मैं अपने रक्तचाप की जांच करता हूँ और रोज रिकॉर्ड करता हूँ / करती हूँ।					
15.	मैं सलाह के अनुसार अपने ब्लड शुगर की जांच करता हूँ / करती हूँ।					
क्रम संख्या	वस्तु	कभी नहीं 0	शायद ही कभी 1	कभी कभी 2	बार-बार 3	हमेशा 4

16.	मैं अपने चिकित्सक के निर्देशानुसार अपने पैरों या टखनों में सूजन की जांच करता हूँ / करती हूँ।					
17.	यदि मैं एक दिन में लगभग 2 किलोग्राम से अधिक वजन प्राप्त करता हूँ / करती हूँ। तो मैं अपने डॉक्टर से मिलूंगा / मिलूंगी।					
18.	अगर मुझे सामान्य से कम पेशाब आता है , तो मैं अपने ट्रांसप्लान्ट डॉक्टर को सूचित करता हूँ / करती हूँ। संक्रमण से बचाव					
19.	मैं अपने शरीर के तापमान की प्रतिदिन जांच करता हूँ / करती हूँ।					
20.	मैं उन लोगों के साथ संपर्क से बचता हूँ/ बचती हूँ। जो जुकाम या बुखार से बीमार हैं ।					
21.	शौचालय का उपयोग करने के बाद मैं अपने हाथों को साबुन से धोता हूँ / धोती हूँ।					
22.	मैं भोजन से पहले अपने हाथ साबुन और पानी से धोता हूँ/ धोती हूँ।					
क्रम संख्या	वस्तु	कभी नहीं 0	शायद ही कभी 1	कभी कभी 2	बार-बार 3	हमेशा 4

23.	मैं घर से बाहर जाते समय फेस मास्क का इस्तेमाल करता हूँ/ करती हूँ। फॉलो-अप					
24.	मैं अपने ट्रांसप्लान्ट डॉक्टर से नियमित रूप से मिलता रहता हूँ/ रहती हूँ।					
25.	मैं मेरे खून (प्रयोगशाला) जांच किया के रूप में निर्धारित।					
26.	जब भी मुझे संक्रमण के लक्षण जैसे कि बुखार, फ्लू, पेशाब करने में दर्द या खांसी होता होती है तब मैं अपने डॉक्टर के पास जाता हूँ/ जाती हूँ। मनोवैज्ञानिक देखभाल					
27.	मुझे पर्याप्त आराम और नींद आता है / आती है।					
28.	मैं योग / विश्राम का अभ्यास करता हूँ / करती हूँ।					
29.	मुझे अपने परिवार से पर्याप्त सहायता मिलती है।					
30.	दुखी / उदास महसूस करने पर मैं अपने डॉक्टर से परामर्श करता हूँ/ करती हूँ।					

Annexure A-4

MGL ADHERENCE SCALE

Instructions: Kindly tick the most appropriate answer for each item. Also tick the reasons applicable to you for non adherence to therapy.

Item	YES	NO
1. Do you ever forget to take your medicine?		
2. Are you careless at times about taking your medicine?		
3. When you feel better do you sometimes stop taking your medicine?		
4. Sometimes you feel worse, when you take the medicine, do you stop taking it?		

एम.जी.एल. पालन पैमाना

निर्देश: कृपया प्रत्येक आइटम के लिए सबसे उपयुक्त उत्तर पर निशान लगाएं

मद	हां	नहीं
1. क्या आप कभी अपनी दवा लेना भूल जाते हैं 2. क्या आप कभी-कभी अपनी दवा लेने में लापरवाह होते हैं 3. जब आप बेहतर महसूस करते हैं तो क्या आप कभी-कभी अपनी दवा लेना बंद कर देते हैं? 4. कभी-कभी आपको और भी बुरा लगता है, जब आप दवा लेते हैं तो क्या आप इसे लेना बंद कर देते हैं?		



Annexure A-5

ujjwal dahiya <ujjwaldahiya3@gmail.com>

Re: Request for permission to use MGL scale

DONALD MORISKY <dmorisky@ucla.edu>

Fri, Oct 12, 2018 at 6:49 AM

To: ujjwaldahiya@aiims.edu

Greetings again, Ujjwal, and here is the Morisky, Green and Levine Adherence Scale, that is free and you can make your own translation. This scale is published in Medical Care, 1986. Professor Larry Green and Dr. Prof. David Levine were my mentors and Principal Investigators on this NHLBI study that resulted in many seminal articles on the role of adherence behavior in all healthcare settings. The Morisky, Green and Levine Adherence Scale is in the public domain and does not need a license. It has been cited over 3000 times in PubMed. I suggest you do a search on this article and find out how it is still being used by thousands of health care centers all over the world. I am also attaching the 1983 article published in the AJPH on the long-term outcomes (morbidity and mortality) resulting from tailored educational interventions on the patients randomized to any combination of educational interventions.

Thank you again for your interest in using my validated diagnostic adherence tool. Please keep me apprised of your progress in using the MGL. Please remember that the MGL is NOT the same as the MMAS-4. Please do not confuse these two very different scales.

I have downloaded several recent citations from the Medical Care article to show you how popular this reference is still being cited. **Happy reading....., and please send me a note that you have received these documents. I hope you enjoy these citations.**

Sincerely,

Dmorisky

Donald E. Morisky, Sc.D., M.S.P.H., Sc.M.
Research Professor and Former Chair
Distinguished Chair Professor at Kaohsiung University, Taiwan
Department of Community Health Sciences
UCLA Fielding School of Public Health

1.

[Association between low serum 25-hydroxyvitamin D and depression in a large sample of Chinese patients with type 2 diabetes mellitus](#)

By: Wang, Yuhong; Yang, Hui; Meng, Pan; et al.

JOURNAL OF AFFECTIVE DISORDERS Volume: 224 Special Issue: SI Pages: 56-60 Published: DEC 15 2017

[View Abstract](#)

Times Cited: 0

(from All Databases)

Usage Count

2.

[The Effect of Antiretroviral Stock-Outs on Medication Adherence Among Patients Living With HIV in Ghana: A Qualitative Study](#)

By: Moriarty, Kathleen; Genberg, Becky; Norman, Betty; et al.

JANAC-JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE Volume: 29 Issue: 2 Pages: 231-240

Published: MAR-APR 2018

3.

[Is a SIMPLE smartphone application capable of improving biological rhythms in bipolar disorder?](#)

By: Hidalgo-Mazzei, Diego; Reinares, Maria; Mateu, Ainoa; et al.

JOURNAL OF AFFECTIVE DISORDERS Volume: 223 Pages: 10-16 Published: DEC 2017

[View Abstract](#)

Times Cited: 0

(from All Databases)

Annexure A-6

DASS21

Name: _____

Date: _____

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree or a good part of time
- 3 Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

अवसाद, चिंता एवं तनाव मापनी (लघु संस्करण)

कृपया प्रत्येक कथन को ध्यान पूर्वक पढ़ें। पिछले एक सप्ताह में यह कथन आपके ऊपर किस हद तक लागू होते हैं इसका निर्धारण उनके सामने बने, खाली स्थानों में से सबसे उपयुक्त में सही का चिन्ह लगाकर करें। प्रश्नों का कोई सही या गलत उत्तर नहीं है यह केवल आपके पिछले अनुभव जानने के लिए है कृपया उत्तर देने में ज्यादा समय न लगायें।

बिलकुल नहीं = ० कुछ हद तक = १ काफी ज्यादा = २ पूरी तरह से = ३

क्र.	कथन	०	१	२	३
१	धीरे धीरे कार्य क्षमता में क्षीणता / कमी ने मुझे परेशान किया था।				
२	मुझे पता है कि मेरा मुँह सूख जाता था।				
३	मैं कोई सकारात्मक भाव अनुभव नहीं कर सका।				
४	मैंने साँस लेने में तकलीफ महसूस की (जैसे कि सामान्य से तेज साँस लेना, शारीरिक श्रम के बिना भी साँस का फूलना महसूस किया)।				
५	किसी भी कार्य की शुरुआत करने में मुझे दिक्कत होती है।				
६	मैंने परिस्थितियों को जरूरत से ज्यादा प्रतिक्रिया दी।				
७	मैंने कम्पन महसूस किया (जैसे- हाँथों में)।				
८	मैंने ऐसा महसूस किया कि मैं कई बार कुछ ज्यादा ही घबरा जाता हूँ।				
९	मैं उस परिस्थिति के बारे में बहुत चिंतित था, जिसमें मैं बहुत बेचैन हो गया था और मैंने बेवकूफी की।				
१०	मैंने अपने आपको ग्लानित/ दोषी महसूस किया।				
११	मैंने अपने आपको बहुत घबराया हुआ महसूस किया।				
१२	मैंने विश्राम करना मुश्किल पाया।				
१३	मैंने अपने आपको उदास और दुखी महसूस किया।				
१४	किसी विशेष उपक्रम या व्यवस्था द्वारा मेरे कार्यों पर नजर रखी जाये यह मुझे बर्दाश्त नहीं है।				
१५	मैंने आतंकित महसूस किया था।				
१६	किसी भी कार्य को करने के लिए मैं अपने आपको उत्साहित कर पाने में असमर्थ पता था।				
१७	मैंने महसूस किया कि मैं ज्यादा योग्य व्यक्ति नहीं था।				
१८	मैंने महसूस किया कि मैं ज्यादा भावुक हो गया था।				
१९	शारीरिक परिश्रम के बिना भी मैं अपने दिल की धड़कनों को महसूस करता था (जैसे- तेज गति से धड़कना या कभी रुक जाना)।				
२०	मैंने बिना किसी कारण के डर महसूस किया।				
२१	मुझे लगा कि जीवन सार्थक नहीं था।				

Annexure A-7

I.D. number

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ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?

Male

Female

What is your **date of birth**?

____ / ____ / ____
Day / Month / Year

What is the highest **education** you received?

None at all

Primary school

Secondary school

Tertiary

What is your **marital status**?

Single

Separated

Married

Divorced

Living as married

Widowed

Are you currently **ill**? Yes No

If something is wrong with your health what do you think it is? _____ illness/ problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks**. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderately	A great deal	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Not at all	Not much	Moderately	A great deal	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good
--	--	-----------	------	---------	------	-----------

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....
.....

THANK YOU FOR YOUR HELP

हूकॉल ब्रीफ (WHOQOL-BREF)*

विश्व स्वास्थ्य संगठन, दिसम्बर 1996

मनोविकार विभाग,

अखिल भारतीय आयुर्विज्ञान संस्थान

नई दिल्ली - 110 029.

आपके बारे में

हम चाहेंगे कि शुरुआत करने से पहले, आप अपने बारे में कुछ सामान्य प्रश्नों के उत्तर दें। सही उत्तर के चारों ओर गोला या खाली स्थान पर सही उत्तर लिखें -

आप क्या हैं? पुरुष स्त्री
आपकी जन्म तारीख क्या है? दिन/महीना/वर्ष ____ / ____ / ____
आपकी शिक्षा कहाँ तक हुई है? बिल्कुल नहीं
प्राथमिक स्कूल तक
माध्यमिक स्कूल तक
हाई स्कूल तक
हाई स्कूल से आगे

आपका वैवाहिक स्तर क्या है?

अविवाहित विवाहित लेकिन अलग हुए
विवाहित तलाकशुदा
विवाहित की तरह विधुर/विधवा
साथ में रहते हुए

क्या आजकल आप बीमार हैं हाँ नहीं

अगर आपके स्वास्थ्य में कुछ गड़बड़ है
तो आपके विचार में यह क्या है?

अनुदेश

यह प्रश्नावली पूछती है कि अपने जीवन की गुणवत्ता (क्वालिटी), स्वास्थ्य और जीवन के अन्य क्षेत्रों के बारे में आप कैसा अनुभव करते हैं। कृपया सभी प्रश्नों के उत्तर दें। यदि किसी प्रश्न के बारे में अनिश्चित हों कि कौन सा उत्तर दिया जाए, तो कृपया उसे चुनें जो सबसे उचित लगता हो है। यह अक्सर आपके मन में आने वाला पहला उत्तर हो सकता है।

कृपया अपने मापदण्डों, आशओं, सुखों एवं चिंताओं को ध्यान में रखें। आपसे आग्रह है कि इन प्रश्नों के उत्तर अपने जीवन के पिछले दो सप्ताहों के आधार पर ही दें। उदाहरण के तौर पर पिछले दो सप्ताहों के आधार पर एक प्रश्न यह हो सकता है:

	बिल्कुल नहीं	थोड़ा	मध्यम	बहुत अधिक	पूरी तरह से
क्या आपको दूसरों से उस तरह को सहारा मिलता है, जिसकी आपको आवश्यकता है?	1	2	3	4	5

पिछले दो सप्ताहों में आपको दूसरों से कितना सहारा मिलता है उसके अनुसार ऊपर दिए गए पाँचों उत्तरों में से सबसे उचित उत्तर को चुनकर उसके साथ वाली संख्या पर गोला बनाकर दर्शाएं। जैसे अगर आपको दूसरों से बहुत अधिक सहारा मिला है तो आप संख्या 4 के चारों ओर गोला बनायेंगे, जैसा कि अगले पृष्ठ पर दर्शाया गया है-

इस प्रश्नावली को उपयोग करने से पहले अनुमति के लिये सम्पर्क करें-

डा० शेखर सक्सेना,

अतिरिक्त आचार्य

मनोविकार विभाग

अखिल भारतीय आयुर्विज्ञान संस्थान, नई दिल्ली - 110 029.

	बिल्कुल नहीं	थोड़ा	मध्यम	बहुत अधिक	पूरी तरह से
क्या आपको दूसरों से उस तरह का सहारा मिलता है, जिसकी आपको आवश्यकता है?	1	2	3	④	5

अगर आपको पिछले दो सप्ताहों में दूसरों से उस तरह का सहारा जिसकी आपको आवश्यकता पड़ी, बिल्कुल नहीं मिला तो संख्या '1' के चारों ओर गोला लगायें। कृपया प्रत्येक प्रश्न को पढ़ें, अपनी भावनाओं का मूल्यांकन करें और प्रत्येक प्रश्न के लिए उस संख्या के चारों ओर गोला बनाएं जो आपके लिए उपयुक्त हो।

	बहुत खराब	काफी खराब	न अच्छा न खराब	काफी अच्छा	बहुत अच्छा
1. अपने जीवन की गुणवत्ता (क्वालिटी) का आप कितना मूल्यांकन करते हैं?	1	2	3	4	5
	बहुत असंतुष्ट	काफी असंतुष्ट	न संतुष्ट न असंतुष्ट	काफी संतुष्ट	बहुत संतुष्ट
2. अपने स्वास्थ्य से आप कितने संतुष्ट हैं?	1	2	3	4	5

निम्नलिखित प्रश्न पूछते हैं कि पिछले दो सप्ताहों में आपने कुछ चीजों को कितना अनुभव किया है?

	बिल्कुल नहीं	थोड़ा	मध्यम	बहुत अधिक	अत्याधिक
3. आपके विचार में दर्द किस हद तक आपको वह करने से रोकता है, जो आपको करना होता है?	1	2	3	4	5
4. रोजमर्रा की जिन्दगी चलाने में आपको किसी भी इलाज की कितनी आवश्यकता पड़ती है?	1	2	3	4	5
5. आप जीवन में कितना आनन्द लेते हैं?	1	2	3	4	5
6. अपने जीवन को किस हद तक आप सार्थक अनुभव करते हैं?	1	2	3	4	5
7. आप कितनी अच्छी तरह से मन को एकाग्र कर सकते हैं?	1	2	3	4	5

	बिल्कुल नहीं	थोड़ा	मध्यम	बहुत अधिक	अत्याधिक
8. अपने दैनिक जीवन में अपने आप को आप कितना सुरक्षित अनुभव करते हैं?	1	2	3	4	5
9. आपका भौतिक वातावरण कितना स्वास्थ्यवर्धक है?	1	2	3	4	5

निम्नलिखित प्रश्न आपसे इस बारे में पूछते हैं कि पिछले दो सप्ताहों में कुछ चीजें या कार्य आपने कितनी पूर्णता से अनुभव किए हैं या कर पाए हैं

	बिल्कुल नहीं	थोड़ा	मध्यम	बहुत अधिक	पूरी तरह से
10. क्या आपमें दिन प्रतिदिन के जीवन कर््यों के लिए पर्याप्त स्फूर्ति (चुस्ती) है?	1	2	3	4	5
11. क्या अपनी शारीरिक बनावट (रूप) को आप स्वीकार कर पाते हैं?	1	2	3	4	5
12. क्या आपके पास अपनी आवश्यकताएं पूरी करने के लिए पर्याप्त धन है?	1	2	3	4	5
13. आपको दिन प्रतिदिन के जीवन में जिन जानकारीयों की आवश्यकता है, वे आपको किस हद तक उपलब्ध हैं?	1	2	3	4	5
14. अवकाश की क्रियाओं के अवसर आपको किस हद तक मिलते हैं?	1	2	3	4	5
15. आप कितनी अच्छी तरह इधर-उधर आ जा पाते हैं?	1	2	3	4	5

निम्नलिखित प्रश्न आपसे इस बारे में पूछते हैं कि पिछले दो सप्ताहों में अपने जीवन के विभिन्न पहलुओं के बारे में आप कितने अच्छे या संतुष्ट रहे हैं?

	बहुत असंतुष्ट	काफी असंतुष्ट	न संतुष्ट न असंतुष्ट	काफी संतुष्ट	बहुत संतुष्ट
16. अपनी नींद से आप कितने संतुष्ट हैं?	1	2	3	4	5

	बहुत असंतुष्ट	काफी असंतुष्ट	न संतुष्ट न असंतुष्ट	काफी संतुष्ट	बहुत संतुष्ट
17. दैनिक जीवन कार्यो को करने की अपनी क्षमता से आप कितने संतुष्ट हैं?	1	2	3	4	5
18. अपनी कार्यक्षमता से आप कितने संतुष्ट हैं?	1	2	3	4	5
19. अपने से आप कितने संतुष्ट हैं?	1	2	3	4	5
20. अपने व्यक्तिगत संबंधों से आप कितने संतुष्ट हैं?	1	2	3	4	5
21. अपने यौन (सैक्स) जीवन से आप कितने संतुष्ट हैं?	1	2	3	4	5
22. अपने मित्रों से आपको जो सहारा मिलता है, उससे आप कितने संतुष्ट हैं?	1	2	3	4	5
23. अपने रहने की जगह की परिस्थितियों से आप कितने संतुष्ट हैं?	1	2	3	4	5
24. स्वास्थ्य सेवाओं तक आपकी पहुंच से आप कितने संतुष्ट हैं?	1	2	3	4	5
25. अपने यातायात के साधन से आप कितने संतुष्ट हैं?	1	2	3	4	5

निम्नलिखित प्रश्न इस बारे में है कि पिछले दो सप्ताहों में आपने कुछ चीजों को कितनी बार महसूस किया है

	कभी नहीं	कभी-कभी	अक्सर	बहुत अधिक बार	हमेशा
26. कितनी बार आप नकरात्मक भावनाएँ (जैसे दुःखी मन, निराशा, घबराहट, उदासी) महसूस करते हैं?	1	2	3	4	5

क्या इस प्रश्नावली को भरने में किसी ने आपकी मदद की?

इस प्रश्नावली को भरने में कितना समय लगा?

इस प्रश्नावली के बारे में आपकी कोई टिप्पणी

आपके सहयोग के लिए धन्यवाद !



Annexure A-8

ujjwal dahiya <ujjwaldahiya3@gmail.com>

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Sat, Aug 3, 2019 at 12:20 PM

To: ujjwaldahiya3@gmail.com

Cc: permissions@who.int

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* Title

* Ms

* First name

* Ujjwal

* Family name

* Dahiya

* Organization/affiliation

* AIIMS

* Web site address

*

* Type of organization

* Government

* If other, please specify

*

* If STM signatory, please select

*

* Position

*

* Telephone

* +91 9899770134

* Address

* F-105, Ansari Nagar West
Delhi-110029

* Country

* India

* Email

* ujjwaldahiya3@gmail.com

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Annexure A-9

List of Experts for validation of Tools

1. Dr.(Mrs.) Harjinder Goyal, Principal
RAK College of Nursing, New Delhi
2. Dr. Sandhya Gupta, Acting Principal, College of Nursing
AIIMS, New Delhi
3. Dr. Pragya Pathak, Associate Professor, College of Nursing
AIIMS, New Delhi
4. Dr. Kusum Kathleen McKeehan, Nursing Advisor
SRHU, Dehradun
5. Dr. Lekha Vishwanath, Professor
SRHU, Dehradun
6. Dr. Soumita Bagchi , Associate Professor
Deptt. Of Nephrology, AIIMS, New Delhi
7. Dr. Koushik Sinha Deb, Associate Professor
Deptt. Of Psychiatry, AIIMS, New Delhi

List of Experts for validation of Nurse led intervention

1. Dr. Arun Kumar Subbiah, Assistant Professor
Deptt. Of Nephrology, AIIMS, New Delhi
2. Dr. Deepak Kumar, Senior Resident
Deptt. Of Nephrology, AIIMS, New Delhi
3. Dr. Sujata Sathpathy, Associate Professor
Deptt. Of Clinical Psychology, AIIMS, New Delhi
4. Dr. Rohit Verma, Assistant Professor
Deptt. Of Psychiatry, AIIMS, New Delhi
5. Dr. Namrata Singh, Senior Dietician
Deptt. Of Dietetics, AIIMS, New Delhi
6. Mrs. Jasmine Kaur, Dietician
Deptt. Of Dietetics, AIIMS, New Delhi
7. Dr. Krishna B, Senior Resident

Deptt. Of Physical Medicine and Rehabilitation AIIMS, New Delhi

8. Mr. Ajeet, Physiotherapist

AIIMS, New Delhi

9. Ms. Geeta Saifi, Tutor,

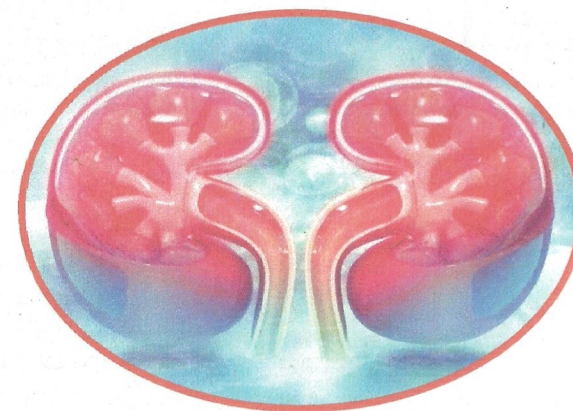
RAK College of Nursing, New Delhi

10. Ms. Sunita Devi, Nursing Officer

Transplant Clinic, AIIMS, New Delhi



Information Booklet on
**Self Care Management after
Kidney Transplantation**



Compiled by
Ujjwal Dahiya
Research Scholar SRHU



After going through the booklet, kidney transplant recipients would be able to:

- Demonstrate understanding of kidneys, its functions and meaning of transplantation.
- Understand the role of immunosuppressants after kidney transplantation.
- Identify the need for adherence to immunosuppressive therapy.
- Become aware of self management regarding



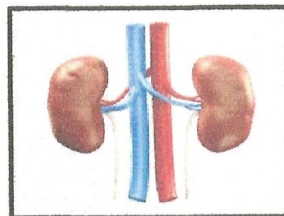
- Medication
- Nutrition and diet
- Avoidance of infections
- Lifestyle modification
- Psychological care
- Follow up



- Discuss the common complications and their prevention after kidney transplantation.

Functions of Kidneys

- The kidneys are powerful chemical factories that perform the following functions:
 - remove waste products from the body
 - remove drugs from the body
 - balance the body's fluids
 - release hormones that regulate blood pressure
 - produce an active form of vitamin D that promotes strong, healthy bones
 - control the production of red blood cells



Kidney Transplantation

- When the kidneys fail, treatment is needed to replace the work your kidneys can no longer do.
- There are two types of treatment for kidney failure — **dialysis** or **kidney transplant**.
- Many people feel that a kidney transplant offers more freedom and a better quality of life than dialysis. When you get a kidney transplant, a healthy kidney is placed inside your body to do the work your own kidneys can no longer do. Although most transplants are successful and last for many years, how long they last can vary from one person to the other.

What are Immunosuppressant Medicines?

- Normally, your body fights off anything that isn't part of itself, like germs and viruses. That system of protection is called your immune system.
- To stop your body from attacking or rejecting the donated kidney, you will have to take medicines to keep your immune system less active (called anti-rejection medicines or immunosuppressant medicines).
- You'll need to take them as long as your new kidney is working. Without them, your immune system would see the donated kidney as "foreign," and would attack and destroy it.
- Anti-rejection medicines can have some side effects. Fortunately, for most people, side effects are usually manageable. You should not decrease the dose of medicines on your own.
- Besides the immunosuppressive medicines, you will take other medicines as well. You will take medicines to protect you from infection, too.

Need to take Immunosuppressants

- Kidney rejection is hard to diagnose in its early stages. Rejection is often not reversible once it starts.
- You should never stop taking your anti-rejection medication no matter how good you feel and even if you think your transplanted kidney is working well.
- Stopping or missing them may cause a rejection to occur.



Self care after kidney transplantation

Self care:

- It is the practice of individuals looking after their own health using the knowledge and information available to them. Self-care is defined as the care by the individual that incorporates any deliberate moves to look after physical, mental and emotional health.



1. Medications

- Take your anti rejection medications daily in the proper dose and at right times as prescribed by the physician.
- Use alarms to remember when to take your medication.
- If you miss a dose, take it as soon as you remember. If it is time for the next dose, do not take a double dose.
- Ask for and review all written instructions for any change in medication dose or frequency.
- Discuss with your treating physician of problems and concerns about medications during every transplantclinic visit.
- Medications prescribed for other comorbid illness should be taken as advised.
- If you take a prescription for some other illness, please discuss them before taking with your doctor. Certain medications can interfere with your anti-rejection medications and keep them from working.
- Continue to take your anti-rejection medication no matter how great you feel, even if you think your transplanted kidney is working well. Stopping them may cause rejection to occur.
- Even though you are taking your medicines every day, you may still develop rejection of the kidney transplant. You need to know your body very well. If you have any of the following, you should consult your treating physician right away:
 - a drop in your urine output
 - a fever above 100 degrees
 - tenderness of your new kidney
 - bloody urine
 - flu-like feelings
 - weight gain (more than 2 kg in two days)



2. Nutrition and Diet

- Eating properly is an important part of the recovery process. Avoid eating outside food. Eat clean and hygienic homemade food. Eat well balanced diet. Maintain a diet low in sodium, low in fat specially saturated fat, low in dietary cholesterol and high in dietary fibre.
- A healthy, balanced diet will help prevent high blood sugar, excess weight gain and promote overall wellness and health.
- A balanced diet includes a variety of fresh fruits and vegetables, lean meats, reduced-fat dairy products, whole grains, and plenty of water as advised by your doctor.
- Additionally, you may need to avoid eating certain types of foods.
 - Raw or undercooked meat, poultry and fish
 - Unpasteurized milk, cheese or yogurt
 - Uncooked or undercooked eggs and any products containing them
 - Pomegranate or pomegranate juice; especially if you are taking cyclosporine or prograf (specific immunosuppressive medicines)
 - Unwashed raw fruits and damaged fruits
 - Unwashed raw vegetables and unwashed salads



3. Avoidance of Infection

- Because immunosuppressive medications interfere with a patient's natural immune system, you need to protect yourself consciously from infection after the surgery by taking the following precautions:
 - Wash hands often.
 - Keep hands away from face and mouth.
 - Stay away from people with colds or other infections.
 - Ask friend to visit only when they are well.
 - If the patient has a wound and must change his own dressing, wash hands before and after.



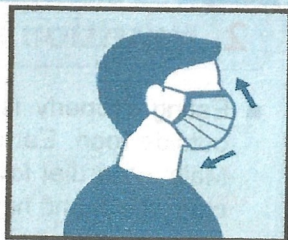
- Wash hands after coughing or sneezing, and throw tissues into the trash immediately.

- If someone in your family becomes ill with a cold or flu, have that individual follow normal precautions (use masks, separate drinking glasses, covering their mouths when coughing, etc.)

- Avoid working in the soil for 6 months after the transplant. Thereafter, wear gloves and mask.

- Avoid handling animal waste and avoid contact with animals who roam outside. Avoid keeping home pets.

- Take good care of your teeth by brushing two times a day and seeing the dentist for regular check-up



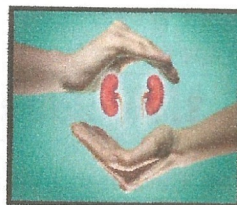
4. Lifestyle modification

- Adequate exercise is important after renal transplantation. It will help you both physically and mentally and will prevent excessive weight gain.

- Regular exercise will help control your cholesterol levels, blood pressure, and weight. Exercise daily. It is suggested to start with walking 15-20 minutes every day for at least four to five times in a week, and gradually increase time as tolerated after consulting with your treating physician.

- Avoid taking tobacco, alcohol and smoking.

- Any form of sports that require physical exertion, body contact such as wrestling and football, and water contacts like in swimming should be avoided.



5. Psychological Care

- Getting a kidney transplant is a major life change, and many patients may feel stressed and anxious about big life changes. Uncertainty about the future of graft and changes in the lifestyle may also lead to some psychological changes. Reach out to your family and friends for support.

- Discuss with your doctor in the transplant clinic about your emotional changes. Maintain a healthy lifestyle. Use helpful ways of coping like meditation, yoga, relaxation therapy etc.

- Practice spirituality by praying or any other form.



6. Follow up

- Regular follow up is required. Weigh yourself regularly. Monitor your Blood pressure regularly. Monitor your blood sugar.



Complications after kidney transplant

- Minor infections, such as urinary tract infections (UTIs), colds and flu, are common after kidney transplants. You should report any of the following problems to your doctor as soon as possible:

- Sores, wounds, or injuries; especially those that don't heal

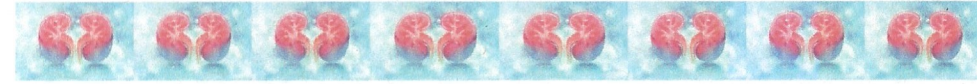
- Urinary tract infection symptoms such as frequent urge to urinate, pain or burning feeling when urinating, cloudy or reddish urine, or bad smelling urine

- Respiratory infection symptoms such as cough, nasal congestion, runny nose, sore or scratchy throat, or fever.

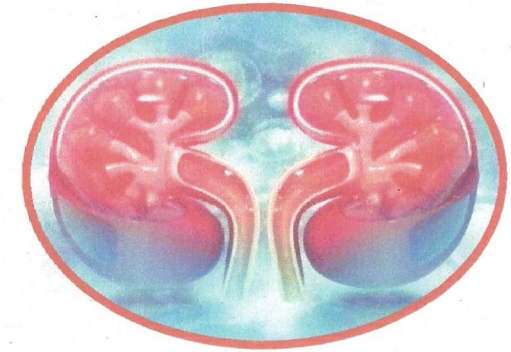


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किडनी ट्रांसप्लांट के बाद अपनी देखरेख के प्रबंधन पर सूचना पुस्तिका



उज्जवल दहिया

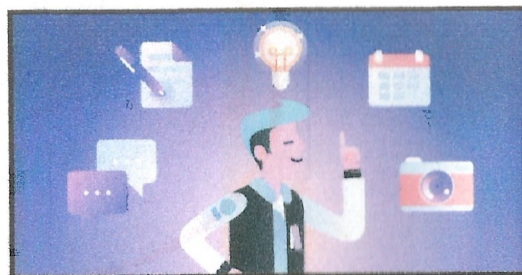
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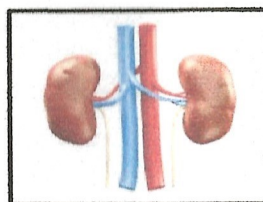


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- लाल रक्त कोशिकाओं के निर्माण को नियंत्रित रखना



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इम्यूनोसुप्रेसेंट्स दवाईयाँ क्या हैं?

- सामान्यतः आपका शरीर किसी भी ऐसी चीज से लड़ता है जो उसका भाग/हिस्सा नहीं है, जैसे — कीटाणु और विषाणु। ये प्रतिरक्षा की प्रक्रिया 'इम्यून सिस्टम' / रोग प्रतिरोधक क्षमता कहलाती है। आपके शरीर को दान की गई किडनी पर आक्रमण करने या अस्वीकार करने से रोकने के लिए, आपको अपने 'इम्यून सिस्टम' को कम सक्रिय बनाने के लिये दवाईयाँ (जो एंटी-रिजैक्शन दवाईयाँ या इम्यूनोसुप्रेसेंट्स दवाईयाँ कहलाती हैं) लेनी होती हैं। आपको चाहिये कि उन्हें तब तक लेते रहें जब तक आपकी नई किडनी काम कर रही है। उनके बिना, आपका इम्यून सिस्टम दान की हुई किडनी को विदेशी के जैसे देख सकता है और आक्रमण करके इसे समाप्त कर सकता है।
- एंटी-रिजैक्शन दवाईयाँ के कुछ दुष्प्रभाव हो सकते हैं। भाग्यवश, अधिकतर लोगों के लिये दुष्प्रभाव प्रायः नियंत्रित होते हैं। आपको दवाईयाँ की खुराक अपने आप से कम नहीं करनी चाहियें। इम्यूनोसुप्रेसेंट्स दवाईयाँ के अतिरिक्त आपको अन्य दवाईयाँ भी लेनी होंगी। अपने आपको संक्रमण से बचाने के लिये भी दवाईयाँ लेंगे।

इम्यूनोसुप्रेसेंट्स लेने की आवश्यकता

- किडनी को अस्वीकार के लक्षणों को उनकी प्राथमिक अवस्थाओं में पकड़ना कठिन है। अस्वीकारता को एक बार प्रारंभ हो जाने के उपरांत प्रायः पलटा नहीं जा सकता। आपको एंटी-रिजैक्शन लेने कभी भी बंद नहीं करने चाहियें भले ही आप कितना ही अच्छा क्यों ना अनुभव/महसूस करें, यहाँ तक कि यदि आपको ये लगे कि आपकी बदली गई किडनी सही से काम कर रही है। उन्हें बंद करना और खुराक लेना भूल जाना किडनी अस्वीकारता का एक कारण हो सकता है।



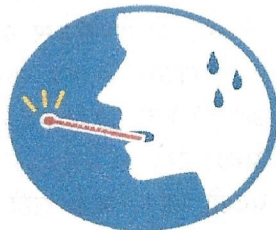
किडनी ट्रांसप्लांट के बाद अपनी देखरेख :

- अपने आस पास उपलब्ध जानकारी और सूचना का प्रयोग करते हुए अपने स्वास्थ्य की देखरेख करने को स्वयं की देखभाल कहते हैं।



1. उपचार:

- अपनी एंटी-रिजैक्शन दवाईयाँ नियमित रूप से, पूरी खुराक के साथ और सही समय पर लें, जैसा कि डॉक्टर ने बताया हो।
- अपनी दवाईयाँ कब लेनी हैं, इसे याद रखने के लिये अलार्म का प्रयोग करें।
- अगर आप कोई खुराक लेना भूल गए हैं तो जितनी जल्दी आपको याद आए आप उसे लें। अगर ये अगली खुराक का समय हो तो आप दो खुराक एक साथ ना लें।
- दवाई की खुराक में या उसकी आवृत्ति में किसी बदलाव की जानकारी के लिये सभी लिखित निदेशों को देखें या पूछें।
- प्रत्येक बार ट्रांसप्लांट क्लिनिक जाने पर दवाईयों से संबंधित समस्याओं और प्रश्नों के लिये आपका उपचार करने वाले डॉक्टर से बात करें।
- साथ में चल रही किसी अन्य बीमारी के लिये निर्देशित दवाईयाँ डॉक्टर की सलाह से लेनी चाहियें।
- यदि आप किसी अन्य बीमारी के लिये निर्देशित दवाईयाँ लेते हैं तो कृपया उन्हें लेने से पहले अपने डॉक्टर से उनके बारे में सुझाव लें।
- अपनी एंटी रिजैक्शन दवाईयाँ लगातार लेते रहें चाहे आप कितना ही स्वस्थ अनुभव कर रहे हों, यहाँ तक कि तब भी जब आपको लगे कि आपकी ट्रांसप्लांट किडनी अच्छे से काम कर रही है। दवाईयों को रोकना रिजैक्शन होने का कारण हो सकता है।
- भले ही आप अपनी दवाईयाँ रोज ले रहे हो तब भी किडनी ट्रांसप्लांट का रिजैक्शन हो सकता है। आपको अपने शरीर को अच्छे से जानना चाहिये। अगर आपको निम्नांकित में से कुछ भी होता हो तो आपको तत्काल अपने डॉक्टर से संपर्क करना चाहिये:
 - आपके पेशाब की मात्रा का कम होना
 - 100 डिग्री का बुखार
 - आपकी नई किडनी में पीड़ा
 - पेशाब में रक्त आना
 - बुखार या जुकाम जैसा अनुभव रहना
 - वजन का बढ़ना (2 दिन में 2 किलो से अधिक)



2. खान-पान और आहार

- भली प्रकार आहार लेना स्वास्थ्य लाभ प्रक्रिया का महत्वपूर्ण भाग है। बाहर के खाने से बचें। साफ और स्वच्छ घर का बना भोजन करें। भली प्रकार संतुलित आहार ग्रहण करें। जिसमें सोडियम की मात्रा कम हो, फैट की मात्रा कम हो, विशेष रूप से सैचुरेटेड फैट की, कोलेस्ट्रॉल कम हो और फाइबर अधिक हो ऐसे आहार का संतुलन बनाएँ।
- एक स्वस्थ संतुलित आहार उच्च ब्लड शुगर/रक्त शर्करा, अत्यधिक वजन का बढ़ना से रोकेगी और संपूर्ण स्वास्थ्य के प्रवर्तन में सहायता करेगी।
- एक संतुलित आहार में ताजे फलों और सब्जियों की प्रजातियाँ, कम वसा वाला मांस, कम वसा वाले दुग्ध उत्पाद, साबुत अनाज और बहुत अधिक पानी सम्मिलित हैं, जैसा कि आपके डॉक्टर द्वारा सुझाया गया है।
- इसके अतिरिक्त आपको कुछ विशेष प्रकार के भोजन को खाना छोड़ना होगा :
 - कच्चा, अधपका मांस, मुर्गा व मछली।
 - अपाश्चीकृत दूध, चीज़ और दही।
 - अधपका भोजन या अधपके अंडे और कोई अन्य उत्पाद जिसमें से शामिल हों।
 - अनार और अनार का जूस, विशेष रूप से जब आप साइक्लोपोरीन या प्रोग्रैफ (विशिष्ट इम्यूनोसुप्रेसिव दवाईयाँ) ले रहे हों।
 - बिना धुले हुए कच्चे फल और खराब हुए फल
 - बिना धुली सब्जियाँ और बिना धुली सलाद।



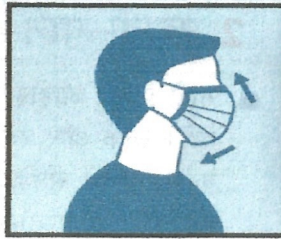
3. संक्रमण से बचाव

- चूँकि इम्यूनोसुप्रेसिव दवाईयाँ एक मरीज की प्राकृतिक प्रतिरक्षा प्रणाली-इम्यून सिस्टम में हस्तक्षेप करती हैं इसलिए सर्जरी के बाद आपको गंभीरता से अपने आपको निम्नांकित सावधानियाँ बरतकर संक्रमण से बचाना चाहिये:
 - बार-बार हाथ धोएँ
 - हाथों को मुँह और चेहरे से दूर रखें।
 - ऐसे लोगों से दूर रहें जिन्हें खाँसी-जुकाम या अन्य कोई संक्रमण हो।
 - दोस्तों से तभी मिले जब वे ठीक/स्वस्थ हों।
 - अगर रोगी को घाव है और अपनी पट्टी अपने आप बदलनी पड़ती है तो उससे पहले और बाद में हाथ अवश्य धोएँ।



- खौंसने या छींकने के बाद हाथ धोएँ और पेपर/नेपकीन को तुरंत कूड़ेदान में डालें।

- अगर आपके परिवार में कोई जुकाम या संक्रमण से बीमार हो जाता है तो उसको कुछ सामान्य सावधानियाँ बरतनी होती हैं (मास्क का प्रयोग करें, पानी पीने के अलग ग्लास रखें, खौंसी आदि करते समय अपने मुँह को ढककर रखें।)



- ट्रांसप्लांट के बाद 6 महीने तक मिट्टी में काम करने से बचें। उसके बाद, दस्ताने और मास्क पहनें।
- जानवरों के मल की सफाई आदि करने से दूर रहें और आवारा जानवरों के संपर्क से दूर रहें। घर में पालतू जानवर रखने से बचें।
- अपने दाँतों को एक दिन में दो बार साफ करते हुए अच्छी देखभाल करें और डेंटिस्ट को नियमित रूप से दिखाते रहें।

4. जीवनशैली/दिनचर्या में बदलाव

- रीनल ट्रांसप्लांट के बाद पर्याप्त व्यायाम आवश्यक है। यह आपको शारीरिक व मानसिक रूप से सहायता प्रदान करेगा और अत्यधिक वजन बढ़ने को भी रोकेगा। नियमित व्यायाम आपके कोलैस्ट्रॉल स्तर, रक्तचाप व वजन को नियंत्रित करने में सहायता करेगा। नित्य व्यायाम करें। यह सुझाव दिया जाता है कि एक सप्ताह में 5 दिन कम से कम 20.30 मिनट प्रतिदिन व्यायाम करें और अपने डॉक्टर से सलाह लेने के बाद इस समय को इतना बढ़ाएँ जितना आप सहन कर सकें। तंबकू/गुटका, शराब और धूम्रपान से दूर रहें।
- ऐसा कोई भी खेल जिसमें शारीरिक तनाव, शरीर का संपर्क जैसे कुश्ती और फुटबॉल तथा पानी का संपर्क हो जैसे तैराकी, उसका त्याग करें।



5. मनोवैज्ञानिक देखरेख

- किडनी ट्रांसप्लांट जीवन का एक बहुत बड़ा बदलाव है और बहुत से रोगी तनाव का अनुभव करते हैं और बड़े जीवन के बदलावों के बारे में चिंतित होते हैं। भविष्य में अधिक परिश्रम ना कर पाने की अनिश्चितता और जीवनशैली में बदलाव भी मनोवैज्ञानिक बदलाव की ओर ले जा सकता है।
- सहयोग के लिए अपने परिवार और मित्रों के पास जाएँ।

- अपने भावनात्मक बदलावों के बारे में ट्रांसप्लांट क्लीनिक में अपने डॉक्टर से बात करें।
- एक स्वस्थ जीवनशैली बनाए रखें।
- संघर्ष या मुकाबला करने के लिये महत्वपूर्ण रास्तों का प्रयोग करें जैसे – ध्यान, योग, विश्राम पद्धति आदि।
- प्रार्थना या अन्य किसी प्रकार से अध्यात्मता का पालन करें।

6. जाँच कराना

- नियमित जाँच आवश्यक है। अपना वजन नियमित रूप से तौलते रहें। अपना रक्तचाप नियमित रूप से नापते रहें। अपना ब्लड शुगर नापते रहें।



किडनी ट्रांसप्लांट के बाद की समस्याएँ

- छोटे-मोटे संक्रमण जैसे मूत्र मार्ग में संक्रमण, सर्दी और बुखार, किडनी ट्रांसप्लांट के बाद सामान्य हैं। निम्नांकित में से किसी भी समस्या के लिए आपको अपने डॉक्टर को जल्दी से जल्दी बताना चाहिए :
 - फोड़े-फुंसी, घाव या कोई क्षति; विशेष रूप से जो सही नहीं हो रही हो।
 - मूत्र मार्ग के संक्रमण के लक्षण जैसे पेशाब जाने की बार-बार इच्छा होना, पेशाब करते हुए दर्द और जलन का अनुभव, नीले या लाल रंग का पेशाब या बुरी गंध वाला पेशाब।
 - सांस लेने संबंधी संक्रमण जैसे सर्दी-जुकाम, बंद नाक, बहती नाक, गले में दर्द या खराश या बुखार।



संदर्भ

- <https://www.organindia.org/post-transplant-care>
- <https://www.kidney.org/atoz>
- Core Concepts in Renal Transplantation, Chandraker, Anil, Sayegh, Mohammed H., Singh, Ajay K. 2012
- Kidney Transplantation - Principles and Practice: Expert Consult, Peter J Morris 2013
- <https://kdigo.org/guidelines/transplant-recipient>



“Ethics Committee”

SRHU/HIMS/E-1/2019/ 11/2

Date: 26/08/2019

To,
Ms. Ujjwal Dahiya,
Ph.D Scholar,
Himalayan College of Nursing
Swami Rama Himalayan University.

Ref: Research Project entitled : “Effectiveness of Nurse led intervention on self care behavior, psychological symptoms and quality of life among kidney transplant recipients in a selected tertiary care hospital in New Delhi.” Submitted by Principal investigator, Ms. Ujjwal Dahiya, Ph.D Scholar, under the guidance of Dr. Kamli Prakash, Professor, Himalayan College of Nursing., Swami Rama Himalayan University.

Dear Ms. Ujjwal Dahiya,

With reference to your submission letter, dated 3/07/2019, the Ethics Committee, SRH University reviewed and discussed your application for approval of the above referred research protocol on 17/08/2019.

The following members were present in the meeting held on 17/08/2019, at 11:30 AM in the deptt of Pharmacology, H.I.M.S., SRH University:

Sr. no.	Name of the Member	Designation and Qualification	Representation as per Schedule Y	Gender	Affiliation with the Institution
1.	Prof. K.C. Mishra	Chairman MBBS, MD, MAMS	Ex. Principal	M	No
2.	Mr. G.N.S. Gurudutt	Member M.A., M.phil.	Social Scientist	M	No
3.	Mr. J.P. Pant	Member M.A. , L.L.B	Practicing Advocate	M	No
4.	Mrs. Manju Chamoli	Member Gram Pradhan, Athurwala	Community Representative	F	No
5.	Prof. Mushtaq Ammed	Member MBBS, MD(Radiotherapy)	Professor, Deptt. of Radiotherapy	M	Yes
6.	Dr. B.P.Kalra	Member MBBS,DCH, DNB(Paediatrics)	Clinician Professor of Paediatrics	M	Yes
7.	Prof. D.C. Dhasmana	Member Secretary, MBBS,MD(Pharmacology)	Pharmacologist	M	Yes

This is to confirm that only members, who were independent of the Investigator of the study, have voted and provided opinion on the study.

The Ethics Committee, Swami Rama Himalayan University, has no objection to the conduct of the study in the present form, as per the submitted protocol, subject to the prior approval of local Ethics Committee empowered to supervise the project at the study site.

Further, the permission is subject to the statutory provisions and permissions, as deemed necessary, to be obtained from concerned authorities.

The Ethics committee, Swami Rama Himalayan University expects to be informed about the progress of the study, any changes in the protocol and asks to be provided a copy of the final report.

The Ethics committee, Swami Rama Himalayan University follows procedures that are in compliance with the requirements of ICH (international Conference on Harmonization) guidelines related to GCP (Good Clinical Practice) and applicable Indian regulations, revised and updated from time to time.

Dr. D.C. Dhasmana,
Member Secretary, Ethics Committee



INSTITUTE ETHICS COMMITTEE
ALL INDIA INSTITUTE OF MEDICAL SCIENCES
Room No 102, 1st Floor Old O.T. Block,
ANSARI NAGAR, NEW DELHI 110029
Tel.No.4579 (Internal), 26594579 (Direct)

Date: 15-04-2019

Chairman

Dr. T.P. Singh,
Basic Scientist

Members:

Dr. Pratap Sharan,
Clinician

Dr. Rama V. Baru
Social Scientist

Dr. Payal Mago,
Lay Person

Sh. Rajan Khosla,
Legal Person

Dr. Sunesh Kumar
Clinician

Dr. Rohit Saxena
Clinician

Dr. Peush Sahni,
Clinician

Dr. Rakesh Lodha
Clinician

Dr. Nikhil Tandon
Clinician

Dr. S.K. Maulik,
Basic Scientist

Dr. V. Sreenivas
Biostatistician

Dr. Subodh Garg
Clinician

Dr. Sameer Bakhshi
Clinician

Member Secretary:

Dr. Atul Sharma
Clinician

Ms. Ujjwal Dahiya

Lecturer

Deptt. of College Of Nursing,
AIIMS, New Delhi

Ref. No.: IEC-597/02.11.2018, OP-02/05.04.2019

Sub: A study on effectiveness of nurse led intervention on self care behavior, psychological symptoms and quality of life among kidney transplant recipients in a tertiary care hospital of New Delhi-A Randomized Controlled Trial.

Dear Ms. Dahiya

This has reference to your above mentioned project. The project was discussed in the Ethics Committee meeting held on 05-04-2019 at 3:30 P.M. in the Ethics Committee Room, AIIMS & the following members of the Ethics Committee attended the meeting:

- | | |
|---|------------------|
| 1. Dr. T.P. Singh, Distinguish Research Professor, Dept. of Biophysics, | Chairman |
| 2. Mr. Rajan Khosla, LLB,- Member Ethics Committee, | Member |
| 3. Dr. Payal Mago, Principal, Shaheed Rajguru College of Applied Sciences | Member |
| 4. Dr. Rama V. Baru, Professor, Jawaharlal Nehru University | Member |
| 5. Dr. Rohit Saxena, Professor, Deptt. of R.P. Centre, AIIMS | Member |
| 6. Dr. Rakesh Lodha, Professor, Deptt. of Paediatrics, AIIMS | Member |
| 7. Dr. S.K. Maulik, Professor, Deptt. of Pharmacology, AIIMS | Member |
| 8. Dr. Peush Sahni, Professor, Deptt. of Gastrointestinal Surgery, AIIMS | Member |
| 9. Dr. V. Sreenivas, Professor, Deptt. of Biostatistics, AIIMS | Member |
| 10. Dr. Sameer Bakhshi, Professor, Deptt. of Medical Oncology, AIIMS | Member |
| 11. Dr. Subodh Garg, Professor, Deptt. of Surgery, AIIMS | Member |
| 12. Dr. Atul Sharma, Professor Deptt. of Medical Oncology, AIIMS | Member Secretary |

The following documents have been submitted for ethical approval:

- Self care behavior of kidney transplant recipients also needs to be assessed as it is a key concept in health promotion, decisions and actions that the individual takes to cope with health problem and therefore improves his/her health, so self care behavior can be one of the outcome measure which will include self care practice and adherence to immunosuppressive therapy.
- Depression, anxiety and stress can be termed as psychological symptoms in the study.
- Change of title to: A study on effectiveness of nurse led intervention on self care behavior, psychological symptoms and quality of life among kidney transplant recipients in a tertiary care hospital of New Delhi-a randomized controlled trial.

The Changes have been approved from ethical angle w.e.f 05.04.2019 subject to the following conditions:

- The approval is valid for the period of the conduct of study according to this protocol under the responsibility **Mr. Ujjwal Dahiya**, Principal Investigator.
- It is hereby confirmed that neither you nor any of the study team members have participated in the voting/decision making procedures of the committee.
- No significant changes to the research protocol should be made and implemented without prior consent of the IEC and any changes/deviations from the protocol which increase the risk for the subjects should be submitted to the IEC and approved by it prior to implementation.
- The study progress report should be made available to the IEC for review every 6 months.
- IEC should be informed about all SAE's occurring in the study as per DCGI guidelines.

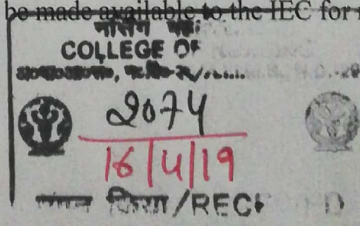
The Study progress report should be made available to the IEC for review every 6 months

With Warm regards

Yours sincerely,

(Dr. Atul Sharma)

Member Secretary Ethics Committee



Annexure A-13

PARTICIPANT INFORMATION SHEET

I Title of the study/ Project Title: A study on effectiveness of nurse led intervention on self care behaviour, psychological symptoms and quality of life among kidney transplant recipients in a selected tertiary care hospital of New Delhi- a randomized controlled trial.

II Principal Investigator: Ms. Ujjwal Dahiya, Research scholar, SRHU Dehradun, Contact No. 9899770134

III Co- Investigator: Dr. Kamli Prakash, Professor, HCN SRHU, Dr. Sandeep Mahajan, Professor, Department of Nephrology AIIMS, Dr. Nand Kumar, Professor, Department of Psychiatry AIIMS.

IV Purpose of the study: We are conducting a study to determine the effect of nurse led intervention on self care behaviour, psychological symptoms and quality of life among kidney transplant recipients. The information learned from this study will help us to develop programmes in improving self care behaviour and quality of life and reducing psychological symptoms in kidney transplant recipients.

V Methods of Study: If you agree to participate in the study, your basic information and scoring with respect to self care behaviour, psychological symptoms and quality of life will be recorded. It will take approximately 30 minutes. You will be placed either of the two groups with computer generated randomization table. One group will be given nurse led intervention and the other group will get the routine care. Participants in both groups will be followed up 2 times, at 3 months after intervention and 6 months after intervention.

VI Expected duration of subject participation: Total duration is 6 months. Information will be recorded 3 times, for each assessment it will take approximately 30 minutes.

VII The benefits to be expected from the research to the subjects or to others: No direct benefits by participating in the study, standard care that is being provided will be continued.

VIII Potential risks and discomforts: There is no risk associated with this study.

IX Confidentiality: All the information provided during the study will be kept confidential and will be utilized only for the study purpose.

X Freedom of individual to participate and to withdraw from research at any time without penalty or loss of benefits to which the subject would otherwise be entitled:

You are free to deny to participate in the study or to withdraw from the study at any time. If you choose not to participate or to withdraw from the study, you will receive the usual care.

XI Contact: In the event that at any time during the course of study you feel that you have not been adequately informed about the study or feel undue stress to continue against your wishes you can contact.

Principal Investigator

Ms. Ujjwal Dahiya

Contact No. 9899770134

CONSENT FORM

Title of project: **A study on effectiveness of nurse led intervention on self care behaviour, psychological symptoms and quality of life among kidney transplant recipients in a selected tertiary care hospital of New Delhi- a randomized controlled trial.**

Name of Principal Investigator: Ms.Ujjwal Dahiya

Mob. No. 9899770134

The contents of the information sheet dated _____ that was provided have been read carefully by me / explained in detail to me, in a language that I comprehend, and I have fully understood the contents. I confirm that I have had the opportunity to ask questions.

The nature and purpose of the study and expected duration of the study, and other relevant details of the study have been explained to me in detail. I have been explained that there are no risks associated with the study. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal right being affected.

I understand that the information collected about me from my participation in this research and sections of any of my medical notes may be looked at by responsible individuals. I give permission for these individuals to have access to my records.

I agree to take part in the above study.

(Signatures / Left Thumb Impression)

Date:

Place:

Name of the Participant: _____

Son / Daughter / Spouse of: _____

Complete postal address: _____

This is to certify that the above consent has been obtained in my presence.

Signatures of the Principal Investigator

Date:

Place:

सहभागी सूचना पत्र

1. **अध्ययन/परियोजना का शीर्षक:** किडनी ट्रांसप्लांट कराने वाले रोगियों के लिए नर्स संचालित हस्तक्षेप का स्वयं देखभाल आचरण, मनोवैज्ञानिक लक्षण तथा जीवन की गुणवत्ता पर प्रभाव का अध्ययन करने हेतु एक यादृच्छिक नियंत्रित परीक्षण।
2. **मुख्य अन्वेषक:** सुश्री उज्ज्वल दहिया, रिसर्च स्कॉलर, एसआरएचयू
संपर्क नम्बर 9899770134
3. **सह-अन्वेषक:** डॉ. कमली प्रकाश प्रोफेसर एचसीएन, एसआरएचयू
डॉ संदीप महाजन, आचार्य, वृक्क विज्ञान विभाग, एम्स
डॉ. नंद कुमार, आचार्य, मनोचिकित्सा विज्ञान विभाग, एम्स
4. **अध्ययन के उद्देश्य:** हम यह अध्ययन किडनी ट्रांसप्लांट कराने वाले रोगियों के लिए नर्स संचालित हस्तक्षेप का स्वयं देखभाल आचरण, मनोवैज्ञानिक लक्षण तथा जीवन की गुणवत्ता पर प्रभाव जानने के लिए कर रहे हैं। इस अध्ययन से प्राप्त जानकारी से हमें स्वयं देखभाल अध्ययन आचरण, मनोवैज्ञानिक लक्षण तथा जीवन की गुणवत्ता में सुधार हेतु किडनी ट्रांसप्लांट कराने वाले रोगियों के लिए कार्यक्रम विकसित करने में मदद मिलेगी।
5. **अध्ययन की विधि:** यदि आप इस अध्ययन में भाग लेने के लिए सहमत हैं तो आपकी मूलभूत जानकारी तथा स्वयं देखभाल आचरण, मनोवैज्ञानिक लक्षण तथा जीवन की गुणवत्ता पर प्रभाव के अध्ययन से संबंधित स्कोर को रिकॉर्ड किया जाएगा। इसमें लगभग 30 मिनट का समय लगेगा। आपको दो समूहों में से किसी एक कंप्यूटर से बनी तालिका के अनुसार एक समूह में रखा जाएगा। एक समूह को नर्स द्वारा संचालित स्वयं उपचार प्रबंधन कार्यक्रम दिया जाएगा और दूसरे समूह को नियमित उपचार दिया जाएगा। दोनों समूह के प्रतिभागियों का उपचार के 3 महीने और 6 महीने बाद दो बार फॉलोअप होगा।
6. **रोगी की सहभागिता की संभावित अवधि:** रोगी की सहभागिता की कुल अवधि 6 महीने की होगी। प्राप्त जानकारी को 3 बार दर्ज किया जाएगा, प्रत्येक मूल्यांकन के लिए लगभग 30 मिनट का समय लगेगा।
7. **रोगी तथा अन्य व्यक्तियों को अध्ययन से मिलने वाले संभावित लाभ:** इस अध्ययन में भाग लेने से रोगी को प्रत्यक्ष रूप से कोई लाभ नहीं मिलेगा, लेकिन जो मानक उपचार आपको दिया जा रहा था वह सूचारु रूप से चलता रहेगा।
8. **अध्ययन से जुड़ा कोई जोखिम:** इस अध्ययन से संबंधित कोई जोखिम नहीं है।
9. **रिकॉर्डों की गोपनीयता का रखरखाव:** अध्ययन के दौरान उपलब्ध कराई गई सभी जानकारी को गोपनीय रखा जाएगा तथा अध्ययन के उद्देश्य से ही उनका उपयोग किया जाएगा।

10. रोगी को इस अध्ययन से किसी भी समय बिना शुल्क या लाभों को खोए बगैर जिसके कि आप हकदार हैं, से भाग लेने और नाम वापस लेने की स्वतंत्रता: आपको किसी भी समय इस अध्ययन में भाग लेने से मना करने या फिर अपनी भागीदारी को समाप्त करने की स्वतंत्रता हैं। यदि आप इस अध्ययन में भाग नहीं लेने या नाम वापस लेने का निर्णय लेते हैं तो भी आपको सामान्य उपचार मिलता रहेगा।
11. **संपर्क:** अध्ययन पाठ्यक्रम के दौरान किसी भी समय यदि आपको लगता है कि आपको इस अध्ययन के बारे में पर्याप्त सूचना नहीं दी गई है या आपको आपकी मर्जी के खिलाफ शामिल होने का तनाव महसूस हो रहा है, तो ऐसे मामलों में आप हमसे संपर्क कर सकते हैं।

मुख्य अन्वेषक

सुश्री उज्जवल दहिया,

संपर्क नम्बर 9899770134

सहभागिता सूचित सहमति प्रपत्र (पी.आई.सी.एफ.)

अध्ययन/परियोजना का शीर्षक: किडनी ट्रांसप्लांट कराने वाले रोगियों के लिए नर्स संचालित हस्तक्षेप का स्वयं देखभाल आचरण, मनोवैज्ञानिक लक्षण तथा जीवन की गुणवत्ता पर प्रभाव का अध्ययन करने हेतु एक यादृच्छिक नियंत्रित परीक्षण।

मुख्य अन्वेषक का नाम: सुश्री उज्जवल दहिया **मो. नं.** 9899770134

मैंने दिनांकके सूचना पत्र में दिए गए विषय को ध्यानपूर्वक पढ़ लिया है/मेरे द्वारा समझे जाने वाली भाषा में स्पष्ट कर दिया गया है तथा मैंने तथ्यों को पूर्णतः समझ लिया है। मैं पुष्टि करता/करती हूँ कि मुझे प्रश्न पूछने का पूर्ण अवसर दिया गया।

मुझे अध्ययन की प्रकृति तथा उद्देश्य एवं संभावित जोखिमों/लाभों तथा अध्ययन की संभावित अवधि एवं अध्ययन से संबंधित अन्य विवरणों को विस्तार से समझा दिया गया है। मैंने समझ लिया है कि मेरी सहभागिता स्वैच्छिक है तथा मैं इस अध्ययन से किसी भी समय बिना कोई कारण बताए, अपने चिकित्सा उपचार अथवा कानूनी अधिकारों को प्रभावित किए बिना किसी भी समय इस अध्ययन से नाम वापिस लेने के लिए स्वतंत्र हूँ।

मैंने समझ लिया है कि इस अनुसंधान में मेरी सहभागिता से एकत्रित सूचना तथा मेरे मेडिकल नोट के किसी भाग को एम्स के जिम्मेदार व्यक्तियों द्वारा देखा जा सकता है। मैं इन व्यक्तियों को अपने रिकॉर्ड देखने की अनुमति देता/देती हूँ।

मैं उपर्युक्त अध्ययन में भाग लेने हेतु सहमत हूँ।

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हस्ताक्षर / बाएं अंगूठे का निशान

दिनांक:

स्थान:

प्रतिभागी का नाम

पुत्र/पुत्री/पत्नी श्री

पूर्ण

आवासीय

पता

.....

प्रमाणित किया जाता है कि उपर्युक्त सहमति मेरी उपस्थिति में ली गई है।

मुख्य अन्वेषक के हस्ताक्षर

दिनांक:

स्थान:

1) गवाह - 1

2) गवाह - 2

.....

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हस्ताक्षर

हस्ताक्षर

नाम

नाम

पता

पता

Annexure A-15

S.No.	Group	AGE	GEN	EDU	MAR	OCC	RES	TYPE	FAM	DONC	SOUR	HIS1	HIS2	HIS3	HIS4	CO1	CO2	CO3	CO4	SMOK	ALCOH	TOBA	TC1	TC2	TC3	SCP1	SCP2	SCP3	SCP4	SCP5	SubG	SCP6	SCP7	SCP8	SCP9	SGP2	SCP1	SCP1	SCP1	SCP1	SGP3	SCP1	SCP1	SCP1	SCP1			
1	1	55	0	2	0	0	1	0	2	0	1	1	0	0	0	0	1	0	0	0	0	0	0	1	0	0	3	3	4	3	3	16	3	3	3	0	9	2	3	3	3	11	3	4	3	3		
2	1	43	1	1	0	0	1	1	1	2	1	1	0	0	0	0	1	0	0	0	0	0	0	0	1	0	3	4	4	2	3	16	4	2	3	1	10	1	3	3	4	11	3	4	3	2		
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10	1	35	0	1	1	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	3	3	3	3	2	14	4	2	3	1	10	1	4	4	4	13	4	3	3	2		
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23	1	59	0	1	0	1	1	0	2	0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0	4	3	4	3	3	17	4	3	3	1	11	0	4	4	4	12	3	4	3	3			
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76	2	29	0	2	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	3	4	4	4	3	18	4	2	3	0	9	1	3	4	3	11	4	4	4	3	
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94	2	48	0	2	1	1	1	1	1	0	1	0	1	0	0	0	0	0	0	0	0	1	0	0	4	3	4	3	3	17	3	2	3	1	9	1	4	4	4	13	4	3	3	3	
95																																													

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L

SCP18	SGP4	SCP19	SCP2	SCP2	SCP2	SCP2	SGP5	SCP	SCP2	SCP2	SGP6	SCP2	SCP	SCP2	SCP3	SGP7	Self	MG1	MG2	MG3	MG4	Adher	DS1	DS2	DS3	DS4	DS5	DS6	DS7	DS8	DS9	DS10	DS11	DS12	DS13	DS14	DS15	DS16	DS17	DS18	DS19	DS2	DS21				
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3																																															

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Adherence to Self-Care among Kidney Transplant Recipients in a Selected Tertiary Care Hospital

Ujjwal Dahiya

Abstract

Self-care is a key factor in kidney transplant recipients to maintain graft function and prevent complications among them. This study was undertaken to assess adherence to self care among kidney transplant recipients in a tertiary care hospital. It was a cross sectional study involving 90 kidney transplant recipients. Adherence to self care was assessed by a structured and validated self care behaviour questionnaire of 30 items. The mean age of the participants was 39.45±8.09 years and 80 percent were male. Majority (55.6%) were married and were residing in rural area (64.6%). Majority (63.3%) of participants were unemployed and had some source of reimbursement (62.2%) for transplantation and immunosuppressive therapy. The participants scored highest (87.2%) in the domain of avoidance of infection whereas psychological care domain scored the least score (55.87%). The total mean self care behaviour percentage score was 67.26 percent. A statistically significant association for lifestyle modification self monitoring domains was found with age and education. Medication management domain was significantly associated with family income ($p=0.009$) and source of reimbursement ($p=0.02$). To conclude, there is a need to develop and integrate self care management programmes in the clinical practice so as to improve the self care behaviour among kidney transplant recipients.

Key words: CKD, kidney transplant recipients, self care, adherence, nursing, lifestyle modification

Chronic kidney disease (CKD) is one of the leading contributor to morbidity and mortality from non-communicable diseases (Bikav et al, 2020). The treatment modalities available for the patients are dialysis and kidney transplantation. Kidney transplantation is the treatment of choice for the patients as it improves the quality of life and survival rate as compared to dialysis (Wyld et al, 2012). The numbers of transplants are increasing and India is no exception. However, the cost involved in transplantation and the immunosuppressive therapy is an important concern for patients in developing countries. The kidney transplant recipients are required to strictly adhere to the immunosuppressive therapy regime for life and perform self-care activities to improve graft function and minimise the complications (Jamieson et al, 2016). The multiple self-management requirements are considered valuable for maintaining good health and minimising the risk of graft loss and complications (Akyolcu, 2020).

According to WHO (2021), self-care is “the ability of individuals, families and communities to promote

health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider.” Self-care refers to ‘the range of behaviour[s] undertaken by individuals to promote or restore their health including adherence to medication, dietary and exercise recommendations; monitoring symptoms; maintaining physical function; executing medical regimens and making decisions about seeking care (Gordon et al, 2009).

Objectives

The objective was conducted with following objectives.

1. To assess the adherence to self care among kidney transplant recipients.
2. To find association between self care and selected sociodemographic variables.

Need for the study

Kidney transplant recipients are required to practice self-care starting immediately post-transplant and continuing for the life of the kidney to ensure the proper functioning and longevity of their kidney graft (Weng et al, 2010). So, the present study was undertaken to explore adherence to self care among kidney transplant recipients in a tertiary care hospital.

The Author is: Research Scholar, Swami Rama Himalayan University, Dehradun, Uttarakhand. Guide: Kamli Prakash, Professor, Himalayan College of Nursing, Swami Rama Himalayan University, Dehradun, Uttarakhand. Co-Guide: 1. Sandeep Mahajan, Professor, Department of Nephrology, All India Institute of Medical Sciences, New Delhi; 2. Nand Kumar, Professor, Department of Psychiatry, All India Institute of Medical Sciences, New Delhi

Table 1: Socio-demographic and clinical profile of study participants (N=90)

Socio-demographic Variables	Frequency (%)
Age (Mean±SD)	39.45±8.09
18-35 years	35 (38.9)
36-50 years	34 (37.8)
51- 65 years	21 (23.3)
Gender	
Male	72 (80)
Female	18 (20)
Transgender	0
Educational status	
Illiterate and Primary	12 (13.3)
Secondary & Sr Secondary	47 (52.2)
Graduation and above	31 (34.4)
Marital status	
Married	50 (55.6)
Single	40 (44.4)
Occupation	
Employed	33 (36.7)
Unemployed	57 (63.3)
Type of residence	
Urban	32 (35.6)
Rural	58 (64.4)
Type of family	
Joint	28 (31.1)
Nuclear	62 (68.9)
Family income per month (in Rs)	
Low	21 (23.3)
Middle	37 (41.1)
High	32 (35.6)
Source of reimbursement	
Yes	56 (62.2)
No	34 (37.8)
Donor type	
Living	88 (97.7)
Cadaver	2 (2.3)
Duration after transplantation (mean±SD)	5.36 (2.12)
Previous medical history	
Pulmonary Koch's	10 (11.5)
Hepatitis B	2 (2.3)
Hepatitis C	1 (1.2)
Comorbidities	
Diabetes mellitus	5 (5.9)
Hypertension	35 (38.9)
Peripheral vascular disease	1 (1.2)
Post-transplant complications	
Infection	40 (44.4)
NODAT (New Onset Diabetes after Transplantation)	24 (26.6)

Review of Literature

Hedayati et al (2017) assessed adherence to immunosuppressive therapy and lifestyle recommendations along with some related factors among kidney transplant patients. The results showed that most kidney recipients were adherent to their drug prescriptions, but were partial, poor, or nonadherent regarding lifestyle recommendations.

Adhikari et al (2018)(9) assessed the compliance with lifestyle recommendations following kidney transplantation and identified the potential determinants of non-compliance. The results showed

that 64.1 percent of the transplant recipients were compliant with the recommended lifestyle measures overall. Separately, compliance rates were dietary 83.66 percent, clinic attendance 88.23 percent, self-monitoring or home monitoring 89.54 percent, laboratory investigations completion 88.23 percent, infection prevention 93.46 percent, and abstinence from addiction 95.42 percent.

Been-Dahmen et al (2018)(10) conducted a study to investigate self-management challenges and support needs experienced by kidney transplant recipients. They found the challenges after transplantation included becoming an expert patient, adjusting daily life activities, dealing with medical regimen, forming relationships with nurses, dealing with social consequences, dealing with emotions related to transplantation and the donor and improving self-image.

Kenawy et al (2019) assessed the compliance of renal transplant patients to medications and lifestyle modifications. The findings showed that 60 percent of the renal transplant patients were compliant with medications and lifestyle. Compliance to preventive measures against infection was observed in 85 percent of patients but only 5 percent were avoiding direct sun exposure.

Methodology

The study was conducted to explore adherence to self care among kidney transplant recipients in a tertiary care hospital. It was a single centre descriptive cross sectional study carried out from October 2019 to December 2019. Considering the study by Adhikari et al, the non-compliance to recommended lifestyle rate taken as 35.9 percent at 95 percent confidence interval with 10 percent margin of error the sample size calculated was 80~90. The sample comprised of 90 consecutive recipients attending the kidney transplant clinic at the hospital during the time of the study. Convenience sampling was used for the study. The kidney transplant recipients aged 18-65 years, who consented to participate in the study and were able to understand Hindi or English were included in the study.

The recipients who got admitted within three months of transplantation and were on some anti anxiety or antidepressant drugs were excluded from the study. Participant information sheet was given to all the participants containing all the de-

tails regarding study. The socio-demographic and clinical profile of patients was collected using the structured self-developed questionnaire. Adherence to self care was assessed by self care behaviour questionnaire developed by the researcher after extensive review of literature and was validated by experts. It consisted of 30 items and was administered to the participants during their visit to transplant clinic. It assessed the seven domains of self care in kidney transplant recipients including nutrition and diet (ND), medication management (MM), lifestyle modification (LM), self monitoring (SM), avoidance of infection (AI), follow-up (FU) and psychological care (PC) in self care. Each item had scoring from 0 to 4 (never, rarely, sometimes, often and always) with a total score of 120. Higher the score better is the adherence to self care. The reliability of self care behaviour questionnaire was $\alpha=0.87$.

Ethical considerations: The study was approved by the Institute Ethics Committee. All patients were provided with a participant information sheet explaining all the aspects of the study and written informed consent was obtained prior to data collection.

Data analysis: Categorical variables were described as frequencies and percentages and quantitative variables as means and standard deviations (SD). Inferential statistics, including t test and analysis of variance (ANOVA) were used. Independent t test was used to find association between independent and dependent variable with only two categories of independent variable and ANOVA was used with three or more than categories of independent variable.

Results

As seen in Table 1, the mean age of the participants

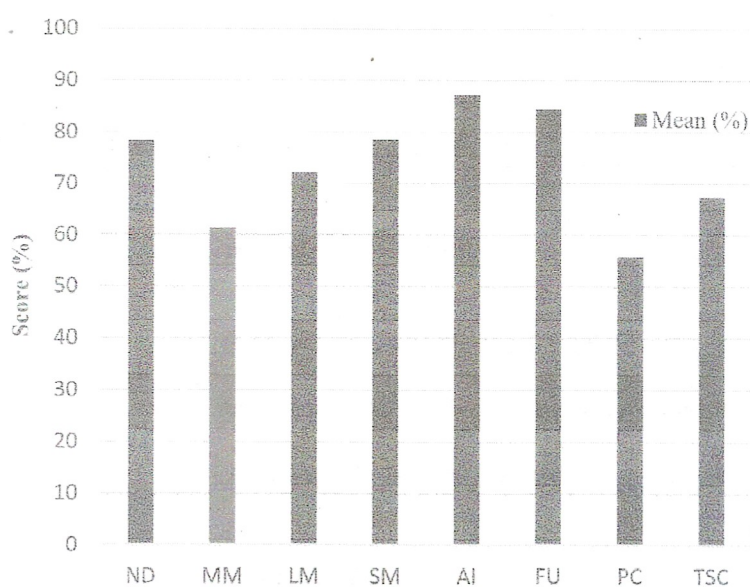


Fig 1: Adherence to Self-care behaviour in different domains.

was 39.4 ± 8.09 years, with the majority being males (80%). Majority 55.6% were married and 34.4% had completed graduation in education. Majority 63.3% were unemployed and 68.9% stayed in nuclear family. 41.1% of participants belonged to high income group. Majority 62.2% had some sort of reimbursement and the mean duration after transplant was 5.36(2.12) years of the participants. 11.5% had history of pulmonary koch's and 38.9% had hypertension as comorbid illness. Majority 44.4% had developed some type of infection and 26.6% had developed NODAT as a complication after the transplant. All participants were taking calcineurin inhibitors (tacrolimus), antiproliferative agents (mycophenolate mofetyl) and steroids (prednisolone) as the treatment post-transplant.

Figure 1 shows the mean adherence to self-care behaviour percentage scores in different domains of the kidney transplant recipients. The highest mean percentage scores can be seen for the domains of avoidance of infection (87.2%) and follow-up (84.4%). Nutrition and diet (78.45%) and self-monitoring (78.65%) domains also showed high mean percentage scores. Whereas, medication management (61.4%) and psychological care (55.87%) domains had low mean percentage scores. The total means self-care percentage score was 67.26 percent.

Table 2 shows the association of self care behaviour domains with selected sociodemographic variables. Significant association was seen with age and lifestyle modification ($p=0.03$), self-monitoring ($p=0.04$), follow-up ($p=0.001$) and total self care behaviour ($p=0.04$) scores. No significant association was found with other domains of self care with age. Educational status was significantly associated with lifestyle modification ($p=0.009$), avoidance of infection ($p=0.03$), psychological care ($p=0.02$) and total self care practice ($p=0.04$) scores. Marital status was significantly associated with self monitoring domain (0.01). The type of family was significantly associated with self monitoring domain (0.003). Family income was significantly associated with nutrition and diet ($p=0.006$), medication management ($p=0.009$), follow up ($p=0.01$) and total self care practice ($p=0.002$) scores. There was significant association of source of reimbursement with Medication management domain ($p=0.01$) of self care.

Discussion

This was a cross sectional study designed to explore adherence to self care behaviour among kidney transplant recipients. The participants were surveyed with structured socio-demographic sheet and self-care behaviour questionnaire. The adherence to self care behaviour

Table 2. Association of self care behaviour domains with selected sociodemographic variables (N=90)

Socio-demographic variables	Adherence to self care domains							
	Nutrition and diet (Mean;(SD)	Medication management (Mean); (SD)	Lifestyle modification (Mean); (SD)	Self monitoring (Mean); (SD)	Avoidance of infection (Mean);(SD)	Follow up (Mean); (SD)	Psychological care (Mean); (SD)	Total self care behaviour (Mean); (SD)
Age								
18-35 years	15.60 (1.70)	9.80 (1.38)	11.37 (1.43)	15.71 (1.63)	17.43 (2.14)	10.03 (0.95)	8.77 (1.21)	80.31 (5.76)
36-50 years	15.82 (1.71)	9.94 (1.30)	12.0 (1.01)	16.15 (1.54)	17.50 (1.33)	10.68 (0.80)	9.24 (1.21)	82.2 (3.79)
51- 65 years	15.62 (1.74)	9.71 (1.23)	11.14 (1.42)	15.10 (1.48)	17.38 (1.85)	9.43 (1.12)	8.76 (1.48)	79.0 (4.59)
ANOVA; p value	0.16; 0.84	0.21; 0.81	3.45; 0.03*	2.98; 0.04*	0.03; 0.97	11.6; 0.001*	1.34; 0.26	3.07; 0.04*
Educational Status								
Illiterate and Primary	15.83 (2.16)	9.83 (1.46)	11.23 (1.49)	15.43 (1.61)	17.67 (1.23)	10.25 (0.45)	9.17 (1.40)	83.08 (3.26)
Secondary & Sr Sec	15.34 (1.77)	9.74 (1.20)	11.63 (0.94)	15.87 (1.70)	17.02 (2.01)	9.94 (1.09)	8.60 (1.26)	78.79 (5.36)
Graduation and Above	16.16 (1.26)	9.97 (1.42)	12.50 (1.00)	16.58 (0.79)	18.0 (1.43)	10.39 (1.11)	9.39 (1.25)	82.74 (3.43)
ANOVA; p-value	2.29; 0.10	0.26; 0.76	4.97; 0.009*	2.78; 0.06	3.43; 0.03*	1.83(0.16)	3.78; 0.02*	8.94; 0.001*
Marital Status								
Married	15.86 (1.64)	9.90 (1.19)	11.94 (1.03)	16.26 (1.06)	17.68 (1.15)	10.16 (0.91)	9.14 (1.35)	82.18 (4.05)
Single	15.60 (1.69)	9.83 (1.37)	11.45 (1.50)	15.60 (1.31)	17.65 (1.56)	10.10 (1.21)	8.78 (1.23)	80.58 (4.82)
t test, p value	0.73; 0.46	0.27; 0.07	1.82; 0.07	2.62; 0.01**	0.10; 0.91	0.26; 0.79	1.32; 0.18	1.71; 0.09
Type of Family								
Joint	15.89 (1.22)	9.86 (1.38)	12.07 (1.01)	16.54 (0.92)	17.68 (1.09)	10.39 (1.10)	9.25 (1.26)	82.68 (3.00)
Nuclear	15.69 (1.82)	9.87 (1.23)	11.56 (1.36)	15.71 (1.26)	17.66 (1.44)	10.02 (1.01)	8.85 (1.13)	80.92 (4.90)
t test, p-value	0.56; 0.57	-0.04; 0.96	1.75; 0.08	3.11; 0.003**	0.05; 0.95	1.58; 0.11	1.33; 0.18	1.75; 0.08
Family income per month (in Rs)								
Low	15.95 (1.68)	9.38 (1.28)	11.57 (1.39)	15.71 (1.84)	17.33 (1.62)	9.67 (1.15)	8.57 (1.28)	80.19 (3.94)
Middle	14.94 (1.54)	9.56 (1.10)	11.28 (1.39)	15.59 (1.29)	17.06 (1.95)	10.06 (1.07)	8.78 (1.36)	78.69 (3.77)
High	16.19 (1.64)	10.32 (1.35)	11.78 (1.20)	15.86 (1.71)	17.84 (1.69)	10.46 (0.86)	9.30 (1.24)	82.78 (5.57)
ANOVA; p-value	5.48; 0.006*	4.94; 0.009*	1.24; 0.29	0.24; 0.78	1.69; 0.19	4.20; 0.01*	2.49; 0.08	6.87; 0.002*
Source of Reimbursement								
Yes	15.70 (1.69)	9.61 (1.20)	11.66 (1.24)	15.91 (1.26)	17.86 (1.31)	10.11 (1.00)	8.96 (1.36)	81.14 (4.41)
No	15.82 (1.62)	10.29 (1.29)	11.82 (1.35)	16.06 (1.15)	17.35 (1.34)	10.18 (1.14)	9.00 (1.23)	82.0 (4.54)
t test, p-value	0.35; 0.72	2.55; 0.01**	0.58; 0.56	0.55; 0.58	1.75; 0.08	0.30; 0.76	0.12; 0.90	0.88; 0.38

*p<0.05- ANOVA; **p<0.05- Independent t test

and the association of different domains with selected socio-demographic variables was assessed. Low scores were seen in medication management (61.4%) domain although medication management was of utmost importance in the maintenance of graft and survival. Low score in psychological care (55.87%) domain was found. Psychological issues were also noticed among kidney transplant recipients that can adversely affect the survival and quality of life of the recipients.

The findings of the study are consistent with a study by Adhikari et al (2018) where high scores were found for self monitoring (89.54%), and avoidance of infection (93.4%). Similar results were reported by Kenawy et al (2019) where compliance to preventive measures against infection was observed in 85 percent of patients. In the present study educational status was significantly associated with lifestyle modification ($p=0.009$), avoidance of infection ($p=0.03$), psychological care ($p=0.02$) and total self care practice ($p=0.04$) scores. These findings are in line with Hedayati et al (2017) where direct relationship was found between adherence to treatment and level of education. Prihodova et al (2014) also reported that low level of education was associated with reduced medication compliance. Said et al (2017) reported that 87.5 percent of kidney transplant recipients were partially compliance to lifestyle modification whereas in the present study the score was 72.25 percent. Significant association was found for total self care behaviour with age in this study ($p=0.04$) as well as one by Said S et al (2017).

Recommendation

Non-adherence to medications can adversely affect the survival and graft outcome. So, it is essential to identify patients at risk for non-adherence and introduce interventions to improve adherence to therapy. Since, it is a single centre study so the study can be replicated in different setting. The factors affecting adherence in our population can also be explored.

Nursing Implications

Nurses can provide education on the importance to adherence to medication among kidney transplant recipients. Nurses can help in early identification of any psychological issues which can further affect the quality of life of the recipients. Similar study can be conducted on larger sample size. Nurses should play an active role in the transplant care team so as to improve the outcome and decrease the complications.

Conclusion

Adherence to medication management and psychological care was low among transplant recipients that can adversely affect the graft outcome and re-

jection of the graft may occur. The level of education and age of the recipient had significant associations with lifestyle modification, self-monitoring and avoidance of infection. So, need-based education can be given by the nurses related to self care to improve graft function and prevent complications. There is a need to develop and integrate self care management programmes in the clinical practice so as to improve the self care behaviour among kidney transplant recipients.

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Annexure A-17



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Adherence to Self-Care among Kidney Transplant Recipients in a Selected Tertiary Care Hospital

Ujjwal Dahiya

Abstract

Self-care is a key factor in kidney transplant recipients to maintain graft function and prevent complications among them. This study was undertaken to assess adherence to self care among kidney transplant recipients in a tertiary care hospital. It was a cross sectional study involving 90 kidney transplant recipients. Adherence to self care was assessed by a structured and validated self care behaviour questionnaire of 30 items. The mean age of the participants was 39.45 ± 8.09 years and 80 percent were male. Majority (55.6%) were married and were residing in rural area (64.6%). Majority (63.3%) of participants were unemployed and had some source of reimbursement (62.2%) for transplantation and immunosuppressive therapy. The participants scored highest (87.2%) in the domain of avoidance of infection whereas psychological care domain scored the least score (55.87%). The total mean self care behaviour percentage score was 67.26 percent. A statistically significant association for lifestyle modification self monitoring domains was found with age and education. Medication management domain was significantly associated with family income ($p=0.009$) and source of reimbursement ($p=0.02$). To conclude, there is a need to develop and integrate self care management programmes in the clinical practice so as to improve the self care behaviour among kidney transplant recipients.

Key words: CKD, kidney transplant recipients, self care, adherence, nursing, lifestyle modification

Chronic kidney disease (CKD) is one of the leading contributor to morbidity and mortality from non-communicable diseases (Bikav et al, 2020). The treatment modalities available for the patients are dialysis and kidney transplantation. Kidney transplantation is the treatment of choice for the patients as it improves the quality of life and survival rate as compared to dialysis (Wyld et al, 2012). The numbers of transplants are increasing and India is no exception. However, the cost involved in transplantation and the immunosuppressive therapy is an important concern for patients in developing countries. The kidney transplant recipients are required to strictly adhere to the immunosuppressive therapy regime for life and perform self-care activities to improve graft function and minimise the complications (Jamieson et al, 2016). The multiple self-management requirements are considered valuable for maintaining good health and minimising the risk of graft loss and complications (Akyolcu, 2020).

According to WHO (2021), self-care is “the ability of individuals, families and communities to promote

health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider.” Self-care refers to ‘the range of behaviour[s] undertaken by individuals to promote or restore their health including adherence to medication, dietary and exercise recommendations; monitoring symptoms; maintaining physical function; executing medical regimens and making decisions about seeking care (Gordon et al, 2009).

Objectives

The objective was conducted with following objectives.

1. To assess the adherence to self care among kidney transplant recipients.
2. To find association between self care and selected sociodemographic variables.

Need for the study

Kidney transplant recipients are required to practice self-care starting immediately post-transplant and continuing for the life of the kidney to ensure the proper functioning and longevity of their kidney graft (Weng et al, 2010). So, the present study was undertaken to explore adherence to self care among kidney transplant recipients in a tertiary care hospital.

The Author is: Research Scholar, Swami Rama Himalayan University, Dehradun, Uttarakhand. Guide: Kamli Prakash, Professor, Himalayan College of Nursing, Swami Rama Himalayan University, Dehradun, Uttarakhand. Co-Guide: 1. Sandeep Mahajan, Professor, Department of Nephrology, All India Institute of Medical Sciences, New Delhi; 2. Nand Kumar, Professor, Department of Psychiatry, All India Institute of Medical Sciences, New Delhi

Table 1: Socio-demographic and clinical profile of study participants (N=90)

Socio-demographic Variables	Frequency (%)
Age (Mean±SD)	39.45±8.09
18-35 years	35 (38.9)
36-50 years	34 (37.8)
51- 65 years	21 (23.3)
Gender	
Male	72 (80)
Female	18 (20)
Transgender	0
Educational status	
Illiterate and Primary	12 (13.3)
Secondary & Sr Secondary	47 (52.2)
Graduation and above	31 (34.4)
Marital status	
Married	50 (55.6)
Single	40 (44.4)
Occupation	
Employed	33 (36.7)
Unemployed	57 (63.3)
Type of residence	
Urban	32 (35.6)
Rural	58 (64.4)
Type of family	
Joint	28 (31.1)
Nuclear	62 (68.9)
Family income per month (in Rs)	
Low	21 (23.3)
Middle	37 (41.1)
High	32 (35.6)
Source of reimbursement	
Yes	56 (62.2)
No	34 (37.8)
Donor type	
Living	88 (97.7)
Cadaver	2 (2.3)
Duration after transplantation (mean±SD)	5.36 (2.12)
Previous medical history	
Pulmonary Koch's	10 (11.5)
Hepatitis B	2 (2.3)
Hepatitis C	1 (1.2)
Comorbidities	
Diabetes mellitus	5 (5.9)
Hypertension	35 (38.9)
Peripheral vascular disease	1 (1.2)
Post-transplant complications	
Infection	40 (44.4)
NODAT (New Onset Diabetes after Transplantation)	24 (26.6)

Review of Literature

Hedayati et al (2017) assessed adherence to immunosuppressive therapy and lifestyle recommendations along with some related factors among kidney transplant patients. The results showed that most kidney recipients were adherent to their drug prescriptions, but were partial, poor, or nonadherent regarding lifestyle recommendations.

Adhikari et al (2018)(9) assessed the compliance with lifestyle recommendations following kidney transplantation and identified the potential determinants of non-compliance. The results showed

that 64.1 percent of the transplant recipients were compliant with the recommended lifestyle measures overall. Separately, compliance rates were dietary 83.66 percent, clinic attendance 88.23 percent, self-monitoring or home monitoring 89.54 percent, laboratory investigations completion 88.23 percent, infection prevention 93.46 percent, and abstinence from addiction 95.42 percent.

Been-Dahmen et al (2018)(10) conducted a study to investigate self-management challenges and support needs experienced by kidney transplant recipients. They found the challenges after transplantation included becoming an expert patient, adjusting daily life activities, dealing with medical regimen, forming relationships with nurses, dealing with social consequences, dealing with emotions related to transplantation and the donor and improving self-image.

Kenawy et al (2019) assessed the compliance of renal transplant patients to medications and lifestyle modifications. The findings showed that 60 percent of the renal transplant patients were compliant with medications and lifestyle. Compliance to preventive measures against infection was observed in 85 percent of patients but only 5 percent were avoiding direct sun exposure.

Methodology

The study was conducted to explore adherence to self care among kidney transplant recipients in a tertiary care hospital. It was a single centre descriptive cross sectional study carried out from October 2019 to December 2019. Considering the study by Adhikari et al, the non-compliance to recommended lifestyle rate taken as 35.9 percent at 95 percent confidence interval with 10 percent margin of error the sample size calculated was 80~90. The sample comprised of 90 consecutive recipients attending the kidney transplant clinic at the hospital during the time of the study. Convenience sampling was used for the study. The kidney transplant recipients aged 18-65 years, who consented to participate in the study and were able to understand Hindi or English were included in the study.

The recipients who got admitted within three months of transplantation and were on some anti anxiety or antidepressant drugs were excluded from the study. Participant information sheet was given to all the participants containing all the de-

tails regarding study. The socio-demographic and clinical profile of patients was collected using the structured self-developed questionnaire. Adherence to self care was assessed by self care behaviour questionnaire developed by the researcher after extensive review of literature and was validated by experts. It consisted of 30 items and was administered to the participants during their visit to transplant clinic. It assessed the seven domains of self care in kidney transplant recipients including nutrition and diet (ND), medication management (MM), lifestyle modification (LM), self monitoring (SM), avoidance of infection (AI), follow-up (FU) and psychological care (PC) in self care. Each item had scoring from 0 to 4 (never, rarely, sometimes, often and always) with a total score of 120. Higher the score better is the adherence to self care. The reliability of self care behaviour questionnaire was $\alpha=0.87$.

Ethical considerations: The study was approved by the Institute Ethics Committee. All patients were provided with a participant information sheet explaining all the aspects of the study and written informed consent was obtained prior to data collection.

Data analysis: Categorical variables were described as frequencies and percentages and quantitative variables as means and standard deviations (SD). Inferential statistics, including t test and analysis of variance (ANOVA) were used. Independent t test was used to find association between independent and dependent variable with only two categories of independent variable and ANOVA was used with three or more than categories of independent variable.

Results

As seen in Table 1, the mean age of the participants

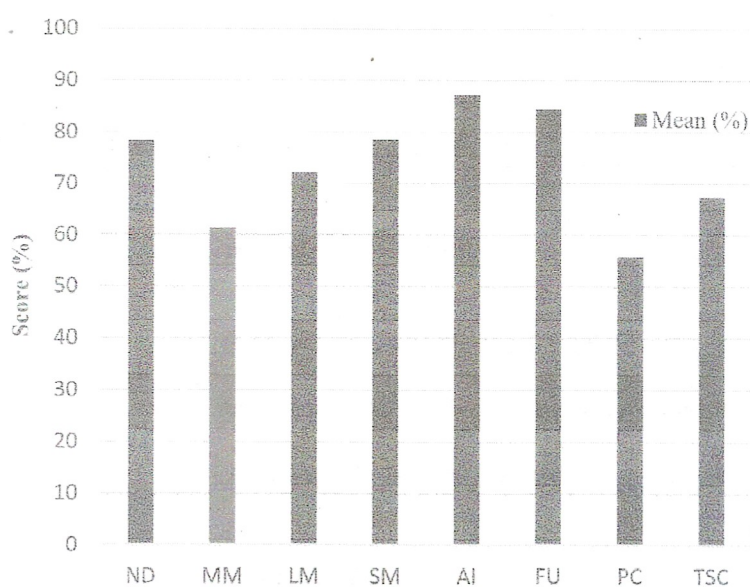


Fig 1: Adherence to Self-care behaviour in different domains.

was 39.4 ± 8.09 years, with the majority being males (80%). Majority 55.6% were married and 34.4% had completed graduation in education. Majority 63.3% were unemployed and 68.9% stayed in nuclear family. 41.1% of participants belonged to high income group. Majority 62.2% had some sort of reimbursement and the mean duration after transplant was 5.36(2.12) years of the participants. 11.5% had history of pulmonary koch's and 38.9% had hypertension as comorbid illness. Majority 44.4% had developed some type of infection and 26.6% had developed NODAT as a complication after the transplant. All participants were taking calcineurin inhibitors (tacrolimus), antiproliferative agents (mycophenolate mofetyl) and steroids (prednisolone) as the treatment post-transplant.

Figure 1 shows the mean adherence to self-care behaviour percentage scores in different domains of the kidney transplant recipients. The highest mean percentage scores can be seen for the domains of avoidance of infection (87.2%) and follow-up (84.4%). Nutrition and diet (78.45%) and self-monitoring (78.65%) domains also showed high mean percentage scores. Whereas, medication management (61.4%) and psychological care (55.87%) domains had low mean percentage scores. The total means self-care percentage score was 67.26 percent.

Table 2 shows the association of self care behaviour domains with selected sociodemographic variables. Significant association was seen with age and lifestyle modification ($p=0.03$), self-monitoring ($p=0.04$), follow-up ($p=0.001$) and total self care behaviour ($p=0.04$) scores. No significant association was found with other domains of self care with age. Educational status was significantly associated with lifestyle modification ($p=0.009$), avoidance of infection ($p=0.03$), psychological care ($p=0.02$) and total self care practice ($p=0.04$) scores. Marital status was significantly associated with self monitoring domain (0.01). The type of family was significantly associated with self monitoring domain (0.003). Family income was significantly associated with nutrition and diet ($p=0.006$), medication management ($p=0.009$), follow up ($p=0.01$) and total self care practice ($p=0.002$) scores. There was significant association of source of reimbursement with Medication management domain ($p=0.01$) of self care.

Discussion

This was a cross sectional study designed to explore adherence to self care behaviour among kidney transplant recipients. The participants were surveyed with structured socio-demographic sheet and self-care behaviour questionnaire. The adherence to self care behaviour

Table 2. Association of self care behaviour domains with selected sociodemographic variables (N=90)

Socio-demographic variables	Adherence to self care domains							
	Nutrition and diet (Mean;(SD)	Medication management (Mean); (SD)	Lifestyle modification (Mean); (SD)	Self monitoring (Mean); (SD)	Avoidance of infection (Mean);(SD)	Follow up (Mean); (SD)	Psychological care (Mean); (SD)	Total self care behaviour (Mean); (SD)
Age								
18-35 years	15.60 (1.70)	9.80 (1.38)	11.37 (1.43)	15.71 (1.63)	17.43 (2.14)	10.03 (0.95)	8.77 (1.21)	80.31 (5.76)
36-50 years	15.82 (1.71)	9.94 (1.30)	12.0 (1.01)	16.15 (1.54)	17.50 (1.33)	10.68 (0.80)	9.24 (1.21)	82.2 (3.79)
51- 65 years	15.62 (1.74)	9.71 (1.23)	11.14 (1.42)	15.10 (1.48)	17.38 (1.85)	9.43 (1.12)	8.76 (1.48)	79.0 (4.59)
ANOVA; p value	0.16; 0.84	0.21; 0.81	3.45; 0.03*	2.98; 0.04*	0.03; 0.97	11.6; 0.001*	1.34; 0.26	3.07; 0.04*
Educational Status								
Illiterate and Primary	15.83 (2.16)	9.83 (1.46)	11.23 (1.49)	15.43 (1.61)	17.67 (1.23)	10.25 (0.45)	9.17 (1.40)	83.08 (3.26)
Secondary & Sr Sec	15.34 (1.77)	9.74 (1.20)	11.63 (0.94)	15.87 (1.70)	17.02 (2.01)	9.94 (1.09)	8.60 (1.26)	78.79 (5.36)
Graduation and Above	16.16 (1.26)	9.97 (1.42)	12.50 (1.00)	16.58 (0.79)	18.0 (1.43)	10.39 (1.11)	9.39 (1.25)	82.74 (3.43)
ANOVA ; p-value	2.29; 0.10	0.26; 0.76	4.97; 0.009*	2.78; 0.06	3.43; 0.03*	1.83(0.16)	3.78; 0.02*	8.94; 0.001*
Marital Status								
Married	15.86 (1.64)	9.90 (1.19)	11.94 (1.03)	16.26 (1.06)	17.68 (1.15)	10.16 (0.91)	9.14 (1.35)	82.18 (4.05)
Single	15.60 (1.69)	9.83 (1.37)	11.45 (1.50)	15.60 (1.31)	17.65 (1.56)	10.10 (1.21)	8.78 (1.23)	80.58 (4.82)
t test, p value	0.73; 0.46	0.27; 0.07	1.82; 0.07	2.62; 0.01**	0.10; 0.91	0.26; 0.79	1.32; 0.18	1.71; 0.09
Type of Family								
Joint	15.89 (1.22)	9.86 (1.38)	12.07 (1.01)	16.54 (0.92)	17.68 (1.09)	10.39 (1.10)	9.25 (1.26)	82.68 (3.00)
Nuclear	15.69 (1.82)	9.87 (1.23)	11.56 (1.36)	15.71 (1.26)	17.66 (1.44)	10.02 (1.01)	8.85 (1.13)	80.92 (4.90)
t test, p-value	0.56; 0.57	-0.04; 0.96	1.75; 0.08	3.11; 0.003**	0.05; 0.95	1.58; 0.11	1.33; 0.18	1.75; 0.08
Family income per month (in Rs)								
Low	15.95 (1.68)	9.38 (1.28)	11.57 (1.39)	15.71 (1.84)	17.33 (1.62)	9.67 (1.15)	8.57 (1.28)	80.19 (3.94)
Middle	14.94 (1.54)	9.56 (1.10)	11.28 (1.39)	15.59 (1.29)	17.06 (1.95)	10.06 (1.07)	8.78 (1.36)	78.69 (3.77)
High	16.19 (1.64)	10.32 (1.35)	11.78 (1.20)	15.86 (1.71)	17.84 (1.69)	10.46 (0.86)	9.30 (1.24)	82.78 (5.57)
ANOVA; p-value	5.48; 0.006*	4.94; 0.009*	1.24; 0.29	0.24; 0.78	1.69; 0.19	4.20; 0.01*	2.49; 0.08	6.87; 0.002*
Source of Reimbursement								
Yes	15.70 (1.69)	9.61 (1.20)	11.66 (1.24)	15.91 (1.26)	17.86 (1.31)	10.11 (1.00)	8.96 (1.36)	81.14 (4.41)
No	15.82 (1.62)	10.29 (1.29)	11.82 (1.35)	16.06 (1.15)	17.35 (1.34)	10.18 (1.14)	9.00 (1.23)	82.0 (4.54)
t test, p-value	0.35; 0.72	2.55; 0.01**	0.58; 0.56	0.55; 0.58	1.75; 0.08	0.30; 0.76	0.12; 0.90	0.88; 0.38

*p<0.05- ANOVA; **p<0.05- Independent t test

and the association of different domains with selected socio-demographic variables was assessed. Low scores were seen in medication management (61.4%) domain although medication management was of utmost importance in the maintenance of graft and survival. Low score in psychological care (55.87%) domain was found. Psychological issues were also noticed among kidney transplant recipients that can adversely affect the survival and quality of life of the recipients.

The findings of the study are consistent with a study by Adhikari et al (2018) where high scores were found for self monitoring (89.54%), and avoidance of infection (93.4%). Similar results were reported by Kenawy et al (2019) where compliance to preventive measures against infection was observed in 85 percent of patients. In the present study educational status was significantly associated with lifestyle modification ($p=0.009$), avoidance of infection ($p=0.03$), psychological care ($p=0.02$) and total self care practice ($p=0.04$) scores. These findings are in line with Hedayati et al (2017) where direct relationship was found between adherence to treatment and level of education. Prihodova et al (2014) also reported that low level of education was associated with reduced medication compliance. Said et al (2017) reported that 87.5 percent of kidney transplant recipients were partially compliance to lifestyle modification whereas in the present study the score was 72.25 percent. Significant association was found for total self care behaviour with age in this study ($p=0.04$) as well as one by Said S et al (2017).

Recommendation

Non-adherence to medications can adversely affect the survival and graft outcome. So, it is essential to identify patients at risk for non-adherence and introduce interventions to improve adherence to therapy. Since, it is a single centre study so the study can be replicated in different setting. The factors affecting adherence in our population can also be explored.

Nursing Implications

Nurses can provide education on the importance to adherence to medication among kidney transplant recipients. Nurses can help in early identification of any psychological issues which can further affect the quality of life of the recipients. Similar study can be conducted on larger sample size. Nurses should play an active role in the transplant care team so as to improve the outcome and decrease the complications.

Conclusion

Adherence to medication management and psychological care was low among transplant recipients that can adversely affect the graft outcome and re-

jection of the graft may occur. The level of education and age of the recipient had significant associations with lifestyle modification, self-monitoring and avoidance of infection. So, need-based education can be given by the nurses related to self care to improve graft function and prevent complications. There is a need to develop and integrate self care management programmes in the clinical practice so as to improve the self care behaviour among kidney transplant recipients.

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