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Educational intervention in improving the Quality of Life of renal transplant patients

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ABSTRACT

Purpose: A study was done to develop and evaluate the effectiveness of an information booklet on "Healthy living after kidney transplantation" in terms of patients knowledge and quality of life (QOL) in renal transplant patients of selected hospitals of Delhi, India.

Methods and material: Structured questionnaire was the tool used. Content validity was obtained by giving it to nine experts. Reliability of tool was established prior to pilot study by KR-20 for knowledge questionnaire and Cronbach Alpha for QOL measurement scale.

The subjects were approached personally in renal transplant clinic and pre test was administered on day one followed by the administration of the information booklet on the same day. On the day 15, post test was done. Data obtained was analyzed and interpreted in the light of objectives and hypothesis using descriptive and inferential statistics.

Result: The study showed that 42% each were in the age group of 18-30 years and 31-50 years and most of the patients were male (72%) and many of them were not working (33%). The data also showed that thirty eight percent of them were educated up to graduate level and thirty nine percent of them had family income of Rs 5001- 20,000 per month. Most of them belong to joint family (63%). There was significant difference between the knowledge and QOL scores of patients before and after administration of information booklet. There was significant correlation found between the knowledge and QOL scores of the patients. The study revealed that there was significant association between knowledge scores of the patients with selected factors like age and education of the patients but there was no significant association between knowledge and factors life gender and occupation. The study also revealed that there was significant association between the QOL of the patients with selected factors like age, family income, duration of transplantation, source of donor, rejection episode, hospitalization, co-morbidities, duration of dialysis prior to transplant and procurement of medicines but it was found that this study doesn't show any significant association of QOL with factors like type of family, number of transplantation and patient's Body Mass Index.

Conclusion: It was concluded that the developed information booklet enhanced the knowledge of the post renal transplant patient on self care

thus improving the QOL of these patients thus the information booklet can be used in different health care units and also in community for the renal transplant patients.

Key words : Quality Of Life, Renal Transplant, Qol

INTRODUCTION

End Stage Renal Disease here by referred as ESRD is an incapacitating chronic disease which is eventually terminal requiring successful renal transplantation (White & Grenyer 1999).

Mani M.K. (1993) reported that the incidence of ESRD in India was more than 100 cases per million population. Transplantation is the treatment of choice for the patients with ESRD. Renal transplantation is leading among the organ transplantation statistics. According to WHO(2011), worldwide around 100,000 organ transplants are performed of which, renal transplant figures around 68300, liver transplant being19900, 5200 heart transplant, 3250 lung transplant and 2800 pancrease transplant.

Fisher et al (1998) mentioned that the aim of renal transplantation is not curative but to improve the kidney functioning and thus improve the ability of the patient to live a better life. Though renal transplantation is currently the treatment of choice for the patients with ESRD yet due to scarcity of donor, this treatment cannot be considered as primary therapy. The prognosis of these patients have improved considerably over the years in respect to the survival of the patient and the graft. Improving the Quality of life (QOL) of this cohort of patients has now a great concern. Cheater (1998) voiced that simply tracking the result of transplant as patient survival results in neglecting the quality of the survival. QOL as mentioned by camphell et al (1976) includes both the condition of the life and the experience of life. Abrams (1973) defines QOL as "the degree of satisfaction or dissatisfaction felt by people with various aspects of their life" Farquhan M (1995) also mentioned that the most preferable outcome of all health care policies is the improved QOL. So, optimizing the QOL outcome of patients undergone transplantation is of utmost importance. Though much has been researched about the QOL of these patients and number of comparative studies also has been done with other cohorts of population yet little has been published by nurse researchers on optimizing the QOL of renal transplant patients. Valderrabano et al (2001) has compared the QOL of post transplant patients with patients on hemodialysis. Karam et al (2003) has compared QOL of long term post renal transplant survivor with that of QOL of general population.

There are many factors influencing the QOL of renal transplant patients like compliance to the treatment regime, awareness of patient regarding self care etc. Among those factors, investigator believes that the knowledge on self care plays a vital role in patient's post transplant QOL, where in, if the patient has adequate knowledge regarding self care after transplant, the patient will have better QOL. Schmid-Mohler G et al (2011) suggested the need of a structured educational program for the post transplant patients. Investigator felt that information booklet on self care for chronically ill patients like transplant patients are helpful and effective in improving their QOL. The booklet can be easily accessed by these patients anytime anywhere whenever he/she needs to refer in respect to their care. Investigator also felt the need to see the effectiveness of such booklet. So, the primary aim of the study was to develop and evaluate the effectiveness of an information booklet in terms of patient's knowledge and QOL in renal transplant patients.

MATERIALS AND METHODS

Research approach:

an evaluative research approach was considered most appropriate as the primary objective of the study was to determine the effectiveness of the information booklet. Criterion measures selected were gain in knowledge and improvement in QOL of renal transplant patients.

Research design:
Pre-experimental design was adopted as the study was done on one group only pre test and post test without any control group. The design can be represented as:

OK_1, OQ_1 – X – OK_2, OQ_2 where OK_1 denotes knowledge of renal transplant patients before administration of information booklet, OQ_1 denotes QOL of renal transplant patients before administration of information booklet. X is the intervention with information booklet on "Healthy living after kidney transplantation" OK_2 and OQ_2 denotes the knowledge and quality of life of kidney transplant patients respectively after administration of information booklet.

Setting:
the study setting was selected government hospital in Delhi India.

Population:
the study population comprises of renal transplant patients attending renal transplant clinic of selected hospital of Delhi, India.

Sampling:
A convenient sampling technique was used to select the samples for the study. Investigator personally approached the patients who qualify as per the set criteria for the study. The samples were asked the willingness to be the part of the study. 60 renal transplant patients were included in the study.

Criteria for sample selection:
Renal transplant patients who are above 18 years of age within one year of post transplant period attending renal transplant clinic and who are willing to participate and who can read and write English and hindi.

Data collection tools and technique:
Personal information perfoma: To collect demographic and transplant related data.

Structured knowledge questionnaire:
To assess the knowledge of transplant patients before and after administration of information booklet.

Structured QOL measurement scale:
To assess the QOL of transplant patients before and after administration of information booklet.

Oppionnaire:
For pretesting the booklet for acceptability and utility after content validation and before administration of the information booklet.

RESULTS

The data was analyzed by using both Descriptive and Inferential statistics as follows:

Analysis of background variables was done in terms of frequencies and percentage.
Mean, median and standard deviation was computed to describe the pre-test and post-test knowledge scores and QoL scores.
In order to determine the effectiveness of information booklet, "t" value was calculated to find out the significant difference between the mean of pre-test and post-test knowledge scores and QoL scores of patients

Co-efficient of co-relation was computed between post-test knowledge score and QoL score.

Chi square was calculated to find association of selected factors with QoL and knowledge scores.

There is significant association between age of the patients with their QoL as shown by obtained chi square value of 11.6 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is significant association between family income of the patients with their QoL as shown by obtained chi square value of 10.7 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is significant association between duration of transplant of the patients with their QoL as shown by obtained chi square value of 8.18 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is no significant association between source of donor of the patients with their QoL as shown by obtained chi square value of 2.2 which is less than the table chi square value (5.99) at 2 df at 0.05 level of significance. Thus, there is no association between them.

Table I a: Frequency and Percentage distribution of background information of the renal transplant patients

N=60

S. NO	SAMPLE CHARACTERISTICS	FREQUENCY	PERCENTAGE
1.	**Age**		
	18- 30	25	42%
	31-50	25	42%
	Above 51	10	16%
2.	**Gender**		
	Male	43	72%
	Female	17	28%
3.	**Occupation**		
	Not working	20	33%
	Government job	14	24%
	Private job	17	28%
	Business	9	15%
4.	**Education level**		
	Below 10^{th}	20	33%
	10^{th} – 12^{th}	13	22%
	12^{th} – graduation	23	38%
	Post graduation	4	7%
5.	**Monthly family income**		
	Less than 5000	17	28%
	5001- 20,000	23	39%
	More than 20,001	20	33%
6.	**Types of family**		
	Nuclear family	21	35%
	Joint family	38	63%
	Stays Alone	1	2%

Table 1a) shows that patients who are in the age group of 18-30 and 31-50 are in equal number (42% each) and mostly are male (72%) and many being not working (33%). The data also shows that thirty eight percent of them are educated up to graduates level and thirty nine percent of them having family income of Rs 5000- 20,000 per month. Most of them belong to joint family (63%).

Table 1 b) : Frequency and Percentage distribution of transplant related information of the renal transplant patients

N=60

S. NO	SAMPLE CHARACTERISTICS	FREQUENCY	PERCENTAGE
1.	**Duration of transplant**		
	≤ 3 months	21	35%
	3-6 months	9	15%
	6-9 months	15	25%
	9-12 months	15	25%
2.	**Source of donor**		
	Live related donor	39	65%
	Live unrelated donor	11	18%
	Cadaveric donor	10	17%
3.	**Rejection episode**		
	None	42	70%
	1-2 times	17	28%
	> 2 times	1	2%
4.	**Hospitalization**		
	None	36	60%
	1-2 times	21	35%
	> 2 times	3	5%
5.	**No of transplantation**		
	1 time	54	90%
	2 times	6	10%
	> 2 times	0	0%
6.	**Associated diseases (can be more then 1)**		
	High blood pressure	24	40%
	Diabetes	16	27%
	Hep B or Hep C	13	22%
	Cardiovascular disease	5	8%
	None	22	37%
	Those having more than one associated diseases		
7.	**Duration of dialysis prior to transplant**		
	Few months	26	43%
	One year	12	20%
	> one year	22	37%
8.	**BMI (body mass index)**		
	≤ 18.4	16	27%
	18.5 ≤ 24.9	36	60%
	25 ≤ 29.9	8	13%
	25 ≤	0	0%
9.	**Procurement of medicine**		
	Self payment	17	28%
	Reimbursement	22	37%
	Family member pays	21	35%

Table 1b) shows the transplant related sample characteristics in which the data shows that 35% of the sample subjects are within 3 months of transplant duration and majority of the donor are live related donors (65%) and there are seventy percent of them who had no rejection episode after transplant and it is their first transplant for majority of the patients (90%). so, there was no need of hospitalization after transplant for majority of the patients (60%). Thirty seven percent of the sample subjects are not having any associated diseases and the BMI of 60% of them having in the normal range. Prior to transplant, 43% of them had few months of dialysis. Thirty seven percent of them get reimbursement for their post transplant medication.

SECTION- II: Findings related to knowledge score of renal transplant patients

TABLE 2 : Mean, Median, Standard deviation, Mean difference, Standard deviation of difference, standard error of mean difference, "t" value from pre test post test knowledge scores

N=60

Knowledge test	Mean	Median	SD	Mean D	SD D	SED	"t value"
Pre test	16.88	17	5.11	10.19	0.97	0.387	26.356*
Post test	27.07	27	4.14				

At df(59), "t value" at 0.05 level of significance is 2.00
* Significant at 0.05 level of significance

Table 2 shows that mean knowledge score of patients post test (27.07) was significantly higher than that in pre test (16.88). The mean difference of 10.19 was statistically found to be significant at 0.05 level of significance as evident from't' value (26.356) for df of 59. Thus, it shows that the obtained mean difference was a true difference and not by chance
Standard deviation of knowledge scores in pre test i.e. 5.11 is more than in post test i.e. 4.14 indicating that there is more variability in the knowledge score in the pre test score

SECTION- III: : Findings related to QOL score of renal transplant patients
TABLE 3 : Mean, Median, Standard deviation, Mean difference, Standard deviation of difference, Standard error of mean difference, "t" value from pre test and post test qol scores

N=60

QoL scores	Mean	Median	SD	Mean D	SD D	SED	"t value"
Pre test	137.97	137	18.38	14.96	3.54	1.20	10.27*
Post test	152.93	154.5	14.839				

At df(59), 't' at 0.05 level of significance is 2.00
* Significant at 0.05 level of significance

Table 3 shows that mean QOL score of patients in post test (152.93) is significantly higher than that in pre test (137.97). The mean difference of 14.96 is statistically found to be significant at 0.05 level of significance as evident from 't' value (10.27) for df of 59 . Thus, it shows that the obtained mean difference was a true difference and not by chance.
Standard deviation of QOL scores of pre test i.e. 18.38 is more than in post test i.e. 14.839 indicating that there is less variability in QOL scores in patients after exposure to information booklet

SECTION- IV: Findings related to relationship between knowledge and QoL scores of patients
TABLE 4
Correlation between post test knowledge and post test QOL scores obtained by patients
N=60

Test	Knowledge score		QoL score		R
Post test	Mean	SD	Mean	SD	
	27.07	4.14	152.93	14.839	0.43*

At df 59, 'r' at 0.05 level of significance is 0.252
* Significant at 0.05 level of significance

Table 4 shows that coefficient of correlation between the QOL and knowledge scores for transplant patients shows significance at 0.05 as obtained 'r' value (0.43) is greater than the table value at df 59 .

SECTION- V

Findings related to association between post test knowledge score and selected factors

TABLE 5 **N=60**

S. No	Selected variables	Knowledge scores		Df	X^2 Obtained value	X^2 Table value	Significance at 0.05 level
		Above median	Below median				
1.	**Age**						
	18-30	17	8	2	9.68	5.99	Significant
	31-50	12	13				
	>51	1	9				
2.	**Gender**						
	Male	23	20	1	0.72	3.84	Not significant
	Female	7	10				
3.	**Occupation**						
	Not working	9	11	3	4.74	7.815	Not significant
	Govt job	8	6				
	Pvt job	7	10				
	Business	6	3				
4.	**Education**						
	Upto 10th	4	16	3	13.42	7.815	Significant
	10th to 12th	7	6				
	12th – graduates	15	8				
	Postgraduate	4	0				

There is significant association between age of the patients with knowledge level as shown by obtained chi square value of 9.68 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance.
There is no significant association between gender of the patients with knowledge level as shown by obtained chi square value of 0.72 which is less than the table chi square value (3.84) at 1 df at 0.05 level of significance.
There is no significant association between occupation of the patients with knowledge level as shown by obtained chi square value of 4.74 which is less than the table chi square value (7.815) at 3 df at 0.05 level of significance.
There is significant association between education of the patients with knowledge level as shown by obtained chi square value of 13.42 which is greater than the table chi square value (7.815) at 3 df at 0.05 level of significance.

SECTION- VI

Findings related to association between post test QoL score and selected factors

TABLE 6

N=60

S. No	Selected variables	QoL scores		Df	X^2 Obtained value	X^2 table value	Significance at 0.05 level
		Above median	Below median				
1.	**Age**						
	18-30	18	7	2	11.6	5.59	Significant
	31-50	11	14				
	>51	1	9				
2.	**Family income**						
	Up to 5000	3	14	2	10.7	5.59	Significant
	5001-20,000	13	10				
	> 20,001	14	6				
3.	**Duration of transplant**						
	≤ 3 month	6	15	3	8.18	7.815	Significant
	3-6 months	6	3				
	6-9months	7	8				

	9-12 months	11	4				
4.	**Source of donor**						
	Live related	25	14	2	10.32	5.59	Significant
	Live unrelated	4	7				
	Deceased donor	1	9				
5.	**Rejection episodes**						
	None	28	14	2	15.6	5.59	Significant
	1-2 times	2	15				
	>2 times	0	1				
6.	**Hospitalization**						
	None	24	12	2	10.86	5.59	Significant
	1-2 times	6	15				
	> 2 times	0	3				
7.	**Number of transplant**						
	1 time	29	25	2	2.96	5.59	Not significant
	2 times	1	5				
	>2 times	0	0				
8.	**Co morbidities**						
	HT	9	15	4	9.85		Significant
	DM	4	12				
	Hepatitis	3	10				
	Cardiovascular	2	3				
	None	15	7				
9.	**Type of family**						
	Nuclear	8	13	2	3.12	5.59	Not significant
	Joint	22	16				
	Stays alone	0	1				
10.	**Duration of dialysis**						
	Few months	18	8	2	6.82	5.59	Significant
	1 year	4	8				
	>1 year	8	14				
11.	**BMI**						
	Less than 18.4	9	7	3	3.26	7.815	Not significant
	18.5 -24.9	15	21				
	25 – 29	6	2				
	>29.1	0	0				
12.	**Procurement of medicine**						
	Self payment	12	5	2	14.12	5.59	Significant
	Reimbursement	4	18				
	Family pays	14	7				

There is significant association between number of rejection episodes of the patients with their QoL as shown by obtained chi square value of 10.32 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is significant association between number of hospitalization of the patients after transplantation with their QoL as shown by obtained chi square value of 10.86 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance. Thus, there is association between them.

There is no significant association between number of transplantation of the patients with knowledge their QoL as shown by obtained chi square value of 2.96 which is less than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is significant association between co-morbidities of the patients with their QoL as shown by obtained chi square value of 9.85 which is greater than the table chi square value (9.488) at 4 df at 0.05 level of significance.

There is significant association between duration of dialysis of the patients with their QoL as shown by obtained chi square value of 6.82 which is greater than

the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is no significant association between types of family of the patients with their QoL as shown by obtained chi square value of 3.12 which is less than the table chi square value (5.99) at 2 df at 0.05 level of significance.

There is no significant association between BMI of the patients with their QoL as shown by obtained chi square value of 3.26 which is less than the table chi square value (7.815) at 3 df at 0.05 level of significance.

There is significant association between procurement of medicine by the patients with their QoL as shown by obtained chi square value of 14.12 which is greater than the table chi square value (5.99) at 2 df at 0.05 level of significance. Thus, there is association between them.

DISCUSSION

The best treatment option for ESRD is renal transplantation. Kidney transplantation is a palliative therapy with the prime aim to prolong life as there is no cure for ESRD. In all palliative care, assessment of QOL becomes important. Investigator believed that the knowledge played an important role directly or indirectly in improving QOL. The present study aimed to develop an information booklet on "healthy living after transplant" in order to increase the knowledge of the transplant patients regarding their self-care thus helping them in improving their QOL in some aspects. The study also found some association of various factors with the knowledge as well as the QOL.

Finding of the study showed that majority of the patients were below 50 years of age and this finding was consistent with the study done by Muthusethupathi et al where they said that about half of the patients were under fifty years of age thus in their most productive years of life.

The present study finding shows that selected factors like age, family income, duration of transplant, duration of dialysis and co morbidities had significant association with QOL where younger the age, better the QOL. It was found that patients with higher family income have better QOL, prior to transplant, lesser duration of dialysis, subjects were found to have better QOL post-transplant, patients with co morbidities were found to have lower QOL than those who doesnot have co morbidities. The above findings were in contrary to the findings of Treesa Anie (2011) who had compared the QOL of renal transplant patients with that of normal population. She found that the QOL of transplant patients were at par with the normal population further she also found that there was no association of QOL with selected factors like age, family income, duration of transplant, duration of dialysis prior to transplantation and associated diseases. Whereas she found significant association of factor like number of hospitalization and rejection episodes with QOL which was consistent with this present study.

A study by Travallai et al (2009) and Chisholm et al (2007) found significant association of family income with QOL which was consistent with present study findings. Similar consistent result was found between QOL and age of patient in the study done by Chisholm et al (2007) and White C (2010).

Findings of Chisholm et al also found that medi-care status of the subjects affect their QOL which was consistent with the findings of present study where it was found that patients who had reimbursement facility of the cost of their post-transplant medicines were found to have better QOL than those who procure medicine by their own expense.

Gregoria et al (2007) found that duration of transplantation had significant association with QOL of the subjects which was again consistent with the finding of present study as discussed above.

Weety Suet and Ching Luk (2004) found in their study that patients expresses their need for information on side effects of medication, diet and exercise after transplantation and the information booklet in present study had the similar content included.

In the present study, it was found that the post knowledge scores had significant correlation with the QOL scores which was consistent with the finding of a study done by Urstad KH et al (2011). The study done by Sayin A and Mutluay R (2007) also supported the findings as they had found in their study that the most significant correlation with QOL was the patient's knowledge which explains that with increased knowledge, there was better QOL of the patients.

As suggested by Gordon Elisa and Wolf Micheal (2009) in their study regarding the intervention by transplant provider with educational materials to improve patient's knowledge which further improves patient's medication adherence and transplant outcome, the present study was a similar attempt to provide education to the post-transplant patients and thus improve their QOL.

CONCLUSIONS

The following conclusions were drawn on the basis of the findings of the study:

- Majority of the transplant patients are male and are mostly young adults, transplantation of elderly patients are rarely seen.
- The majority of the kidney donors were live related donors though cadaveric donors also taking its part now unlike few years back.
- Majority of the patients who had undergone transplant belong to joint family and from middle class income group.
- There was a significant association between the knowledge and the age of the patients as well as the education level of the patients.
- There was a significant association between the quality of life and selected factors like age, family income, duration of transplant, source of donor, rejection episodes, hospitalization, co morbidities, duration of dialysis and procurement of medicines.
- Information booklet regarding healthy living after transplantation was found to be an effective strategy to enhance the knowledge and quality of life of renal transplant patients.

Compliance with ethical standards:
The study was taken after taking proper permission to conduct. No intervention was carried on the patients except giving the information booklet which was validated from subject experts and reliability checked.

Informed consent: written informed consent was taken from all the patients who participated in the study.

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Conflict of interest:
No conflict of interest exist .

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