

Live related donors in India: Their quality of life using world health organization quality of life brief questionnaire

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ABSTRACT

Context: Organ selling is now legally banned in India. Numerous studies have documented that organ vendors have a poor quality of life (QOL) following kidney donation. Aims: This study was designed to assess the QOL of living related donors in India. Settings and Design: This study was a single-center prospective study.

Materials and Methods: The QOL of 106 consecutive related kidney donors was compared before and 6 months after the donation using the World Health Organisation Quality of Life Brief Questionnaire.

Statistical Analysis Used: STATA 9.0 (College Station, Texas) was used and a p value less than 0.05 was considered significant.

Results: The response rate was 94.3% and the mean age was 43.2±11.95 years. Females constituted 73% of the population. Our study showed a significant improvement in the QOL among three of the four domains. The surgical technique (86-mini open donor nephrectomy, and 14 laparoscopic donor nephrectomy), education status, and marital status did not make any difference in the change in the QOL.

Conclusions: Despite a number of our donors being unemployed and not being well educated, live related kidney donation improves the QOL of donors.

Key words: Live related renal donors, quality of life, world health organization quality of life brief questionnaire

INTRODUCTION

Renal transplantation from living related donors is an ideal option for patients with end-stage renal disease. Living kidney donation is safe and is associated with low morbidity and mortality.^[1] Numerous studies on the physical impact of organ donation have documented that renal donation does not put the donor at an increased risk of renal failure or clinically

relevant consequences such as arterial hypertension or proteinuria.^[2] However the donor who plays a pivotal role in the entire process of transplantation is often neglected, as the focus shifts to the recipients' performance, following the transplant. Assessment of health-related quality of life (QOL) is superior in determining the personal burden of illness than measures of disease status. Previous studies in this regard^[3-12] were standardized and validated only for a particular cultural background, involved too few participants, had a low response rates, and compared the donors with the general population. There is a paucity of studies from India assessing the QOL of live related donors using a standardized questionnaire. This study was carried out to assess the impact of live related renal donation upon the related donors in India and to identify the various determinants of the QOL outcome.

MATERIALS AND METHODS

Study design

This was a prospective study with a follow-up design with each subject being evaluated before and after kidney donation.

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Setting

The initial assessment of the donors was done 2 weeks prior to transplantation in the outpatient department of the hospital. The follow-up assessment was done at the renal transplant follow-up clinic at 6 months after the donation.

Selection of participants

Consecutive live related renal donors who were willing to participate in this study were included. All donors gave their informed consent prior to their inclusion in this study. This study was performed in accordance with ethical standards laid down by the ethics committee of the hospital.

Interventions

The donors were interviewed 2 weeks prior to the surgery and were encouraged to complete the World Health Organization Quality of Life Brief Questionnaire (WHO QOL BREF). QOL indices are increasingly recognized as crucial outcome measures in the evaluation of therapeutic interventions. Accordingly a plethora of instruments have been developed, many of which suffer from disease or cultural specificity thus making comparative studies difficult. In response to these limitations, the World Health Organization developed the WHOQOL-100, a valid and responsive measure of QOL that is applicable across cultures.^[13] This was developed in association with 15 countries and was tested in 30 field centers. It is available in all major international languages including Hindi. The WHO QOL assesses the individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.^[13] However the

WHOQOL group noted that the WHOQOL-100 might be too lengthy for some uses. Hence an abbreviated form of the WHOQOL, the WHO QOL-BREF, was developed.

WHO QOL BREF consists of four domains assessing the QOL – physical, psychological, social relationship, and environmental.^[14] Donors unable to understand the English questionnaire were given a questionnaire in Hindi. This questionnaire has been validated in Hindi.^[15] The questions pertaining to the four domains of the WHO QOL BREF are given in Table 1.

The primary outcome of this study was the comparison between QOL scores before and after kidney donation. We currently recover live donor kidneys through laparoscopy as well as a mini-donor nephrectomy. The study also assessed if the QOL was altered depending on the technique used for graft retrieval.

One hundred and sixteen live related donors were recruited in this study. Ten donors did not donate due to recipient-related problems. Six donors were lost to follow-up and one hundred donors were followed up for 6 months.

Statistical analysis

Consecutive live related donors were recruited for this study. Statistical analysis was done using STATA 9.0 (College Station, TX, U.S.A). Data were presented as mean ± standard deviation or median (range) or number (percentage) as appropriate. Paired *t* Test was used to test the before kidney donation and after kidney WHO QOL BREF domains (physical, psychological, social relationship,

Table 1: The world health organization quality of life brief questionnaire

Domain	Questions
Physical domain	Q3 – To what extent do you feel that (physical) pain prevents you from doing what you need to do?
	Q4 – How much do you need any medical treatment to function in your daily life?
	Q10 – Do you have enough energy for everyday life?
	Q15 – How well are you able to get around?
	Q16 – How satisfied are you with your sleep?
	Q17 – How satisfied are you with your ability to perform your daily living activities?
	Q18 – How satisfied are you with your capacity for work?
	Psychological
	Q6 – To what extent do you feel your life to be meaningful?
	Q7 – How well are you able to concentrate?
	Q11 – Are you able to accept your bodily appearance?
	Q19 – How satisfied are you with yourself?
	Q26 – How often do you have negative feelings such as blue mood, despair, anxiety, depression?
Social relationship	Q20 – How satisfied are you with your personal relationships?
	Q21 – How satisfied are you with your sex life?
	Q22 – How satisfied are you with the support you get from your friends?
Environmental	Q8 – How safe do you feel in your daily life?
	Q9 – How healthy is your physical environment?
	Q12 – Have you enough money to meet your needs?
	Q13 – How available to you is the information that you need in your day-to-day life?
	Q14 – To what extent do you have the opportunity for leisure activities?
	Q23 – How satisfied are you with the conditions of your living place?
	Q24 – How satisfied are you with your access to health services?

and environmental). Student's test was used to compare the difference in means of the WHO QOL BREF domains and gender and surgical technique. ANOVA was used to compare the difference in means before and after kidney donation of WHO QOL BREF domains among the groups age groups, education status, and recipient outcome. A *P*-value of less than 0.05 was considered statistically significant.

RESULTS

The response rate in the present study was 94.3%. The demographic details of the study population is given in Table 2. There were no operative complications in this study. One donor had prolonged paralytic ileus requiring nasogastric decompression, but responded and made rapid recovery. One donor had minimal wound gaping and required secondary suturing.

Quality of life

All donors showed an improvement in the QOL post organ

Table 2: Demographic data

Trait	N = 100	
Sex		
Male	27	
Female	73	
Age		
<30	19	
31-40	20	Mean age-
41-50	31	43.2±11.95 (22-65)
>50	30	
Marital Status		
Married	85	
Unmarried	8	
Live in relationship	1	
Married but separated	2	
Divorcee	1	
Widow/widower	3	
Education status		
Illiterate	23	
Primary school	18	
Secondary school	18	
Tertiary school	20	
Graduation	21	
Employment status		
Employed	22	
Unemployed	12	
Housewife	66	
Relationship with recipient		
Mother	42	
Father	15	
Brother	9	Sibling = 17
Sister	8	
Spouse	24	
Son	2	

donation [Table 3]. There was significant improvement in the QOL in the physical domain (15.66±1.82 vs. 16.51±1.71; *P*<0.0001), the Psychological domain (14.03±2.29 vs. 16.71±2.25; *P*<.0001), and the environmental domain (13.68±2.06 vs. 14.58±1.81; *P*<.0001) before and after organ donation. There was improvement in the social relationship domain but this was not statistically significant. (15±2.41 vs. 15.33±2.63; *P* = 0.0569).

The surgical technique

The difference in the WHO QOL scores before and after the kidney donation was compared between the donors who had underwent mini-open donor nephrectomy (*n* = 86) and those who had underwent laparoscopic donor nephrectomy (*n* = 14). There was no significant difference between the two in all the four domains.

According to education

The improvement of the QOL was independent of the education status of the donors.

According to recipient outcome

Among the 100 recipients of the study group, there were five recipients who experienced morbidity due to uncontrolled sugars, orchitis, and chest infection. There were three recipient deaths and one recipient lost the donated kidney to antibody-mediated graft rejection.

The QOL scores were compared among the three groups namely donors without recipient morbidity or mortality, donors with recipient morbidity, and donors with recipient mortality. There was a significant decrease in the QOL in physical domain (16.69±1.58 vs. 15.43±2.04 vs. 14±1.89; *P*= 0.002), psychological domain (17.08±1.8 vs. 14.67±3.16 vs. 11.33±1.8; *P* = 0.00), social relationship domain (15.6±2.38 vs. 13.33±2.79 vs. 15.67±2.96; *P* = 0.007), and environment domain (14.71±1.61 vs. 12.08±2.8 vs. 15.5±1.96; *P* = 0.001) among the donors whose recipient died or graft was lost. The recipients' outcome thus had a significant impact on the QOL of the donors.

DISCUSSION

The current study had a very high response rate. This high response rate (94.3%) as compared to other studies (60–89.8%)^[3,5,8,12] was largely due to the follow-up setting being the transplant clinic as it was convenient for the donors to accompany their recipients for follow up. Most of the donors in our study were females. This was higher than other studies where the female donors comprised 24.8–54%.^[4,8,10] This is largely due to cultural, economic, and social factors

There is a paucity of data using the WHO QOL BREF questionnaire to evaluate the QOL of live related renal donors in India. In our study, there was a significant improvement in the QOL in the physical, psychological,

Table 3: World health organization quality of life brief questionnaire scores before and after kidney donation

WHO QOL bref domain	Before donation		After donation		P value
	Mean \pm SD	Range (median)	Mean \pm SD	Range (median)	
Physical	15.66 \pm 1.82	10.29–18.86 (15.43)	16.51 \pm 1.71	10.86–19.43 (16.57)	<0.0001
Psychological	14.03 \pm 2.29	7.33–20.0 (14.0)	16.71 \pm 2.25	8.0–20.0 (17.33)	<0.0001
Social relationship	15 \pm 2.41	8–20 (14.67)	15.33 \pm 2.63	5.33–20.0 (16.0)	0.056
Environment	13.68 \pm 2.06	7.5–18.5 (13.5)	14.58 \pm 1.81	7.0–18.5 (14.5)	<0.0001

environment domains. The improvement in the social relationship domain was worth mentioning. In a similar study done in UK, by Lumsdaine *et al.*^[6] the mean QOL in the physical domain before donation was higher than in the present study but it remained lower than the pre donation score at one year follow up. However the psychological, social relationship and environmental domains remained unchanged. The studies done using SF 36 observed that the donors had a better or similar QOL in the domains pertaining to physical elements.^[3,4,9] There was an adverse impact of donation upon the mental components in one study^[9] and in the other studies the mental components were similar to general population.^[3,4]

While most of the studies used SF 36 as the instrument to measure the health-related QOL, a study from Brazil by Padrao^[16] *et al.* used both WHO QOL BREF and SF 36 in the same donor population. It was observed that there was a significant improvement in the psychological, social, and environmental domains of the WHO QOL BREF. The results of SF 36 questionnaire were similar to controls except in emotional and vitality domains where the donors had significantly better scores. The study concludes that there was a weak correlation in the results of the two questionnaires though neither could be proven as superior. Huang *et al.*^[17] in Taiwan comparing both these instruments found that the SF 36 measured health-related QOL while the WHO QOL BREF measured the global QOL.

The higher QOL of donors following the kidney donation in our study as compared with other studies might be due to the fact that the present study compared the donors before and after kidney donation, unlike the other studies which compared the donors' QOL with that of the general population. There is little data available on the QOL in India in the general population using the WHO QOL BREF score. We feel it may be more appropriate to compare their QOL pre- and postdonation.

Comparison of the quality of life with various parameters

In this study there was no relationship of the donors' QOL with gender. The influence of gender upon the QOL varies among the different studies. But the predominant trend is that gender has no effect on the QOL.^[4,8,9] Johnson *et al.* noticed that female donors have a stressful experience with donation than their male counterparts.^[5]

Age did not have any influence over the QOL in our study. Few studies did not show any impact of age upon the QOL of the donors.^[4,9] In the study by Giessing *et al.*,^[3] donors had an increasingly significant SF-36 scores with an increase in age but donors aged 31–40 years had a worse outcome following donation.

Not many studies have studied the education status of the donors and its relationship with the QOL. A high percentage of the donors in the current study were illiterate (23%), which is the highest in existing literature, while in other studies the lowest education status recorded was grammar school – 5% in Schover *et al.*^[8] study, 4% in a study by Johnson *et al.*^[5] Both the above studies did not study the QOL in relation to the education status. In the present study, there was no relationship of the QOL and the donors' education status. Thirty-two percent of the housewives were illiterate as compared to 23% in the whole sample. Illiteracy and unemployment are confounding factors for QOL. At baseline, upon univariate analysis, there was no difference in the QOL scores according to the education and unemployment. Similar results were obtained at follow-up where there was no significant difference. Since the univariate analysis did not reveal any influence of education, employment status upon QOL, we avoided doing a multivariate analysis to overcome the confounding effect.

In the present study, the QOL of donors whose recipients made uneventful recovery had significantly higher scores in all the domains of the WHO QOL as compared with those donors whose recipients experienced postoperative morbidity and readmissions and those donors who experienced loss of recipient or loss of the donated kidney. Similar results were found in literature, for example, in the study by Schover *et al.*,^[8] where 40 donors whose graft had failed reported less positive health perceptions than did 104 donors whose graft was working well. Smith *et al.*^[9] found that the emotional state of the recipient rather than the physical state (as measured by length of stay, creatinine level, graft failure) that was associated with donor psychosocial outcome. Westlie *et al.*^[12] in their study reported that donors whose recipient had died had a worse psychological state.

Although the number of laparoscopic donor nephrectomy done in the study population was less, there was no significant

difference in the postdonation QOL scores. The difference in the WHO QOL scores before and after kidney donation did not show any significant difference. In a study by Kok *et al.*,^[19] the laparoscopic donors had less physical pain, bodily fatigue, and higher QOL scores in all domains. But in a study by Joseph Buell *et al.*,^[20] there was no significant difference in the QOL between the laparoscopic and mini open donor nephrectomy groups although the laparoscopic donors had an earlier recovery and an earlier return to work. In the study by Giessing *et al.*,^[3] the surgical technique made no difference to the QOL of the donors.

All the donors (100%) in our study including those who experienced graft loss or recipient death agreed to donate again if they could. This result was consistent in other studies^[4,5,7]

Comparison with live paid kidney donation in India

Paid kidney donation though not legal, still does happen in India where there is a large under-privileged population willing to be paid for kidney donation. A study done by Goyal *et al.*^[21] noted that paid kidney donation resulted in a decline in health as well as a decline in the economic status of the paid donors. Of the donors, 79% would not recommend others to donate for sake of money, which reflected their experience of paid donation. Our study on the QOL of live related donors in India, in contrast shows the remarkable improvement in QOL as evidenced by the willingness to donate again if possible by all the donors in our study.

CONCLUSION

Live related renal donors have a significant improvement in the QOL following renal donation using the WHO QOL BREF. The quality of life of the donor was poor when the graft was lost or the recipient died. There was no difference in the quality of life between the laparoscopic and mini open donor nephrectomy groups. The study reiterates that in the developing world live related organ donation is associated with an excellent quality of life despite higher rates of illiteracy.

REFERENCES

1. Kasiske BL, Bia MJ. The evaluation and selection of living kidney donors. *Am J Kidney Dis* 1995;26:387-98.
2. Johnson EM, Remucal MJ, Gillingham KJ, Dahms RA, Najarian JS, Matas AJ. Complications and risks of living donor nephrectomy. *Transplantation* 1997;64:1124-8.
3. Giessing M, Reuter S, Schonberger B, Deger S, Tuerk I, Hirte I, *et al.* Quality of life of living kidney donors in Germany: a survey with the Validated Short Form-36 and Giessen Subjective Complaints List-24

- questionnaires. *Transplantation* 2004;78:864-72.
4. Isotani S, Fujisawa M, Ichikawa Y, Ishimura T, Matsumoto O, Hamami G, *et al.* Quality of life of living kidney donors: the short-form 36-item health questionnaire survey. *Urology* 2002;60:588-92.
5. Johnson EM, Anderson JK, Jacobs C, Suh G, Humar A, Suhr BD, *et al.* Long-term follow-up of living kidney donors: quality of life after donation. *Transplantation* 1999;67:717-21.
6. Lumsdaine JA, Wray A, Power MJ, Jamieson NV, Akyol M, Andrew BJ, *et al.* Higher quality of life in living donor kidney transplantation: prospective cohort study. *Transpl Int* 2005;18:975-80.
7. Minz M, Udgiri N, Sharma A, Heer MK, Kashyap R, Nehra R, *et al.* Prospective psychosocial evaluation of related kidney donors: Indian perspective. *Transplant Proc* 2005;37:2001-3.
8. Schover LR, Streem SB, Boparai N, Duriak K, Novick AC. The psychosocial impact of donating a kidney: long-term follow-up from a urology based center. *J Urol* 1997;157:1596-601.
9. Smith GC, Trauer T, Kerr PG, Chadban SJ. Prospective psychosocial monitoring of living kidney donors using the Short Form-36 health survey: results at 12 months. *Transplantation* 2004;78:1384-9.
10. Tanriverdi N, Ozcurumez G, Colak T, Duru C, Emiroglu R, Zileli L, *et al.* Quality of life and mood in renal transplantation recipients, donors, and controls: preliminary report. *Transplant Proc* 2004;36:117-9.
11. Tellioglu G, Berber I, Yatkin I, Yigit B, Ozgezer T, Gulle S, *et al.* Quality of life analysis of renal donors. *Transplant Proc* 2008;40:50-2.
12. Westlie L, Fauchald P, Talseth T, Jakobsen A, Flatmark A. Quality of life in Norwegian kidney donors. *Nephrol Dial Transplant* 1993;8:1146-50.
13. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998;46:1569-85.
14. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995;41:1403-9.
15. Saxena S, Chandiramani K, Bhargava R. WHOQOL-Hindi: a questionnaire for assessing quality of life in health care settings in India. *World Health Organization Quality of Life. Natl Med J India* 1998;11:160-5.
16. Padrao MB, Sens YA. Quality of life of living kidney donors in Brazil: an evaluation by the short form-36 and the WHOQOL-bref questionnaires. *Clin Transplant* 2009;23:621-7.
17. Huang IC, Wu AW, Frangakis C. Do the SF-36 and WHOQOL-BREF measure the same constructs? Evidence from the Taiwan population. *Qual Life Res* 2006;15:15-24.
18. Fehrman-Ekholm I, Brink B, Ericsson C, Elinder CG, Duner F, Lundgren G. Kidney donors don't regret: follow-up of 370 donors in Stockholm since 1964. *Transplantation* 2000;69:2067-71.
19. Kok NF, Lind MY, Hansson BM, Pilzecker D, Mertens ZB, Knipscheer BC, *et al.* Comparison of laparoscopic and mini incision open donor nephrectomy: single blind, randomised controlled clinical trial. *BMJ* 2006;333:221.
20. Buell JF, Lee L, Martin JE, Dake NA, Cavanaugh TM, Hanaway MJ, *et al.* Laparoscopic donor nephrectomy vs. open live donor nephrectomy: a quality of life and functional study. *Clin Transplant* 2005;19:102-9.
21. Goyal M, Mehta RL, Schneiderman LJ, Sehgal AR. Economic and health consequences of selling a kidney in India. *JAMA* 2002;288:1589-93.

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