

Living kidney donors – a prospective study of quality of life before and after kidney donation

Garcia MFFM, Andrade LGM, Carvalho MFC. Living kidney donors – a prospective study of quality of life before and after kidney donation.

Abstract: Although the safety of living kidney donation has been well established, prospective studies examining the physical and psychosocial aspects of the donor's quality of life are still scarce. Thus, the purpose of this prospective work was to assess the quality of life of 50 consecutive donors before and after kidney transplantation. All donors were asked to respond to both a donor questionnaire and the short-form 36-item health survey (SF-36). Interviews were individually conducted before, three months after, and over one yr after transplantation. Donation was considered a positive experience by all patients and had no impact on any physical or psychosocial aspect of the donor's life. Improved self-esteem and better quality of life after donation were reported in 52% of the cases. All donors would donate again and encouraged donation. SF-36 data indicated improvement in post-donation mental and physical scores among living donors closely related to recipient. Overall, most donors had a positive experience, felt no changes in quality of life, experienced enhanced self-esteem, would donate again, and recommended donation.

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According to the World Health Organization, quality of life is defined as “individuals' perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns.”

The focus on a patient's quality of life has increased greatly during the past 20 yr as the combined effects of improvements in living conditions, advances in medicine, and heightened awareness of health issues have led to a remarkable increase of human life expectancy. Over the past five yr, life expectancy in Brazil has significantly increased as a result of economic growth and the implementation of a national public healthcare system (1). However, such increase in life expectancy has been accompanied by chronic diseases and their complications and sequels, causing quality of life to decline.

End-stage renal disease (ESRD), like other chronic illnesses, is associated with high rates of mortality/morbidity and imposes a high economic burden on the healthcare system.

Kidney transplantation is the best treatment for most patients with ESRD. As compared with dialysis, it provides better quality of life, increased degree of vocational rehabilitation, lower costs, and longer survival (2–6).

To offset the shortage of deceased donor kidneys for transplantation and the growing time on waiting lists, living donor transplantation has been increasingly performed. Living donor transplantation provides superior long-term graft survival in addition to the advantages of an elective setting, optimal conditions for allograft retrieval, improved HLA matching, shorter cold ischemic time, and decreased immunosuppression regimens.

There is substantial evidence that healthy living kidney donors are able to return to a normal lifestyle after unilateral nephrectomy. Indeed, perioperative mortality after living kidney donation is 0.03% while morbidity, including minor complications, is less than 10%. Therefore, owing to its safety and excellent outcomes, the use of living donor kidneys has been strongly encouraged in the literature (3, 7–12).

In Brazil, a total of 4630 kidney transplantations were performed during the year 2010. Of these, 35% used living donors. Kidney donation by living donors is regulated by Law # 10.211 of March 23, 2001, specifically in its article 9, which determines that every legally competent person can freely donate tissues, organs, and parts of their living body to spouses, relatives up to the fourth degree of kin, or any other individual for therapeutic purposes or transplantations, provided that judicial authorization is granted. According to this law, any kind of incentive or compensation is prohibited. The Brazilian Unified Health System pays all expenses associated with kidney transplantation and donor surgery so that there is no cost to the recipient or the donor at any time during treatment.

Although the safety of living kidney donation has been well established, prospective studies examining the physical and psychosocial aspects of the donor’s quality of life are still scarce (13–16). Thus, the purpose of this work was to assess the quality of life of 50 consecutive kidney donors before and after open nephrectomy. To our knowledge, this is the first and largest consecutive study on this topic.

Patients and methods

This prospective cross-sectional study including 50 consecutive kidney donors was conducted between November 2007 and November 2009 at the Botucatu Medical School Hospital, São Paulo State University-UNESP.

Approval for the study was obtained from the institutional review board (199/08), and written

informed consent was provided by all study participants. All donors underwent open retroperitoneal nephrectomy via mini-flank incision, which is the technique most frequently used in Brazil.

All subjects were asked to respond to both a donor questionnaire and the short-form 36-item health survey (SF-36) (17). Interviews were individually conducted by the same investigator at three different time points: (i) before open nephrectomy (20 ± 27 d); (ii) about three months after transplantation (126 ± 89 d); and (iii) over one yr after transplantation (445 ± 164 d).

The donor questionnaire was developed by Coelho et al. (18) for the assessment of living donors. It consists of 28 questions covering the following topics: demographics (gender, age, education level, and relationship to recipient); reasons for donation; recipient status after transplantation; adequacy of information provided by the medical staff about donation; pressure to donate; length of hospital stay; need for hospital readmission; time away from work and other everyday activities; expenses incurred; changes or limitations in job, sexual, or emotional performance; overall pre- and post-donation expectations; relationship with recipient after transplantation; donation pros and cons; and repeating donation.

The SF-36 is a standardized instrument for measuring quality of life that contains 36 items and measures eight health domains: physical functioning, role limitations owing to physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations owing to emotional problems, and mental health. Two summary measures of physical health and mental health were constructed from the eight subscales (Table 1).

Table 1. Short-form 36 health status scales and interpretation of low and high scores in kidney donors

	Low score	High score
Physical health summary scores		
Physical functioning	Limited in performing all physical activities, including bathing or dressing because of health	Performing all types of physical activities, including the most vigorous, without limitations caused by health
Role-physical	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health
Bodily pain	Very severe and extremely limiting pain	No pain or limitation as a result of pain
General health	Evaluates personal health as poor and believes it is likely to get worse	Evaluates personal health as excellent
Mental health summary scores		
Vitality	Feels tired and worn out all the time	Feels full of energy all the time
Social functioning	Extreme and frequent interference with normal social activities because of physical or emotional problems	Performs normal social activities without interference from physical or emotional problems
Role-emotional	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities
Mental health	Feels nervous and depressed all the time	Feels peaceful, happy, and calm all the time

Statistical analysis

Analyses were performed using SPSS software (version 13.0 SPSS, Inc., Chicago, IL, USA). The Kolmogorov–Smirnov test was used to verify departures from normality. Where the assumption of normality was tenable, data were summarized as means and standard deviation. Where data were found to be skewed and not normally distributed, results were summarized as median and ranges. Donor questionnaire data were summarized using percentages. SF-36 scores were estimated by QualityMetric Health Outcomes™ Scoring Software 4.5 (QualityMetric Incorporated, Lincoln, RI, USA) using original/raw data. Physical and mental summary scores were compared by mixed model analysis using unstructured covariance matrix. Summary scores were analyzed as the dependent variable and time as a fixed factor. Significance level was set at $p < 0.05$.

Results

All 50 donors participated in the interviews conducted before and one yr after transplantation (100% response rate), while only two missed the interviews held at three months (96% response rate).

Demographic characteristics of the study population are summarized in Table 2. Donor mean age was 41 yr (41.02 ± 9.18 , range of 25–68 yr) with 62% being women. All donors were either related or married to the recipient. The majority (62%) had completed only elementary school.

Table 2. Donor demographics and relationship to recipient

	n (%)
Donor age at transplantation (yr) (41.02 ± 9.18 yr)	
25–29	4 (8)
30–39	18 (36)
40–49	20 (40)
50–59	7 (14)
60–69	1 (2)
Gender	
Female	31 (62)
Male	19 (38)
Education level	
Elementary	31 (62)
High school	14 (28)
College	5 (10)
Relationship	
Sibling	21 (42)
Parent	13 (26)
Uncle/aunt	6 (12)
Cousin	5 (10)
Spouse	4 (8)
Nephew/niece	1 (4)

In all cases, the reason for donation was altruistic, and the decision to donate was voluntary. Transplantation outcome was unsuccessful in only three cases. Two recipients died with a functioning kidney graft within the first month after transplantation, and one had early graft loss secondary to venous thrombosis. SF-36 results in these cases did not differ from the remaining, and no other adverse effect, such as graft loss or death, occurred throughout the study period.

Median hospital stay was five d (two d before and three d after open nephrectomy). There was no case of hospital readmission or post-operative complications. Only two donors (4%) were dissatisfied with the information provided by the medical staff about the transplantation process.

Sixty percent of the donors returned to daily activities after one to two months, whereas 22% returned earlier. Ninety-eight percent said that performance at work remained unchanged or improved after donation as they were able to perform the same activities and work for the same amount of time before transplantation. As kidney transplantations are paid by the public healthcare system in Brazil, 80% of the respondents found donation to be little or no financial burden.

No change in sexual life was observed, and psychologic limitation/change was reported by only two donors (4%). Self-esteem and quality of life were considered to have improved by 26 donors (52%), whereas the remaining 24 (48%) reported no changes.

Fifty-eight percent of the donors perceived that the transplantation process (surgery, hospitalization, outcomes, etc.) corresponded to their expectations, while 26% thought that it went beyond the expected in a positive way. In 95% of the cases, the relationship between donor and recipient was closer after transplantation. Donor SF-36 summary scores are shown in Table 3.

In comparison with pre-transplantation scores (Table 3 and Fig. 1), Physical Health summary score was lower at three months and higher at one yr, while Mental Health summary score was similar at three months and higher at one yr after donation. One year after nephrectomy, 72% of donors considered their current health status as improved whereas 22% rated it as comparable to pre-donation levels.

Discussion

Overall, the vast majority of donors reported no regretting or negative impact on quality of life after transplantation, and the decision to donate was altruistic in 100% of the cases. Notably,

Table 3. Mental and physical summary scores of quality of life in kidney donors (SF-36) before, three months after, and at least one yr after open nephrectomy

Summary scores	MDN	P 25	P 75	MEAN	SD	Max	Min	p
Physical								
Before	59.67	56.8	61.3	58.16	4.4	63.4	44.1	
3 months	59.66	55.0	60.4	56.53	6.5	69.2	39.8	0.037
1 yr	60.40	59.3	61.7	59.78	3.1	63.5	47.8	0.003
Mental								
Before	55.26	52.0	58.4	54.26	5.8	63.8	37.2	
3 months	57.07	53.3	59.6	54.53	8.3	62.7	19.6	0.23
1 yr	56.88	54.3	59.0	56.16	4.4	62.6	40.5	0.04

MDN, median; P 25, percentile 25; P 75, percentile 75; SD, Standard deviation; Max, maximum value; Min, minimum value; p value x before.

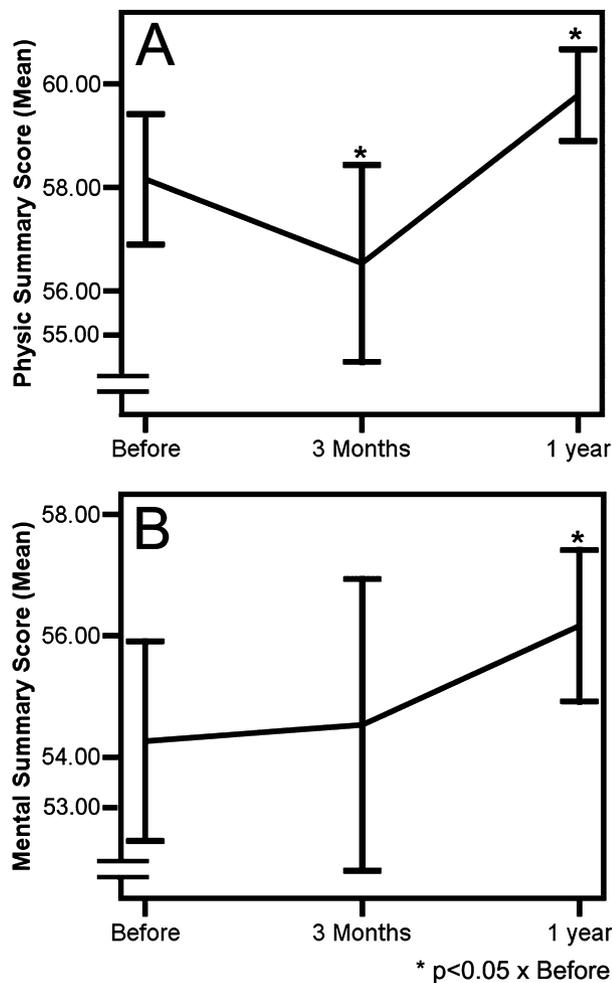


Fig. 1. Short-form-36 summary scores before, three months after, and one yr after donation. (A) Physical health score and (B) mental health scores.

transplantation failure did not affect donor’s attitude toward donation. Indeed, the three donors experiencing adverse transplantation outcome reported a feeling of accomplishment, boosted self-esteem, and no regretting. Similar findings were reported by Padrão and Sens (12), who observed

that, among 15 donors whose recipients died or suffered graft loss, reported quality of life similar to that of non-donors. In contrast, Johnson et al. (19), in a study of 524 donors, found that donors experiencing recipient death were more likely to say they would not donate again if it were possible.

In this study, summary measures of physical health and mental health scores were higher at one yr post-transplantation when compared to pre-transplantation scores. The fact that only related donors, who usually have close affective ties with the recipient, were assessed, most probably accounted for the difficulty to concentrate at work, and anguish about the recipient suffering and possible death reported pre-transplantation. The decrease in physical health scores observed after three months probably reflected the discomfort experienced during convalescence, while the increase in both physical and mental scores found one yr after donation probably resulted from the fact that all concerns were solved, and donors had returned to full activity.

Virzi et al. (20) observed worsening in physical and general health scores from pre-transplantation to four months post-transplantation. Giessing et al. (21) reported higher physical scores at 75.4 ± 8.8 months post-transplantation among donors as compared to references. Lima et al. (9) found that general health scores were higher in donors than in non-donors at the late post-operative period.

In disagreement with others, quality of life after transplantation was improved in our study population. However, Virzi et al. (20) observed significant physical worsening from pre-transplant to four months post-transplant. This might be explained by the fact that, in their study, mean donor age was 54.2 yr, whereas among our donors it was 41 yr.

Studies focusing on the quality of life of living kidney donors before and after transplantation are scarce in the literature. Most studies applying

SF-36 have assessed donors only once after transplantation with donors being at different post-operative times, probably resulting in bias owing to a time effect. Moreover, time of assessment greatly differed from study to study.

Many have compared their findings with the scores of the general population. Such comparison is also likely to be biased because, in contrast to individuals in the general population, among whom diseases such as hypertension, diabetes, obesity, etc. are prevalent, potential live kidney donors are required to achieve a higher than normal health status prior to donation. Moreover, differences in age, educational, cultural, and socioeconomic backgrounds are known to have some influence on quality of life. Yet, other investigators have assessed donors before and after transplantation, but post-transplantation assessment was performed only once, and the sample size was very small (5, 20, 22, 23).

As in most prior studies, one of the limitations of this work is the fact that it was conducted in a single center. However, this allowed conducting individual in-person interviews with all donors, yielding an overall response rate of 99.3%.

The strength of this study lies in its consecutive, prospective cross-sectional design. The same donors were assessed at three distinct time points: before, three months after, and over one yr after transplantation. To our knowledge, the only similar work found in the literature is that of Lumsdaine et al. (24). However, besides not being consecutive, their study included only 40 patients, and the World Health Organization Quality of Life Questionnaire (WHOQOL), rather than the SF-36, was used for quality of life assessment.

Conclusion

In 52% of the donors, there was improvement in self-esteem and quality of life, while in the remaining 48% no changes were observed. Moreover, all donors rated donation as a positive experience, would readily donate again, and recommended donation.

In brief, our findings in a population of related donors with close affective ties with the recipient indicated improvement in donor quality of life one yr after donation.

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Authors' contributions

Garcia participated in the performance of the research. Andrade contributed to analysis and interpretation of data and Carvalho contributed to conception and design, and final approval of the version to be published.

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