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LIVING DONORS

Impact Assessment in Living Kidney Donation: Psychosocial Aspects in the Donor

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ABSTRACT

Background. Living donor kidney transplantation has a positive influence on graft survival and recipient quality of life (QoL). We assessed the psychosocial impact of donation to the donor.

Methods. Before and after the procedure 32 living kidney donors (mean age 41 years) completed the Zung Self-Rating Anxiety and Depression Scales; a Sociodemographic, Short-Form 36 Health Survey (SF-36), and a Donation Perceptions Questionnaire.

Results. Living kidney donors were siblings (62.5%), parents (34.4%), or a daughter (3.1%). Transplantation was not successful in two cases: one recipient death and one graft failure. No significant changes were observed in donor QoL except for the SF-36 social functioning subscale that showed significant improvement after donation ($P = .038$). A reduction in depression symptom frequency was verified after donation (from 65.6% to 46.9%). There was an almost significant decrease in depression scores ($P = .077$), which was in fact was significant when one considered only successful transplants ($P = .021$). There was no significant variation in anxiety scores among donors. Time since transplantation was inversely correlated with overall anxiety ($r = .443, P = .011$), and with somatic anxiety subscales ($r = .357, P = .045$). For most donors, the decision to donate was easy and spontaneous. Nearly all donors would donate again and strongly encourage others to donate.

Conclusions. Except for the social functioning scale that improved, no significant changes were observed in QoL of living kidney donors after the procedure. Depression scores significantly decreased after donation, but anxiety scores remained stable. Donors, who were mostly siblings, showed positive perceptions about donation, did not regret their decision, and strongly recommend it to others.

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KIDNEY TRANSPLANTATION has improved life expectancy and quality of life (QoL) for renal patients when compared with maintenance dialysis.[1,2] Scarcity of organs from cadaveric donors has become a critical problem. Data from the United States revealed that during 2002, 3396 people died on the waiting list for a kidney, among the about 60,000 patients were listed and a waiting an organ in 2004.[3] The organ scarcity has encouraged living kidney donors programs, which have become a critical source of organs.[4] In the United States, living kidney donors exceeded the number of cadaveric donors in 2001 (United Network for Organ Sharing database, 2004).

Several reasons have justified living donation: the low risk to the donor, the favorable risk-benefit ratio, the psychological benefits to the donor. The altruism, and the autonomy.[5–9] The literature indicates beside the low morbidity and mortality rate, high levels of satisfaction were observed among donors.[10] Nevertheless, attention has been called to the possible inconsistency of these arguments and to the necessity of increasing the number of organs retrieved from deceased donors.[3] These controversies demand continuous assessment of donors including the psychosocial consequences of donation. Psychosocial evaluation of candidates for living related kidney donation is an important issue that has been the object of several studies.[11,12]

Evaluation of the QoL of donors has supported the practice of living donor kidney transplantation, although there are some financial and occupational disadvantages, some deterioration of QoL, and greater need for psychological support.[13,14] Some workers have described dissatisfaction with medical services as well as problems with unexpected obesity and hypertension.[15]

Portuguese law (Law No. 12/1993 revised in April 2007, No. 6537/2007) that regulates organ transplantation within the public health system established "opting in" as its foundation. The policy for organ donation has recently changed; previously candidates for donation could be third-degree related donors. Since June 2007 (Law No. 22/2007) all people can be kidney donors with the usual exceptions (minors and mentally disturbed).

In the North of Portugal 668 patients are a waiting kidney transplantation. The mean national time on the waiting list is 3.5 years. According to Transplant Portuguese Organization data,[16] 496 cadaveric and 38 living donor kidney transplantations were performed in 2006.

Our living donor kidney program was implemented in 2002 with 55 patients transplanted by December 2006. A protocol of psychosocial evaluation, including donor and recipient assessment, was integrated into the program from the beginning. Usually, the donors came to the program due to medical information about living donation, which had been given to the patients and their families, or through public news regarding this issue, as namely the media, patients' associations, friends, and Internet. According to Portuguese law and until June of 2007, all candidates for donation had to be related to the recipient. This protocol includes donor and recipient assessments. In this study, we sought to assess the psychosocial impact of donation and QoL in living kidney donors, using pre- and posttransplant data.

SUBJECTS AND METHODS

The sample consisted of 32 kidney candidates who underwent living donation. As this study intended to examine changes in donor QoL, the evaluative psychological tests were performed before and after kidney donation.

Data Collection

A sociodemographic questionnaire included items of age, gender, school level, professional activity/current employment situation, marital status, and relation to recipient. Information regarding donor and recipient postoperative courses and complications was collected from the participant's medical records.

Evaluative Intruments

Donors were evaluated with Zung Self-Rating Anxiety Scale, Zung Self-Rating Depression Scale, Short-Form 36 Health Survey Questionnaire (SF-36), and also a Kidney Donor Perceptions Questionnaire.

Zung Self-Rating Anxiety Scale is a 20-item self-administered scale designed to measure anxiety.[17] Zung Self-Rating Depression Scale is a 20-item self-administered scale designed to measure depression.[18] SF-36 is a well-validated generic questionnaire widely used to assess quality of life. This questionnaire includes 36 items divided into eight scales: physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Scores can be obtained for each scale or aggregated into two summary scores: a Mental Component Summary and a Physical Component Summary. Both scale and summary scores reflect the level of impairment in health-related quality of life. A higher score represented a better QoL.[19]

Kidney Donor Perceptions Questionnaire had 13 questions about donor decision, decision difficulties and motivations, quality of donor–recipient relationship, donation outcome, pain from surgery, financial burden, quality of received information presurgery, attitudes toward donation (willingness to donate again and recommendation for living donor kidney).

Statistical Analysis

Descriptive data and results are reported as mean values and standard deviations for continuous variables and as frequency distributions for categorical variables. The Kolmogorov-Smirnov test was used to assess significant departure from normality. All variables presented normal distributions, thus pairwise comparisons before and after donation were performed using Student paired t test. Correlations were studied with Pearson correlation coefficients. In all analysis, $P < .05$ was considered statistically significant. Statistical analysis was performed using SPSS, version 15.0.

RESULTS

Donor Demographic and Social Data

The study sample comprised 32 donors, mainly women (n = 17, 53.1%) of mean age 41 years (range = 21 to 64 years). All donors were family members, predominantly siblings

Table 1. Donors' Quality of Life Assessment Before and After Donation

	Before	After	*P*
Physical functioning	88.5 ± 20.9	89.1 ± 15.2	.902
Physical role	90.1 ± 26.0	83.6 ± 34.0	.418
Bodily pain	86.5 ± 22.1	83.7 ± 19.8	.616
General health perception	72.5 ± 20.5	79.7 ± 18.9	.097
Overall vitality	69.7 ± 18.9	70.6 ± 17.2	.825
Social functioning	79.1 ± 26.7	89.8 ± 19.4	.038*
Emotional role	90.8 ± 26.5	94.8 ± 19.1	.510
Mental health	74.5 ± 20.1	71.9 ± 19.9	.553

*Statistically significant.

(n = 20; 62.5%), followed by mothers (n = 8; 25.0%), fathers (n = 3; 9.4%), a daughter (n = 1; 3.1%) of the recipient. Most kidney donors were married (n = 22, 68.8%); six were single (18.8%); and four were separated/divorced (12.5%). Twenty-nine donors were employed (90.6%) at the time of donation, two were retired (6.2%), and one, unemployed (3.1%). Most donors (n = 21, 65.7%) had a school level of less than 10 years; only 11 donors (34.3%) had a level equal to or higher than 10 years, and just 4 of these 11 had obtained graduate degrees.

Complications Following Living Donor Kidney Transplantation

There were no deaths among the donor population, and no one suffered a major postoperative complication. In relation to recipients, one death of the recipient occurred at 27 days after transplantation as a result of a septic shock, and one graft failed from vascular thrombosis at 40 days after transplantation.

Quality of Life of Donors Before and After Kidney Donation

QoL in living donors was compared at two time points: before and 18.8 ± 12.8 months after donation. In regard to SF-36 questionnaire, only social functioning scores showed a significant change after donation, an improvement from 79.1 to 89.8 (P = .038). The remaining SF-36 subscales—physical functioning, bodily pain, general health perception, physical role, overall vitality, mental health, and emotional role—were not significantly different before and after donation (Table 1). Considering only patients in whom the living donor kidney transplantation was successful at time of the second interview (n = 30), better scores were observed not only in social functioning, which significantly improved after donation (from 81.2 to 92.9, P = .006), but also in general health perception, which showed a strong tendency toward improvement (from 72.9 to 81.5, P = .059).

Depression and Anxiety of Donors Before and After Kidney Donation

Results from Zung showed 37.5% (n = 12) of donors displayed mild and 21.9% (n = 7), moderate scores of depression before donation (65.6%). An almost significant reduction was observed among mean values of depression scores after donation (from 2.01 to 1.69, P = .077), and these values decreased among 15 donors (46.9%) after transplantation (Table 2). As expected, considering only successful transplants (excluding donors whose related recipients died or had graft failure after transplantation), a substantial improvement of depression symptoms was confirmed, namely from 20 (66.7%) to 13 donors (43.3%). In addition significantly lower scores for depression were noted after donation (from 2.03 to 1.63, P = .021).

Concerning anxiety, five donors (15.6%) revealed anxiety scores before donation, but only three (9.2%) had them after donation. Nevertheless, overall scores of anxiety did not significantly differ before and after donation in all anxiety subscales. Similar results were reported considering only the 30 successful transplants.

Scores of total anxiety were inversely correlated with time since transplantation (r = .443, P = .011), namely somatic anxiety (r = .357, P = .045).

Kidney Donor Perceptions Questionnaire After Kidney Donation

Concerning the Kidney Donor Perceptions Questionnaire, 30 donors (93.8%) had decided on donation by themselves and they were the first ones to suggest the donation; only two donors (6.3%) were asked for donation by the recipient. When donation was decided by donor's own initiative, the wish to donate was the main reason for that decision (28 donors), and only two felt a moral obligation to donate.

When asked about their feelings about donation, 24 donors (75.0%) answered that it was an easy decision without thinking too much; six donors (18.8%) hesitated a little; and only 2 (6.3%) had difficulty making up their mind and regarded the decision to be complicated.

Most donors (n = 26, 81.2%) were not worried about the future in relation to their health, but some were afraid that donation might damage their health (n = 6, 18.8%); others feared that giving up one kidney might shorten their life span (n = 7, 21.9%).

Twenty-six donors (81.3%) felt that they could trust the recipient to be responsible and take care of the donated kidney, but one donor feared that the recipient might not do so well enough.

Most donors (n = 26, 81.3%) felt that they were well informed about medical and surgical procedures beyond transplantation to make a decision about donation. Never-

Table 2. Donors' Depression and Anxiety Before and After Donation

	Before donation, *n* (%)	After donation, *n* (%)
Depression		
No depression	11 (34.4)	17 (53.1%)
Mild depression	12 (37.5)	8 (25.0%)
Moderate depression	7 (21.9)	7 (21.9%)
Severe depression	2 (6.3)	—
Anxiety	5 (15.6)	3 (9.2)

theless, four donors (12.5%) admitted that they felt that there was little information about donation to take a decision. For two donors (6.3%), the lack of available information was one of the most important reasons for anxiety before deciding to donate.

The donation process had minimal financial implications for most donors (n = 24, 75.0%); however, seven donors reported moderate financial problems, while one participant stated severe financial consequences (time away from work, loss of wages, expenses with medical consults). Most donors felt that they had the necessary financial and bureaucratic support; for instance, 27 donors (84.4%) got insurance coverage after donation and 21 donors (65.6%) were discharged from the payment of medical consultations.

More than 90% of donors (n = 29) considered the information and instructions received from the medical team prior to surgery as adequate and helpful.

For most donors (n = 29, 90.6%), the recipient's general health was much better after transplantation. One donor said that the health of the recipient was slightly better; one believed that it was worse; and one donor did not answer this question.

When asked if they would donate again, 31 of the 32 donors (96.9%) stated that they would donate again if it was possible. Furthermore, 27 (84.4%) subjects would encourage others to donate, while the remaining five donors (15.6%) thought that they should not encorage others to donate because this should be an individual decision.

DISCUSSION

The present post–living donor kidney transplantation follow-up study observed good QoL among living donors before and after the procedure. QoL results showed no significant differences after surgery in all SF-36 scales, with the exception for social function scale that had significantly improved. This observation could point to better social functioning and improvement in personal relationships of donors and that donation may have a positive psychological impact on the donor. The literature has demonstrated similar patterns, without significant changes in QoL, but also noted age-related problems with deterioration of QoL especially among people of younger ages.[7,13] Our sample included only related donors who had a direct burden from chronic illness in the recipient, affecting family life. Transplantation could mean the possibility to have a better social life and a psychological relief.

The psychosocial impact of donation has been recognized and reported in literature: increased rates of mental distress and intrafamilial conflicts,[20] positive long-term psychological donor well-being,[10] low psychosocial morbidity,[12] psychosocial risks for donors.[21] All of these factors strongly advise the importance of psychological advice and support for donors. Mild depression and family problems have been the most extensively documented negative psychosocial issues after living donation. The majority of these were related to graft failure or recipient death after transplantation.[22]

In our study, anxiety was present before and after donation, but only in a small number of cases. Depression showed more impressive figures: 65.6% of donors had mild or moderate depression before, and 46.9% after surgery. These figures are above those observed for depression in the general population (14% to 20%).[23]

Only two participants exhibited severe values of depression symptoms predonation. These findings did not constitute a reason for refusal of the candidates, but it implied a need for psychosocial support for those with moderate and psychiatric treatment for a few with same levels. Our sample size did not allow us to relate depression to recognized variables: demographic, quality of recipient relationship, personality factors, or others. This would be an important matter to elucidate, as well as the importance of depression in these populations. The relatedness and burden of care may explain the importance of these psychopathologic values. Psychopathologic evaluation should constitute a regular procedure in kidney donation candidates.

Most donors were siblings of the recipient, consistent with the literature,[24] which was interesting considering the different legal background.

Results from other studies indicated that despite complications, a great majority of donors were willing to donate again, they strongly recommend others to do the same.[11,13,24] Our results demonstrated the same tendency among Portuguese donors. We must consider that these referred donors were the accepted ones; we do not know how many candidates were refused because of false motivations. Motivation is an important issue,[25] as is the way psychosocial assessment evaluates it, particularly when there are no legal restrictions for donation.

The decision for donation was easy, requiring little thought; in the great majority of donors, it was volunteered, without being asked to donate, and people had no fear for their lives. Like other studies,[22] satisfaction with donation was high among Portuguese donors, and only one donor showed regret. They would recommend donation and they would do it again, irrespective of complications occurring in the recipients or themselves. Moral obligation, stated by a minority, may always be a background but when prevalent should imply a thorough psychological work with the candidate to clarify the true willingness for donation. A few had negative attitude statements: they were afraid that donation could be ineffective, feared not having family approval, unconfident about recipients' capacities to take care of graft. In our country, and because of donors' protection from the public health system, financial implications to donors were felt to have little significance.

Information was felt to be adequate and altruistic feelings were an important part of donor satisfaction. Even in the case of a fatal outcome of the recipient, the donor seemed to benefit from knowing that all was done to help.

This study confirmed that living donor kidney transplantation did not adversely affect the lives of donors. Positive

aspects have been met, but also some potential problems have been raised by living donation. Psychological and psychiatric support of living donors may often be needed. Psychological assessment and structured protocols and programs are necessary in living donor kidney transplantation.

Careful donor selection, with appropriate pretransplantation psychological assessment and psychiatric consulting, allows donation without major psychological consequences. Significant problems may occur among donors after a failed transplantation; special attention must be paid to these donors. Follow-up psychosocial evaluations of donors are important.

REFERENCES

1. Port FK, Wolf RA, Mauger EA, et al: Comparison of survival probabilities for dialysis patients vs cadaveric renal transplant recipients. J Am Med Association 270:1339, 1993
2. Gatchalian RA, Leehey DJ: Mortality among patients on dialyses, patients on dialyses awaiting transplantation and transplant recipients. N Engl J Med 342:893, 2000
3. Steinberg D: An "Opting In" paradigm for kidney transplantation. Am J Bioethle 4:4, 2004
4. Garcia VD, Garcia CD, Keitel E, et al: Living kidney transplantation in Brazil: unwanted procedure of choice in view of cadaver organ shortage. Transplant Proc 35:1182, 2003
5. Johnson EM, Remucal MJ, Gilligham KJ, et al: Complications and risks of living donor nephrectomy. Transplantation 64:1124, 1997
6. Hilhorst MT: Directed altruistic living organ donation: partial but not unfair. Ethical Theory Moral Pract 8:197, 2005
7. Ku JH: Health-related quality of life of living kidney donors: review of the short form 36-health questionnaire survey. Transpl Int 18:1309, 2005
8. Fehman-Ekholm I, Duner F, Brink B, et al: No evidence of accelerated loss of kidney function in living kidney donors: results from a cross-sectional follow-up. Transplantation 72:444, 2001
9. Lamanna MA: Giving and getting: altruism and exchange in transplantation. J Med Humanit 18:169, 1997
10. Jordan J, Sann U, Janton A, et al: Living kidney donor's long-term psychological and behaviour after nephrectomy—a retrospective study. J Nephrol 17:728, 2004
11. Sterner K, Zelikovsky N, Green C, et al: Psychosocial evaluation of candidates for living related kidney donation. Pediatr Nephrol 21:1357, 2006
12. Özçürümez G, Tanriverdi N, Çolak T, et al: The psychosocial impact of renal transplantation on living related donors and recipients: preliminary report. Transplant Proc 36:114, 2004
13. Giessing M, Reuther S, Schonberger B, et al: Quality of life of living kidney donors in Germany: a survey with the validated Short Form-36 and Giessen subjective complains list-24 questionnaires. Transplantation 78:864, 2004
14. Smith GC, Trauer T, Kerr PG, et al: Prospective psychosocial monitoring of living kidney donors using the short form-36 health survey: results at 12 months. Transplantation 78:1384, 2004
15. Lima DX, Petroianu A, Haute HL: Quality of life and surgical complications of kidney donors in the late post-operative period in Brazil. Nephrol Dial Transplant 21:3238, 2006
16. Transplant Portuguese Organization. Available at: http://www.opt.min-saude.pt. Accessed August 2007
17. Zung WW: A rating instrument for anxiety disorders. Psychosomatics 12:371, 1965
18. Zung WW: A self-rating depression scale. Arch Gen Psychiatry 12:63, 1965
19. Ware J, Sherbourne C: The MOS 36-item short form health survey (SF-36). I. Conceptual framework and item selection. Med Care 30:473, 1992
20. Reimer J, Rensing A, Haasen C, et al: The impact of living-related kidney transplantation on the donor's life. Transplantation 81:1268, 2006
21. Franklin PM, Crombie AK: Live related renal transplantation psychological, social and cultural issues. Transplantation 76: 1247, 2003
22. Schover LR, Streem SB, Boparai N, et al: The psychosocial impact of donation a kidney: long-term follow-up from a urology based center. J Urol 157:1596, 1997
23. Gelder M, Gath D, Mayou R, et al: Mood disorders. In: Oxford Psychiatry. 3rd ed. Oxford: Oxford University Press; 1996, p 197
24. Fisher PA, Kropp DJ, Fleming EA: Impact on living-kidney donors: quality of life, self-image and family dynamics. Nephrol Nurs J 32:1, 2005
25. Switzer GE, Dew MA, Butterworth VA, et al: Understanding donors' motivations: a study of unrelated bone marrow donors. Soc Sci Med 45:137, 1997