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ORIGINAL ARTICLE

# Higher quality of life in living donor kidney transplantation: prospective cohort study

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## Summary

This prospective, longitudinal cohort study investigated the effect of donating or receiving a kidney on quality of life and relationship dynamics. Forty donors and 35 recipients from two UK transplantation centres completed the World Health Organisation quality of life questionnaire (WHOQOL) with additional questionnaires before, 6 weeks and one year after operation. Before donation the donor mean quality of life score in the physical domain was 18.8. This was significantly higher than the UK value for a healthy person of 16.4 ($P < 0.001$). Six weeks after operation, donor score reduced to UK normative levels however improved again at one year (17.7). Recipient mean physical domain score before was 11.4, significantly lower than the UK norm ($P < 0.01$), increasing to 16.0 one year after. Both donor ($P < 0.009$) and recipient ($P < 0.05$) experienced a significant improvement in their mutual relationship. Recipients expressed anxiety about the donor before operation. Donors were not concerned about living with one kidney. We concluded that living kidney donation has no detrimental effect on the physical or psychological well being of donors one year after donation. Transplantation results in a major improvement in quality of life for the recipient. Most donors would donate again, if this were possible.

## Introduction

For many patients with end-stage renal failure, a living donor kidney transplant offers the optimum treatment and can avoid the need for dialysis. The short- and long-term clinical benefits to the recipient, of a planned operation from a healthy donor with a brief cold ischaemic time are well documented and result in a superior graft survival compared with cadaveric kidney transplants [1–3]. The clinical benefits for the donor are less clear. During the donor assessment period previously undetected health problems may be identified and treated [4] and those who are deemed suitable donors enjoy reassurance concerning their health status [5].

Many previous studies examining quality of life issues in living donor kidney transplantation have been retrospective, or have focused on cohorts of either donors or recipients in isolation. In the US, one study revealed that live-kidney donors have similar or higher scores in all quality of life domains compared with the healthy US population and this observation was independent of the time since donation [6]. Another European study demonstrated that recipients of both living donor and cadaveric transplants had mean quality of life scores within one standard deviation (SD) of the norm for healthy individuals [7]. Although such studies are useful, there is a lack of objective longitudinal data examining the relationship dynamics and quality of life of both donor and recipient

as a pair through the process of living kidney donation and transplantation.

The definition of quality of life is much debated. The World Health Organization quality of life group (WHOQOL) describe 'an individual's perceptions 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' [8]. One of the key points in assessment of quality of life is the individual's perception. The 'disability paradox' has been demonstrated in some studies that have shown that patients with serious and persistent disabilities score their quality of life higher than many external observers would anticipate [9]. This theory may be tested in the unique field of transplantation when a person with a chronic illness receives an intervention that improves physical disability and allows freedom from dialysis.

Relationships between donor, recipient and other family members provide a complex challenge. Feelings of guilt have more prominence in the recipients of transplants originating from living donors compared with cadaveric donors [7]. Individuals donating a kidney were less likely to say they would donate again (if it were possible) if they were donating to a person who was not a close blood relative or if the recipient of their kidney had died in the first year after transplantation [6]. Qualitative studies investigate complex relationships further, however, again many are retrospective and baseline findings may be difficult to compare.

The lack of good quality and objective data concerning quality of life outcomes for living kidney donors and transplant recipients means that it is difficult for health care professionals to provide advice to individuals considering kidney donation other than in the context of clinical measures such as graft survival and operative risk. The present study was designed specifically to investigate the effect of donating or receiving a kidney between donor and recipient pairings on their quality of life and relationship dynamics over time.

## Methods

This prospective, longitudinal study was undertaken between January 2000 and January 2004 in the transplant units of the Royal Infirmary, Edinburgh and Addenbroke's Hospital, Cambridge. Both centres had similar policies regarding donor and recipient selection, preoperative assessment and perioperative care. During the course of the study all donor nephrectomies were performed using an open technique with or without resection of the 12th rib. Only adult subjects (>18 years) were invited to participate as agreed with the local ethical approval committees. Both donor and recipient were asked to complete two questionnaires each at three time points: before; 6 weeks after and 1 year after the live-donor transplant. The questionnaires included the WHOQOL Bref and an additional questionnaire examining relationship issues and concerns related to the procedure.

The WHOQOL Bref is a shortened form of the WHOQOL 100 and discriminates between 'well' and 'ill' subjects [8]. This was felt to be particularly important as many quality of life questionnaires are designed to assess the impact of illness on a population. As this study compared 'healthy' donors and patients with end-stage renal failure the WHOQOL Bref was selected. Data were also available to compare an age-matched well population in the UK. Twenty-six questions produce scores for four domains; physical, psychological, social and environmental, related to quality of life. The data were transformed and analysed with SPSS, using Mann–Witney or Kruskal–Wallis *H* test as appropriate (SPSS, Chicago, IL, USA). Data are presented as boxplots. Additional questionnaires were designed using a 10 cm linear-analogue scale with a member of the WHOQOL group (MJP) assisting in the development of the questions. The respondents were asked to state their response from minimum to maximum views on the scale. The recipients completed the same questionnaire at the same time points. The donor pre and postoperative questionnaire differed to encompass further social and economic issues experienced post-donation.

The donor and recipient pairs were asked to complete the questionnaire separately, to avoid conflict of responses. The majority were completed during routine clinic visits, although due to geographical limitations a number was posted and returned. The questionnaires were numerically coded and anonymous, although demographic details were requested.

## Results

### Patient inclusion and characteristics

From January 2000 to December 2002 fifty-two donor and recipient pairs consented to participate, three pairs declined. Twenty-three of the pairs were parent to adult child, 11 siblings, 16 spousal and 2 other nonrelated. Forty donors and 35 recipients completed the questionnaires at all three-time points. Individuals who did not complete questionnaires at all time points were excluded from analysis. Treatment for renal failure for the 35 recipients included 13 undergoing haemodialysis; 14 peritoneal dialysis and 8 were transplanted before renal replacement was necessary. All donors underwent open nephrectomy in this selected group. The mean age of the donor was 49 years (range 24–71 years), the recipient's mean age 37 years (range 19–54 years). Twenty-five donors were female and 15 donors male, 17 recipients were female and

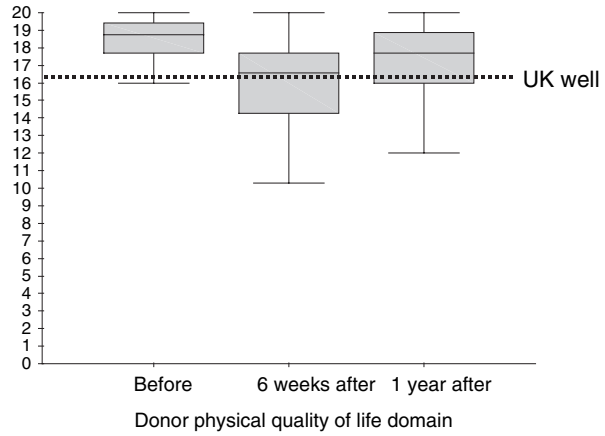


**Figure 1** World Health Organization quality of life group physical domain scores for adult donors of kidneys before, 6 weeks and 1 year after kidney donation. The broken line represents the median physical domain score in an age- and sex-matched healthy UK population. There was a significant reduction in physical domain scores 6 weeks after donation ($\chi^2 = 17.2$; d.f. = 2; $P < 0.0001$ Kruskal–Wallis $H$ test) with scores returning to predonation levels by 1 year.

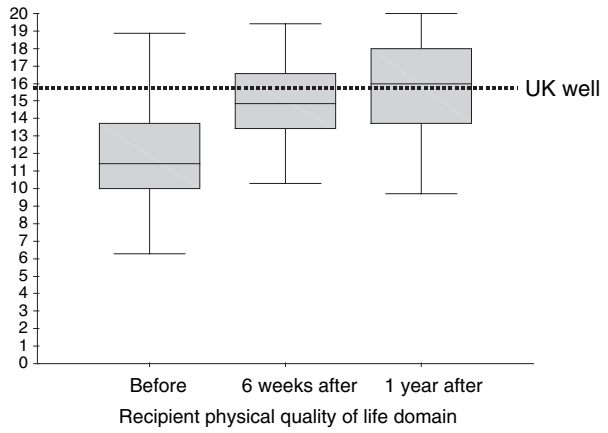


**Figure 2** World Health Organization quality of life group physical domain scores for recipients of living donor kidney transplants before, 6 weeks and 1 year transplantation. The broken line represents the median physical domain score in an age- and sex-matched healthy UK population. Living donor kidney transplantation resulted in a significant increase in physical domain scores ($\chi^2$=26.6; d.f. =2; $P < 0.0001$ Kruskal–Wallis $H$ test).

18 male. One recipient died within 1 year of transplant and one recipient received two live-donor transplants over the time period, the first having failed within 1 year. No donor suffered a major perioperative complication.

### Quality of life assessment

The WHOQOL scores are reported in the four domains – physical, psychological, social and environmental. The mean physical scores for donors are summarized in Fig. 1 and further domain scores in Table 1. Recipients mean physical score are demonstrated in Fig. 2 and further domain scores in Table 2.

Within the physical domain the mean score for the donor was significantly higher than the UK normative value for a healthy person ($P < 0.001$). Six-week after donation, the physical domain scores of donors reduced to normative levels however improved again at 1 year, although did not reach predonation levels. By contrast the mean score for the recipient before transplantation was significantly lower than the UK normative value for a well person (11.4 pretransplant vs. 16.4 UK norm $P < 0.01$). The physical domain quality of life measurement for the recipient significantly improved by 6 weeks and continued to improve such that by 1 year following living kidney transplantation it was not significantly different from the UK normative value for a well person.

Donor psychological domain scores before kidney donation were significantly greater than UK normative values for a well person ($P < 0.012$). Although the donor psychological domain mean decreased 6 weeks postdonation, this score remained significantly higher than the UK population normative value ($P < 0.001$). The recipient psychological domain scores before transplant were not significantly different from the UK normative value. However, following transplantation the psychological domain scores increased such that they were significantly higher than UK normative values at 6 weeks and 1 year ($P < 0.01$). There was no significant difference between the donor and recipient psychological domain scores 1 year after kidney donation or transplantation, respectively.

There were no significant changes in either the social or environmental domain scores of the donor or recipient groups before and after kidney donation or transplantation.

**Table 1.** World Health Organization quality of life group psychological, social and environmental domain scores for adult donors of kidneys used for living donor kidney transplantation.

| | Before | 6 weeks | 1 year | UK well ($n = 245$) |
|---|---|---|---|---|
| Psychological | 16.7 (16.0–8.0) | 16.0 (14.7–6.7) | 16.0 (14.0–7.2) | 14.6 (12.0–7.5) |
| Social | 17.3 (9.3–0.0) | 17.3 (10.6–0.0) | 17.3 (6.7–0.0) | 15.4 (11.7–8.0) |
| Environmental | 17.0 (12.0–0.0) | 16.5 (9.00–0.0) | 16.0 (11.0–0.0) | 14.7 (11.4–6.7) |

| | Pre | 6 weeks | 1 year | UK well ($n = 245$) |
|---|---|---|---|---|
| Psychological | 15.3 (12.7–6.0) | 16.0 (14.7–6.7) | 16.0 (15.3–6.7) | 14.6 (12.0–7.5) |
| Social | 16.0 (9.3–20.0) | 16.0 (8.00–20.0) | 16.0 (10.6–20.0) | 15.4 (11.7–18.0) |
| Environmental | 16.0 (8.5–10.0) | 16.5 (10.0–19.5) | 16.0 (9.0–19.5) | 14.7 (11.4–16.7) |

**Table 2.** World Health Organization quality of life group psychological, social and environmental domain scores for adult recipients of kidneys used for living donor kidney transplantation.

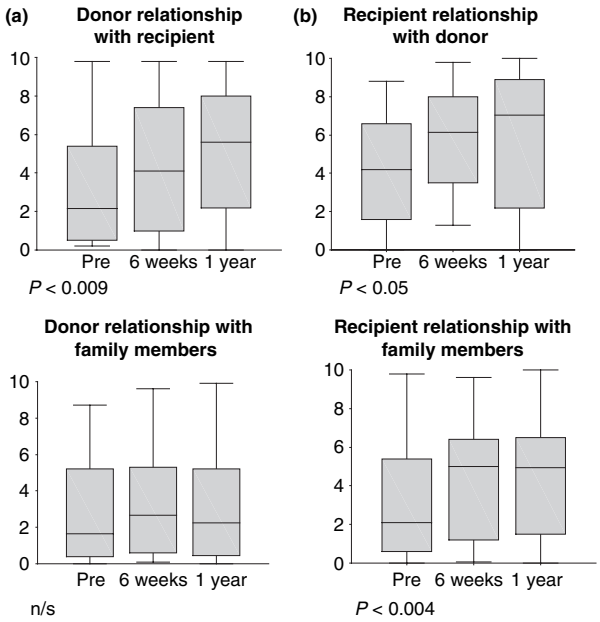


**Figure 3** Changes in relationships between donor and recipient before and after living donor kidney transplantation. Donors (a) and recipients (b) both reported significant improvement in their relationships with each other following kidney donation and transplantation, respectively.

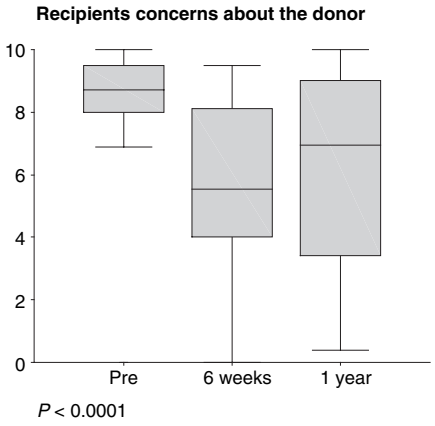


**Figure 4** Recipients' concerns about the welfare of the donor before and after living donor kidney transplantation.

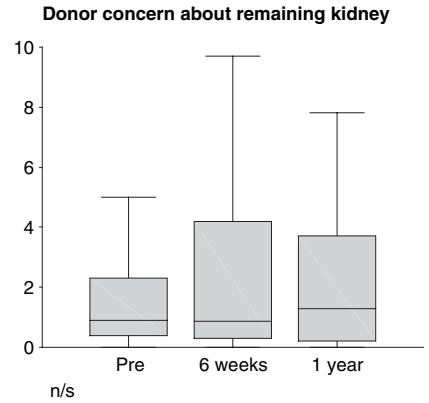


**Figure 5** Level of concern of donors over their remaining kidney before and after living kidney donation.

## Relationship and social issues

The impact of the issue of live-kidney donation on the relationship of the pairing and family member and friends was addressed. The participants were asked to score on a linear analogue scale if the issue of live-kidney donation had improved their relationship. The scale measured 10 cm (0: not at all – 10: extreme amount). The donor and recipient were also asked if the issue of live-kidney donation had an adverse effect on relationship using the same scale. Both donor and recipient experienced a significant improvement in their mutual relationship (Fig. 3). When asked if the issue of live-kidney donation had any adverse effect on their relationship, the donor mean score was 0.8 (predonation), 1.7 (6 weeks post) and 2.2 (1 year post). The recipient mean score was lower: 0.6 (pretransplant), 0.6 (6 weeks after) and 0.7 (1 year later).

The recipients were asked to score their level of concern about the donor on the same 10 cm scale (Fig. 4). Initially the recipients expressed a high level of concern (mean score 8.8) reducing at 6 week to 5.4. The donor was asked about their level of concern about their remaining kidney (Fig. 5). Consistently the donors did not worry about their remaining kidney – 0.8 (before the operation and 6 weeks after) and increasing to 1.0 (1 year after). Postoperatively, when asked about scar discomfort experienced the mean donor score was 2.0 at 6 weeks and 2.4 at 1 year. When asked, if it were possible, would they donate a kidney again, the donor mean score was 8.9 at 6 weeks and 9.3 at 1 year.

## Discussion

The goal of healthcare today is to improve the quality of life of patients, in addition to curing physical illness [10]. In 1946, the World Health Organization defined health as 'a state of complete physical, mental and social well being and not merely the absence of disease and infirmity' [11]. We have shown that removing a healthy organ from an individual causes short-term infirmity. This prospective, longitudinal study has demonstrated that living donor kidney transplantation does not adversely affect the longer term physical, psychological and social well-being of donors and substantially improves many aspects of the lives of recipients. The intense medical evaluation of potential living kidney donors results in the selection of only healthy, motivated individuals. In addition, all live-kidney donors are encouraged to achieve a level of fitness prior to donation. In the light of this it is perhaps not surprising that the physical domain score for donors before operation is above the national norm, confirming results of previous studies [12]. Likewise for the recipient, the physical improvement following transplantation confirms the benefit of this form of treatment.

The donors achieve a higher than normal psychological score predonation, decreasing at 6 weeks and 1 year, although remain at a level above the healthy population. It is possible that the selection of motivated individuals, coupled with the reassurance afforded by completion of the assessment process and the knowledge that the donor is fit to precede, improves psychological well being before donation. Similarly, for the recipient the knowledge that a transplant is imminent may increase a sense of psychological well being, in spite of the observed concerns that the recipient has for the safety of the donor.

No significant change in the social and environmental domain scores of either donor or recipient was observed. This is reassuring information for future donors that no adverse effect is caused by donation. It was anticipated that for the recipient, freedom from dialysis might have resulted in improved social and environmental interaction. The lack of change may reflect the fact that a number of transplants were 'pre-emptive', that is undertaken before dialysis was instituted or the intensity of the follow-up after transplantation. Benefits in social and environmental domains may become more apparent in the longer term, when the recipient does not require such intense follow-up.

Both the donor and recipient are informed in detail about the risks and benefits of living donor transplantation [13], with great emphasis on the risks to the donor undergoing a major operation. Thus recipient concerns about the donor are high before surgery, decreasing in response to successful outcome and donor recovery. The donors continue to have a low level of concern about living with a solitary kidney. The emphasis during assessment that donation will only proceed with minimum risk to the donor and maximum benefit to the recipient [12] may partly reassure donors, alongside the life-long follow-up commitment of the transplant team.

The impact of living kidney donation does not appear to have adverse effects on relationships either between donor and recipient or with other family members. The rigorous evaluation process may preclude pairs with the potential for family conflict. Donors consider that the act of donation improves relationships with the recipient and to a lesser extent with family and friends, whose support is vital in the postoperative period.

This study has demonstrated that living donor kidney transplantation does not adversely affect the lives of donors and substantially improves many aspects of the lives of recipients. Careful donor selection allows those with a higher than normal physical quality of life to donate without impairing their physical or psychological status. As a group, the issue of donation and transplantation does not have an adverse effect on relationships, further work will analyse individual effect. The majority of living donors would donate again, providing reassuring information for potential donors.

## References

1. D'Alessandro A, Sollinger HW, Knechtle SJ, *et al.* Living related and unrelated donors for kidney transplantation – a 28 year experience. *Ann Surg* 1995; **3**: 353.
2. Asderakis A, Augustine T, Dyer P, *et al.* Pre-emptive Kidney Transplantation: the attractive alternative. *Nephrol Dial Transplant* 1998; **13**: 1799.
3. Terasaki PI, Cecka JM, Gjertson DW, Takemoto S. High survival rates of kidney transplants from spousal and living unrelated donors. *N Engl J Med* 1995; **333**: 333.
4. Jones JW, Halldorson J, Elick DK, *et al.* Unrecognised health problems diagnosed during living donor evaluation: a potential benefit. *Transplant Proc* 1993; **25**: 3083.
5. Fehrman-Ekholm I, Elinder C-G, Stenbesk M, *et al.* Kidney donors live longer. *Transplantation* 1997; **64**: 976.
6. Johnson EM, Anderson JK, Jacobs C, *et al.* Long-term follow of living kidney donors: quality of life after donation. *Transplantation* 1999; (Mar 15) **67**: 717.
7. Griva K, Ziegelmann JP, Thompson D, *et al.* Quality of life and emotional responses in cadaver and living related renal transplant recipients. *Nephrol Dial Transplant* 2002; (Dec) **17**: 2204.
8. Harper A, Power M (on behalf of the WHOQOL Group). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998; **28**: 551.

9. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med* 1999; **48**: 977.
10. Smith GC, Trauer T, Kerr P, Chadban SJ. Prospective psychosocial monitoring of living kidney donors using the SF-36 health survey. *Transplantation* 2003; **76**: 807.
11. Hathaway D, Barr M, Ghobrial M, *et al.* Assessing quality of life in organ transplant recipients: progress and priorities. *Prog Transplant* 2003; **13**: 1.
12. Records of the World Health Organisation. New York: Constitution of the World Health Organisation, 1946.
13. Risks To The Donor. Chapter 5.0. United Kingdom Guidelines for Living Donor Kidney Transplantation, The Renal Association, 2002 (January): 2 pp.