

Original Article

Quality of life and emotional responses in cadaver and living related renal transplant recipients

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Abstract

Background. The specific impact of transplantation on living related donor (LRD) and cadaver (CAD) kidney transplant recipients and their health-related quality of life (HQoL) has received little attention. This study examined the role of sociodemographic, medical and psychological factors in these two groups.

Methods. A total of 347 transplant recipients (76 LRD and 271 CAD patients) completed the Short Form 36 Health Survey and Transplant Effects Questionnaire.

Results. Overall, transplant patients showed satisfactory HQoL particularly with respect to emotional well being. HQoL levels were found to be equivalent in both transplant groups. ANCOVAs showed that LRD recipients expressed more guilt in relation to the donor ($P < 0.001$). Multivariate analysis revealed that worry about the viability and functioning of the transplant alone predicted 15.1% of the variance in the SF-36 mental composite score (MCS) whereas age, income, comorbidities and time on dialysis explained 37.8% of the variance in the SF-36 physical composite score (PCS). Multiple regression analyses performed separately for LRD and CAD patients showed that predictors of MCS and PCS between the two groups were similar.

Conclusions. Our results indicate that different forms of transplantation (LRD vs CAD) may lead to different emotional responses albeit with no apparent quality of life differences. In particular, feelings of guilt appear to be prominent in LRD transplantation.

Keywords: cadaver; living related donor; psychological factors; quality of life; renal transplantation

Introduction

Renal transplantation is generally accepted as the optimal treatment for most patients with end-stage

renal disease (ESRD). The benefits of renal transplantation have usually been described in terms of a better quality of life [1], reduced medical expenses [2] and prolongation of life [3,4].

The outcomes of renal transplantation have improved with the use of cyclosporin with significant improvements in graft and patient survival rates [5]. In the UK, 15% of all renal transplants are from living related donors (LRDs) [6]. LRD transplants have been considered to offer a number of advantages over cadaver (CAD) kidney transplants, in particular the reduction in both warm and cold ischaemia times. In addition, the elective nature of the surgery allows a more complete evaluation and preparation of the recipient and donor so the transplant operation can be performed when donor's and recipient's health and preparation for transplantation is optimal. It may permit a shorter delay between starting dialysis and transplantation and also a chance to avoid the potential negative consequences and medical risks of chronic dialysis [7]. More importantly, the clinical outcomes of kidney transplantation such as graft and recipient survival rates have been found to be substantially better when organs are from either related or unrelated living donors [5,8,9] such that receiving a kidney from a LRD confers up to 7% increase in survival in Europe [10].

In contrast to the abundance of research on the clinical outcomes of CAD and LRD transplantation, consideration of other relevant outcomes in relation to transplant source has been less extensive. The patients' health-related quality of life (HQoL) has been considered to be a treatment goal in addition to survival [11]. Numerous studies have examined HQoL in kidney transplant patients either in comparison to dialysis or prospectively pre- and post-transplantation [12]. There is ample evidence in support of the relatively higher HQoL associated with transplantation relative to dialysis treatments [1,13–15]. Very few studies, however, have systematically investigated HQoL in LRD compared with CAD transplant recipients. The two studies that have made this comparison on global quality of life and health status

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indicators (e.g. life satisfaction and functional ability) reported no differences between the two transplant groups [16,17].

The transplant literature has also highlighted that the receipt of a new kidney may give rise to a new set of stressors, psychosocial challenges and adaptive demands [18]. These include the need to adhere to a post-transplant regimen with all the potential medication side effects [19,20]. Also, closely related are the specific emotional responses associated with receiving a transplant. These range from mild anxiety or worry regarding the viability of the graft, to 'extreme' cases of more pervasive fear of rejection [21]. Emotions related to the act of donation, including feelings of gratitude, indebtedness and guilt towards the donor or the donor family, are also frequently reported by transplant recipients [22,23]. These specific emotional and behavioural responses to transplantation and the mode of transplantation (LRD vs CAD), may impinge upon HQoL.

The present study was designed as a systematic evaluation of HQoL, and emotional and behavioural processes in LRD and CAD transplant recipients. The primary aims of this study were (i) to compare HQoL and emotional adjustment in CAD and LRD transplant recipients and (ii) to identify sociodemographic and psychological factors that are associated with HQoL in patients with a functioning renal transplant.

Subjects and methods

Participants

The study was conducted at the Royal Free Hospital and Middlesex Hospital in London, UK from October 1998 to October 1999. Following ethical approval, transplant patients treated in the two renal units were invited to participate. Inclusion criteria included age over 16 years, a minimum of 3 months since transplant operation, not being concurrently hospitalized or treated for rejection or infection episodes, and fluency in written and spoken English. Out of 453 patients contacted, 347 patients consented to the protocol (response rate = 76.6%). The recruited sample consisted of 54.4% males, with a mean age 46.8 (13.95) years and a mean of 8.6 (6.55) years since their transplant. Approximately 25% ($n=75$) had received their transplant from a LRD.

Measures

Participants' medical records were reviewed to obtain information about previous dialysis and transplant history, time with the current transplant, type of donor, relationship to LRD, primary kidney disease diagnosis and comorbidity (intercurrent non-renal comorbidity). The presence/absence of eight of the most common comorbid disorders (plus an 'other' category) was recorded. These included diabetes mellitus, hypertension, ischaemic heart disease, peripheral vascular disease, cerebrovascular disease, cancer, bone diseases and chronic obstructive airways disease.

Transplant Effects Questionnaire (TxEQ) [24]

This 23-item questionnaire was specifically developed to measure the emotional and behavioural responses considered

important to transplant recipients. The TxEQ contains five sub-scales that assess worry about the transplant (six items; e.g. 'I am worried about damaging my transplant'), feelings of guilt towards the donor (five items; e.g. 'I feel guilty about having taken advantage of the donor'), disclosure of transplantation (three items; e.g. 'I avoid telling other people that I have a transplant'), medication adherence (five items; e.g. 'sometimes I forget to take my anti-rejection medicines'), and perceived responsibility to do well (four items; e.g. 'I think that I have a responsibility to the transplant team to do well'). The questionnaire comprises 24 items, presented in a mixed order and rated by the participants on a five-point Likert scale ranging from 'strongly disagree' to 'strongly agree' (scored from 1 to 5). Subscale scores are expressed as a mean by dividing the total score by the number of items, hence ranging from 1 to 5. Higher scores signify more worry about the transplant, more guilt, more disclosure, more perceived responsibility, respectively, and greater adherence. The questionnaire has data to support its internal structure and factorial validity and has been found to have acceptable internal consistency, test-retest reliability and face validity [24].

Short Form Health Survey (SF-36)

HQoL was measured with the 36-item Medical Outcome Study Short Form Health Survey [25]. The UK version 2 of the SF-36 was used to ensure face validity and maximize acceptability in British participants [26]. The SF-36 is a generic multidimensional measure of HQoL that contains eight sub-scales representing physical functioning (PF), social functioning (SF), role limitations due to physical health problems (RPh), role limitations due to emotional problems (REm), mental health (MH), vitality (VT), bodily pain (BP) and general health perceptions (GH). Sub-scale scores were transformed to 0–100 scales with higher scores indicating better HQoL. Subsequently the scale scores were standardized to the scale scores of a general UK population sample ($n=8889$, age range 18–64 years, 43.4% were male) by subtracting the general population mean from the individual mean and dividing by the corresponding scale SD from the general population. The resulting so-called standard score or Z-score indicates how many SDs the observed SF-36 scores of dialysis or transplant patients fall below or above the scores of the reference population when the scores of the reference population are set to 0. To facilitate interpretation and comparisons to the norms, normative-based scoring was used [27]. Normative-based scoring involves a linear t -transformation to ensure that all SF-36 sub-scales and composite scores had a mean of 50 and a SD of 10 in the general UK population. The physical and mental components of the eight scales were combined into a physical composite score (PCS) and a mental composite score (MCS) [28]. The SF-36 has been proved reliable and valid in various demographic and patient populations including ESRD and transplant patients [29].

Work status/vocational rehabilitation

Work rehabilitation as indexed by perceived ability to work and current work status, is considered to be an objective indicator of HQoL since it may be seen as reflecting physical status/abilities. Current work status was measured by an item

asking participants to indicate whether they were at the time employed full-time, part-time, retired, unemployed or looking after home and family. Perceived ability to work was assessed by a single question developed by Evans *et al.* [13]: 'are you now able to work full time, part time, or not at all?'

Data analysis

Sociodemographic and medical differences between CAD and LRD patients were examined using independent *t*-tests for continuous variables or chi-square analysis for categorical data. Analyses of covariance, ANCOVAs, were used to investigate the effect of transplant type on the HQoL domains and TxEQ sub-scales. Intercorrelations among study variables were examined using Pearson's correlation coefficient (when variables were not normally distributed Spearman's correlations were applied). Univariate relationships between independent variables (sociodemographic, clinical and psychological) on the one hand, and SF-36 scores on the other, were assessed using independent *t*-tests, ANOVAs, Pearson *R* correlations or where appropriate their non-parametric equivalents. All significant variables (set at $P < 0.1$) identified from univariate analysis were included in the hierarchical multiple regressions using the forward method and a level of $P < 0.05$ as an entry criterion. All these analyses were performed on the combined sample and separately for each transplant type group. Independent variables entered the regression equations in a specified order: (i) sociodemographic factors (i.e. age, gender), (ii) clinical variables (i.e. comorbidities), and (iii) psychological variables.

Results

Sociodemographic and medical characteristics of the CAD and LRD transplant patients are shown in Table 1. Age, annual income and time spent on dialysis

differed significantly between the two groups. LRD transplant recipients were younger (mean 40.37 years, SD 11.93) than CAD transplant patients (mean 48.59 years, SD 14.03) [$F(1, 340) = 21.37$, $P < 0.001$], reported higher annual income ($\chi^2 = 11.04$, $P = 0.014$) and had spent significantly less time on dialysis prior to their transplant (mean 17.07 months, SD 24.94) than CAD transplant patients (mean 37.88 months, SD 40.78) [$F(1, 296) = 16.04$, $P < 0.001$]. The difference in time on dialysis was anticipated given the elective nature of LRD transplantation that allows shorter delay between dialysis and transplantation. In subsequent comparisons between the two groups these differences were controlled statistically.

The effects of transplant type

ANCOVA (covarying for age, income and dialysis duration) revealed a significant transplant type effect on one study outcome (Table 2). [Reported degrees of freedom vary due to missing data. Missing data ranged from 5 ($n = 18$) to 12.3% ($n = 44$) in SF-36 and TxEQ. This was mainly due to patients' missing individual questionnaire items so the total HQoL and TxEQ scores could not be computed. A considerable number of transplant respondents refused to disclose details of annual income ($n = 80$, 22.3%) (by ticking appropriate 'do not wish to answer' option) and hence this has produced more missing data.] LRD transplant patients expressed significantly stronger feelings of guilt towards the donor (mean 2.70, SD 0.80) relative to CAD transplant recipients [mean 2.05, SD 0.63; $F(3, 200) = 26.27$, $P < 0.001$]. There was a tendency for LRD patients to be more reluctant to disclose or talk about their transplant experience (mean 4.03, SD 0.85) relative to CAD transplant counterparts [mean 3.68, SD 1.10; $F(3, 207) = 3.58$, $P = 0.06$]. There was no

Table 1. Participants' sociodemographic and clinical characteristics

	LRD patients ($n = 76$) Mean (SD)/% (n)	CAD patients ($n = 271$) Mean (SD)/% (n)	t -value/ χ^2	P -value
Age (years)	40.37 (11.93)	48.59 (14.03)	$t = 5.06$	< 0.001
Gender (% female)	40.8 (31)	47.3 (129)	$\chi^2 = 1.00$	0.317
Time since transplant (years)	9.28 (6.20)	8.37 (6.65)	$t = -1.10$	0.261
No. of comorbidities	1.54 (1.54)	1.95 (1.75)	$t = 1.96$	0.064
Diabetes (%)	6.6 (5)	8.8 (24)	$\chi^2 = 0.381$	0.537
Hypertension (%)	56.6 (43)	72.5 (198)	$\chi^2 = 7.076$	0.008
Heart conditions (%)	6.6 (5)	15 (41)	$\chi^2 = 3.70$	0.054
No. of previous transplants	1.11 (0.31)	1.14 (0.35)	$t = -0.90$	0.368
Dialysis experience prior transplant (%)	81.1 (60)	96.3 (260)	$\chi^2 = 20.71$	< 0.001
Time on dialysis (months)	17.07 (24.94)	37.88 (40.78)	$t = 5.19$	< 0.001
Education (age years left school)	18.38 (3.46)	17.67 (4.68)	$t = -1.16$	0.273
Relationship status (% in a relationship)	65.3 (49)	60.1 (163)	$\chi^2 = 0.66$	0.414
Work status (% employed)	75.3 (55)	50.5 (138)	$\chi^2 = 13.07$	< 0.001
Ability to work (able to work full-time/part-time)	82.2 (60)	66 (175)	$\chi^2 = 7.049$	0.008
Annual family income (%)			$\chi^2 = 10.59$	0.014
0-£10 000	15.8 (9)	29.5 (56)		
£10 001-£20 000	19.3 (11)	27.4 (52)		
£20 000-£30 000	21.1 (12)	19.5 (37)		
> £30 000	43.9 (25)	23.7 (45)		
Own home (%)	60.5 (46)	63.8 (171)	$\chi^2 = 1.54$	0.792

Table 2. HQoL and emotional responses of CAD and LRD transplant patients (means and SDs)

Variables	LRD patients	CAD patients	F	P-value
TxEQ sub-scales				
Worry about transplant	3.29 (0.80)	3.02 (0.85)	0.384	0.536
Guilt	2.70 (0.80)	2.05 (0.63)	26.269	<0.001
Disclosure	3.68 (1.10)	4.03 (0.85)	3.585	0.06
Adherence	4.26 (0.81)	4.34 (0.68)	0.008	0.930
Responsibility	3.76 (0.81)	3.76 (0.78)	0.829	0.364
SF-36 sub-scale ^a				
General health	43.42 (11.84)	42.41 (12.55)	0.654	0.420
Physical functioning	45.51 (12.83)	38.75 (15.80)	2.035	0.155
Social functioning	44.71 (8.92)	43.03 (9.60)	1.149	0.285
Role limitations (physical)	45.56 (12.32)	40.99 (15.13)	1.304	0.255
Role limitations (emotional)	47.55 (11.4)	46.06 (13.31)	0.699	0.404
Bodily pain	49.49 (11.53)	46.87 (15.75)	0.721	0.397
Vitality	51.2 (8.16)	51.50 (12.53)	0.957	0.329
Mental health	48.74 (9.41)	50.12 (10.06)	0.227	0.635
PCS	45.12 (12.83)	40.11 (15.30)	0.351	0.554
MCS	48.94 (7.56)	50.78 (9.37)	0.233	0.630

^aNormative-based scoring: in all SF-36 sub-scales the general population mean is 50 and the SD is 10.

significant difference in reported levels of worry with regard to transplant, with both groups being equally concerned with the viability and functioning of their graft.

HQoL levels as measured by the eight SF-36 sub-scales were found to be similar in both LRD and CAD transplant recipients. Group mean scores in all sub-scales were all within 1 SD of those reported for the general population as were the SF-36 PCS and MCS. The number of individuals who could be considered to have severely impaired HQoL, defined as a composite HQoL score (PCS or MCS) of 2 or more SDs below the general population mean (corresponding to the lowest 2.5% scoring of the general population), was calculated. Using this criterion, 22.6% ($n=79$) of the total transplant sample (24.5% of CAD patients, $n=67$ and 15.8% of LRD patients, $n=12$) were found to be severely impaired on the PCS. In contrast, only 10% of transplant respondents (11.8% of LRD patients, $n=9$ and 9.5% of CAD patients, $n=26$), had MCS scores that were similarly impaired. These findings suggest that for a proportion of individuals emotional well being remains uncompromised despite the severely affected physical HQoL. Chi-square analysis showed that the incidence of physical HQoL impairment was greater in CAD than LRD patients ($\chi^2=7.627$, $P=0.022$). MCS impairment incidence was similar between the two transplant groups.

A significant association was also noted between transplant type and work status indices. There were significant differences between the two transplant groups in perceived ability to work and current employment status (Table 1). More LRD patients were in full- or part-time employment ($n=55$, 75.3%)

compared to CAD patients ($n=138$, 50.5%) ($\chi^2=13.07$, $P<0.001$). Moreover, a larger proportion of LRD patients considered themselves as able to work full- or part-time ($n=60$, 82.2%) than CAD patients ($n=175$, 66%) ($\chi^2=7.05$, $P=0.008$). These differences are more likely to be due to the significant age differences observed between the two groups rather than being attributed to transplant type. Regardless of their transplant source, more patients perceived themselves as able to work either full- or part-time than were actually working ($n=235$, 69.5% vs $n=193$, 56.8%).

Associations between variables

Correlational analysis between sociodemographic, medical variables and TxEQ sub-scales showed that increasing age was associated with less worry regarding the transplant ($r=-0.25$, $P<0.001$), less guilt (Spearman's $\rho=-0.14$, $P=0.012$), higher adherence to immunosuppressive medication ($\rho=0.24$, $P<0.001$) and more perceived responsibility to do well ($\rho=0.28$, $P<0.001$). In addition, the number of comorbid conditions was positively correlated with more disclosure ($\rho=0.17$, $P<0.001$).

Significant, albeit weak associations, were also found between the five TxEQ sub-scales suggesting links between emotional and behavioural aspects of post-transplantation adjustment. Stronger feelings of guilt were significantly correlated with more worry about the transplant ($\rho=0.25$, $P<0.001$), higher perceived responsibility ($\rho=0.19$, $P=0.001$), lower disclosure ($\rho=-0.24$, $P<0.001$), and poorer medication adherence ($\rho=-0.20$, $P<0.001$). Worry about the transplant also correlated with feelings of greater responsibility to do well ($\rho=0.21$, $P<0.001$) and less disclosure about the transplant ($\rho=-0.14$, $P=0.013$).

Factors associated with HQoL

Univariate analyses showed several significant associations between HQoL and sociodemographic and psychological variables (Table 3).

The physical dimensions of SF-36 were strongly associated with age, with scores deteriorating as a function of age (Spearman's correlation coefficients, ρ , ranging from -0.14 to -0.42). Interestingly, age was also found to be positively, albeit weakly, associated with emotional well being, i.e. higher MCS scores ($r=0.17$, $P=0.003$).

Annual income was also associated with the HQoL, particularly physical well being. ANOVA comparisons between patients on the four different income groups indicated that transplant patients on the lowest income brackets (i.e. earning $<£10\,000$ per year) had significantly poorer HQoL, as indexed by lower scores on PCS [$F(3, 230)=23.59$, $P<0.001$], PF [$F(3, 243)=24.44$, $P<0.001$], BP [$F(3, 242)=16.34$, $P<0.001$], RPH [$F(3, 242)=22.33$, $P<0.001$], GH [$F(3, 241)=4.76$, $P=0.003$], SF [$F(3, 243)=9.50$, $P<0.001$] and REm [$F(3, 240)=8.01$, $P<0.001$] than patients with

Table 3. Correlations between SF-36 sub-scales^a and psychological and sociodemographic variables in the combined transplant sample

	PF	GH	Pain	RPh	REm	MH	SF	VT	PCS	MCS
Age	−0.42***	−0.14**	−0.18***	0.28***	−0.073	0.10	−0.097	−0.019	−0.37***	0.17*** ^b
Education	0.22***	0.061	0.18**	0.17**	0.046	−0.048	0.051	0.045	0.26***	−0.10
Transplant duration	0.023	0.011	−0.035	0.063	0.045	−0.019	0.052	0.013	0.011	0.05
Dialysis duration	−0.20***	−0.078	−0.13*	−0.14*	−0.077	0.025	−0.16**	−0.03	−0.15*	0.052
No comorbidity	−0.43***	−0.29***	−0.30***	−0.36***	−0.14*	−0.093	−0.20***	−0.16**	−0.44***	0.043
Transplant worry	−0.081	−0.25***	−0.14*	−0.12*	−0.23***	−0.43***	−0.24***	−0.24***	−0.044	−0.25***
Guilt	−0.026	−0.036	−0.015	−0.026	−0.13*	−0.14*	−0.12*	−0.031	0.005	−0.10
Disclosure	−0.046	0.035	−0.008	−0.038	0.072	0.12*	0.012	0.031	−0.066	−0.10
Adherence	0.053	0.049	0.029	0.085	0.15**	0.13*	0.103	0.031	0.023	0.13*
Responsibility	−0.094	0.023	−0.094	−0.069	−0.075	−0.076	−0.058	0.087	−0.058	0.024

PF, physical functioning; GH, general health perceptions; BP, bodily pain; RPh, role limitations due to physical problems; REm, role limitation due to emotional problems; MH, mental health; SF, social functioning; VT, vitality; PCS, physical composite score; MCS, mental composite score.

*** $P < 0.001$, ** $P < 0.01$, * $P < 0.05$.

^aHigher scores in all SF-36 sub-scales and composite scores signify better HqoL.

^bPearson's correlation coefficient.

higher incomes. No systematic differences were found between the three higher income groups.

An increasing number of comorbid conditions correlated with decreasing HqoL scores in eight of the 10 SF-36 sub-scales. Correlation coefficients, rho, ranged from −0.16 to −0.44 (Table 3). Ischaemic heart disease, in particular, was associated with lower scores (i.e. poorer HqoL) in PCS ($U = 3625$, $P < 0.001$), PF ($U = 4121$, $P < 0.001$), RPh ($U = 4456$, $P = 0.002$), GH ($U = 4691$, $P < 0.003$), BP ($U = 4606$, $P = 0.001$) and REm ($U = 4956$, $P < 0.02$). Diabetes mellitus was also found to be associated with lower scores in PCS ($U = 2353$, $P < 0.001$), PF ($U = 2714$, $P < 0.001$), RPh ($U = 2662$, $P < 0.001$), BP ($U = 3410$, $P = 0.05$) and SF ($U = 3158$, $P = 0.02$). As expected, longer times spent on dialysis were associated with lower scores on the PCS and poorer scores on some physical sub-scales (physical functioning, role limitations due to physical problems and pain) of the SF-36 (Table 3).

Among the psychological variables, worry about the transplant was consistently correlated with all the psychosocial dimensions of SF-36 and some of the physical SF-36 scores (such as RPh, BP, GH and VT). Guilt correlated with mental health, role limitations due to emotional problems and social functioning, and disclosure correlated only with mental health (Table 3). Higher scores in the psychological dimensions of SF-36 (MCS, MH, REm) correlated with better medication adherence.

To examine which variables accounted for the variance in the physical and mental HqoL in a multivariate analysis, hierarchical multiple regression analyses were conducted. The variables selected for these analyses were those significantly associated in the univariate analyses. The results indicated that age, income, comorbidity and time spent on dialysis prior to transplantation were significant multivariate predictors of the PCS of the SF-36 in the total transplant sample, accounting for 37.8% of the variance (Table 4).

The regression model to predict MCS in the combined transplant sample explained 15.1% of the variance with only worry about the transplant being

significant (Table 4). The relatively little success in predicting MCS suggests that factors other than those assessed may be more important.

Multiple regressions were also performed separately for the two transplant groups. In LRD patients, age ($\beta = -0.541$, $P = 0.0032$), income ($\beta = 0.692$, $P < 0.001$), time spent on dialysis ($\beta = 0.402$, $P = 0.0124$) and worry about the transplant ($\beta = -0.381$, $P = 0.021$) explained a large amount (50.5%) of the variance in PCS. In contrast, for CAD patients, significant predictors of PCS were age ($\beta = -0.245$, $P < 0.001$), income ($\beta = 0.298$, $P < 0.001$), number of co-morbid conditions ($\beta = -0.302$, $P < 0.001$), and time spent on dialysis ($\beta = -0.153$, $P = 0.03$), accounting for 35.8% of the variance. In the regression equations to predict MCS, only worry about the transplant was a significant predictor, explaining alone 17.9 and 17.4% of the variance in MCS for LRD and CAD transplant patients, respectively.

Discussion

The present study was designed to examine and compare the emotional responses and quality of life of those receiving renal transplants from LRDs and CAD donors. After controlling for sociodemographic and clinical case mix differences between the two groups, different emotional responses were found. In particular, feelings of guilt were found to be more prominent in LRD transplant recipients irrespective of recipients' age, time elapsed since transplantation, time on dialysis and income. The significantly higher levels of guilt reported by LRD recipients are understandable given the different relationship between the transplant recipients and donor and their family [30] and the recognition of the sacrifice made by the donor. Most LRD kidney transplant recipients continue to have a relationship with the donor and in this study all donors were relatives of the recipients. The sacrifice made by the donor, the physical cost of donation and the perceived ongoing risk of having only one kidney may

Table 4. Hierarchical multiple regressions models to predict physical and mental quality of life in transplant patients: cumulative explained adjusted variance (Adj. R^2) and standardized regression coefficients (β)

Predictors	All transplants		LRD transplants		CAD transplants	
	PCS Adj. R^2/β^b	MCS Adj. R^2/β	PCS Adj. R^2/β	MCS Adj. R^2/β	PCS Adj. R^2/β	MCS Adj. R^2/β
Block 1	0.271	0.039	0.382	-0.006	0.228	0.032
Age (years)	-0.218***	0.136 ns	-0.540**	-0.704 ns	-3.353***	1.936 ns
Income bracket	0.328***	0.352 ns	5.341***	1.750 ns	4.158***	0.003 ns
Gender (female)	0.190 ns	-0.914 ns	1.788 ns	1.038 ns	-0.293 ns	-0.671 ns
Education	0.680 ns	-1.219 ns	0.950 ns	-0.665 ns	0.698 ns	-0.809 ns
Block 2	0.378	0.036	0.437	-0.052	0.358	0.051
Transplant source ^c	0.771 ns	0.665 ns				
Transplant duration	-1.073 ns	-0.028 ns	1.712 ns	-0.770 ns	-1.680 ns	0.103 ns
Dialysis duration	-2.385*	1.264 ns	-2.641*	-1.420 ns	-2.20*	1.958 ns
Comorbidity	-4.473***	0.679 ns	0.629 ns	0.224 ns	4.190***	1.342 ns
Block 3		0.151	0.505	0.179		0.174
Worry	-	-4.874***	-2.421*	-3.292**	-	-4.454***
Guilt	-	-	-	-	-	-
Disclosure	-	-	-	-	-	-
Adherence	-	-	-	-	-	-
Responsibility	-	-	-	-	-	-

*** $P < 0.001$; * $P < 0.05$; ns, not significant.

^aThe adjusted variance (Adj. R^2) indicates the proportion of the outcome variance, which is accounted by the set of predictors used. It was used in preference over R^2 as the latter tends to overestimate the success of the model when applied to the real world. Adj. R^2 provides a more conservative estimate that takes into account the number of variables in the model and the number of observations (participants) the model is based on.

^bThe standardized regression coefficient indicates the strength of the association between the predictor and the dependent variable.

^cTransplant source was not entered in the regression analyses performed separately for LRD and CAD transplant recipients; -, variables not entered as they did not satisfy the regression entry criterion ($P < 0.05$).

understandably lead to feelings of guilt. Although their incidence rates are very low both early post-operative as well as later risks are attached to living donor transplantation [31]. It is likely that transplant recipients will be very well aware of these risks [32]. Recipients of CAD transplantation do not have any pre-existing relationship with the donor or his/her family and the prospect for future personal contact was limited, given the current practice in the UK of discouraging or prohibiting direct contact between CAD transplant recipients and donor families. Even in cases where some contact, typically in the form of correspondence, is established between CAD recipients and donor families, this form of interaction tends to be more impersonal and exclusively regulated via the transplant co-ordinating centres. Although the recipient of a LRD kidney may well have increased levels of guilt and there have been some reports of depression and disrupted family relationships after donation to a family member [33], most published reports have indicated an improved sense of well being, quality of life and a boost in self-esteem for living kidney donors [34,35].

The findings on HQoL were consistent with those reported by Evans *et al.* [16] and Julius *et al.* [17] in that HQoL appears to be unaffected by transplant type. Both LRD and CAD transplant recipients reported equivalent HQoL levels in all SF-36 sub-scales with mean scores for both groups being within 1 SD of the mean of a normal population. This finding is reassuring and further documents the great attractions of renal transplantation as a mode of treatment

that largely restores individuals' HQoL. The mean scores of the group do, however, mask the fact that a substantially high number of transplant patients ($n = 79$, 22.6%) have a PCS on the SF-36 which was severely impaired, being more than 2 SDs below the general population mean. Such a score corresponds to the 2.5th percentile of the distribution of HQoL scores in the general population. This finding indicates that even though mean scores were all close to that of the population, 22% of the 349 patients assessed reported significant limitations in all physical activities, such as walking or climbing stairs, were severely bothered by pain and rated their health as poor. This finding may have clinical implications as poor HQoL has been found to be independently associated with poorer outcomes such as increase in mortality and hospitalization rate [36,37].

In keeping with previous research on the general population, increased age was associated with poorer physical capacity [25]. The other main indicators of reduced physical capacity in our transplant groups were the number of comorbid conditions, longer time spent on dialysis and income [15,38]. In contrast, these factors did not affect mental health indicators of quality of life. The emotional well being scores of the SF-36 (MCS) were more strongly associated with psychological variables (TxEQ sub-scales). Although the differences between LRD and CAD recipients were not manifest in HQoL, the emotional responses to the transplant did affect the quality of life. Feelings of guilt, a tendency not to disclose the transplant and worry about the viability of the transplant were

associated with the mental components of the SF-36 on univariate analysis. In particular, overall worry about the transplant appears to be a key determinant of individuals' emotional well being following transplantation in both TX groups. Worry about the transplant was also found to be associated with physical well being in LRD patients. It is important to recognize that these emotional responses, which are specific to transplantation are not assessed by traditional quality of life instruments but do have broader ramifications. Importantly, they are issues which have the potential to be addressed in clinical care.

It should be recognized, however, that despite the observed significant associations between psychological factors and mental HQoL in the regression analysis, a large proportion of the variance in HQoL remained unexplained. Numerous factors not measured in this study are likely to impinge upon HQoL in this population. For instance, the side effects of immunosuppressive medication and the resultant distress have been associated with decreases in HQoL among transplant recipients [39]. The levels of social support received have also been found to be important in many chronic illnesses and to predict HQoL in transplant recipients [14]. HQoL is a multidimensional concept and predictors are likely to be multiple and varied.

In conclusion, renal transplantation imparts HQoL levels comparable to that of the normal population but it also raises new concerns. Feelings of guilt towards the donor, and donor's family, a tendency not to disclose that they have received a transplant, and worry about the viability of the transplant, were reported by the majority of renal transplant participants. Guilt appears to be more pronounced in LRD transplant recipients. The study emphasizes the value of using transplantation-specific measures sensitive enough to capture the emotional concerns and worries of transplant recipients and further suggests that feelings of guilt and worry may be an appropriate focus for interventions to bolster patients' emotional adjustment to transplantation.

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References

1. Cameron JI, Whiteside C, Katz J, Devins GM. Differences in quality of life across renal replacement therapies: a meta-analytic comparison. *Am J Kidney Dis* 2000; 35: 629–637
2. Karlberg I, Nyberg G. Cost-effectiveness in studies of renal transplantation. *Int J Technol Assess Health Care* 1995; 11: 611–622
3. Schnuelle P, Lorenz D, Trede M, Van Der Woude FJ. Impact of renal cadaveric transplantation on survival in end-stage renal failure; evidence for reduced mortality risk compared with hemodialysis during long-term follow-up. *J Am Soc Nephrol* 1998; 9: 2135–2141
4. Wolfe RA, Ashby VB, Milford EL *et al.* Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 1999; 341: 1725–1730
5. Berkoben M, Schwab S. Dialysis or transplantation: fitting the treatment to the patient. *Annu Rev Med* 1999; 50: 193–205
6. Select Committee of Experts on the Organisational Aspects of Cooperation in Organ and Tissue Transplantation. International figures on organ donation and transplantation activities (1998). *Organs and Tissues* 1999; 3: 141–146
7. Asderakis A, Augustine T, Dyer P *et al.* Pre-emptive kidney transplantation: the attractive alternative. *Nephrol Dial Transplant* 1998; 13: 1799–1803
8. Cecka JM. The UNOS Scientific Renal Transplant Registry. *Clin Transplant* 1999; 1–21
9. Ojo AO, Port FK, Mauger EA, Wolfe RA, Leichtman AB. Relative impact of donor type on renal allograft survival in black and white recipients. *Am J Kidney Dis* 1995; 25: 623–628
10. EBPG Expert Group on Renal Transplantation. European Best Practice Guidelines for Renal Transplantation (Part 1). Produced by the EBPG Expert Group on Renal Transplantation. Section III: the transplant recipient from initial transplant hospitalization to 1 year post-transplant. *Nephrol Dial Transplant* 2000; 15 [Suppl 7]: 52–85
11. Rettig RA, Lohr KN. Measuring, managing and improving quality in the end-stage renal disease treatment setting. *Am J Kidney Dis* 1994; 24: 228–234
12. Apolone G, Mosconi P. Review of the concept of quality of life assessment and discussion of the present trend in clinical research. *Nephrol Dial Transplant* 1998; 13 [Suppl 1]: 65–69
13. Evans RW, Manninen DL, Garrison LP *et al.* The quality of life of patients with end stage renal disease. *N Engl J Med* 1985; 312: 553–559
14. Hathaway DK, Winsett RP, Johnson C *et al.* Post transplant quality of life models. *Clin Transplant* 1998; 12: 168–174
15. Jofre R, Lopez-Gomez JM, Moreno F, Sanz-Guajardo D, Valderrabano F. Changes in quality of life after renal transplantation. *Am J Kidney Dis* 1998; 32: 93–100
16. Evans RW, Hart GL, Manninen DL. A comparative assessment of the quality of life of successful kidney transplant patients according to source of graft. *Transplant Proc* 1984; 16: 1353–1358
17. Julius M, Hawthorne VM, Carpentier-Alting P, Kneisley J, Wolfe RA, Port FK. Independence in activities of daily living for end-stage renal disease patients. Biomedical and demographic correlates. *Am J Kidney Dis* 1989; 1: 61–69
18. Wainwright SP, Fallon M, Gould D. Psychosocial recovery from adult kidney transplantation: a psychosocial review. *J Clin Nurs* 1999; 8: 233–245
19. Fallon M, Gould D, Wainwright SP. Stress and quality of life in the renal transplant patient; a preliminary investigation. *J Adv Nurs* 1997; 25: 562–570
20. Bunzel B, Laederach-Hofmann K. Solid organ transplantation: are there predictors for posttransplant noncompliance? A literature overview. *Transplantation* 2000; 70: 711–716
21. Kong IL, Molassiotis A. Quality of life, coping and concerns in Chinese patients after renal transplantation. *Int J Nurs Stud* 1999; 36: 313–322
22. Pillay BJ, Schlebusch L, Louw J. Illness behaviour in live-related and cadaver renal transplant recipients. *S Afr Med J* 1992; 81: 411–415
23. Chaturvedi SK, Pant VL. Emotional reactions and long term emotional adjustment in renal transplant recipients. *Indian J Psychol Med* 1985; 8: 3–9
24. Ziegelmann JP, Griva K, Hankins M *et al.* The Transplant Effects Questionnaire (TxEQ). The development of a questionnaire to assess the multidimensional outcome of organ transplantation: example of end-stage renal disease. *Br J Health Psychol* 2002; 7 (in press)
25. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). *Med Care* 1992; 30: 473–483
26. Jenkinson C, Stewart-Brown S, Petersen S, Paice C. Assessment of the SF-36 version 2 in the United Kingdom. *J Epidemiol Community Health* 1999; 53: 46–50
27. Ware JE. SF 36 Health Survey Update. *Spine* 2000; 25: 3130–3139

28. Ware JE, Kosinski M, Keller SK. *Physical and Mental Health Summary Scales. A User's Manual*. The Health Institute, Boston, MA, 1994
29. Edgell ET, Coons SJ, Carter WB *et al*. A review of health-related quality-of-life measures in end-stage renal disease. *Clin Ther* 1996; 18: 887–938
30. Aikawa A. Determinants of the magnitude of indebtedness in Japan. A comparison of relative weight of the recipient's benefits and donor costs. *J Psychol* 1989; 124: 523–534
31. Najarian JS, Chavers BM, McHugh LE, Matas AJ. 20 years or more of follow-up of living kidney donors. *Lancet* 1992; 340: 807–810
32. Jones J, Payne WD, Matas AJ. The Living donor—risks, benefits, and related concerns. *Transplant Rev* 1993; 7: 115–128
33. Russell S, Jacob RG. Living-related organ donation: the donor's dilemma. *Patient Educ Couns* 1993; 21: 89–99
34. Johnson EM, Anderson JK, Jacobs C *et al*. Long-term follow-up of living kidney donors: quality of life after donation. *Transplantation* 1999; 67: 717–721
35. Peters TG, Repper SM, Jones KW, Walker GW, Vincent M, Hunter RD. Living kidney donation: recovery and return to activities of daily living. *Clin Transplant* 2000; 14: 433–438
36. DeOreo PB. Hemodialysis patient-assessed functional health status predicts continued survival, hospitalization, and dialysis-attendance compliance. *Am J Kidney Dis* 1997; 30: 204–212
37. Mapes DL, McCullough KP, Meredith D, Locatelli F, Valderrabano F, Held PJ. Quality of life predicts mortality and hospitalization for hemodialysis patients in the US and Europe. *J Am Soc Nephrol* 1999; 10: 249A.
38. Valderrabano F, Jofre R, Lopez-Gomez JM. Quality of life in end-stage renal disease patients. *Am J Kidney Dis* 2001; 38: 443–464
39. DeGeest S, Moons P. The patient's appraisal of side-effects: the blind spot in quality-of-life assessments in transplant recipients. *Nephrol Dial Transplant* 2000; 15: 457–459

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