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Health-related quality of life of patients awaiting kidney and simultaneous pancreas–kidney transplants

THIDA M MYINT,[1] DENISE V O'SHAUGHNESSY,[2] SAMUAL MARSHALL,[3] MIRNA VUCAK-DZUMHUR[1] and GRAHAME J ELDER[1,4]

[1]Department of Renal Medicine, Westmead Hospital, [2]Renal Resource Centre, Royal North Shore Hospital, [3]Postgraduate Medical School, University of Notre Dame, and [4]Osteoporosis and Bone Biology Division, Garvan Institute of Medical Research, Sydney, New South Wales, Australia

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Correspondence:
Assoc. Prof. Grahame Elder, Department of Renal Medicine, Westmead Hospital, Westmead, NSW 2145, Australia. Email: g.elder@garvan.org.au

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SUMMARY AT A GLANCE

Two major messages are carried by this manuscript. First, young patients on waiting list for renal or kidney–pancreas transplant can live with significantly worse quality of life than the general dialysis population. Second, the effect of psychosocial intervention (besides putting a patient on waiting list) should be explored.

ABSTRACT:

Aim: **Patients undergoing kidney and simultaneous pancreas–kidney (SPK) transplants are younger and fitter than the general dialysis population. Intuitively these patients might have better quality of life (QOL) than the general dialysis population, but their QOL scores are not well characterized. The aim of this study was to compare QOL of patients about to undergo kidney or SPK transplants with Australian dialysis outcomes and practice patterns (DOPPS) data and multiple comorbidity and age-adjusted general population data.**

Methods: **Patients attending Westmead Hospital for transplants from August 2009 to December 2011 were invited to complete the Kidney Disease QOL-SF™ 1.3 (KDQOL-SF™ 1.3) questionnaire regarding their immediate pretransplant QOL. This QOL instrument is predictive of hospitalizations and mortality. The questionnaire was completed within 4 weeks of transplantation.**

Results: **Of 180 patients seen within 4 weeks of transplantation 95 (53%) responded, with no differences from non-responders in age, sex, comorbidities or perioperative complications. Compared with DOPPS, these patients had better physical function and less pain, but significantly lower scores for role physical (CI: −19 to −4, $P = 0.004$) and role emotional (CI: −17 to −2, $P = 0.018$). Patients undergoing SPK transplants reported even poorer general health, energy, social support and function. Patients had lower emotional and social function than people with multiple comorbidities, with whom they shared poor general and mental health and vitality. Scores were markedly lower than the general population except for bodily pain (female).**

Conclusion: **Younger, fitter patients are more vulnerable to effects of their illness on social, emotional and physical interactions and may benefit from targeted support.**

INTRODUCTION

Health is a state of physical, mental, and social well-being rather than merely the absence of disease, and health-related quality of life (HRQoL) instruments have been developed and validated to measure health holistically. A number of studies have reported that reduced HRQoL is common among patients with chronic kidney disease (CKD), and assessed using the Kidney Disease Quality of Life-Short Form™ (KDQOL-SF™, Rand Corporation, Santa Monica, CA, USA) questionnaire, HRQoL is predictive of hospitalizations and mortality.[1–6] Although some studies have assessed HRQoL in mixed CKD population[7–10] there is surprisingly little information on the HRQoL of patients awaiting kidney and simultaneous pancreas–kidney (SPK) transplantation, or comparisons of HRQoL between these groups and the general dialysis population. However, in cross sectional studies, patients who have received kidney transplants have higher SF-36 scores than those who have not,[11] and one study reported few significant differences between kidney and SPK transplant

candidates who were generally assessed within the year before their transplant.[12] Compared with the general dialysis population, it might be reasonable to expect that kidney and SPK transplant candidates would have better HRQoL in a number of domains, because they are medically fit for surgery, are generally younger and may have less comorbidity. The aim of this cross sectional study was to assess the HRQoL of patients in the period immediately before their kidney or SPK transplant, and to compare the HRQoL of these patients with other Australian dialysis patients, Australians with multiple comorbidities and with general population data.

METHODS

For this study, we used the KDQOL-SF™ 1.3, a self-reported instrument developed for patients with CKD including those on dialysis. It is composed of 43 kidney disease targeted items and a 36-item health survey that provides an overall health rating based on the SF-36™. This generic core measures physical health status in 4 domains; Physical functioning, Role Physical, Bodily Pain and General Health, while mental health status is measured in 4 additional domains; Vitality, Social Functioning, Role Emotional and Mental Health. The KDQOL-SF™ 1.3 also contains a screening item about sexual activity. The final overall health item asks respondents to rate their health on a scale from 0 to 10 ranging from 'worst possible' to 'best possible'. The complete questionnaire takes approximately 16 min to complete.

All patients who received a kidney or SPK transplant at Westmead Hospital (the Australian national pancreas–kidney transplant centre) between August 2009 and December 2011 were scheduled to attend the Renal Metabolic Bone Clinic within 4 weeks of the transplant date. Those who attended were given an invitation letter to participate in this HRQoL assessment. They were provided with an information sheet regarding the study, which clearly indicated that participation was voluntary and anonymous and provided information on the use and storage of the data collected. They were also provided with a KDQOL-SF™ 1.3 questionnaire,[13] the core components of which are designed for recall over periods of 4 weeks, and remain valid for longer periods following a surgical procedure.[14] The questionnaire was modified so that before each question, the words 'In the 4 weeks just before your transplant' were added. Patients who wished to participate returned the completed questionnaire by prepaid postage. Exclusion criteria included patients who died or for any reason were unable to attend the clinic in the first post-transplant month, including patients whose care was transferred to another unit (Fig. 1). The study was approved by the Western Sydney Local Health District Human Research Ethics Committee.

Statistical analysis

Scoring of the KDQOL-SF™ 1.3 transforms the raw numerical response into a scale from 0 to 100, with higher values reflecting a more favourable health state. Using the survey instrument available from the RAND Corporation web site,[15] items in the same scale are then averaged to create a composite mean score. The mean score of each domain was then compared with general population data and with data relating to people who have multiple comorbidities, based on information collected from the state of South Australia in 2002.[16] These surveys sampled households in South Australia, approximately 75% of which were from metropolitan areas and the remainder from country towns with a population of 1000 or more. Each survey yielded at least 3000 completed interviews with a response rate above 70% and a participation rate between 77% and 85%. In the multiple comorbidity survey, people in the sampled population had between three and five of six possible health conditions, comprising arthritis, osteoporosis, diabetes, chronic bronchitis or emphysema, transient ischaemic attack and stroke. When categorized by gender and age decile 45 to 54 years to match patients in the current study, numbers in the comparator groups ranged from 180 to 500. Patients in the current study were also compared with patients in the 2009 Australian dialysis outcomes and practice patterns (DOPPS) study.[17] Statistical analyses were performed using SPSS 20.0 (SPSS Inc., Chicago, IL, USA) and differences between data set means were analysed by independent *t*-tests using GraphPad Prism version 6.00. Probability values <0.05 were considered significant and results are expressed as mean values ± SD or median and range.

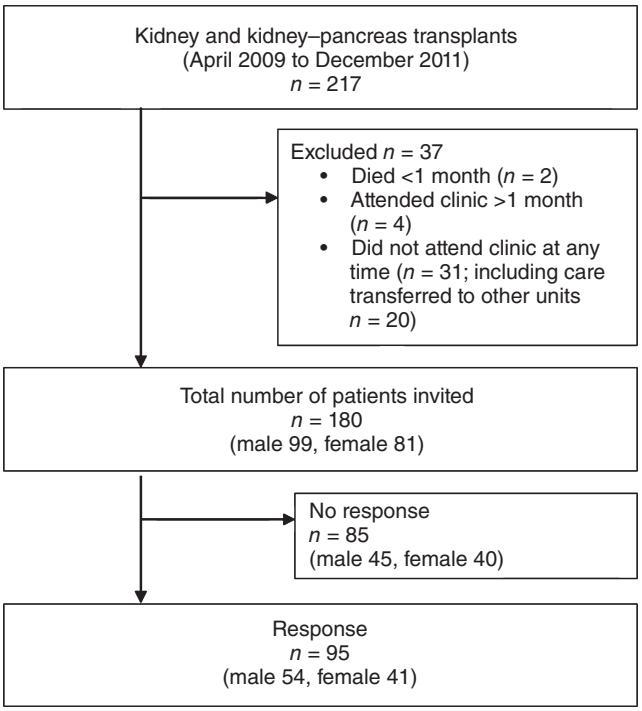

Fig. 1 Flow diagram showing patients participating in or excluded from the study.

RESULTS

A total of 217 patients were transplanted from August 2009 to December 2011 and of these, 37 were excluded (Fig. 1). Of the remaining 180 patients, 95 patients (53%) replied to the questionnaire, comprising 54% of male and 50% of female. All patients asked to participate were in CKD-stages 5 or 5D at the time of transplantation, and characteristics of the kidney and simultaneous pancreas–kidney transplant recipients are listed in Table 1. This table also compares questionnaire responders and non-responders by age, sex, mode of

Table 1 Patient characteristics and comparison of questionnaire responders and non-responders

Characteristic	Responders	Non-responders	*P*-value
Combined patients			
Patient number	95 (M 54, F 41)	85 (M 45, F 40)	
Mean age (years)	47 ± 11 (M)	48 ± 13 (M)	0.75
	45 ± 13 (F)	42 ± 12 (F)	0.20
HD	54%	51%	0.67
PD	28%	33%	0.51
Pre-emptive	18%	16%	0.80
Dialysis vintage (months)	34 ± 36	37 ± 34	0.51
Haemoglobin (g/dL)	11.5 ± 1.5	11.8 ± 1.6	0.20
Serum calcium (mmol/L)	2.23 ± 0.18	2.27 ± 0.16	0.12
Serum phosphate (mmol/L)	1.65 ± 0.53	1.66 ± 0.62	0.90
Awaiting Kidney			
Patient number	69 (M 36, F 33)	57 (M 30, F 27)	
Mean age (years)	51 ± 11 (M)	50 ± 14 (M)	0.76
	46 ± 14 (F)	44 ± 14 (F)	0.57
HD	58%	53%	0.55
PD	25%	33%	0.28
Pre-emptive	17%	14%	0.61
Dialysis vintage (months)	42 ± 41	42 ± 37	0.94
Haemoglobin (g/dL)	12.0 ± 1.0	12.0 ± 1.7	0.14
Serum calcium (mmol/L)	2.23 ± 0.19	2.29 ± 0.17	0.07
Serum phosphate (mmol/L)	1.60 ± 0.52	1.61 ± 0.63	0.92
Awaiting SPK			
Patient number	26 (M 18, F 8)	28 (M 14, F 14)	
Mean age (years)	40 ± 9 (M)	41 ± 6 (M)	0.90
	39 ± 8 (F)	36 ± 7 (F)	0.45
HD	42%	46%	0.76
PD	39%	33%	0.62
Pre-emptive	19%	21%	0.84
Dialysis vintage (months)	16 ± 19	27 ± 26	0.08
Haemoglobin (g/dL)	11.3 ± 1.6	11.5 ± 1.5	0.40
Serum calcium (mmol/L)	2.22 ± 0.19	2.24 ± 0.15	0.68
Serum phosphate (mmol/L)	1.85 ± 0.51	1.74 ± 0.57	0.47

Pre-emptive patients had CKD stage 5 not yet on dialysis. All other patients were undergoing dialysis. CKD, chronic kidney disease; F, female; HD, haemodialysis; M, male; PD, peritoneal dialysis; SPK, simultaneous pancreas–kidney.

Table 2 Comparison of HRQoL scores; patients immediately prior to transplantation and Australian population norms

Domain	Pretransplant	Population norms	*P*-value (95% CI)
Male	(*n* = 54)	(*n* = 261)	
Physical function	58 ± 24	88 ± 19	<0.001 (–36, –24)
Role – physical	30 ± 37	79 ± 37	<0.001 (–61, –39)
Bodily pain	65 ± 28	76 ± 25	0.005 (–18, –3)
General health	38 ± 20	74 ± 21	<0.001 (–42, –30)
Mental health	62 ± 21	79 ± 19	<0.001 (–22, –11)
Role – emotional	47 ± 45	86 ± 32	<0.001 (–49, –29)
Social function	53 ± 26	87 ± 24	<0.001 (–42, –27)
Energy/vitality	36 ± 22	66 ± 22	<0.001 (–36, –24)
Female	(*n* = 41)	(*n* = 365)	
Physical function	62 ± 23	82 ± 22	<0.001 (–28, –13)
Role – physical	29 ± 38	75 ± 39	<0.001 (–58, –33)
Bodily pain	70 ± 25	72 ± 27	0.55 (–11, 6)
General health	47 ± 21	72 ± 24	<0.001 (–32, –17)
Mental health	68 ± 18	76 ± 20	0.02 (–14, –2)
Role – emotional	60 ± 43	83 ± 34	<0.001 (–34, –11)
Social function	56 ± 27	85 ± 25	<0.001 (–37, –21)
Energy/vitality	37 ± 24	59 ± 22	<0.001 (–30, –15)

Table 3 Comparison of HRQoL scores; patients immediately prior to transplantation and Australians with multiple comorbidities

Domain	Pretransplant (*n* = 95)	Multiple comorbidities (*n* = 58)	*P*-value (95% CI)
Physical function	59 ± 24	48 ± 28	0.008 (3, 20)
Role – physical	29 ± 37	33 ± 39	0.54 (–16, 9)
Bodily pain	67 ± 27	51 ± 29	<0.001 (7, 25)
General health	42 ± 21	43 ± 26	0.78 (–9, 6)
Mental health	65 ± 20	70 ± 22	0.15 (–12, 2)
Role – emotional	52 ± 44	67 ± 42	0.052 (–28, 0.2)
Social function	54 ± 27	67 ± 31	0.008 (–22, –3)
Energy/vitality	36 ± 22	43 ± 25	0.08 (–15, 0.7)

dialysis, dialysis vintage, haemoglobin, calcium and phosphate values, with no significant between-group differences in these characteristics. There were also no significant differences in associated comorbid conditions and perioperative complications (data not shown).

Table 2 compares the HRQoL scores of patients with CKD over the 4 weeks prior to transplantation and the scores of South Australians matched by age and gender. Male and female CKD patients scored significantly lower on all scales of the SF-36 component of the KDQOL-SF™ 1.3; physical function, role physical, general health, mental health, role emotional, social function and energy/vitality. However, for women, there was no significant difference on the bodily pain scale.

Table 3 compares the HRQoL scores of patients with CKD immediately prior to transplantation with the scores of Australians with multiple comorbidities. Patients with CKD in the immediate pretransplant period had significantly better physical function and less bodily pain, but in the domains of role physical, general health and mental health their scores were comparable. Renal patients had lower scores for social function and a trend towards lower scores on the role emotional and energy scales.

Table 4 compares the HRQoL scores of patients about to undergo transplantation with Australian dialysis patients assessed in the 2009 DOPPS. The mean age of patients in the current study was 18 years less than patients included in DOPPS, who had a mean age of 64 ± 14 years, and patients in the current study had shorter time on dialysis at 34 *versus* 60 months (Table 1). Patients undergoing transplantation are carefully screened to exclude active cardiovascular disease, whereas the prevalence of coronary artery disease in DOPPS patients was 63%, other cardiac pathology 30%, peripheral vascular disease 33% and cerebrovascular disease 19% (17).

Table 4 Comparison of HRQoL scores; patients immediately prior to transplantation and 340 Australian dialysis patients included in DOPPS 2009

Test domain	Pretransplant (n = 95)	Australian DOPPS (n = 340)	P-value (95% CI)
SF-12 Mental component summary	43 ± 11 (89)	47 ± 12 (265)	0.007 (–7, –1)
SF-12 Physical component summary	38 ± 9 (89)	35 ± 12 (265)	0.02 (0.7, 6)
Physical function	59 ± 24 (93)	35 ± 36 (321)	<0.001 (17, 32)
Role – physical	29 ± 37 (93)	41 ± 30 (311)	0.004 (–19, –4)
Bodily Pain	67 ± 27 (94)	60 ± 31 (336)	0.045 (0.2, 15)
General health	42 ± 21 (95)	43 ± 29 (335)	0.81 (–7, 5)
Mental health	65 ± 20 (95)	67 ± 23 (325)	0.51 (–7, 3)
Role – emotional	52 ± 44 (93)	62 ± 30 (319)	0.02 (–17, –2)
Social function	54 ± 27 (95)	58 ± 33 (340)	0.26 (–11, 3)
Energy/vitality	36 ± 22 (95)	37 ± 28 (333)	0.81 (–5, 7)
Burden of kidney disease	37 ± 28 (95)	36 ± 28 (326)	0.69 (–5, 8)
Symptoms/problems	68 ± 19 (93)	73 ± 19 (327)	0.009 (–10, –1)
Effects of kidney disease	58 ± 26 (95)	63 ± 23 (327)	0.08 (–10, 0.5)

Numbers available for comparison are in parentheses. DOPPS, dialysis outcomes and practice patterns; SF-12, short form 12.

Table 5 Comparison of HRQoL scores; patients immediately prior to kidney or simultaneous pancreas–kidney (SPK) transplantation

Test domain	Pre-kidney transplant (n = 69)	Pre-SPK transplant (n = 26)	P-value (95% CI)
General health	44 ± 20	35 ± 22	0.06 (–0.4, 18)
Social function	60 ± 25	39 ± 26	<0.001 (9, 32)
Energy/vitality	41 ± 22	25 ± 20	0.002 (6, 25)
Mental health composite	44 ± 10	39 ± 11	0.07 (–0.4, 9)
Social support	77 ± 20	64 ± 19	0.004 (4, 22)
Dialysis staff encouragement	88 ± 17	78 ± 24	0.04 (0.2, 19)

Only those domains with between-group P-values <0.1 are included.

However, there were no significant differences with DOPPS data for values of haemoglobin, serum calcium or phosphate. The majority of DOPPS patients and those in the current study met 2009 suggested target ranges for haemoglobin and calcium, while mean values of serum phosphate in both groups were at or above the 2009 suggested target range of 0.8 to 1.6 mmol/L.[18] Compared with DOPPS patients, HRQoL evaluation of patients about to undergo transplantation provided evidence of better physical function and less pain. However, these patients scored lower for the SF-12 mental component summary, role physical and role emotional and for symptoms and problems, with a trend towards reduced scores for the effects of kidney disease.

Patients about to undergo SPK transplantation were aged 39 (17–52), and were younger than kidney only patients aged 51 years (17–71) ($P < 0.001$). Additionally they had a shorter time on dialysis of 13 (0–120) *versus* 26 (0–156) months ($P = 0.009$). Nevertheless, these patients with type 1 diabetes reported poorer energy, social support and function, lower levels of dialysis staff encouragement and non-significant reductions in general and mental health (Table 5).

DISCUSSION

The KDQOL-SF™ 1.3 used in this study is a well validated tool for the assessment of HRQoL in patients with CKD and on dialysis. In addition to questions pertaining to general health, its kidney-targeted items interrogate the 'burden of kidney disease' as it affects daily life, frustration and feeling like a burden on others. Questions covering 'symptoms and problems' include how bothered a respondent feels, and deal with physical symptoms such as sore muscles, chest pain, cramps, itch, numbness, shortness of breath, lack of appetite, lassitude, nausea or problems of dialysis access. 'Effects of kidney disease on daily life' includes items about fluid and dietary restrictions. Additional areas covered include ability to work and travel, dependency on medical staff, staff encouragement and general satisfaction, quality of social interactions and social support, cognitive function, sexual satisfaction, sleep and personal appearance.[19] Despite limited psychometric evidence, it is likely that these questions capture what is important to patients, and internal consistency reliability estimates have exceeded 0.80, with the exceptions of cognitive function (0.68) and quality of social interaction (0.61).[20]

When the collection of these data commenced in 2009, only 11% (1105) of the 10 341 Australian patients undergoing dialysis were on the transplant waiting list. Of these, 88% (977) were less than 65 years of age.[21] Not only are patients awaiting transplantation younger than the general dialysis population, they are also generally healthier on account of pretransplant screening. This study shows that although their physical function is better and they have less pain than a representative selection of the general Australian dialysis population assessed by DOPPS, they are more vulnerable to the effects of their illness in areas of social, emotional and physical interactions (role physical and role emotional). This may reflect the higher social, emotional and physical interaction needs of patients at an earlier phase of their lives, who may not be in long-lasting relationships and who have peers with high expectations in all of these areas. These people may have compromised employment and career opportunities, income levels, social activities and greater difficulty with the formation or maintenance of friendships, intimate relationships and family life. These losses can result in a lack of purpose, reduced social inclusion and support, financial distress and insecurity, and substantially reduced living standards. Many younger, healthier people living with dialysis view it as an imposition limiting all aspects of life, and often feel cheated. By contrast, older people often view dialysis as a life-prolonging bonus, and the regular social contact and attention offered by other patients and staff may be seen as a life-enhancing experience. Compared with

patients awaiting kidney transplants, patients awaiting SPK transplantation reported even poorer energy, vitality and social function and felt they had less social support and dialysis staff encouragement. These findings differ from those of Gross and coworkers,[12] who reported few significant differences between kidney and SPK transplant candidates other than for a higher rate of depression in patients awaiting kidney transplants. Not surprisingly, and similar to that study, QOL scores of patients awaiting transplantation in the current study were markedly lower than those of the general population in all domains, except for the experience of bodily pain by female patients. Patients awaiting transplantation also had lower emotional and social function scores than people with multiple comorbidities, with whom they shared similar poor general and mental health and vitality.

This study has a number of limitations. Selection bias may have occurred because of patients not attending the clinic and receiving questionnaires. As shown in Figure 1, of the 217 eligible patients 11 (5%) whose care remained at our unit were excluded for this reason, while an additional 20 did not receive questionnaires, because their care were transferred to their referring unit. Because participation was voluntary, the response rate was relatively low at 53%, which may also have biased our results. However, we did determine that responders and non-responders shared similar demographic characteristics and medical complication rates. Interestingly, participation in epidemiological studies does appear to have declined over the last few decades,[22] but rates of response do not necessarily correlate to validity.[23] Compared with the current study, a 66% response rate was reported for a self-administered questionnaire completed within a dialysis unit,[24] a 45% response rate for a questionnaires posted to home peritoneal dialysis patients[25] and a 33% response rate was reported for a postal survey that included multiple questionnaires.[26] Because of the number of patients available for analyses, we combined patients awaiting kidney and SPK transplants for some analyses. This may have reduced those scores, because patients awaiting SPK transplantation had poorer HRQoL in a number of domains. Data on patients enrolled in DOPPS, people with multiple comorbidities and general population norms were based on limited numbers, which may not be representative, and in some cases predated the dialysis data by a number of years. For general population data, QOL scores decreased in most domains as people aged, and we used the general population age decile 45 to 54 for comparisons with study patients. Because the mean age of our patients was at the lower end of this age decile, this may have reduced our capacity to detect significant differences between pretransplant patients and the general population. Finally, it is possible that the effects of immunosuppressive medications and recent hospitalization may have interfered with the ability of some patients to provide accurate information on their immediate pretransplant HRQoL. However, patients were all sufficiently well to attend an outpatient clinic, and were assessed within 4 weeks of surgery. Others have shown that at 3 months after surgery, recall (using the SF-12) correlates with moderate accuracy to preoperative assessments of the physical and mental component summaries.[14] In fact, because adaptation to changing health presents a challenge to measurements of quality of life changes, it has been suggested that retrospective measurement may provide a more valid baseline upon which to assess change in HRQoL than conventional prospective methods.[27]

In conclusion, measuring HRQoL in patients with CKD stages 5 and 5D, who are younger than the general dialysis population and are judged fit for transplantation, reveals significant reductions in perceived health in a number of important domains. Although transplantation might be expected to improve their overall HRQoL, younger patients awaiting kidney transplants may benefit from targeted support, potentially including peer group support in the online community, and even more benefit might accrue to patients awaiting SPK transplantation.

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