Quality of life in end-stage renal disease patients: Differences in patient and spouse perceptions

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Abstract

Objectives: Spouses and other proxies consistently rate patient quality of life (QOL) lower than patients rate it themselves. This pattern has been observed in end-stage renal disease (ESRD), cancer, stroke and other chronic illnesses, but it has not been explained. The purpose of the current paper is to examine similarities and differences in spouse and patient ratings of the QOL of patients with ESRD.

Method: Patients with ESRD and their spouses participated in baseline and one-year follow-up interviews. Both patients and spouses rated the patient's QOL, mood, functional ability, subjective health, and kidney disease symptoms. Spouses also rated their own QOL.

Results: Spouses rated all patient characteristics, including QOL, as worse than did the patient. Change in perceptions of patient's mood and their subjective health predicted both patient and spouse ratings of patient QOL. Change in spouse's perceptions of patient's functional ability predicted spouse ratings of patient QOL, but not the patient's own ratings. Finally, change in the spouse's own QOL explained additional variance in their rating of the patient's QOL.

Conclusion: Patients and spouses perceive patient QOL and predictors of patient QOL differently. Implications include the need to be aware of negative bias in spouse ratings of patients of QOL and other psychosocial variables, especially when spouse perceptions are considered by health care professionals. Discussing differences in patient and spouse perceptions in clinical settings with both patients and spouses will allow for a more comprehensive understanding of patient status.

Keywords

quality of life; proxy ratings; end-stage renal disease; spouses

Introduction

The quality of life (QOL) of patients with end-stage renal disease (ESRD) has long been a research topic of interest, first because dialysis treatment provided new hope to patients with

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kidney disease and more recently because its care regimen is associated with considerable stress for both patients (Gudex, 1995; Pucheu, Consoli, D'Auzac, Francias, & Issad, 2004; Tyrrell, Paturel, Cadec, Capezzali, & Poussin, 2005) and their families (Belasco, Barbosa, Bettencourt, Diccini, & Sesso, 2006; Belasco & Sesso, 2002; Morelon, Berthoux, Brun-Strang, Fior, & Volte, 2005). While much prior research has described patient-rated QOL and spouse-rated QOL across a range of chronic illnesses, less is known about how spouses perceive the patient's QOL, especially in the context of ESRD.

Since spouses are often involved in health care decisions for the patient, it is important that they accurately understand changes in the patient's QOL. Pruchno, Lemay, Feild, and Levinsky (2006) found that spouse ratings of patient QOL predicted the spouse's substituted judgments for end-of-life decisions in ESRD patients. Even in situations when patients can speak for themselves (as is the case with most ESRD patients and all patients in this study), proxy ratings of patient QOL might influence empathy for the patient, motivation to provide functional or emotional support, and/or the nature of health care advice given by the spouse. Finally, spouses are often an active part of the patient's treatment team and may provide information about the patient to health care professionals. As such, learning about spouse perceptions of the patient's QOL is an important part of effective patient care.

To date, most research on proxy ratings of QOL has focused on establishing the accuracy of proxy ratings when compared to patient ratings. Proxy ratings of QOL across chronic illnesses have been found to be reasonably accurate, with strong to moderate correlations and intraclass correlations between patient and proxy reports (Rebollo, Alvarez-Ude, Valdes, & Estebanez, 2004; Sandgren, Mullens, Erickson, Romanek, & McCaul, 2004; Sneeuw, Sprangers, & Aaronson, 2002). However, when ratings from patients and proxies are compared, proxy ratings of patient QOL are consistently lower than the patient's own rating. This is the case across chronic diseases including ESRD, cancer and advanced HIV disease as well as for critically ill patients, those in day hospitals, and those in rehabilitation facilities (Clipp & George, 1992; Forjaz & Guarnaccia, 1999; Gundy & Aaronson, 2008; Meers et al., 1995; Rebollo et al., 2004; Sneeuw et al., 2002). While differences between patient and proxy ratings are not always dramatic, they are generally statistically significant and consistent. As such, they warrant further study.

One important issue related to proxy ratings is the relationship between the patient and the proxy. Family members are often included in proxy research, and consistently rate patients' QOL and functional ability lower than the patients do (Ball, Russell, Seymour, Primrose, & Garratt, 2001; Hoe, Katona, Orrell, & Livingston, 2007; Magaziner, Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997; Sneeuw et al., 2002; Yip, Wilber, Mrytle, & Grazman, 2001). Researchers using family proxy raters have not examined differences between ratings based on type of family relationships (i.e. spouse *vs.* adult child). In the current study, an proxy raters are spouses.

Why might spouses rate the patient's QOL lower than the patients do? Three explanations are possible. First, spouses and patients may use different criteria in rating QOL. Correlates of QOL range widely. In a recent review on QOL in renal disease patients, Kimmel and Patel (2006) report that patient ratings of QOL are associated with factors ranging from mortality

and morbidity to depression, sleep and pain. Correlational studies show that a single item measure of overall QOL is correlated with depression, life satisfaction, illness burden, and social support (Hoe et al., 2007; Patel, Shah, Peterson, & Kimmel, 2002), as well as pain, symptom count, and spiritual beliefs (Kimmel, Emont, Newmann, Danko, & Moss, 2003). In their longitudinal study, Franke, Reimer, Philipp, and Heeman (2003) reported that psychological distress predicted lower patient-rated QOL at one-year follow-up, especially for patients who do not receive kidney transplants. It is not known if spouses use the same criteria as patients, which is one of the new questions driving the current study.

However, even if spouses and patients use the same criteria in assessing overall QOL, a second explanation for the QOL discrepancy may be that they rate those criteria differently. Prior research supports this explanation, with proxy raters reporting significantly lower scores than elderly patients on most subscales of the SF-36 (Ware & Sherbourne, 1992), including Physical Functioning, Mental Health, General Health, Bodily Pain and Vitality (Ball et al., 2001; Yip et al., 2001) as well as other measures of QOL (Williams et al., 2006). It follows that different assessments of the components of QOL may lead to different assessments of overall QOL.

A third explanation of differences in patient and proxy ratings of patient QOL is that characteristics of the spouses themselves influence their perception of the patient's QOL (Cremeens, Eiser, & Blades, 2006; Neumann, Araki, & Gutterman, 2000). In a review of 24 studies on proxy evaluations of elderly patients, Neumann et al. (2000) concluded that caregivers with more subjective stress from caregiver duties evaluate patients more poorly. Williams et al. (2006) found that proxy depression and caregiver burden significantly predicted proxy rating of the stroke patients' QOL, with less depressed and less burdened caregivers rating patient QOL higher. Hoe et al. (2007) found that caregiver depression and anxiety were correlated with their ratings of dementia patient's QOL although in a regression model they were not significant predictors. Others have shown that proxy mood and caregiver strain affect the level of agreement between patient and proxy ratings (Hilari, Owen, & Farrelly, 2007).

Prior research exploring these explanations for proxy-patient differences has utilized cross-sectional designs, with measurements by the patient and the proxy at only one point in time. Longitudinal research allows an enhanced understanding of change in predictors of patient and proxy ratings, not simply correlates. By utilizing patient and spouse ratings at both baseline and one-year follow-up as predictors in regression models, the results of the analyses demonstrate if change in those variables over the one year period predicts the dependent variable (in this study QOL). Change over time is especially important in chronic illness since the patient's health and well-being changes with progression and remission of the disease. In ESRD disease, there are periods of stability and decline though the treatment regimen is consistently demanding (Gokal & Hutchinson, 2002).

The one demographic factor consistently associated with QOL in ESRD is race. African American patients report better QOL (Hicks, Cleary, & Ayanian, 2004) and higher well-being than Caucasian patients (Unruh et al., 2004). As such, patient race will be included in the regression analyses to both understand and control for the influence of race.

Hypotheses

Three hypotheses follow each of the explanations for the difference in spouse and patient ratings of patient QOL. Hypothesis I states that the patients and spouses will use different criteria when rating follow-up patient QOL. Hypothesis 2 states that patients and spouses will rate the predictor variables differently, with patient ratings of themselves more favorable than spouse ratings of the patient. Examining differences in patient and spouse ratings of all variables in both baseline and follow-up interviews will provide support for any consistency in negative bias of spouses over time. Hypothesis 3 states that change in the spouse's rating of their own QOL will significantly predict their rating of the patient's QOL. By including the spouse QOL at baseline and follow-up as predictors, the impact of change in spouse QOL over time is considered, which allows us to consider how the spouse changes in the context of chronic illness.

In the current study, patients were rated on several of the correlates of QOL described in prior research by both the patient and the spouse. As such, the hypotheses can be tested with regression analyses and related sample *t*-tests. Hypothesis 1 is tested by comparing two multiple regression equations (1) with the patient rating of their own QOL at follow-up as the dependent variable and (2) with the spouse rating of the patient QOL at follow-up as the dependent variable. The predictor variables in the patient model are race, baseline variables (subjective health, kidney symptoms, mood, functional ability and QOL), and follow-up variables (health, kidney symptoms, mood, and functional ability). In the spouse regression model, race, spouse ratings of the patient at baseline (subjective health, kidney symptoms, mood, functional ability, QOL), spouse rating of their own QOL at baseline, spouse ratings of patient at follow-up (subjective health, kidney symptoms, mood, functional ability), and spouse rating of their own QOL at follow-up are examined as predictors.

Method

Participants

Patients with ESRD and their spouses were recruited for the study though advertisements, recruitment at dialysis centers and from a mailing to a random sample of patients receiving financial assistance from the Centers for Medicare and Medicaid for dialysis treatment. There were no significant differences on variables analyzed in this study based on recruitment method other than race. Respondents from the random sample were more likely to be black than those recruited from the convenience sample. Detailed information regarding recruitment methods is available in Feild, Pruchno, Bewley, Lemay, and Levinsky (2006).

Couples were eligible for the study if patients had ESRD and were on hemodialysis for at least 6 months, were of age 55 years or older, and were married or co-habitating for at least 5 years. Both patients and spouses also had to be English speaking, and free of mental, hearing and speech impairments that would impact their ability to participate in a phone interview.

A total of 315 couples were recruited into the study at baseline. Patients and spouses had been married for an average of 41.38 years (SD = 13.23). Data were collected from both

ESRD patients and their spouses at baseline and 1-year follow-up. A total of 211 couples were interviewed at the 12-month follow-up. Sixty-nine of the original participants were deceased at follow-up, and the remaining 35 were not interviewed for a variety of reasons, most commonly because they were too ill or mentally incompetent ($n = 12$) or not interested ($n = 9$).

Procedure

The majority of participants were interviewed over the phone. Participants living within one hour of Boston had the baseline interview in person ($n = 37$), all others and all follow-up interviews were conducted by phone. Independent sample *t*-tests showed that there were no significant differences in the means of variables used in this analysis as a function of mode of interview (all *p*-values >0.05). The interview included a range of questions about health, mental health, well-being and preferences for treatment continuation. At each time of measurement, patients and spouses within each couple were interviewed by different interviewers. Interviews with patients and spouses were conducted within a mean of 5.6 (SD = 8.1) days of one another.

Statistical analysis

Analyses were conducted with SPSS Version 14. Two separate regression equations were calculated. While multicollinearity was expected to be an issue in the analyses, the tolerance of each variable was >0.20, suggesting that the beta coefficients are stable. In the first regression, the dependent variable was the patients' rating of their QOL at follow-up. Race, baseline variables (subjective health, kidney symptoms, mood, functional ability and QOL), and follow-up variables (health, kidney symptoms, mood and functional ability) were independent variables.

In the second regression equation, the dependent variable was the spouse's rating of the patient's QOL. The independent variables included the spouse ratings of the patient at baseline (subjective health, kidney symptoms, mood, functional ability, QOL), spouse rating of own QOL at baseline, spouse ratings of patient at follow-up (subjective health, kidney symptoms, mood, functional ability), and spouse rating of their own QOL at follow-up.

Paired sample *t*-tests were used to compare the patient ratings and spouse ratings of each variable (i.e. patient baseline rating of QOL and spouse baseline rating of the patient's QOL).

Measures

Each variable was assessed during the baseline interview and at 1-year follow-up interviews. For each variable, the patient rated themselves and the spouse rated the patient using the same measure. In addition, the spouse rated their own QOL.

Quality of life

Quality of life was measured with a one-item overall assessment, 'How would you rate [your/the patient's] overall QOL at present: excellent, very good, good, fair or poor?' High scores indicate high QOL with a theoretical range from I to 5. This one-item measure has

strong correlation, concordance, and criterion-related validity with other patient-completed QOL tools (a 22-item, a 5-item and a picture face scale) and is sensitive to change over time (Sloan et al., 1998).

Subjective health

Subjective health was measured with the one-item question widely used in health research: 'In general, would you say that [your/the patient's) health is poor, fair, good, very good or excellent?' High scores indicate high subjective health and possible scores range from 1 to 5. This single item measure of subjective health has been found to be a reliable (Lundburg & Manderbacka, 1996) and valid measure of general health in older adult samples, including as a significant predictor of mortality (Idler & Benyamini, 1997; Mossey & Shapiro, 1982).

Kidney disease symptoms

Fifteen symptoms commonly associated with kidney disease (i.e. thirst, muscle cramps, numbness in hands/feet) were rated on a 0–3 scale (no problem, mild problem, moderate problem, severe problem). The theoretical range of scores was 0–45, and higher scores were associated with more symptoms.

Mood

Overall mood during the past week was assessed with the 10-item Philadelphia Geriatric Center Positive Affect and Negative Affect Scale (Lawton, Moss, Fulcomer, & Kleban, 1982). Negative affect scores were reverse-coded so that higher affect scores indicate more positive affect and less negative affect, or better mood. The theoretical range of scores is 10–50.

Functional ability

This scale measures extent of difficulty (no difficulty, some difficulty, much difficulty, unable) with 10 activities (i.e. walking up and down a flight of stairs without resting). Items were coded so that higher scores indicate higher functional ability, with a theoretical range of 0–30 (Fitti & Kovar, 1987).

Results

Bivariate correlations among patient variables and spouse variables are reported in Table 1. All correlations were in the direction expected based on the hypotheses. All of the independent variables at baseline and follow-up (patient subjective health, kidney symptoms, functional ability, mood) are correlated with patient QOL at baseline and follow-up interviews with two exceptions (follow-up mood is not correlated with baseline function or follow-up function). All spouse ratings of patient QOL are correlated with spouse ratings of patient (including ratings of patient's health, kidney symptoms, functional ability, mood), and also the spouse's own QOL at both baseline and follow-up. Regression analyses were used in order to investigate predictive relationships between the variables or interest.

Tables 1 and 2 demonstrate support for Hypothesis 1 : patient and spouses do use different criteria when assessing patient QOL. Table 2 shows results of the regression analysis for the

patient rating of their own QOL. In this model, 36.3% of the variance in patient ratings of their QOL was explained by baseline and follow-up measures of subjective health, kidney symptoms, functional ability, and mood. When baseline and follow-up variables are in a regression model, the independent variables at follow-up represent how change in that variable predicts the dependent variable. As such, improvements in patient subjective health ($B = 0.198$, $p = 0.006$) and increase in patient mood ($B = 0.159$, $p = 0.000$) were significant predictors of patient QOL at 12-month follow-up. Baseline QOL was also a significant predictor ($B = 0.342$, $p < 0.000$), as is expected when baseline measures of the dependent variable are in a regression model.

Table 3 shows the results of the regression model predicting the spouse rating of the patient's QOL. 55.4% of the variance was accounted for by the baseline and follow-up independent variables. When all variables were entered, improvements in spouse ratings of patient subjective health ($B = 0.271$, $p < 0.000$), increases in spouse ratings of mood ($B = 0.252$, $p < 0.000$), and increases in spouse ratings of patient functional ability ($B = 0.227$, $p = 0.019$) all significantly predicted higher spouse ratings of patient QOL at follow-up. The baseline measure of the dependent variable, spouse rating of patient QOL was also a significant predictor ($B = 0.180$, $p = 0.009$). Change in the spouse's own QOL predicted their rating of the patient's QOL, such that improvements in the spouse's QOL predicted higher ratings of the patient's QOL ($B = 0.284$, $p < 0.000$), supporting Hypothesis 3.

Table 4 shows the means and standard deviations for all variables in the. Related sample t-tests were used to compare patient and spouse ratings of the paired variables (i.e. patient rating of QOL paired with spouse rating of patient QOL). As expected, the mean rating of QOL by the patient is significantly higher than the mean rating by the spouse (Baseline: $M_{patient} = 3.35$, $M_{spouse} = 2.90$, $t(313) = 6.29$, $p < 0.000$; Follow-up: $M_{patient} = 3.30$, $M_{spouse} = 2.98$, $t(202)3.37$, $p = 0.001$). This pattern repeats, with patient ratings 'better' than spouse ratings for each predictor variable at baseline and follow-up measures, which provides support for Hypothesis 2.

Discussion

This study replicates prior research demonstrating that patients perceive their QOL as 'better' than spouses perceive the patient's QOL. While the difference in patient and spouse ratings of QOL at both baseline and follow-up interviews are statistically significant, the differences are small (baseline: 3.35 *vs.* 2.9, follow-up: 3.30 *vs.* 2.98). Although there is not a large numerical difference in patient and spouse ratings, the corresponding mean spouse rating on the Likert scale is less than 'good' and the mean patient rating is better than 'good'. However, it is also important to note that with means this close together, differences may not be obvious to health care staff members collecting clinical information from patients and spouses. It is also important to note that the discrepancy in perception could benefit the patient if the spouse has more empathy for the patient, stays more closely involved in patient care, or advocates for the patients needs.

The three hypothesized explanations for differences in spouse and patient ratings of patient QOL were partially or fully supported. The analyses partially supported Hypothesis 1, which

stated that there would be different predictors of QOL for spouses versus patients. For spouses, change in functional ability was a significant predictor of the spouse rating of patient QOL at follow-up. It was not significant for patient ratings. Spouses may be more attentive to the patient's functional ability because of changes in demands on caregivers as function changes. In this study, patients reported very small changes in functional ability over the 12-month period (Table 4). As time passes and functional ability changes more dramatically, function may have more of an impact on patient perceptions of QOL.

Support for Hypothesis 1 was partial because there were similarities between patient and spouse predictors to note. For both spouses and patients, baseline rating of QOL, improvements in mood and improvements in subjective health significantly predicted ratings of patient QOL at follow-up. Subjective health is closely linked to QOL in most research on health-related QOL (Kimmel & Patel, 2006), as it is in this sample. It is important to note that prior research shows that depressive symptoms are consistently associated with QOL (Franke et al., 2003; Kimmel & Patel, 2006). Although the Philadelphia Geriatric Center Positive Affect and Negative Affect Scale (Lawton, Moss, Fulcomer, & Kleban, 1982) is not a direct measure of depressive symptoms, it was utilized in the analyses because patients and spouses assessed patient mood with this scale. The CES-D would have been a more appropriate measure of depressive symptoms based on past research (Hoe et al., 2007; Patel et al., 2002). However, both scales do include positively and negatively worded items that are assessed for the past week on a Likert scale. Future research in this area would benefit from utilizing the CES-D or similar patient reported measure of actual depressive symptoms, rather than more generic mood states.

Neither patients nor spouses attended to the number of symptoms specific to kidney disease when rating overall QOL. The lack of significance of kidney disease specific symptoms suggests that the results may be generalizable outside of the context of ESRD Since chronic health problems come in all forms for older couples it would be interesting to replicate these findings in couples coping with a different health conditions.

It is also important to note that the patient regression model accounted for 36.3% of the variance in QOL, while the model predicting spouse ratings of patient QOL accounted for over half of the variance in the dependent variable, 55.4%. In future research, including additional variables related to QOL (i.e. depressive symptoms, pain, social support, spirituality) may explain more variance, however, the analyses as proposed for this study were limited to the variables assessed by both the patient and the spouse. Personality characteristics, notably optimism, pessimism and resilience, may be critical' components of understanding how patients and spouses perceive a chronically ill person's QOL. Future research can continue to answer the questions posed in this study by expanding upon variables measured by both patients and spouses.

Hypothesis 2 was fully supported. Across all variables included in this study, the patients rated themselves as significantly 'better' than the spouse rated them. This is consistent with prior research comparing proxy and patient reports of identical or similar subscales on the SF-36 (Ball et al., 2001; Williams et al., 2006; Yip et al., 2001). It is important to note that despite the statistically significant differences in patient and spouse perceptions, most prior

research shows that proxy assessments are rarely drastically different from one another, with moderate positive bivariate correlations, and acceptable intraclass correlations noted across chronic illnesses in a review study (Sneeuw et al., 2002). In turn, some researchers tout family proxy raters as accurate and acceptable (Rebollo et al., 2004; Sneeuw et al., 2002), and others caution against the use of proxy ratings when the patients are unable to report their well-being (Ball et al., 2001; Kane et al., 2005; Meers et al., 1995; Williams et al., 2006; Yip et al., 2001). The findings in this study support the latter by demonstrating that the spouse's own QOL influences their perception of the patient's QOL. Although spouses can play an important role in many clinical situations, health care professionals must at the least be aware that the patient might report the same information differently. The patient could benefit if the physician initiated a discussion about negative bias in spouse perceptions rather than immediately taking spouse assessments as 'correct'.

The analyses fully supported Hypothesis 3, indicating that change in the spouse's own QOL predicts their rating of patient QOL, even when controlling for related patient variables. It follows that the patient's characteristics and the spouse's QOL are critical to the spouse's assessment of the patient's QOL. From as far back as Freud's theories of projection bias, we have suspected that when individuals evaluate someone else, part of their perception reflects something about the rater as well (Gay, 1988). The implications can be as minimal as a spousal dispute and as far reaching as public policy requiring substituted judgments regarding end-of-life care (Pruchno et al., 2006).

These results may help to explain why proxy ratings are consistently lower than patient ratings across chronic diseases and types of proxy raters. The finding that spouses seem to rate patient QOL based in part on their own well-being is not to say that the spouses are inaccurate. First, subjective measures are subjective and not based on a true or correct 'answer'. Also, because of the intimate nature of marital relationships, there is understandable overlap between one partner's experience and that of their spouse.

It is important to note that any spouse rating of a patient may reflect as much about how the spouse is doing as how the patient is doing Although spouse and patient ratings are similar, consistent, though small, differences emerge. Based on the results of this study, the spouse's own well-being and caregiver responsibilities influence their perception of the patient. Physicians who gather discrepant information could point this out and discuss it with both the patient and the spouse present. This can provide the physician with a more complete understanding of the patient's well-being than can be obtained from either source alone and also might provide an opportunity to discuss caregiver burden with both patient and spouse.

There are limitations to this study. While the findings may generalize to other couples coping with ESRD, it is unknown if the same pattern would emerge with other chronic illnesses. Another limitation of this project is use of a single-item to assess QOL. There are several multi-item QOL scales available that have been used With ESRD patients (Kimmel, 2000) and using one may have yielded different results (e.g. SF-36; Ware & Sherbourne, 1992) Also, the predictor variables were limited to those rated by both the spouse and the patient, and future research may benefit from expanding the list of independent variables.

The spouse is an important part of ESRD patients' medical care, in the roles of both caregiver and informant. Prior research has linked patient outcomes to spouse characteristics (Clarke, Walker & Cuddy, 1996; Daneker, Kimmel, Ranich & Peterson, 2001; Kurz, 2001). Research with African-American ESRD patients has shown that marital discord is associated with patient mortality (Daneker et al., 2001). In addition, prior research shows that caregivers can be 'burdened' by this role. This project shows that in addition to the direct impact of caregiving on the patient and the caregiver, the spouse's perception of the patient is influenced by caregiving too.

Future research will continue to explore the impact of chronic illness on patients and on caregivers. But as shown in this study, we can go beyond the direct impact on each person in the dyad to developing an understanding of how the chronic illness impacts how the spouse and patient view one another. This has important implications for interpreting information provided by informants in medical settings and understanding communication and empathy between couples coping with chronic illness.

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Table 1.

Bivariate correlations among patient variables and spouse variables.

Bivariate correlations between patient variables

	1	2	3	4	5	6	7	8	9	10
Baseline										
1. Subjective health	1									
2. Kidney symptoms	−0.398 **	1								
3. Functional ability	0.376 **	−0.499 **	1							
4. Mood	0.410 **	−0.363 **	0.268 **	1						
5. QOL	0.493 **	−0.334 **	0.319 **	0.459 **	1					
Follow-up										
6. Subjective health	0.543 **	−0.360 **	0.192 **	0.285 **	0.409 **	1				
7. Kidney symptoms	−0.330 **	0.752 **	−0.379 **	−0.331 **	−0.281 **	0.398 **	1			
8. Functional ability	0.313 **	−0.454 **	0.790 **	0.248 **	0.245 **	0.307 **	−0.471 **	1		
9. Mood	0.246 **	−0.400 **	0.134	0.598 **	0.334 **	0.233 **	−0.391 **	0.125	1	
10. QOL	0.455 **	−0.287	0.174 *	0.341 **	0.539 **	0.457 **	−0.300 **	0.200 **	0.347 **	1

Bivariate correlations between spouse variables

	1	2	3	4	5	6	7	8	9	10	11	12
Baseline – spouse rates patient												
1. Subjective health	1											
2. Kidney symptoms	−0.487 **	1										
3. Functional ability	0.439 **	−0.412 **	1									
4. Mood	0.532 **	−0.554 **	0.285 **	1								
5. QOL	0.647 **	−0.485 **	0.376 **	0.608 **	1							
Baseline – spouse rates self												
6. QOL	0.366 **	−0.295 **	0.174 **	0.472 **	0.525 **	1						
Follow–up – spouse rates patient												
7. Subjective health	0.576 **	−0.328 **	0.385 **	0.325 **	0.404 **	0.379 **	1					

Bivariate correlations between spouse variables

	1	2	3	4	5	6	7	8	9	10	11	12
8. Kidney symptoms	−0.309 **	0.644 **	−0.256 **	−0.362 **	−0.275 **	−0.274 **	−0.366 **	1				
9. Functional ability	0.396 **	−0.387 **	0.842 **	0.229 **	0.301 **	0.164 *	0.454 **	−0.334 **	1			
10. Mood	0.527 **	−0.431 **	0.260 **	0.732 **	0.537 **	0.446 **	0.442 **	−0.431 **	0.375 **	1		
11. QOL	0.542 **	−0.339 **	0.289 **	0.447 **	0.536 **	0.439 **	0.588 **	−0.339 **	0.415 **	0.591 **	1	
Baseline – spouse rates self												
12. QOL	0.418 **	−0.244 **	0.151 *	0.432 **	0.445 **	0.573 **	0.357 **	−0.210 **	0.191 **	0.436 **	0.554 **	1

Note:

*
=$p < 0.05$;

**
=$p < 0.01$.

Table 2.

Predictors of patient rating of QOL at follow-up (adjusted $R^2 = 0.363$).

	Beta (standardized)	p
Demographic		
Race	0.105	0.066
Baseline		
Subjective health	0.142	0.076
Kidney symptoms	0.026	0.781
Functional ability	−0.096	0.332
Mood	−0.059	0.457
QOL	0.342 ***	0.000
Follow-up		
Subjective health	0.198 **	0.006
Kidney Symptoms	−0.775	0.439
Functional ability	0.061	0.532
Mood	0.159 ***	0.000

Note:

**
  $=p<0.01$;

***
  $=p<0.01$.

Table 3.

Predictors of spouse rating of patient QOL at follow-up (adjusted $R^2 = 0.554$).

	Beta (standardized)	p
Demographic		
Race	−0.017	0.728
Baseline – spouse rates patient		
Subjective health	0.045	0.532
Kidney symptoms	0.007	0.928
Functional ability	−0.168	0.067
Mood	−0.072	0.388
QOL	0.180[**]	0.009
Baseline – spouse rates self		
QOL	−0.029	0.652
Follow-up – spouse rates patient		
Subjective health	0.271[***]	0.000
Kidney symptoms	−0.012	0.854
Functional ability	0.227[*]	0.019
Mood	0.252[***]	0.000
Baseline – spouse rates self		
QOL	0.284[***]	0.000

Note:

[*] $=p<0.05$;

[**] $=p<0.01$;

[***] $=p<0.01$.

Table 4.

Means, standard deviations and paired sample *t*-tests for all variables.

	Patient rates self		Spouse rates patient			
	Mean	SD	Mean	SD	*t* (df)	*p*
Baseline						
QOL	3.35	1.06	2.90	1.08	6.29 (313)	0.000
Health	2.78	1.06	2.40	1.0S	5.68 (314)	0.000
Kidney symptoms	13.05	7.36	15.57	7.34	−5.94 (314)	0.000
Function	21.28	6.41	18.80	6.56	8.27 (314)	0.000
Mood	37.65	5.60	34.35	6.36	8.92 (313)	0.000
Follow-up						
QOL	3.30	0.968	2.98	1.07	3.37 (202)	0.001
Health	2.79	1.03	2.29	1.04	2.58 (209)	0.001
Kidney symptoms	11.03	6.94	13.48	7.21	−4.50 (202)	0.000
Function	21.79	6.00	18.94	6.58	7.05 (202)	0.000
Mood	38.12	5.68	34.21	6.48	7.16 (200)	0.000