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A Longitudinal Quality of Life Study in Kidney Transplant Caregiver-Patient Dyads

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ABSTRACT

Follow-up care after kidney transplantation requires considerable time and effort from both patients and caregivers. We performed a single-center, prospective, longitudinal quality of life (QOL) assessment of 10 living donor (LD) and 9 deceased donors (DD) transplant caregiver-patient dyads over the first-year post-transplant. Both caregivers and patients reported transient worsening of physical QOL early post-transplant with higher physical QOL at six months post-transplant for LD patients, compared with DD patients. DD caregivers reported decreased mental QOL, increased economic hardship, and increased caregiving strain at six months post-transplant, compared with baseline and compared with LD caregivers. These findings highlight stressors and QOL changes experienced by both dyad members post-transplant, and potential benefits of LD kidney transplantation.

INTRODUCTION

Kidney transplantation remains the definitive therapy for appropriately selected patients with end-stage kidney disease (ESKD), offering decreased mortality and improved quality of life (QOL) (deBoer et al., 2024). However, transplantation is a complex procedure requiring frequent follow-up care and adherence to a complex medical regimen and includes significant perioperative and long-term risks related to immunosuppression. Social determinants of health (SDOH) can pose barriers to people seeking access to a transplant, such as the availability of dependable and stable caregivers, transportation issues, and financial resources, which are often interdependent factors. Specifically, a stable caregiver is a standard requirement for transplant and is associated with improved post-transplant adherence and survival (Mollberg et al., 2015; Rodrigue et al., 2010). Post-transplant care requires significant time and effort from caregivers as well as transplant patients, which affects the QOL of both members of the caregiver-patient dyad. Additionally, concerns regarding the burden of caregiving responsibilities can inhibit the identification of caregivers, thus limiting access to transplants for some patients.

In a previous pilot study of living donor kidney transplant (LDKT) caregiver-patient dyads, we demonstrated mostly positive changes in QOL for both caregivers and patients following LDKT, with some notable differences between dyad members (Whittington et al., 2025). In our small cohort, caregiving strain increased early post-transplant at one month, but improvements in caregiving strain were reported at six and 12 months, compared to pre-transplant. Improvements in economic hardship were reported by both dyad members post-transplant, but these differences were not significant.

The primary limitation of this early cohort was that it only included LDKT dyads, and the study population possessed

high levels of education and employment, high rates of preemptive transplant, and no delayed graft function (DGF). To increase the understanding of QOL impact in a cohort more representative of the heterogeneity of the ESKD population, we studied a group of deceased donor kidney transplant (DDKT) caregiver-patient dyads and compared them to the cohort of LDKT dyads. LDKT recipients receive a kidney from a living person. These surgeries are scheduled, offer shorter waiting times, and LDKT is associated with better outcomes. DDKT recipients are those who receive a transplant from a person who has health condition they are unable to survive. Organs are allocated from the national waitlist, resulting in longer wait times. Additionally, DDKT kidneys are associated with higher risks of delayed graft function (DGF) and expected shorter graft survival. We hypothesize that stressors affecting QOL would be greater in the DDKT dyads, given risks of worse baseline health related to typically longer periods on dialysis, longer wait times for a transplant, and frequently lower levels of socioeconomic status (SES). Additionally, DDKT recipients commonly experience higher rates of delayed graft function and post-transplant complications (Budhiraja et al, 2022, Park et al, 2020).

METHOD

We performed a prospective, longitudinal investigation of dyads comprised of patients who received a kidney transplant at a single center in North Carolina and their caregivers, assessing QOL, financial hardship, and depression/anxiety measures over a 12-month period. Twenty dyads were enrolled in this study, including 10 LDKT recipients and their caregivers, and 10 DDKT recipients and their caregivers. Patients were allowed to identify more than one caregiver. Exclusion criteria were patient age <18 years, multi-organ transplants, patients with major cognitive impairment, and dyads not proficient in English. One DDKT dyad withdrew consent after the one-month visit and was thus excluded from any analysis leaving 19 patients included in the study. One LDKT patient moved out of state and was lost to-follow-up after the one-month visit post-transplant. This single LDKT dyad is included in the baseline data. The remaining 18 dyads were followed through the end of the one-year study period, and there were no missing study visits or surveys for any members of the other 18 dyads. One DDKT patient experienced primary non-function of their kidney graft. These responses were included in the analyses according to intention-to-treat principles.

Primary and secondary caregivers were identified by the transplant patient. All transplant patients identified a primary caregiver, and five patients identified a secondary caregiver. A stable and readily available caregiver to assist with transportation, accompany patients to medical visits, and share responsibility for medication administration and changes are standard requirements for transplant listing. In two of our living-donor dyads, the patient's spouse was the living donor. In those cases, a secondary caregiver assumed or assisted with the primary caregiving responsibilities during the first month while the living donor recovered from surgery. In three DD dyads, the secondary caregivers included adult-age children (n = 2) or a sibling (n = 1) of the patients. Secondary caregivers assisted the primary caregiver with the care of the patient during the early post-transplant period. Both primary and secondary caregivers were followed for the duration of the study in all cases, but caregivers who were living donors and secondary caregivers were excluded from the analysis of primary-caregiver QOL outcomes. Given the confounding potential related to recent surgery or decreased involvement at later time points by the secondary caregivers, their outcomes would have had undue influence on the results of this study.

LDKT patients were enrolled and completed their baseline assessment at the time of their preoperative visit, which was performed within a two-week window prior to the scheduled kidney transplant. LDKT caregivers who were present at the preoperative visit were approached for consent at that time and completed baseline questionnaires. DDKT patients were enrolled and completed baseline assessments at the time of admission for transplant surgery. DDKT caregivers were approached, consented, and completed questionnaires during this admission. In both groups, caregivers who were not present were contacted by phone, informed of the study, asked to provide verbal consent, and then received an invitation to the REDCap questionnaires via email (Harris et al., 2009; Harris et al., 2019). All caregiver assessments were completed prior to the DDKT patients' discharge from the transplant admission.

Data was collected in a REDCap database (Harris et al., 2009; Harris et al., 2019). Participants (both caregivers and patients) completed questionnaires on an electronic tablet in clinic. If participants did not complete the surveys during their clinic visit, they were emailed a personal link for survey completion via the REDCap database. Participants were surveyed at the preoperative visit (baseline) and at one, three, six, and 12 months following transplantation (Harris et al., 2009; Harris et al., 2019).

Caregivers completed a Caregiver Quality of Life Questionnaire (CQLQ) (French et al., 2002)(Appendix C) at all time points, and the (1) Centers for Epidemiological Studies – Depression (CES-D) (Radloff, 1977) (Appendix B); (2) Caregiver Strain Index (CSI) (Thornton & Travis, 2003b) (Appendix D); (3) Economic Hardship Questionnaire (EHQ) (Lempers et al., 1989) (Appendix E); and (4) Short-form 12 (SF-12) Health Survey (Appendix F) at baseline, one month, six months, and 12 months following transplantation

(American Psychological Association, 2011; De Marchis et al., 2023; Thornton & Travis, 2003a; Ware et al., 1996; Weitzner et al., 1998). Transplant patients completed a truncated Kidney Disease Quality of Life (KDQOL ™) (Hays, 1994) (Appendix A) at all time points, and the CES-D (Radloff, 1977) and EHQ (Lempers et al., 1989) surveys at baseline, one month, six months, and 12 months following transplantation (RAND Health, 2026). (*Study tools are provided as supplementary appendices A-F.*)

Description of Study Tools

KDQOL (Kidney Disease Quality of Life; Appendix A) is a kidney-specific measure of health-related QOL that includes 12 items about physical and mental health (the SF-12), four items on the burden of kidney disease/symptoms, eight items on the effects of kidney disease on daily life and 12 questions assessing symptoms and problems of kidney disease (Hays et al., 1994).

CES-D (Center for Epidemiologic Studies Depression Scale; Appendix B) is a 20-item questionnaire developed to screen for depressive disorders. The CES-D has a total possible score of 60 points, with higher scores indicating higher levels of anxiety and depression symptoms (Radloff, 1977).

CQLQ (Caregiver Quality of Life Questionnaire; Appendix C) (French et al, 2002) is designed to assess physical and emotional QOL of those who are primary caregivers for an ill person. The CQLQ consists of 19 items that assess the caregiver's health and physical, social, emotional, and functional well-being (Bates et al., 2016).

CSI (Caregiver Strain Index; Appendix D) is a 13-item questionnaire designed to measure strain associated with the provision of long-term care, which includes items/categories related to: Financial, Physical, Psychological, Social, and Personal Strain (Thornton & Travis, 2003).

EHQ (Economic Hardship Questionnaire; Appendix E) (Lempers et al., 1989) is a 12-item questionnaire that focuses on changes in a household's standard of living and spending associated with a financial burden. The EHQ was originally developed to assess economic hardship with parenting and has been applied to stress with disease states in households (Lempers et al., 1989; O'Neil et al., 2014). Higher scores indicate greater economic hardship.

SF-12 Health Survey (Short Form; Appendix F) is a shortened version of the SF-36 questionnaire, and measures limitations in physical, social, and usual roles due to health problems, pain, mental health, emotional problems, energy, and general health perceptions. It is widely used in many contexts. Scoring of the SF-12 yields two summary measures: the Physical Component Summary (PCS) and the Mental Component Summary (MCS), with the PCS including parameters of physical functioning and pain, while the MCS focuses on psychological and mental health questions (Bohannon et al., 2004; Ware et al., 1996).

Group demographics were compared according to Fisher's exact test for categorical variables and one-way ANOVA for continuous variables, with mean and standard deviations reported. Survey data were scored according to published scoring rules, except for the EHQ, which lacks published scoring criteria (Lempers et al., 1989; Radloff, 1977; Thornton & Travis, 2003b). For EHQ, participants' responses were tallied and summed as a raw score with responses being scored from zero to three points, according to the Likert scale. For SF -12 PCS and MCS, scores above 50 indicate a better-than-average health-related quality of life, while scores below 50 suggest below-average health. For EHQ and CES-D, higher scores indicate higher levels of economic hardship and depression/anxiety symptoms, respectively (Lempers et al., 1989, Radloff, 1977). Delayed graft function (DGF) was defined as dialysis within the first seven days after transplantation.

There were no missing assessment time points for any caregivers or patients within the one-year follow-up. There were minimal missing responses within a given survey. There were no surveys missing in full, except for the 1 LD dyad who was lost-to-follow-up after 1 month and the withdrawn dyad as noted above. There were no surveys missing. For the SF-12, three DDKT patients had missing responses, representing less than 0.5% of data for those individuals. One living donor caregiver had a 0.3% missing response rate, and one secondary caregiver had 0.07% missing responses for the SF-12 questionnaire. In these cases, the prior response for the missing item was carried forward and input to prevent a loss of all the data at that study time point for that participant due to inability to properly score results.

To compare differences over time for both caregiver and patient groups, paired *t*-tests were utilized with an expected difference of zero. Cross-sectional comparisons at a given time point between caregivers and patients were performed using one-way ANOVA. Longitudinal panel data line plots were created to show trajectories for caregivers and patients according to mean values. A two-sided p-value <0.05 was considered significant. All analyses were performed using STATA/IC 15.1 for Windows (StataCorp., 1996–2026). This study was approved by the Wake Forest University School of Medicine Institutional Review Board.

RESULTS

Demographics

For the 19 dyads, the mean age was 52 ± 12 years among caregivers and 54 ± 15 years among patients (p = 0.62). Among

LD caregivers, 67% were female and 58% of DD caregivers were female (p = 1.0), whereas 50% of LD patients and 88% of DD patients were female (p = 0.14) (Table 1). Differences in race were not significant across the cohort: 25%% LD and 50% DD caregivers identified as African American/Black (p = 0.4), and 30% LD and 44% DD patients identified as African American/Black persons (p = 0.65) (Table 1). For education level, 83% of LD caregivers and 55% of LD patients completed a post-secondary degree, compared with 41% of DD caregivers and 44% of DD patients (Table 1). The majority of caregivers and patients were married (70–80% across groups) (Table 1). The most common relationship for caregivers to patients was spouse, which was higher among living donor dyads (67% LD vs. 42% DD, p = 0.07) (Table 3).

Patient characteristics

Among patients, 50% of LD and 44% of DD received transplants preemptively, 30% of LD and 33% of DD were on peritoneal dialysis, and 20% of LD and 22% of DD patients were on hemodialysis (HD) (Table 2). Longer dialysis duration was present among DD patients, compared with LD, but these differences were not significant (DD: 1061 ± 980 days vs. LD: 570 ± 566 days, p = 0.36) (Table 2). Additionally, 30% of LD patients and 56% of DD patients had pre-transplant diabetes (p = 0.24). Body mass index (BMI) was 29 ± 6 kg/m^2 for LD patients and 32 ± 6 kg/m^2 for DD patients (p = 0.17). Fit testing and proportion of highly immuno-sensitized calculated panel reactive antibody (CPRA) patients were comparable between LD and DD kidney transplant patients (Table 2). Among DD patients, 67% received donations after donor circulatory death (DCD) kidney allografts, and 22% received Kidney Donor Profile Index (KDPI) >85% grafts.

Post-transplant length of hospital stay for LD patients was shorter, 3.9 ±1.1 days, versus 5.4 ±1.5 days for DD patients (p = 0.02). DGF occurred in 33% of DDKT patients versus 0% of LDKT patients (p = 0.09). Mean serum creatinine levels were 1.4 ± 0.3 and 1.4 ± 0.3 mg/dL at six and 12 months for LD patients, compared with 1.8 ± 0.8 and 1.6 ± 0.6 mg/dL for DD patients, p = 0.19 and 0.34, respectively (Table 2).

Physical (PCS) and Mental (MCS) Quality of Life (QOL) Scores

For the SF-12 physical component summary (PCS), patients (both LD and DD recipients) had lower physical QOL at baseline, compared with caregivers (P: 44 ± 7 vs. C: 53 ± 5, p = 0.0001) and experienced a temporary worsening of their physical QOL after transplantation (baseline: 44 ± 7 vs. one-month: 32 ± 7, p <0.0001) (Table 4). Patients experienced subsequent improvements in their SF-12 PCS, with at least comparable PCS scores at 12 months post-transplant compared to baseline (baseline: 44 ± 7 vs. one-month: 48 ± 9, p = 0.11) (Table 4). A temporary worsening of PCS scores was noted among caregivers at the six-month follow-up time point (baseline: 53 ± 5 vs. six-month: 49 ± 9, p = 0.02), with subsequent improvement back to baseline by 12 months (baseline: 53 ± 5 vs. 12-month: 52 ± 7, p = 0.38). (Table 4). At baseline, as measured by the SF-12 PCS, LD and DD patients had comparable physical QOL (DD: 45 ± 4 vs. LD: 43 ± 9, p = 0.58) (Table 5). At six months, PCS scores were significantly higher in LD patients (DD: 40 ± 8 vs. LD: 49 ± 8, p = 0.04), driven by declining scores among DD patients and improvements in LD patients (Table 5). There was no longer a significant difference in PCS scores at 12 months between the groups, due to interval improvement in DD PCS scores (DD: 45 ± 7 vs. LD: 50 ± 9, p=0.27) (Table 5). There were no significant differences in SF-12 PCS scores between LD and DD caregivers over the duration of follow-up (Table 6). Figure 1 illustrates the longitudinal trajectories of PCS for the LD and DD caregiver-patient dyads, as measured by SF-12 PCS.

Mental QOL, as measured by the SF-12 MCS, was not significantly different between caregivers and patients in the full cohort at each time point, and there were no significant changes over the first-year post-transplant (Table 4). Baseline mental QOL, as measured by MCS, was higher among DD patients (DD: 55 ± 7 vs. LD: 43 ± 9, p = 0.045), but DD and LD patients had comparable mental QOL at follow-up time points related to increased MCS scores among LD patients compared to baseline (Table 5). MCS was not different between LD and DD caregivers at any time points, but there was a trend toward lower MCS among DD caregivers at three-months (DD: 44 ± 14 vs. LD: 50 ± 10, p = 0.36) with subsequent improvement by 12-months (DD: 51 ± 12 vs. LD: 50 ± 5, p = 0.82) (Table 6). The longitudinal MCS trajectories for the LD and DD caregiver-transplant patient dyads are displayed in Figure 2.

Anxiety and depression as measured by CES-D (Radloff, 1977) were comparable between caregivers and patients at baseline (P: 11.1 ± 8.7 vs. C: 9.3 ± 5.2, p = 0.47) (Table 4). There were no significant changes in CES-D (Radloff, 1977) scores among caregivers at the 6- and 12-month follow-up time points (six-month: 11.7 ± 11.4, p = 0.31 and 12-month: 10.7 ± 10.1, p = 0.51 vs. baseline: 9.3 ± 5.2) (Table 4). Patients did demonstrate a trend towards improved CES-D (Radloff, 1977) anxiety and depression symptoms by these later follow-up time points (six-month: 7.3 ± 8.6 and 12-month: 7.7 ± 8.8 vs. baseline: 11.1 ± 8.7, p = 0.15 and 0.20 respectively) (Table 4). LD patients had higher CES-D (Radloff, 1977) scores at baseline just failing to meet statistical significance in this small cohort (DD: 7.1 ± 9.4 vs. LD: 15.0 ± 9.8, p = 0.05), but subsequent CES-D (Radloff, 1977) scores were comparable for LD and DD patients by 12 months post-transplant (DD: 7.0 ± 6.7 vs. LD: 8.3 ± 10.8, p = 0.76) (Table 5). For CES-D (Radloff, 1977), anxiety and depression symptoms were

highest at six-months for DD caregivers while LD caregiver scores were at their lowest at this follow-up time point (DD: 15.4 ± 8.5 vs. LD: 8.1 ± 6.1, $p = 0.08$) (Table 6).

Economic Hardship (EHQ) and Caregiving Strain (CSI)

Patients reported lower economic hardship (EHQ; Economic Hardship Questionnaire (Lempers et al., 1989)) scores compared to caregivers, despite many dyads sharing a household, but these differences were not significant (Table 4). Among patients, DD had significantly lower EHQ than (Lempers et al., 1989) LD (DD: 2.3 ± 2.1 vs. LD: 9.4 ± 8.7, $p = 0.03$). Over time, EHQ (Lempers et al., 1989) scores trended up among DD patients by the end of the first year, while LD trended down, resulting in comparable scores between DD and LD patients by the end of follow-up (DD: 5.4 ± 5.1 vs. LD: 6.1 ± 6.4, $p = 0.81$) (Table 5). Baseline EHQ (Lempers et al., 1989) was lower among DD caregivers but was not significantly different from LD (DD: 5.0 ± 4.2 vs. LD: 9.9 ± 7.9, $p = 0.13$). Similarly, EHQ (Lempers et al., 1989) scores increased among DD caregivers post-transplant representing higher levels of economic hardship compared with improving EHQ (Lempers et al., 1989) according to decreasing scores among LD caregivers by 12 months post-transplant (DD: 6.3 ± 7.8 vs. LD: 6.7 ± 4.0, $p = 0.91$) (Table 6). These EHQ (Lempers et al., 1989) trajectories are depicted in **Figure 3**.

Caregiver strain improved according to lower CSI (Thornton & Travis, 2003b) scores by 12 months post-transplant, but this change was not significant (baseline: 4.6 ± 5.5 vs. 12-months: 2.8 ± 4.3, $p = 0.23$) (Table 4). CSI (Thornton & Travis, 2003b) was comparable between DD and LD caregivers at baseline (DD: 4.4 ± 6.2 vs. LD: 4.9 ± 4.7, $p = 0.88$) (Table 6). DD caregivers reported higher levels of strain evidenced by higher CSI (Thornton & Travis, 2003b) scores at six months compared with lower CSI (Thornton & Travis, 2003b) scores among LD caregivers, but this difference did not achieve significance (DD: 6.9 ± 6.6 vs. LD: 3.0 ± 3.4, $p = 0.18$) (Table 6). CSI (Thornton & Travis, 2003b) scores improved for both groups of caregivers by 12 months (DD: 2.8 ± 4.9 vs. LD: 2.6 ± 3.7, $p = 0.89$). Figure 4 illustrates the different CSI (Thornton & Travis, 2003b) trajectories for LD and DD caregivers (Table 6).

DISCUSSION

Post-transplant care and caregiving burden

Post-transplant care is complex as well as time and labor intensive. As such, an identified and willing caregiver is considered a prerequisite for transplant eligibility. The elements of post-transplant care, such as frequent clinic visits, blood and urine tests, medication changes, readmissions, and complications, can affect the QOL of both caregivers and transplant patients. Prior studies have demonstrated that high levels of caregiving burden are linked to caregiver burnout (Zaalberg et al., 2023). Additionally, increased caregiving burden can augment risks of medication errors, elder abuse or neglect, and can even lead to an increase in caregiver mortality (Ching et al., 2025; Zaalberg et al., 2023).

This study sought to analyze the impact of kidney transplantation on QOL for both members of the caregiver-patient dyad. The primary limitation of this study remains the small sample size of this cohort, which limits statistical power. However, it is among the first to examine the effects of LDKT and DDKT on both members of the caregiver-patient dyad, including longitudinal changes over the post-transplant period, assess caregiver strain and economic hardship, and analyze differences between LD and DD cohorts.

Education and employment

Education levels were lower among the DD dyads compared with LD dyads, but these levels remained high for an ESRD population with almost half of DD caregivers and DD patients having a college degree as compared with the published literature documenting only 15% of ESRD patients possessing a college degree (Khattak et al., 2012). Similarly, employment rates were lower for DD caregivers and patients, with only one third of DD patients employed compared to half of LD patients (Table 1). For those on dialysis pre-transplant, LD patients had a 40% employment rate compared to 20% for their DD counterparts. This finding aligns with previous research by Kirkeskov et al. (2021), who reported lower employment rates among those on dialysis, secondary to the time and health burden of dialysis and other personal and clinical indicators.

Preemptive transplantation and dialysis rates

Preemptive transplant rates were high for both cohorts in this study with 44% of DD patients and 50% of LD patients transplanted preemptively (Table 2) compared to published norms for kidney transplant populations with preemptive rates typically at less than 20% (Jay et al., 2016). Additionally, DDKT patients who were on dialysis prior to transplant had nearly a two-fold longer dialysis vintage compared to LDKT on dialysis. Diabetes status and dialysis vintage (Table 2; dialysis days), are well-established predictors of negative post-transplant outcomes, potentially worsening QOL for both members of the dyad (Jadlowiec et al., 2022).

Delayed graft function (DGF) in kidney transplantation

Finally, DGF occurred among one-third of DD patients. DGF requires significant additional resources and is associated with longer length of hospital stay and higher readmission rates (Kim et al., 2020; Jadlowiec et al., 2022;). In addition, DGF can affect caregivers' perceptions of their loved one's physical health.

Physical well-being (SF-12 PCS)

Overall, caregivers as well as patients were noted to experience a temporary worsening of their physical QOL according to SF-12 PCS scores in the first month post-transplant, with subsequent improvements by three months (Table 4; Figure 1). These trajectories were comparable between DD and LD cohorts, with significantly higher PCS for LD patients compared with DD patients at six months post-transplant, and a trend toward higher PCS among LD patients at 12 months compared to baseline (Table 6). Notably, patients in this study reported baseline PCS scores (mean=44) that were much higher than dialysis norms (mean=37-38), reflecting the high rates of preemptive transplant status, high fit-test scores, and other factors noted above inherent to candidacy for transplantation (Peipert et al., 2019; Roshanravan et al, 2019; Mittal et al, 2001). Additionally, not all ESKD patients are eligible for transplantation, due to comorbidities and frailty. This can also contribute to significant differences in the PCS scores in this population of kidney transplant patients (Table 5), and the general dialysis population (Peipert et al., 2019, Roshanravan et al, 2019; Mittal et al, 2001). This study (Table 5) corroborates prior studies, such as Smith et al.'s work, noting persons who receive a transplant experience higher QOL than both peritoneal dialysis (PD) and hemodialysis patients (HD) (2018). While one may expect a significant increase in perceived physical health following transplant compared to baseline, it is important to be cognizant that time burden and health barriers experienced with dialysis are offset by the daily management of a functioning transplant, including medication adherence and coping with potential side effects of these medications.

Mental QOL (SF-12 MCS)

Overall, mental QOL, as measured by SF-12 MCS scores, was comparable between caregivers and patients and stable over the follow-up period (Table 4; Figure 2). LD patients reported lower baseline MCS scores, but showed improvement by one month, resulting in comparable MCS scores for LD and DD patients at later time points (Table 5). Anxiety and depression symptoms according to CES-D (Radloff, 1977) were not significantly different between caregivers and patients or over the follow-up period, but a trend towards improved anxiety and depression symptoms as evidenced by lower CES-D (Radloff, 1977) scores was noted among patients at six and 12-months post-transplant (Table 4). DD caregivers (Table 6) reported a notable dip in mental QOL according to lower SF-12 MCS (Ware et al., 1996) scores at three-months and worsened anxiety and depression symptoms according to increased CES-D (Radloff, 1977) scores at six- and 12-months post-transplant compared to baseline with peak CES-D (Radloff, 1977) scores at six months (87% higher than baseline) (Table 6).

Economic hardship (EHQ)

Economic hardship reports an individual's ability to afford basic needs. Overall, EHQ (Lempers et al., 1989) trajectories were stable for both caregivers and patients' post-transplant (Figure 3; Table 4). Caregivers reported higher EHQ (Lempers et al., 1989) scores at each time point compared with patients, but these differences were not significant. LD caregivers and patients reported higher EHQ (Lempers et al., 1989) scores than DD dyads at baseline (Table 5; Table 6). Subsequently, economic hardship levelsimproved in both LD caregivers and patients with downtrending EHQ scores, post-transplant, resulting in comparable scores to their DD counterparts at one-year post-transplant (Table 5; Table 6). Peak EHQ (Lempers et al., 1989) scores representing increased hardship were noted among DD caregivers at 6-months when compared to their baseline or LD caregivers (Table 6).

Disparities, education, employment

Kimmel et al. reviewed data from the US Renal Data System (USRDS) collected from 2000–2008 which showed that the median household income for those with ESKD was $37,500 (2013). This compares to the 2008 poverty line for a family of four, of $21,200 (Department of Health and Human Services, 2008). African American/Black patients were noted to earn an average of $26,742, which was 64% of the earnings of their white counterparts (Kimmel et al, 2013). Individuals with fewer financial resources are less likely to receive a transplant, especially a living donor kidney transplant (LDKT), perpetuating socioeconomic disparities (Bailey et al, 2014). Lower economic status has also been linked to lower health-related QOL (Hwang & Oh, 2024). Pre-transplant employment and education level influence post-transplant QOL, financial security, and contribute to a sense of identity (Alma et al.,2023). Under the Conditions for Coverage (CfC) set by Centers for Medicare and Medicaid Services (CMMS), dialysis centers are required to provide education and referral for vocational rehabilitation. (Federal Register, 2008). In addition to providing education and referral to vocational rehabilitation services, it has been suggested that ensuring patients actually use these resources is critical to supporting sustainable employment post-transplant (Alma et al., 2023). Pre-transplant employment was identified to be the strongest predictor of post-transplant employment (Kirkeskov et al., 2021). Prior employment, coupled with education level, was found to lead to increased job opportunities post-transplant and flexibility, as well as access to better insurance and healthcare (Kirkeskov et al., 2021). This is relevant in considering the impact social workers can have on employment, leading to improved post-transplant outcomes (Kirkeskov et al., 2021).

Caregiver strain (CSI)

Finally, there was a trend toward improved CSI (Thornton & Travis, 2003b) across the overall cohort and individually for LD and DD caregivers by end of study period (Table 6; Figure 4). Of note, higher CSI (Thornton & Travis, 2003b) was reported at six months among DD caregivers compared with baseline, potentially reflecting the factors noted above, including DGF and readmissions, which occur more commonly among DDKT patients (Table 6).

Implications for Nephrology Social Work Practice

Transplant referrals and education

Nephrology social workers embedded in dialysis units have many opportunities to affect access to transplantation, especially LDKT, among ESKD patients. Social workers in the dialysis setting are frequently tasked with coordinating transplant referrals and working to ensure patients are transplant ready (Levan et al., 2025). Transplant education often begins before transplant referrals occur, when patients initiate dialysis in the outpatient unit.

Employment and emotional/economic health

Additionally, there are frequent misconceptions regarding the ability of patients to work or pursue education opportunities at the initiation of dialysis related to erroneous perspectives on physical ability or concerns related to financial impacts, such as receiving disability benefits. Nephrology social workers have the unique opportunity to dispel these myths and work to encourage and support patient's vocational efforts. Continued employment can have a positive impact on both caregivers' and patients' perception of economic health as demonstrated in the LD cohort. Pre-transplant employment is a strong predictor of post-transplant employment, leading to increased EHQ (Lempers et al., 1989) and potentially improved mental QOL and access to better healthcare (Kirkeskov et al., 2021). Support provided by social workers targeting vocational needs can positivity affect both DDKT and LDKT patient outcomes. Given the differences in post-transplant outcomes, the importance of persons on dialysis maintaining vocational and volunteer connections as a bridge to enhanced post-transplant success cannot be overstated (Kirkeskov et al., 2021). Addressing vocational rehabilitation and support for transplant readiness in the dialysis unit is critically needed. CMS Conditions for Coverage (CfCs) include a requirement to provide information and support regarding vocation rehabilitation to patients, but competing priorities assigned to nephrology social workers (NSWs) may prevent the dedicated time required to address this important aspect of transplant readiness (Federal Register, 2008). This process involves more than just providing information; it also should include engaging in meaningful conversations with people on dialysis to explore options and understand the patient's perspectives regarding employment.

Limitations

This study was conducted at a single site. Significant heterogeneity of the population served by transplant centers may exist across other regions of the country. Expanding this study to larger numbers of patients, more complex and higher acuity patients, and regionally diverse centers is necessary to better understand risk factors and the impact follow-up care has on both the recipients' and caregivers' QOL across larger and more diverse populations.

CONCLUSION

In this study of LDKT and DDKT caregiver-patient dyads, temporary worsening of physical (SF-12 PCS (Ware et al., 1996)) QOL was noted in the first month post-transplant for both members of the dyad, with subsequent improvement back to baseline over later follow-up time points (Figure 1; Table 4). Significantly higher physical (SF-12 PCS (Ware et al., 1996)) QOL was noted in LDKT patients compared with DDKT patients at six months post-transplant (Table 5). Trajectories for mental (SF-12 MCS (Ware et al., 1996)) QOL were stable for both caregivers and patients overall (Figure 2; Table 4). Lower mental (SF-12 MCS (Ware et al., 1996)) QOL, higher anxiety and depression symptoms (CES-D, (Radloff, 1977)), higher economic hardship (EHQ (Lempers et al., 1989)), and increased caregiving strain (CSI (Thornton & Travis, 2003b)) were noted among DD caregivers by six-month post-transplant (Table 6). These findings highlight differences in the stresses and QOL changes experienced by caregivers and patients following kidney transplantation and potential benefits of LDKT.

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TABLES

Table 1. Baseline Characteristics of Kidney Transplant Patients and Caregivers

	Caregiver			Patient		
Characteristic	**LD**	**DD**	***p*-value**	**LD**	**DD**	***p*-value**
	n=12	*n*=12		*n*=10	*n*=9	
Age	47 ± 13	51 ± 12	0.44	50 ± 16	58 ± 15	0.27
Female gender	8 (67%)	7 (58%)	1.00	5 (50%)	8 (88%)	0.14
African American/Black race	3 (25%)	6 (50%)	0.40	3 (30%)	4 (44%)	0.65
Education level			0.05			1.00
High school	1 (8%)	7 (58%)		2 (22%)	3 (33%)	
Attended college/technical school	1 (8%)	0 (0%)		2 (22%)	2 (22%)	
Associate/bachelor degree	6 (50%)	4 (33)%		3 (33%)	3 (33%)	
Graduate degree	4 (33%)	1 (8%)		2 (22%)	1 (11%)	
Employed/working	11 (92%)	9 (75%)	0.59	5 (50%)	3 (33%)	0.65
Married	8 (73%)	8 (80%)	1.00	7 (70%)	7 (77%)	1.00

Notes: DD: deceased donor; LD: living donor

Table 2. Pre-transplant Patient and Transplant Characteristics

	LD	**DD**	***p*-value**
Patient variables			
Dialysis days (excludes preemptive patients)	570 ± 566	1061 ± 980	0.36
Dialysis status/type			1.00
Preemptive transplant/No dialysis	5 (50%)	4 (44%)	
PD	3 (30%)	3 (33%)	
HD	2 (20%)	2 (22%)	
Diabetes			0.24
Type 1	1 (10%)	0 (0%)	
Type 2	2 (20%)	5 (56%)	
No diabetes	7 (70%)	4 (44%)	
BMI	29 ± 6 kg/m^2	32 ± 6 kg/m^2	$p = 0.17$
Fit (self)*	4.4 ± 5.1	5.7 ± 4.6	0.62
Fit (physical)*	12.5 ± 0.8	12.4 ± 0.9	0.89

	LD	DD	*p*-value
CPRA >95%	1 (10%)	1 (11%)	1.00
Transplant variables			
Donor age	50 ± 10	51 ± 10	0.79
DCD (DDKT only)	NA	6 (67%)	
Donor AKI (DDKT only)	NA	1 (11%)	
KDPI (DDKT only)	NA	64 ± 29	
KDPI >85% (DDKT only)		2 (22%)	
CIT in hours (DDKT only)		19.6 ± 1.9	
Post-transplant variables			
Length of stay (days)	3.9 ± 1.1	5.4 ± 1.5	0.02
DGF (dialysis in first 7 days)	0 (0%)	3 (33%)	0.09
Creatinine at 6 months (mean ± SD)	1.4 ± 0.3	1.8 ± 0.8	0.19
Creatinine at 12 months (mean ± SD)	1.4 ± 0.3	1.6 ± 0.6	0.34

Notes: AKI: acute kidney injury; CIT: cold ischemia time; CPRA: calculated panel reactive antibody; DCD: donation after circulatory death; DD: deceased donor; DDKT: deceased donor kidney transplant; DGF: delayed graft function; HD: hemodialysis; KDPI: kidney donor profile index; LD: living donor; PD: peritoneal dialysis

*Fit (self); Fit (physical)

Table 3. Caregiver Characteristics at Baseline.

	LD	DD	*p*-value
Relationship to patient			0.07
Spouse/partner	8 (67%)	5 (42%)	
Parent	1 (8%)	0 (0%)	
Child	1 (8%)	4 (33%)	
Sibling	0 (0%)	3 (25%)	
Other relative	1 (8%)	0 (0%)	
Friend	1 (8%)	0 (0%)	
Living donor	2 (17%)	NA	
Alternate caregiver	2 (17%)	3 (25%)	1.00
Dependents	4 (33%)	3 (25%)	

Notes: DD: deceased donor; LD: living donor

Table 4. Quality of Life (QOL) Measures in a Full Cohort of Kidney Transplant Caregivers and Patients

N = 20 patient/caregiver dyads; *n* = 18 dyads responding

	Baseline	1 month post-transplant	*p*-value**	3 months	*p*-value**	6 months	*p*-value**	12 months	*p*-value**
SF12 - PCS									
Caregivers	53 ± 5	47 ± 11	**0.01**	53 ± 7	0.78	49 ± 9	**0.02**	52 ± 7	0.38
Patients	44 ± 7	32 ± 7	**<0.0001**	43 ± 9	0.62	45 ± 9	0.68	48 ± 9	0.11
p-value*	**0.0001**	**<0.0001**		**0.0004**		0.15		0.09	
SF12 - MCS									
Caregivers	49 ± 7	49 ± 11	0.80	46 ± 12	0.27	49 ± 9	0.93	50 ± 10	0.52
Patients	50 ± 12	50 ± 9	0.88	53 ±9	0.40	54 ± 9	0.20	51 ± 11	0.74
p-value*	0.81	0.86	NS	0.09	NS	0.10	NS	0.87	NS
EHQ									
Caregivers	7.1 ± 6.3	7.4 ± 5.1	0.79	NS	NS	7.3 ± 7.0	0.93	6.5 ± 6.3	0.74
Patients	5.9 ± 7.2	5.4 ± 6.0	0.68	NS	NS	4.8 ± 4.9	0.45	5.8 ± 5.6	0.95
p-value*	0.59	0.31	NS	NS	NS	0.23	NS	0.73	NS
CES-D									
Caregivers	9.3 ± 5.2	9.4 ± 8.9	0.95	NS	NS	11.7 ± 11.4	0.31	10.7 ± 10.1	0.51
Patients	11.1 ± 8.7	10.3 ± 8.1	0.72	NS	NS	7.3 ± 8.6	0.15	7.7 ± 8.8	0.20
p-value*	0.47	0.76	NS	NS	NS	0.21	NS	0.36	
CSI									
Caregivers	4.6 ± 5.5	NA	NS	NS	NS	5.2 ± 5.6	0.77	2.8 ± 4.3	0.23

** one-way ANOVA to compare values between caregiver and recipient at that time point; ** paired t-test to compare values between that follow-up time point and baseline*

Notes: SF12 – PCS: Short Form -12 Health Survey– Physical Component Score; SF12 – MCS: Short Form -12 Health Survey– Mental Component Score; EHQ: Economic Hardship Questionnaire; CES-D: Centers for Epidemiological Studies – Depression; CSI: Caregiver Strain Index, NS indicates no survey administered for that time period.

Table 5. QOL Scores for Living Donor vs. Deceased Donor Kidney Transplant Patients

		Baseline	1 month	3 months	6 months	12 months
SF12 – PCS	DD	45 ± 4	32 ± 5	40 ± 10	40 ± 8	45 ± 7
	LD	43 ± 9	31 ± 9	45 ± 7	49 ± 8	50 ± 9
	p-value	0.58	0.91	0.18	**0.04**	0.27
SF12 – MCS	DD	55 ± 7	49 ± 9	52 ± 8	53 ± 11	50 ± 12
	LD	43 ± 9	51 ± 9	53 ± 10	56 ± 7	52 ± 11
	p-value	**0.045**	0.65	0.69	0.50	0.73
EHQ	DD	2.3 ± 2.12	4.0 ± 4.5	NS	5.1 ± 4.4	5.4 ± 5.1
	LD	9.4 ± 8.7	6.9 ± 7.1	NS	4.4 ± 5.5	6.1 ± 6.4
	p-value	**0.03**	0.32	NS	0.78	0.81
CES-D	DD	7.1 ± 9.4	9.1 ± 7.2	NS	9.3 ± 9.0	7.0 ± 6.7
	LD	15.0 ± 9.8	11.4 ± 9.2	NS	5.3 ± 8.1	8.3 ± 10.8
	p-value	0.05	0.56	NS	0.340	0.76

Notes: SF12 – PCS: Short Form -12 Health Survey– Physical Component Score; SF12 – MCS: Short Form -12 Health Survey– Mental Component Score; EHQ: Economic Hardship Questionnaire; CES-D: Centers for Epidemiological Studies – Depression, NS indicates no survey administered for that time period.

Table 6. QOL Scores for Living Donor vs. Deceased Donor Kidney Transplant Caregivers

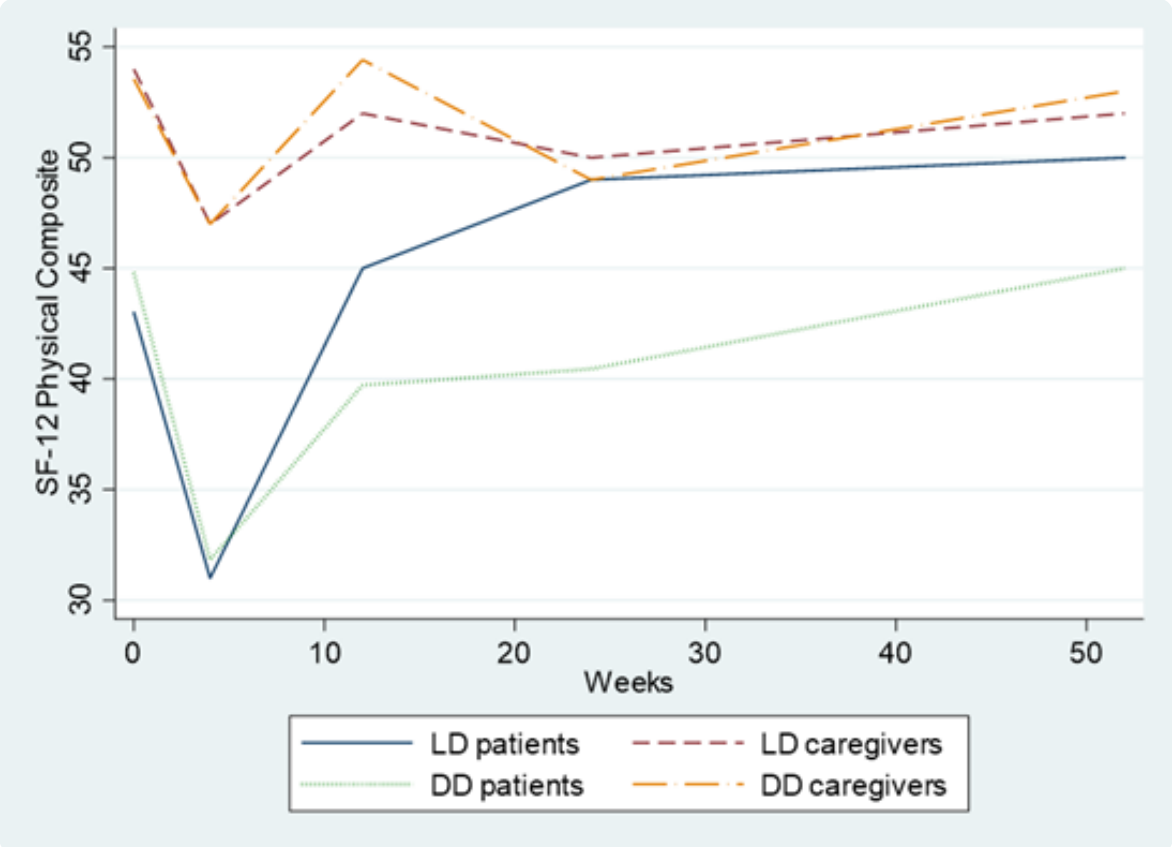
		Baseline	1 month	3 months	6 months	12 months
SF12 - PCS	DD	53 ± 3	47 ± 7	54 ± 3	49 ± 7	53 ± 6
	LD	54 ± 7	47 ± 15	52 ± 9	50 ± 11	52 ± 8
	p-value	0.89	0.92	0.45	0.70	0.82
SF12 - MCS	DD	48 ± 7	53 ± 7	44 ± 14	47 ± 11	51 ± 12
	LD	49 ± 7	45 ± 13	50 ± 10	51 ± 6	50 ± 5
	p-value	0.77	0.14	0.36	0.43	0.82
EHQ	DD	5.0 ± 4.2	8.1 ± 5.2	NS	8.8 ± 8.7	6.3 ± 7.8
	LD	9.9 ± 7.9	6.6 ± 5.3	NS	5.4 ± 3.7	6.7 ± 4.0
	p-value	0.13	0.57	NS	0.36	0.91
CES-D	DD	8.2 ± 5.2	8.5 ± 9.4	NS	15.4 ± 8.5	12.6 ± 12.2
	LD	10.6 ± 5.3	10.4 ± 8.8	NS	8.1 ± 6.1	8.3 ± 6.7
	p-value	0.39	0.69	NS	0.08	0.420

		Baseline	1 month	3 months	6 months	12 months
CSI	DD	4.4 ± 6.2	NC	NS	6.9 ± 6.6	2.8 ± 4.9
	LD	4.9 ± 4.7	NC	NS	3.0 ± 3.4	2.6 ± 3.7
	p-value*	0.88	NS	NS	0.18	0.89

Notes: SF12 – PCS: Short Form -12 Health Survey– Physical Component Score; SF12 – MCS: Short Form -12 Health Survey– Mental Component Score; EHQ: Economic Hardship Questionnaire; CES-D: Centers for Epidemiological Studies – Depression; CSI: Caregiver Strain Index, NS indicates no survey administered for that time period.

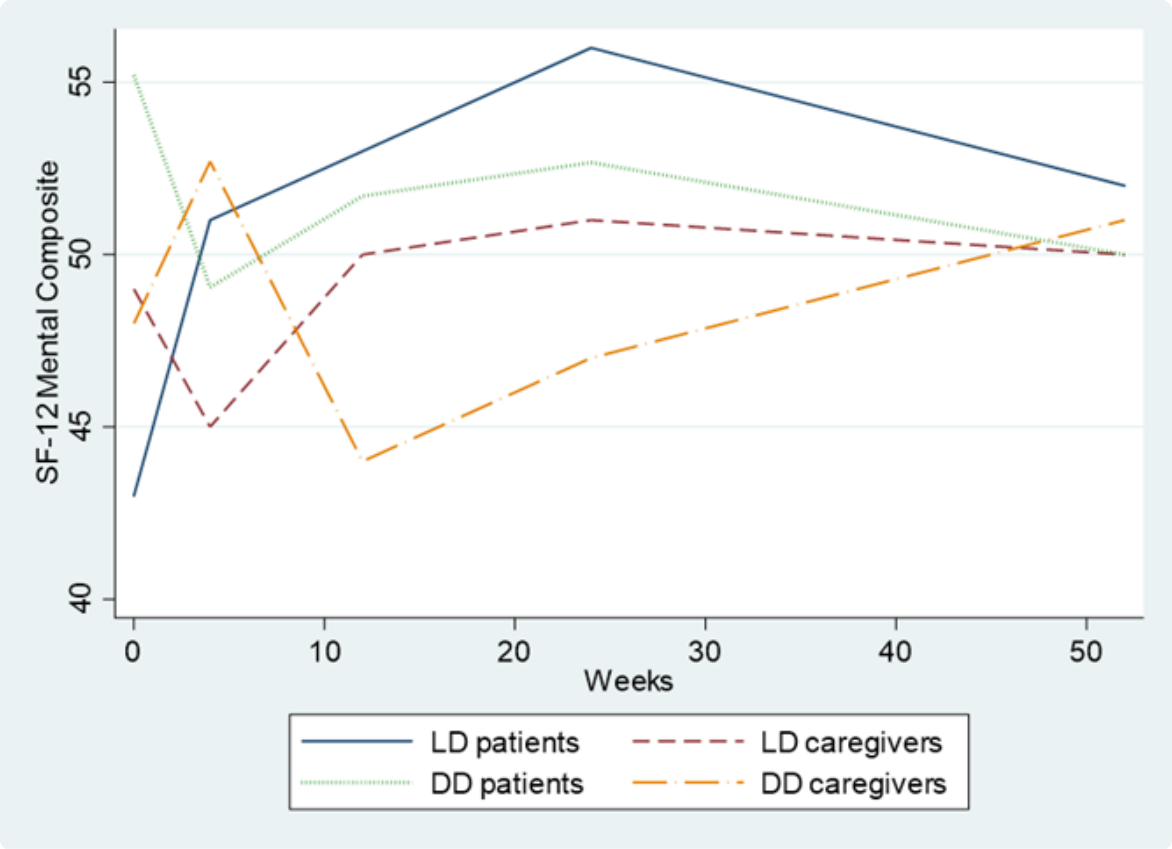
FIGURES

Figure 1. Longitudinal Physical QOL Trajectories (SF-12 PCS) in Caregiver–Patient Dyads



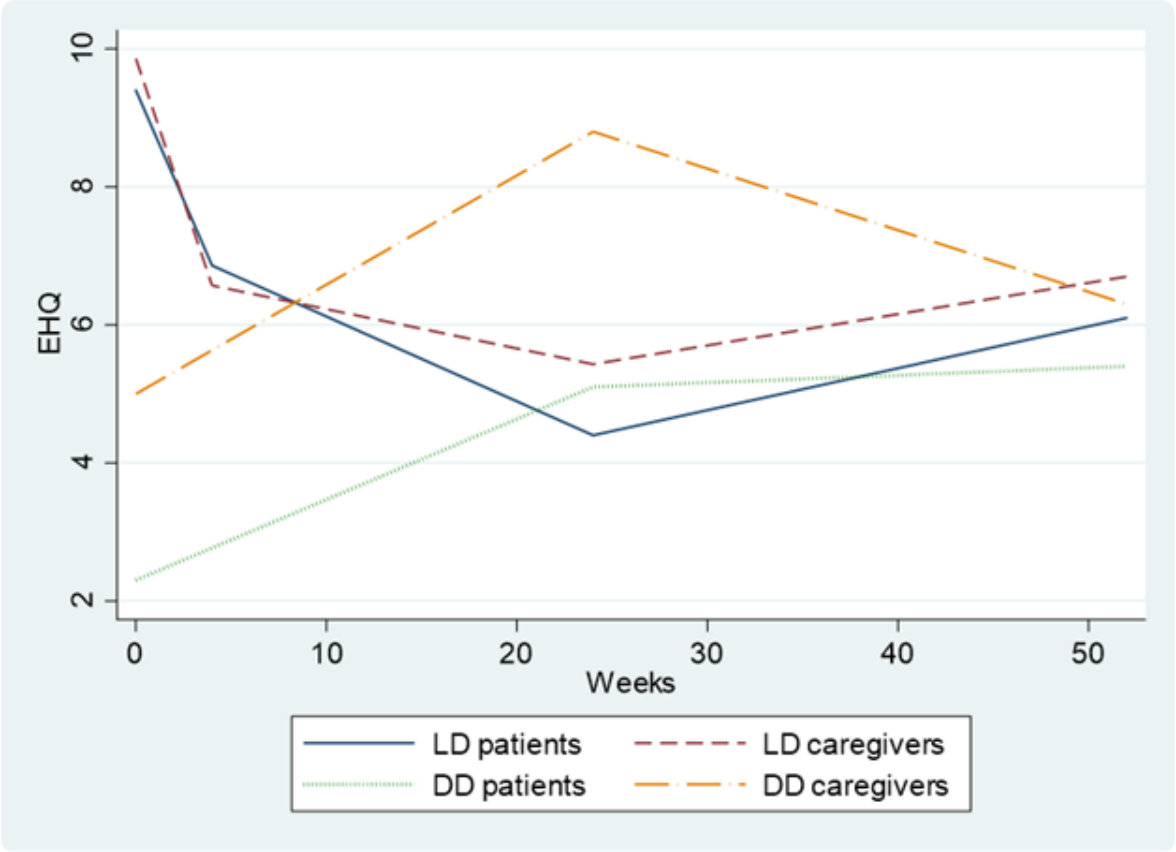
Notes: DD: deceased donor; LD: living donor

Figure 2. Longitudinal Mental QOL Trajectories (SF-12 MCS) in Caregiver–Patient Dyads



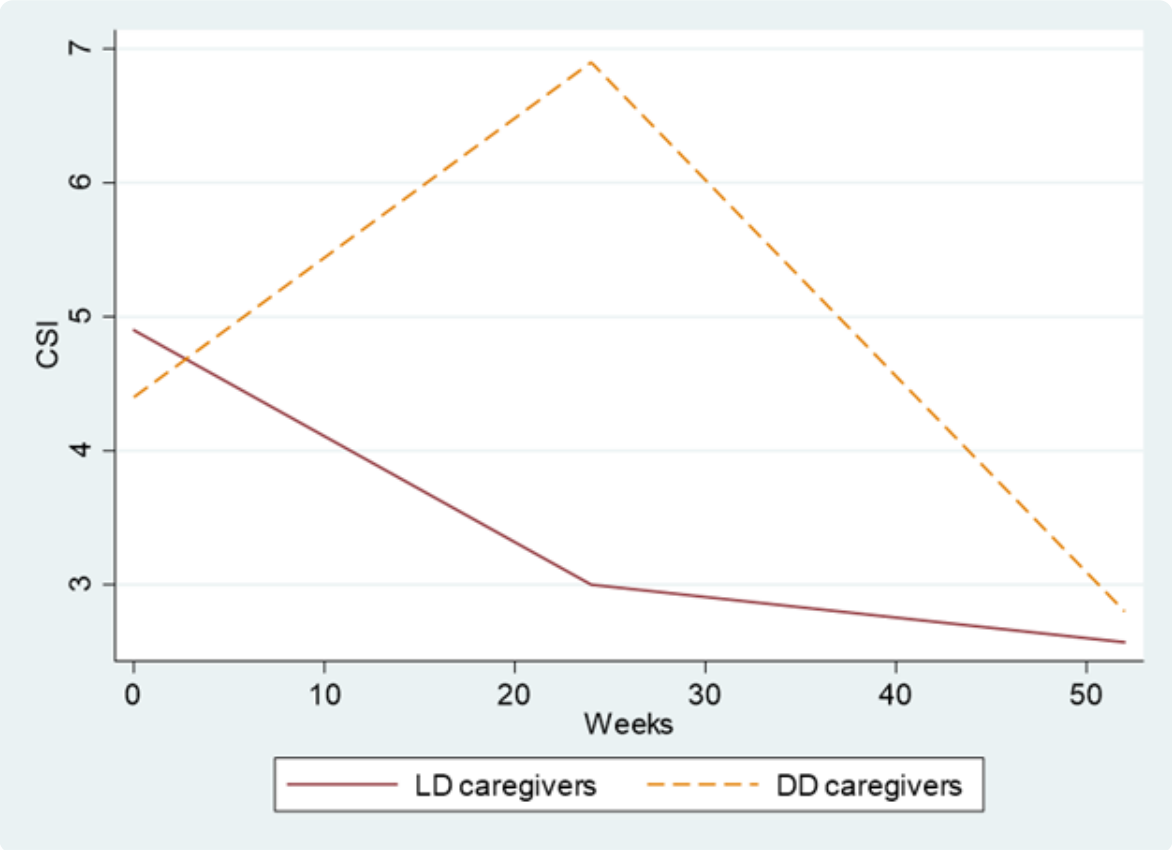
Notes: DD: deceased donor; LD: living donor

Figure 3. Longitudinal Trajectories of Economic Hardship (EHQ) in Caregiver–Patient Dyads



Notes: DD: deceased donor; LD: living donor

Figure 4. Longitudinal Trajectories of Caregiving Strain (CSI) Among LDKT and DDKT Caregivers



Notes: DD: deceased donor; LD: living donor

Appendices

Appendix A. KDQOL (Kidney Disease Quality of Life (KDQOL) instrument, truncated)

Q 1. In general, would you say your health is:

Excellent	**Very Good**	**Good**	**Fair**	**Poor**

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot.	**Yes, limited a little.**	**No, not limited at all.**
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
3. Climbing several flights of stairs.			

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	**No**
4. Accomplished less than you would like.		
5. Were limited in the kind of work or other activities.		

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	**No**
6. Accomplished less than you would like.		
7. Didn't do work or other activities as carefully as usual.		

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?						
10. Did you have a lot of energy?						
11. Have you felt downhearted and blue?						

12. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time

How true or false is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
13. My kidney disease interferes too much with my life.					
14. Too much of my time is spent dealing with my kidney disease.					

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
15. I feel frustrated with my kidney disease.					
16. I feel like a burden on my family.					

During the past 4 weeks, to what extent were you bothered by each of the following?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
17. Soreness in your muscles?					
18. Chest pain?					
19. Cramps?					
20. Itchy Skin?					
21. Dry Skin?					
22. Shortness of breath?					
23. Faintness or dizziness?					
24. Lack of appetite?					

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
25. Washed out or drained?					
26. Numbness in hands or feet?					
27. Nausea or upset stomach?					
28a. (Hemodialysis patient only) Problems with your access site?					
28b. (Peritoneal dialysis patient only) Problems with your catheter site?					

Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
29. Fluid restriction?					
30. Dietary restriction?					
31. Your ability to work around the house?					

	Not at all bothered	Somewhat bothered	Moderately bothered	Very much bothered	Extremely bothered
32. Your ability to travel?					
33. Being dependent on doctors and other medical staff?					
34. Stress or worries caused by kidney disease?					
35. Your sex life?					
36. Your personal appearance?					

Appendix B. CES-D (Centers for Epidemiological Studies – Depression) (Radloff, 1977)

Here are some statements that people sometimes make to describe how they have felt, or how they have been, since they have had kidney disease. Please rate how often you have felt or behaved this way *during the past week*. (0 = Rarely or none of the time (less than 1 day). 1 = Some or a little of the time (1–2 days); 2 = Occasionally or a moderate amount of time (3–4 days); 3 = Most or all of the time (5–7 days).

	0. Rarely	1. Some of the time	2. Moderate Times	3. Most of the time
1. I was bothered by things that usually don't bother me.				
2. I did not feel like eating, my appetite was poor.				
3. I felt that I could not shake off the blues even with help from my family and friends.				
4. I felt that I was just as good as other people.				
5. I had trouble keeping my mind on what I was doing.				
6. I felt depressed.				
7. I felt that everything I did was an effort.				
8. I felt hopeful about the future.				
9. I thought my life had been a failure.				
10. I felt fearful.				

11. My sleep was restless.				
12. I was happy.				
13. I talked less than usual.				
14. I felt lonely.				
15. People were unfriendly.				
16. I enjoyed life.				
17. I had crying spells.				
18. I felt sad.				
19. I felt that people disliked me.				
20. I could not "get going."				

Appendix C. CQLQ (Cough Quality of Life Questionnaire) (French et al., 2002)

Below is a list of statements that will be used to assess quality of life. Please circle or make the number that best represents how you have felt over the last week.

	1. Strongly agree	2. Somewhat agree	3. Neutral	4. Somewhat disagree	5. Strongly disagree
1. I have been healthy this past week.	☐	☐	☐	☐	☐
2. I am content with the quality of life I experienced this past week.	☐	☐	☐	☐	☐
3. I experience lack of energy.	☐	☐	☐	☐	☐
4. Because of my care-taking responsibilities, I have trouble meeting the needs of my family.	☐	☐	☐	☐	☐
5. I am able to express my emotional needs.	☐	☐	☐	☐	☐
6. I am able to express my physical needs.	☐	☐	☐	☐	☐
7. My family is supportive of my emotional needs.	☐	☐	☐	☐	☐

	1. Strongly agree	2. Somewhat agree	3. Neutral	4. Somewhat disagree	5. Strongly disagree
8. My friends are supportive during this time of my loved one's illness.	☐	☐	☐	☐	☐
9. I have meaningful conversations with my loved one about his/her diagnosis/illness.	☐	☐	☐	☐	☐
10. My emotional needs are not being met.	☐	☐	☐	☐	☐
11. I have felt sad or overwhelmed.	☐	☐	☐	☐	☐
12. I am coping with my loved one's illness.	☐	☐	☐	☐	☐
13. I have felt nervous or anxious.	☐	☐	☐	☐	☐
14. I have worried about my loved one's condition getting worse.	☐	☐	☐	☐	☐
15. I have worried that my loved one is dying.	☐	☐	☐	☐	☐
16. I am able to fulfill my regular daily activities.	☐	☐	☐	☐	☐
17. I am able to enjoy my life.	☐	☐	☐	☐	☐
18. My sleep cycle is interrupted by the physical needs of my loved one.	☐	☐	☐	☐	☐
19. I am content with my current quality of life.	☐	☐	☐	☐	☐

Appendix D. CSI (Caregiver Strain Index) (Thornton & Travis, 2003b)

Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis.	Yes, sometimes.	No.
1. My sleep is disturbed. (For example: the person I care for is in and out of bed or wanders around at night.)	☐	☐	☐
2. Caregiving is inconvenient. (For example: helping takes so much time or it's a long drive over to help.)	☐	☐	☐
3. Caregiving is a physical strain. (For example: lifting in or out of a chair; effort or concentration is required.)	☐	☐	☐
4. Caregiving is confining. (For example: helping restricts free time or I cannot go visiting.)	☐	☐	☐
5. There have been family adjustments. (For example: helping has disrupted my routine; there is no privacy.)	☐	☐	☐
6. There have been changes in personal plans. (For example: I had to turn down a job; I could not go on vacation.)	☐	☐	☐
7. There have been other demands on my time. (For example: other family members need me.)	☐	☐	☐
8. There have been emotional adjustments. (For example: severe arguments about caregiving).	☐	☐	☐
9. Some behavior is upsetting. (For example: incontinence; the person I care for has trouble remembering things; or the person I care for accuses people of taking things.)	☐	☐	☐
10. It is upsetting to find the person I care for has changed so much from his/her former self. (For example: he/she is a different person than he/she used to be.)	☐	☐	☐
11. There have been work adjustments. (For example: I have to take time off for caregiving duties.)	☐	☐	☐
12. Caregiving is a financial strain.	☐	☐	☐
13. I feel completely overwhelmed. (For example: I worry about the person I care for; I have concerns about how I will manage.)	☐	☐	☐

Appendix E. EHQ (Economic Hardship Questionnaire) (Lempers et al., 1989)

For the following 10 questions, choose one of the answers listed below:
During the last 4 weeks, how often did your family:

	A. Never	B. Sometimes	C. Often	D. Very often
1. Cut back on social activities and entertainment expenses?				
2. Postpone major household purchases?				
3. Postpone clothing purchases?				
4. Change transportation patterns to save money?				
5. Change food shopping or eating habits to save money?				
6. Cut back on charitable contributions?				
7. Reduce household utility use?				
8. Sell some possessions?				
9. Postpone medical care to save money?				
10. Take additional employment to help meet expenses?				

11. Which of the following best described what has happened to your family income during the past 6 months?

Has increased very much.

Has increased somewhat.

Has stayed the same.

Has decreased somewhat.

Has decreased very much.

12. Which of the following best describes your family financially at this time:

No problems.

Minor problems.

Major problems.

Extreme problems.

Appendix F. SF-12 (Short Form -12 Health Survey; includes PCS and MCS) (Ware et al., 1996)

1. In general, would you say your health is:

Excellent	**Very Good**	**Good**	**Fair**	**Poor**

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot.	**Yes, limited a little.**	**No, not limited at all.**
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.			
3. Climbing several flights of stairs.			

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	**No**
4. Accomplished less than you would like.		
5. Were limited in the kind of work or other activities.		

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	**No**
6. Accomplished less than you would like.		
7. Didn't do work or other activities as carefully as usual.		

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?						
10. Did you have a lot of energy?						
11. Have you felt downhearted and blue?						

12. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time