

# Spouse caregivers of kidney transplant patients: quality of life and psychosocial outcomes

**Context**—Most kidney transplant programs require patients to identify a primary caregiver who can assist them throughout the transplant process. Little is known about the quality of life, caregiving strain, and psychosocial functioning of these caregivers.

**Objectives**—To characterize the psychosocial functioning of spouse/partner caregivers.

**Design, Settings, and Participants**—Cross-sectional survey administered to spouse/partner caregivers of patients before (n = 33) and after (n = 46) kidney transplantation at a transplant center in New England.

**Main Outcome Measures**—Quality of life, life satisfaction, caregiving strain and benefit, mood, and social intimacy.

**Results**—Relative to normative samples and published data involving other transplant caregivers, caregivers of kidney transplant patients had favorable quality of life, life satisfaction, psychological, and social intimacy outcomes. Life satisfaction scores were significantly lower for caregivers before than after kidney transplantation, but otherwise the 2 cohorts did not differ significantly from each other. Most caregivers both before and after kidney transplantation reported clinically high levels of caregiving strain, as well as several caregiving benefits.

**Conclusion**—Our data are consistent with results of other studies in showing that spouses experience considerable caregiving strain both before and after transplantation. However, caregivers of kidney transplant patients overall have good quality of life, life satisfaction, mood, and social intimacy. More prospective research is necessary to characterize better how these outcomes change over time throughout the transplant process. (*Progress in Transplantation*. 2010;20:335-343)

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## Notice to CE enrollees:

A closed-book, multiple-choice examination after this article tests your ability to accomplish the following objectives:

1. Identify 3 benefits to kidney transplant recipients who have a high-quality support system throughout the transplant process
2. State the time frame in which caregiver strain is reported to be highest in the pretransplant phase
3. Explain 3 factors that may contribute to continued caregiver strain after kidney transplantation

**K**idney transplantation offers patients with chronic kidney failure hope of a better quality of life (QOL) and the possibility of longer survival.<sup>1-3</sup> However, the success of kidney transplantation depends, in

part, on the availability and stability of a nonprofessional primary caregiver, usually the spouse, to assist the patient in managing the needs of chronic kidney disease and subsequent transplantation. Indeed, the absence of this type of informal caregiving is considered by most kidney transplantation programs in the United States to be an absolute or a relative contraindication to transplant listing.<sup>4</sup> Evidence in other areas indicates that greater availability and/or higher quality support throughout the transplant process is associated with better psychological adjustment in patients, more optimal adherence behaviors, and longer survival.<sup>5-10</sup>

Notwithstanding the social support requirement for transplant listing at many centers, very little research has been done on transplant caregiving while wait-listed for kidney transplantation or after kidney transplantation. Caregivers of adults with chronic kidney disease and end-stage renal disease have heightened

Table 1 Common caregiving activities before and after kidney transplantation

Before kidney transplantation	After kidney transplantation
Learn about chronic kidney disease, dialysis, and kidney transplantation	Provide direct health care to patient upon discharge from hospital
Provide transportation to hemodialysis sessions 3 times per week	Accompany patient to regular posttransplant surgical and medical appointments
Assist with continuous ambulatory peritoneal dialysis daily	Monitor patient's vital signs and health status closely
Accompany patient to regular medical appointments	Organize, manage, and/or supervise administration and adherence to immunosuppression medications
Monitor patient's vital signs and health status closely	Monitor lifestyle modifications to reduce new health risks (eg, skin cancer, cardiovascular disease, metabolic syndrome, infection)
Organize, manage, and/or supervise medication administration and adherence	Reconnect with family members and friends
Monitor dietary and nutritional requirements	Provide encouragement, support, and comfort to patient
Navigate the complex pretransplant evaluation process	Maintain other roles and responsibilities (eg, childcare, elderly care, work)
Assist patient with necessary lifestyle modifications	Continue to manage financial issues, health insurance, and medication coverage
Communicate regularly with multiple health care providers	
Complete health insurance eligibility forms	
Manage more limited financial resources	
Keep family members and friends informed of the patient's health status	
Discuss living kidney donation option with others	
Provide encouragement, support, and comfort to patient	
Prepare and/or participate in fund-raising activities to cover medical expenses	
Maintain other roles and responsibilities (eg, child care, elderly care, work)	

psychological stress, impaired physical health, and relationship strain.<sup>11-13</sup> However, these studies generally did not include patients awaiting kidney transplantation and, therefore, may underestimate caregiving strain. In one of the only studies to examine functioning of caregivers of kidney transplant recipients, Wicks et al<sup>14</sup> found that the perceived burden and QOL of 19 caregivers did not improve from before kidney transplantation to 6 months after transplantation and that half of the caregivers reported increased burden after transplantation.

Our collective clinical experience suggests that the caregiving demands both before and after kidney transplantation can be extensive and exhausting (Table 1). In addition, caregivers also may absorb those responsibilities previously held by the patient, but now relinquished because of the patient's worsening physical and mental health status. They must cope with the uncertainty and anxiety associated with transplant eligibility, long transplant waiting times, hospitalizations, graft failure, and death of their loved one. Role changes in the marital relationship necessitated by the patient's illness and its treatments may contribute to interpersonal distance, lower emotional or physical intimacy, more conflict and resentment, and altered family dynamics. Caregivers may socialize with friends, extended family members, and coworkers less often because of time demands and increased isolation. Importantly, spouse caregivers may find it difficult to effectively balance their own personal care needs with

those of the patient, especially considering the increasing age at which patients are listed for and receive kidney transplants. It is conceivable that more spouse caregivers are simultaneously attending to their own and the patient's physical and/or mental health needs. Throughout the transplant spectrum, the intensity of caregiving is likely to vary depending on the presence of comorbid conditions and the degree to which these health conditions further compromise the patient's physical well-being, psychological adaptation, cognitive functioning, and self-care capabilities.

Even in the face of considerable strain, some individuals report deriving intrapersonal benefit and satisfaction from informal caregiving.<sup>15,16</sup> Even in the context of transplantation, research has shown that some caregivers identify forming a closer relationship with the patient, gaining a new or different life perspective, and discovering their inner strength as unanticipated benefits of transplant caregiving.<sup>17</sup> The degree to which caregivers of kidney transplant patients experience these same benefits is unknown.

It is important for the transplant community to characterize the impact of caregiving of kidney transplant patients for several reasons. First, such data would enable transplant professionals to better inform caregivers about the range of demands and the strain that they can anticipate both before and after transplantation. Second, if transplant programs continue to require informal caregiving as a condition of transplant listing, they may be obliged to better understand the impact

that caregiving has on those serving in that capacity. Such understanding is particularly important in light of the higher mortality rate among strained caregivers relative to control subjects who were not caregivers.<sup>18</sup> Third, knowing the QOL, psychological, and relationship impact of caregiving—both before and after kidney transplantation—may facilitate the development of psychosocial interventions designed to optimize the well-being of caregivers of kidney transplant patients (directly) and kidney transplant patients (indirectly).

This study had 3 principal objectives: (1) To collect preliminary data to help guide the design of a prospective kidney transplantation caregiving study. Specifically, we wanted to characterize the QOL, life satisfaction, mood, strain, benefits, and social intimacy of spouse/partner caregivers of kidney transplantation patients. We hypothesized that caregivers would have more impaired functioning on these outcome measures when compared with available normative samples. (2) To examine whether these outcomes differed in cross-sectional cohorts of caregivers before and after kidney transplantation. We hypothesized that caregivers before kidney transplantation, largely because of the demands associated with managing chronic kidney failure, would report lower QOL, higher psychological stress, and more caregiving strain than would caregivers after kidney transplantation. (3) To explore the relationships among these different caregiving outcomes. A companion study<sup>19</sup> was conducted with spouse caregivers of liver transplant patients.

## Methods

### Selection and Recruitment of Participants

Caregivers of kidney transplantation patients at Beth Israel Deaconess Medical Center in Boston, Massachusetts, were approached in person or by mail about the study between August 2007 and September 2008. Adults who self-identified as the patient's primary caregiver and spouse, who were at least 21 years old and spoke English, who were not previous living kidney donors, and who provided informed consent were eligible for the study. The patient associated with the self-identified caregiver had to be either listed for kidney transplantation or a kidney transplant recipient. If a kidney transplant recipient, the patient could not be on dialysis. We limited our recruitment to spouse caregivers, whom we defined as those legally married to the patient or a cohabitating partner of the patient, including same-sex relationships.

Caregivers who met the inclusion criteria and who accompanied the patient to a scheduled transplant clinic appointment were informed of the study by one of the investigators or a clinical research assistant. Those who consented to participate in the study completed the questionnaires on site or returned them to us by mail. We also mailed a letter to kidney transplantation

patients known by the investigators to have a spouse caregiver. Patients were informed of the study's purpose and they were asked to share the enclosed study information sheet with their spouse. Spouse caregivers who wanted to take part in the study returned to us a preprinted participation form. Once we received this participation form, we mailed the questionnaire and a prepaid return envelope to the caregiver. The latter recruitment strategy was used to overcome the inherent bias that might result from enrolling into the study only those caregivers who attend outpatient clinic appointments. All study procedures were approved by the institutional review board.

### Questionnaires

Caregivers completed several standardized questionnaires with known validity and reliability in the assessment of QOL, life satisfaction, caregiving strain and benefit, mood, and social intimacy. In addition to these questionnaires, caregivers provided their age, sex, race, how long they have had a relationship with the patient, and the duration of the patient's illness (before kidney transplantation) or time since transplantation (after kidney transplantation). Also, responding caregivers used a 5-point rating scale (1 = poor to 5 = excellent) to rate their perception of the patient's physical health status in the past 3 months.

*SF-36v2 Health Survey.* The SF-36v2 Health Survey (SF-36)<sup>20</sup> is a widely used generic health-related QOL measure that assesses self-perceptions of health across 8 domains: physical functioning, role functioning—physical, role functioning—emotional, vitality, pain, general health, social functioning, and mental health. Scores range from 0 to 100, with higher scores reflecting better QOL. Individual domain scores are combined to yield 2 composite scores: Physical Component Summary (PCS) and Mental Component Summary (MCS).

*Quality of Life Inventory.* The Quality of Life Inventory (QOLI)<sup>21</sup> comprises 32 statements reflecting 16 life domains that were rated by the caregiver for their relative importance (0 = not important, 1 = important, 2 = extremely important) and current satisfaction level (-3 = very dissatisfied to +3 = very satisfied). These domains include health; self-esteem; goals-and-values; money; work; play; learning; creativity; helping; love relationship; relationships with children, relatives, and friends; home; neighborhood; and community. A weighted life satisfaction rating was obtained for each domain, and a standardized overall T score was calculated. Higher scores indicate higher life satisfaction.

*Profile of Mood States—Short Form.* The Profile of Mood States—Short Form (POMS)<sup>22</sup> lists adjectives that caregivers use to rate (0 = not at all to 4 = extremely)

how they felt in the past week. Responses yield scores across 6 scales, including Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment. A total mood disturbance score is also calculated. With the exception of the Vigor-Activity scale, higher scores indicate more mood disturbance.

*Caregiver Strain Index.* The Caregiver Strain Index (CSI)<sup>23</sup> assesses the strain of caring for medically compromised patients. It has good construct validity and internal consistency, and it has been used by our research group with caregivers of both liver and kidney transplant patients.<sup>6,12</sup> Caregivers used a “yes-no” format to indicate whether they experienced any of the 13 caregiver strains. The number of yes responses is totaled, with higher scores indicative of more strain. Also, the endorsement of 7 or more items is indicative of clinically significant caregiver strain.

*Caregiver Benefit Index.* The Caregiver Benefit Index (CBI)<sup>17</sup> is used to assess the potential benefits of serving in a caregiver capacity. Respondents used a “yes-no” format to indicate whether they experienced the 12 caregiving benefits. A total score is obtained, with higher scores indicative of more perceived benefit.

*Miller Social Intimacy Scale.* The Miller Social Intimacy Scale (MSIS)<sup>2</sup> was developed to measure the perception of closeness in a relationship. It has shown good reliability and validity, and we have used it in the transplant setting with both patients and caregivers.<sup>25,26</sup> A total intimacy score is obtained, with higher scores reflective of greater perceived intimacy. Also, scores are calculated for 2 intimacy subscales: frequency (eg, When you have leisure time how often do you choose to spend it with him/her?) and intensity (eg, How affectionate do you feel toward him/her?).

### Statistical Analysis

Preliminary analyses were conducted to examine the underlying distributional properties of all variables and patterns of missing data. Missing data were replaced by using the multiple imputation strategy. Means, standard deviations, and proportions were calculated to summarize sample characteristics and outcomes for caregivers both before and after kidney transplantation. To assess the first study aim, *t* tests were done to compare caregivers' mean scores on the various questionnaires with published normative and comparison samples.<sup>17,20,21,25</sup> For the second study aim, we used *t* tests to determine whether mean scores differed between caregivers before kidney transplantation and caregivers after kidney transplantation. To assess the third aim of the study, Pearson correlation coefficients were calculated to determine the associations between

caregiver strain and benefit, QOL, mood, life satisfaction, social intimacy, and sociodemographic characteristics. Statistical significance was operationalized as a probability value of .05 or less. As noted previously, these data were collected as part of a pilot study to inform the design of a prospective study of caregiving in kidney transplant patients. As such, we were interested in identifying clinically relevant group differences and associations between variables. Therefore, an a priori decision was made not to correct for the possibility of type I error due to the large number of comparisons. All analyses were conducted by using SPSS 16.0 for Windows (SPSS Inc, Chicago, Illinois).

## Results

### Sample Characteristics

We approached 114 spouse caregivers of kidney transplant patients about the study, and 96 (84%) initially consented to participate. However, 79 caregivers (69%; 33 before and 46 after kidney transplantation) actually completed the entire questionnaire packet. Most of the 17 caregivers who initially consented but then did not participate in the study reported that they did not have enough time to complete the questionnaires while in the outpatient clinic (eg, patient was called in to see transplant physician or had to go to another clinic for follow-up tests). Table 2 summarizes sociodemographic characteristics of the caregivers before and after kidney transplantation and shows that these 2 cohorts did not differ significantly from each other.

### Study Cohort Compared With Normative or Published Data

Table 3 presents the summary score means and standard deviations for the current study cohort compared with available normative and published data. Caregivers of kidney transplant patients had a higher mean SF-36 PCS score ( $t=3.0$ ,  $P=.003$ ) and a lower SF-36 MCS score ( $t=2.0$ ,  $P=.04$ ) relative to a large US normative sample. Also, kidney transplantation caregivers had a lower mean POMS total mood disturbance score ( $t=3.1$ ,  $P=.003$ ) and a higher mean MSIS total intimacy score ( $t=4.8$ ,  $P<.001$ ) compared with a small sample of lung transplant caregivers. Caregivers of kidney transplant patients did not differ significantly on any of the measures from a similar cohort of caregivers of liver transplant patients before and after transplantation.

### Comparisons From Before to After Transplantation

Caregivers before kidney transplantation (mean [SD], 47.1 [10.8]) had significantly lower QOLI total scores than did caregivers after kidney transplantation (51.6 [9.1];  $t=2.0$ ,  $P=.05$ ). Using the QOLI

Table 2 Sociodemographic characteristics of caregivers before and after kidney transplantation

Characteristic <sup>a</sup>	Before (n=33)	After (n=46)	Statistical test
Age, mean (SD), y	53.8 (11.9)	55.0 (10.0)	$t=0.48, P=.63$
Sex, female	17 (52)	25 (54)	$P=.82^b$
Race, white	29 (88)	40 (87)	$P=.42^b$
Relationship duration, mean (SD), y	25.2 (14.9)	23.5 (13.3)	$t=0.52, P=.61$
Rating of patient's health in past 3 months			
Poor	4 (12)	7 (15)	$\chi^2=4.6, P=.37$
Fair	12 (36)	10 (22)	
Good	11 (33)	17 (37)	
Very good	6 (18)	8 (17)	
Excellent	0 (0)	4 (9)	
Illness duration, mean (SD), mo	40.4 (10.9)		
Dialysis, yes	15 (45)		
Time on kidney transplant waiting list, mo			
<12	1 (3)		
12-23	9 (27)		
24-48	11 (33)		
>48	12 (36)		
Time since kidney transplantation, mo			
<12		13 (28)	
12-23		7 (15)	
24-48		11 (24)	
>48		15 (33)	

<sup>a</sup> Values are number (%) unless otherwise indicated.

<sup>b</sup> Only  $P$  value is reported because the Fisher exact test does not yield a formal test statistic or critical value.

classification system,<sup>21</sup> most caregivers both before kidney transplantation (24, 73%) and after kidney transplantation (39, 85%) reported average or high life satisfaction. Only 9 caregivers (27%) before kidney transplantation and 7 caregivers (15%) after kidney transplantation reported low or very low life satisfaction. Examination of individual QOLI domains showed that caregivers before kidney transplantation reported more dissatisfaction with their self-esteem (mean [SD], 2.1 [3.2] vs 3.4 [2.2];  $t=2.1, P=.04$ ), helping behaviors (2.0 [2.6] vs 3.3 [2.3],  $t=2.3, P=.02$ ), and friendships (2.2 [2.3] vs 3.4 [2.3],  $t=2.4, P=.02$ ) than caregivers after kidney transplantation reported.

Caregivers before and after kidney transplantation did not differ significantly on any of the SF-36 summary or scaled scores (all  $P$  values  $>.14$ ), POMS total mood disturbance score (before kidney transplantation 12.2 [17.7] vs after kidney transplantation 10.3 [13.7];  $t=0.5, P=.61$ ), or MSIS total intimacy score (before 72.0 [9.3] vs after 70.5 [11.8] kidney transplantation;  $t=0.6, P=.54$ ). Overall, 23 caregivers (29%) had a clinically elevated POMS total mood disturbance score, and 33 (42%) had a clinically low MSIS intimacy total score.

On the CSI, the mean number of strain items endorsed was 6.9 for caregivers both before and after kidney transplantation ( $P=.94$ ). Using the suggested

clinical cutoff score of 7 or higher, 19 caregivers before kidney transplantation (58%) and 24 caregivers after kidney transplantation (52%) were classified as having high caregiving strain. Overall, the most commonly endorsed types of caregiving strain was having to make changes in personal plans (71%), having to make adjustments in the family because of disrupted routines (70%), disturbed sleep (66%), having to make emotional adjustments (63%), having to make adjustments at work (61%), and dealing with competing time demands (57%; see Figure).

Mean total CBI scores were 10.0 (SD, 2.0) for caregivers before kidney transplantation and 9.9 (SD, 2.1) for caregivers after kidney transplantation ( $t=0.3, P=.76$ ). All caregivers reported 5 or more benefits associated with caregiving. The most commonly endorsed caregiving benefits included giving emotional support to the patient (92%), realizing what is important in life (87%), spending more time with the patient (83%), a stronger emotional bond with the patients (80%), and discovering one's own inner strength (78%).

#### Relationships Between Outcome Measures and Sociodemographic Characteristics

For the entire sample, more total mood disturbance (POMS) was associated with perceptions of worse

Table 3 Summary score mean (SD) for the current study cohort compared with normative and published data

	Current study cohort (n=79)	Normative sample <sup>a</sup>	Liver transplant caregivers <sup>19</sup> (n=86)	Lung transplant caregivers <sup>25</sup> (n=28)
Physical summary component (SF-36)	53.4 (6.7)	50.0 (10.0) <sup>b</sup>	52.8 (8.8)	
Mental component summary (SF-36)	47.7 (11.9)	50.0 (10.0) <sup>c</sup>	44.9 (14.5)	
Total life satisfaction (QOLI)	49.8 (10.0)	50.0 (10.0)	50.7 (9.9)	49.0 (7.7)
Total mood disturbance (POMS)	11.1 (15.5)		15.9 (18.3)	20.6 (9.7) <sup>b</sup>
Caregiver strain (CSI)	6.9 (3.7)		7.4 (3.5)	
Caregiver benefit (CBI)	9.9 (2.0)		10.4 (2.2)	
Total social intimacy (MSIS)	71.1 (10.8)		72.2 (9.8)	58.1 (16.0) <sup>b</sup>

Abbreviations: CBI, Caregiver Benefit Index; CSI, Caregiver Strain Index; MSIS, Miller Social Intimacy Scale; POMS, Profile of Mood States; QOLI, Quality of Life Inventory.

<sup>a</sup> Normative samples: SF-36<sup>26</sup> (N=6742) and QOLI<sup>21</sup> (N=798)

<sup>b</sup> Current study cohort mean that differs significantly ( $P < .01$ ) from other sample means in that row.

<sup>c</sup> Current study cohort mean that differs significantly ( $P < .05$ ) from other sample means in that row.

patient health ( $r = -0.28$ ,  $P = .01$ ), lower mental QOL (SF-36 MCS,  $r = -0.78$ ,  $P < .001$ ), lower life satisfaction (QOLI,  $r = -0.41$ ,  $P < .001$ ), and lower intimacy (MSIS,  $r = -0.26$ ,  $P = .03$ ). More caregiving strain (CSI) was associated with perceptions of worse patient health ( $r = -0.32$ ,  $P = .004$ ) and lower mental QOL (SF-36 MCS,  $r = -0.29$ ,  $P = .01$ ). Also, for caregivers before kidney transplantation, caregiving strain was higher when the patient was on hemodialysis (vs not yet on dialysis,  $t = 3.2$ ,  $P < .001$ ). More caregiving benefit (CBI) was associated with more life satisfaction (QOLI,  $r = 0.37$ ,  $P = .002$ ), higher intimacy (MSIS,  $r = 0.43$ ,  $P < .001$ ), and longer duration of the relationship ( $r = 0.28$ ,  $P = .02$ ).

## Discussion

Overall, we found that kidney transplantation caregivers are generally not experiencing more impaired QOL or psychological distress in comparison to normative data for caregivers of other solid organ transplant patients. The majority of caregivers report good physical and mental QOL, average to high life satisfaction, no clinical mood disturbances, numerous benefits of caregiving, and moderately high levels of relationship intimacy with the patient. Although most empirical studies suggest compromised functioning in caregivers of patients with end-stage renal disease, we did not find this to be the case. Our findings seem to be more consistent with those reported by Wicks et al,<sup>27</sup> who found that most of the 96 caregivers of patients with end-stage renal disease who were studied had good QOL and relatively little burden.

Despite this favorable clinical picture, however, we found that more than half of all kidney transplantation caregivers reported clinically significant caregiving strain. We expected high strain levels for caregivers before kidney transplantation, based on prior literature showing that providing care for patients with

end-stage renal disease is burdensome and stressful.<sup>11,12</sup> However, we were surprised to find that caregivers after kidney transplantation reported a similarly high level of caregiving strain and that this strain was not correlated with time since transplantation. Because kidney transplantation eliminates the need for dialysis and improves QOL for most of its recipients, we expected the caregiving burden to be substantially lower in the months and years following transplantation. One possible explanation for the burden not being lower is that patients still have follow-up appointments, medical tests, rehospitalizations, medication regimens, and lifestyle modifications in the months after transplantation, all of which can affect perceived caregiving strain. Also, some caregivers after kidney transplantation may continue to provide caregiving assistance because the patient has other comorbid health problems that were not ameliorated by transplantation. Psychological distress, fatigue, sleep disturbances, and other similar problems are common for many kidney transplant recipients,<sup>28-30</sup> and these issues may increase caregiving strain as well.

Caregiver outcomes were not significantly correlated with sociodemographic characteristics. Caregiving strain, life satisfaction, mood, and social intimacy did not appear to vary with the caregiver's age, sex, or relationship duration. This result is somewhat surprising in light of previous findings that older and women caregivers tend to experience more strain than younger adults or men experience.<sup>7,11-13</sup> Our data trended toward more distress in older female caregivers, but our sample size was too small for such differences to reach statistical significance in the current study. Spouses who perceived the patient's physical health to be worse reported more mood disturbance and higher caregiving strain. Certainly, caregiving demands are likely to increase as the patient's physical health deteriorates and the need for more intense medical monitoring

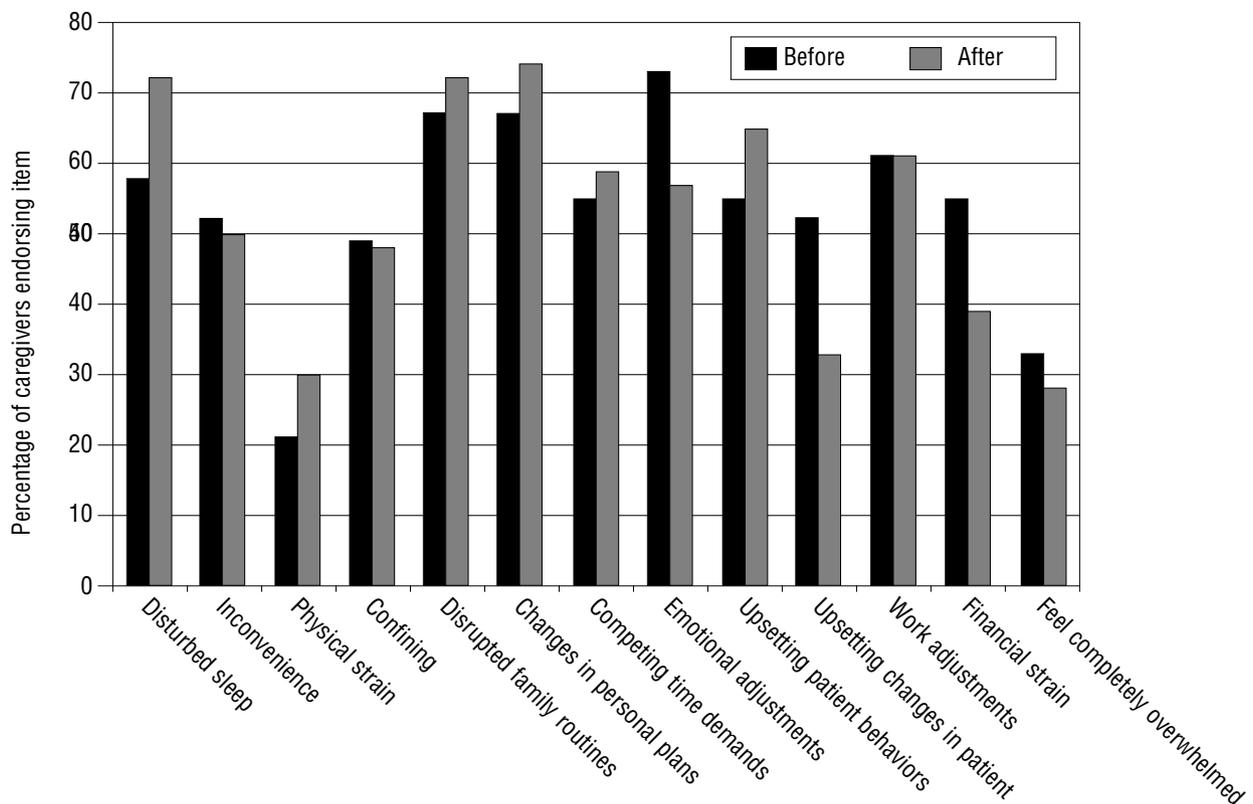


Figure Percentage of caregivers endorsing items on the Caregiver Strain Index before (n=33) and after (n=46) kidney transplantation.

increases. Indeed, consistent with other recent findings, we found that caregivers before transplantation whose spouses were receiving hemodialysis reported more distress than did caregivers whose spouses were not yet receiving renal replacement therapy. The need for hemodialysis indicates a significant decline in renal function and the dialysis schedule can be very disruptive to the family routines, work responsibilities, and leisure activities of both patients and their caregivers. The relationship between the patient's physical health status and caregiver adaptation warrants further investigation.

Most spouses of kidney transplant patients appear to be adjusting well to the complex and demanding caregiving role. It is especially noteworthy that many such caregivers report substantial benefit-finding in their caregiving activities, which may reflect an optimistic disposition and an adaptive psychological coping style. Such benefit-finding mirrors what we have found in other transplant caregivers, and we previously hypothesized that it may play an important role in attenuating the negative effects of transplant caregiving.<sup>19,25</sup> We recommend that any assessment of transplant caregivers' psychological adjustment and strain simultaneously consider whether caregiving has contributed to any positive outcomes for the spouse, including a closer relationship with the patient, receiving

assistance from family and friends, and personal or spiritual growth. Interventions developed for transplant caregivers also should consider how maximizing benefit-finding may improve mood, lower perceived stress, and enhance emotional closeness with the patient.

### Limitations

Study findings should be considered in the context of several important methodological limitations. First, a requirement of transplant listing at our center is that patients must have a stable support system. It is likely that our cohort from before kidney transplantation comprises caregivers with higher overall psychological functioning and solid relationships with the patient, relative to those caregivers whose spouses are not listed for transplant. Also, caregivers experiencing more psychological distress may have chosen not to participate in the study or may have underreported distress levels to avoid jeopardizing their spouse's listing status. Second, findings should not be generalized beyond the sociodemographic characteristics of this small sample. For instance, we enrolled relatively few minority caregivers, a subgroup that has higher levels of caregiving burden.<sup>31</sup> Third, the cross-sectional study design does not allow us to comment on how the caregiver outcomes change over time. One might expect caregiving strain and psychological distress to

increase as the patient's functional status and self-care abilities decline.

Finally, we did not gather data about the patients' medical status or psychological functioning, which may be important predictors of caregiver functioning. As we noted earlier, we are in the planning stages of a larger prospective study that will allow us to assess how caregiver functioning fluctuates throughout the transplant process (waiting before kidney transplantation, recovery after kidney transplantation, long-term survivorship) and the degree to which it is influenced by changes in the patient's physical and emotional well-being. Moreover, a longitudinal approach will enable us to examine specific causes of caregiver strain, which could yield practical recommendations for transplant programs on how to effectively assess and perhaps attenuate such strain.

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**CE Test** Test ID 4000-153: Spouse caregivers of kidney transplant patients: quality of life and psychosocial outcomes

**Learning objectives:** 1. Identify 3 benefits to kidney transplant recipients who have a high-quality support system throughout the transplant process  
 2. State the time frame in which caregiver strain is reported to be highest in the pretransplant phase  
 3. Explain 3 factors that may contribute to continued caregiver strain after kidney transplantation

**1. Factors that may be associated with a high level of caregiver strain after kidney transplantation include which of the following?**

- a. Complex medication regimens
- b. The transplant recipient's perceived need to attend support group meetings
- c. The transplant recipient's need to be free of oversight
- d. The transplant recipient's inability to let go of the sick role

**2. Other factors that have been reported to contribute to caregiver strain after kidney transplantation include which of the following?**

- a. The recipient's high energy levels
- b. The recipient's continuous complaints about nausea
- c. The recipient's sleep disturbances
- d. Fear of losing the transplanted organ

**3. Caregiver distress is reported to be highest before kidney transplant in which of the following instances?**

- a. The patient receives the call to go to the hospital for a transplant
- b. The patient is receiving hemodialysis
- c. The patient's potassium level rises to >6.2 mEq/L
- d. A living donor cannot be found

**4. Higher quality of support throughout the transplant process has been reported to be associated with which of the following outcomes?**

- a. Better psychological adjustment
- b. More adherence
- c. Longer survival
- d. All the above

**5. According to this study, caregiver strain was not significantly correlated with which of the following?**

- a. The patient's physical health
- b. Whether the patient received hemodialysis
- c. The caregiver's age
- d. Mental quality of life

**6. The intensity of caregiving across the transplant spectrum varies most on the basis of which of the following factors?**

- a. Length of time the patient and spouse were married
- b. Comorbid conditions
- c. Length of time since transplant
- d. The caregiver's age

**7. Research has shown that some caregivers develop a closer relationship with the patient during the transplant process and...**

- a. ...gain a different life perspective.
- b. ...find more meaning in community relationships.
- c. ...increase cognitive functioning.
- d. ...increase socialization with friends.

**8. The outcomes of research on caregiver burden provides transplant professionals with which of the following?**

- a. Data to understand the stress of the transplant recipient
- b. Data to educate caregivers on the range of demands that they may experience during the transplant process
- c. Data to help increase cognitive functioning
- d. Data on sleep disturbances in transplant recipients

**9. According to this study, transplant professionals may benefit from which of the following outcomes of research about caregiver burden?**

- a. Improved understanding about the long-term health of caregivers and recipients
- b. Improved understanding about patient and family relationships
- c. Understanding the impact of stress on outcomes of kidney transplant
- d. Understanding the impact of serving as a caregiver for transplant recipients

**10. Many spouses report substantial benefit-finding in their caregiving activities, which may reflect which of the following?**

- a. An increased sense of intimacy
- b. An adaptive psychological coping style
- c. An increased acceptance of the transplant process
- d. An improved long-term relationship with the recipient

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

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Test ID: 4000-153 Form expires: December 1, 2012 Contact hours: 1.0 ABTC CCTC Fee: NATCO members, \$0; nonmembers, \$35 Passing score: 7 correct (70%)

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