

# Quality of life and psychosocial functioning of spouse/partner caregivers before and after liver transplantation

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**Abstract:** Spouse/partner caregivers of liver transplant (LTx) patients play an important role both before and after transplantation. However, very little research has examined the quality of life (QOL), caregiving strain, and psychological functioning of these caregivers. In this study, we examined these outcomes and their correlates in 86 (49 pre-LTx, 38 post-LTx) spouse/partner caregivers. The physical QOL of caregivers was not impaired, and numerous caregiving benefits were identified (e.g., realizing what is important in life, discovering one's own inner strength, giving emotional support to the patient). However, a relatively high proportion of both pre-LTx and post-LTx caregivers had clinically low mental QOL (29% and 35%, respectively), low life satisfaction (45% and 32%, respectively), and high caregiving strain (59% and 81%, respectively). Both pre- and post-LTx caregivers, particularly women, had more total mood disturbance than a normative sample. Higher caregiving strain was significantly correlated with lower mental QOL, lower life satisfaction, and more mood disturbance. Overall, findings suggest that caregiving strain is prominent through the LTx spectrum. There is a need for prospective research to identify the patterns of caregiver outcomes over time and to examine the benefits of clinical interventions for caregivers.

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Most liver transplant (LTx) programs require patients to have an available and stable primary caregiver to assist them throughout the transplant process (1–3). Adults with end-stage liver disease experience dramatic changes in physical functioning, mental status, and cognitive abilities, which make it difficult to navigate the complex health care and transplant demands in isolation. Caregivers may assume some of the day-to-day activities that previously were the responsibility of the patient, closely monitor the patient's health status, ensure optimal adherence to medications and lifestyle modifications, communicate regularly with the transplant team, attend outpatient clinic appointments, advocate for the patient, and provide ongoing emotional support and encouragement (4).

While caregivers may be any adult with a close genetic or emotional relationship with the transplant patient, they most commonly are spouses

who reside with the patient. For these spouse caregivers, social and emotional isolation may occur because they increasingly are confined to their homes to care for the patient. The nature of the spousal relationship may change over time, which can lead to conflict, confusion, and interpersonal distancing. The transplant waiting period may precipitate depression, anxiety, fear, and anger for caregivers as they prepare for the possibility of the patient's death vs. a prolonged life after transplantation. Their own quality of life (QOL) may suffer, as they may sometimes neglect their own needs for the benefit of the patient. Also, the collective stress and strain of caregiving may compromise the patient's adaptation throughout the transplant process and may also affect post-transplant outcomes.

Considering the importance ascribed to the caregiving role by the transplant community, surprisingly few studies have examined caregiver

functioning in the context of LTx. Two studies have examined caregiving issues during the pre-LTx period. Bolckhir et al. (5) studied primary caregivers of 42 patients listed for liver or kidney transplantation and found that 19% had symptoms of clinical depression. However, they did not separately examine rates of depression in the LTx caregivers, of which only 55% were spouses. Meltzer and Rodrigue (6) studied 28 LTx caregivers (46% spouses) and found that they had higher levels of caregiver strain than kidney transplant caregivers and a normative comparison sample. Only one study has examined post-LTx caregiving stress. In a sample of 24 post-LTx caregivers (79% spouses) in Israel, Cohen et al. (7) found high rates of caregiving strain and relational deprivation, especially among female caregivers.

In addition to the paucity of data regarding transplant caregiver distress and quality of life, little is known about the potential unexpected benefits that might accrue to caregivers of transplant patients. There is some preliminary evidence that liver and lung transplant caregivers experience some benefits, including discovering inner strength, gaining new life perspective, and feeling wanted or needed (6). Such benefits may help to buffer feelings of caregiving stress and burden.

The current study addressed three primary aims: (i) to characterize the QOL, life satisfaction, mood, strain, and social intimacy of spouse/partner caregivers of LTx patients, (ii) to determine whether these outcomes differed in cross-sectional cohorts of pre- vs. post-LTx spouse/partner caregivers, and (iii) to examine the relationship among these different dimensions of caregiver functioning. Based on prior research, we hypothesized that spouse/partner caregivers would report less favorable scores on these outcome measures than available normative samples and that pre-LTx caregivers would have lower QOL and higher psychological stress than those in the post-LTx period. Information from this study will be useful in designing interventions to assist caregivers throughout the LTx process.

## Methods

### Participant recruitment

Study participants were recruited from Beth Israel Deaconess Medical Center (BIDMC) in Boston, Massachusetts (August 2007 to September 2008). To be eligible for the study, caregivers had to self-identify as the patient's primary caregiver and spouse, be at least 21 yr old, proficient in English, and provide informed consent. Also, the patient

must be either listed for LTx or a LTx recipient. Spouses were defined as those legally married or cohabitating partners, including same-sex relationships.

Two recruitment strategies were used. First, caregivers were approached in the Transplant Institute outpatient waiting room. Those who consented to study participation completed the questionnaires on-site. Second, as caregivers who attend clinic appointments may be more engaged in the caregiving process and may have a different experience than those who are unable to attend appointments regularly, we mailed letters to patients known by the transplant staff to have a spouse/partner caregiver. The letter provided patients with written materials about the study, and they were asked to give this information to their spouse. Caregivers who wanted to participate in the study completed a pre-printed participation form, mailed it back to the research team, and then completed the questionnaires by mail. All study procedures were approved by the Institution Review Board.

### Assessment protocol

*Quality of life (QOL).* The SF-36v2 Health Survey (SF-36) (8, 9) was used to measure QOL. The SF-36 is a generic health-related QOL measure that assesses self-perceptions of health across eight 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 higher QOL. In addition to the individual domain scores, the SF-36 yields two composite scores – Physical Component Summary (PCS) and Mental Component Summary (MCS).

*Life satisfaction.* The Quality of Life Inventory (QOLI) (10) comprises 32 statements reflecting 16 specific life domains empirically shown to reflect life satisfaction. The life domains include health, self-esteem, goals-and-values, money, work, play, learning, creativity, helping, love relationship, friendships, relationship with children, relationship with relatives, home, neighborhood, and community. Using a 3-point scale (0 = not important, 1 = important, 2 = extremely important), caregivers rated how important each of the life domains is to their overall happiness and then used a six-point scale (–3 = very dissatisfied to +3 = very satisfied) to rate how satisfied they are in each domain. A weighted life satisfaction rating is calculated for each domain, a total raw score is

determined from these ratings, and the total raw score is then converted to a standardized *T* score. Higher scores indicate a higher life satisfaction. The QOLI has good temporal stability (0.73 two-wk test-retest reliability), satisfactory internal consistency ( $\alpha = 0.79$ ), and good convergent validity (i.e., significantly correlated with other measures of life satisfaction and QOL) (10).

*Mood.* The Profile of Mood States-Short Form (POMS-SF) (11) was used to assess mood disturbance. Caregivers read descriptive adjectives and indicated on a five-point scale (0 = not at all to 4 = extremely) the extent to which they felt that way in the past week. Item scores were summed to yield a Total Mood Disturbance score and six factor scores: Tension–Anxiety, Depression–Dejection, Anger–Hostility, Vigor–Activity, Fatigue–Inertia, and Confusion–Bewilderment. With the exception of the Vigor–Activity score, higher scores indicate more mood disturbance.

*Caregiver strain and benefit.* The Caregiver Strain Index (CSI) (12) is a 13-item questionnaire designed to screen for caregiver burden in adult caregivers of medically compromised patients. Respondents indicate whether they have experienced any strain by responding “yes” or “no” to each item. It has been used with liver and kidney transplant caregivers (6), and it has shown good construct validity and internal consistency (12). Higher scores reflect more strain, and endorsement of seven or more items is indicative of clinically significant caregiver strain (12).

The Caregiver Benefit Index (CBI) was created to examine benefit-finding in transplant caregivers (6, 13). Respondents indicate (“yes” or “no”) whether they find benefit as a caregiver in 12 different areas. Higher scores indicate more perceived benefit. Questions focus predominantly on benefit derived from helping the patient, spending time with the patient, personal growth, and interpersonal benefit.

*Social intimacy.* The Miller Social Intimacy Scale (MSIS) (14) was used to assess caregiver’s perceptions of closeness in the spousal relationship. The MSIS yields scores on two intimacy subscales: Frequency (e.g., when you have leisure time how often do you choose to spend it with him/her?) and Intensity (e.g., how affectionate do you feel toward him/her?), as well as a Total Intimacy Score. Higher scores indicate greater intimacy. The MSIS has been used with transplant patients and caregivers and has shown good reliability and validity (13–15).

*Sociodemographic information.* In addition to completing questionnaires, caregivers provided the following information: age, gender, race, relationship duration, rating of patient’s health over past three months (1 = poor to 5 = excellent), illness duration (pre), and time since transplant (post).

#### Statistical analysis

Descriptive statistics were calculated to summarize sample characteristics and outcome measures. Scores on all outcome measures were compared to normative and comparison samples using *t*-tests. We used the normative data, drawn from the U.S. general population, for the SF-36 ( $n = 6742$ ) (9) and QOLI ( $n = 798$ ) (10), as well as data from other published studies (POMS, CSI, MSIS) (6, 13). Next, we calculated the proportion of caregivers with clinically significant scores on the outcome measures. Bivariate correlations were calculated to assess the associations between caregiver strain/benefit, emotional distress, QOL, social intimacy, and sociodemographic characteristics. *T*-tests were calculated to compare mean scores on the outcome measures between pre- and post-LTx caregivers. An *a priori* decision was made not to adjust for multiple comparisons (i.e., using Bonferroni correction or other alternative method) because this was a pilot study designed to identify potentially important and significant (clinically) variables for inclusion in a larger prospective study. Finally, we conducted logistic regression analyses to identify significant predictors of caregiving strain. Statistical significance was operationalized as a probability value of  $\leq 0.05$ . All analyses were conducted using SPSS 16.0 for Windows.

## Results

### Study enrollment

One hundred and eleven spouse/partner caregivers were either approached in the outpatient clinic or via mail; 104 provided verbal consent (94%) and 86 (49 pre-LTx, 37 post-LTx) completed the questionnaire battery (77%). Caregivers who did not complete the questionnaires after providing verbal consent cited insufficient time and scheduling conflicts as the primary reasons.

### Sample characteristics

Pre- and post-LTx caregiver characteristics are summarized in Table 1. These two caregiver cohorts did not differ significantly on any of the sociodemographic parameters. The majority of

Table 1. Sociodemographic characteristics of pre-LTx and post-LTx caregivers

	Pre-LT (n = 49)	Post-LT (n = 37)	p-value
Age, yr	55.2 ± 8.6	55.4 ± 8.9	0.91
Gender, female	37 (75.5%)	31 (83.8%)	0.43
Race			
White	47 (95.9%)	33 (89.2%)	0.24
Black	2 (4.1%)	2 (5.4%)	
Asian	0 (0.0%)	2 (5.4%)	
Relationship duration, yr	26.2 ± 13.4	26.0 ± 13.0	0.93
Rating of patient's health in past three months			
Poor	10 (20.4%)	5 (13.5%)	0.24
Fair	20 (40.8%)	9 (24.3%)	
Good	13 (26.5%)	15 (40.5%)	
Very good	6 (12.2%)	7 (18.9%)	
Excellent	0 (0.0%)	1 (2.7%)	
Illness duration, months.	32.8 ± 13.7		
Time since LTx, months.		25.9 ± 21.4	

caregivers were middle-aged ( $55.3 \pm 8.6$  yr, range = 34–79), women (79%), and white (93%). Pre-LTx patients had a mean illness duration of  $32.8 (\pm 13.7)$  months, and post-LTx patients had a mean time since transplant of  $25.9 (\pm 21.4)$  months.

## QOL

Relative to the SF-36 normative sample, pre-LTx caregivers had significantly lower Social Functioning ( $t = 2.30$ ,  $p = 0.02$ ), Role-Emotional ( $t = 2.33$ ,  $p = 0.03$ ), Mental Health ( $t = 3.27$ ,  $p = 0.001$ ), and Mental Component Summary ( $t = 3.54$ ,  $p < 0.001$ ) mean scores (Table 2). Using a score of  $\geq 1$  SD below the normative sample mean to define clinical significance, 12%

Table 2. SF-36 scaled and component scores for LTx caregivers in the study sample and for the SF-36 normative sample

	Pre-LTx caregivers (n = 49)	Post-LTx caregivers (n = 37)	Normative Sample (9) (n = 6742)
Physical functioning	50.2 ± 9.3	51.4 ± 7.8	50.0 ± 10.0
Role-physical	50.9 ± 8.7	50.2 ± 9.0	50.0 ± 10.0
Bodily pain	50.5 ± 10.1	52.5 ± 10.2	50.0 ± 10.0
General health	50.0 ± 11.1	51.2 ± 11.5	50.0 ± 10.0
Vitality	48.7 ± 11.8	50.0 ± 12.8	50.0 ± 10.0
Social functioning	46.7 ± 10.9*	47.8 ± 11.6	50.0 ± 10.0
Role-emotional	46.8 ± 13.5*	44.5 ± 12.7**	50.0 ± 10.0
Mental health	45.3 ± 13.2*	47.0 ± 13.3	50.0 ± 10.0
Physical component summary	52.2 ± 9.0	52.5 ± 8.7	50.0 ± 10.0
Mental component summary	44.9 ± 14.5*	44.9 ± 14.6**	50.0 ± 10.0

Data are expressed as mean ± SD.

Asterisk denotes statistically significant differences ( $p < 0.05$ ) between normative sample mean and either pre-LTx mean (\*) or post-LTx mean (\*\*).

( $n = 6$ ) and 29% ( $n = 14$ ) had clinically low physical and mental health QOL, respectively.

Post-LTx caregivers' mean scores on the SF-36 were significantly lower than those of the normative sample for Role-Emotional ( $t = 3.33$ ,  $p = 0.001$ ) and Mental Component Summary ( $t = 3.08$ ,  $p = 0.002$ ). Eleven percent ( $n = 4$ ) and 35% ( $n = 13$ ) had clinically low physical and mental health QOL, respectively.

Pre- and post-LTx caregivers did not differ significantly from each other on any of the SF-36 scores (all  $p$  values  $> 0.05$ ). Overall, QOL scores were not associated with sociodemographic characteristics, although a higher (more favorable) caregiver rating of the patient's health in the past three months was associated with a higher (better) SF-36 Mental Component Summary score ( $r = 0.41$ ,  $p < 0.0001$ ).

## Life satisfaction

Overall life satisfaction classifications based on responses to the QOLI are presented in Table 3 (10). The majority of pre-LTx (27, 55%) and post-LTx (25, 68%) caregivers reported Average or High life satisfaction. However, 22 (45%) pre-LTx and 12 (32%) post-LTx caregivers reported Low or Very Low life satisfaction, respectively. Caregivers reported more dissatisfaction in the Money (33% pre-LTx, 41% post-LTx), Health (29% pre-LTx, 19% post-LTx), and Play (27% pre-LTx, 24% post-LTx) domains (Table 4).

Pre- and post-LTx caregivers did not differ significantly from each other on their overall life satisfaction classification ( $\chi^2 = 3.06$ ,  $p = 0.38$ ) or on any of the weighted life satisfaction domain scores (all  $p$  values  $> 0.05$ ). Overall, a higher total life satisfaction score was associated with older age ( $r = 0.28$ ,  $p = 0.009$ ) and a more favorable rating of the patient's health ( $r = 0.25$ ,  $p = 0.02$ ). For

Table 3. Overall life satisfaction classifications based on QOLI overall  $t$  score

	Pre-LTx caregivers (n = 49)	Post-LTx caregivers (n = 37)
Life satisfaction classification		
High	4 (8.2%)	7 (18.9%)
Average	23 (46.9%)	18 (48.7%)
Low	15 (30.6%)	7 (18.9%)
Very Low	7 (14.3%)	5 (13.5%)

Data are expressed as N (%).

$t$ -score cutoffs as published in Frisch (10).

QOLI, Quality of Life Inventory.

Table 4. Weighted life satisfaction ratings for each domain on the QOLI (and the proportion reporting dissatisfaction in this life domain)

Life satisfaction domain	Pre-LTx caregivers (n = 49)	Post-LTx caregivers (n = 37)
Health	1.76 ± 3.3 (29%)	2.08 ± 3.7 (19%)
Self-esteem	2.59 ± 2.6 (15%)	2.30 ± 3.8 (16%)
Goals-and-values	2.65 ± 2.6 (14%)	2.68 ± 2.8 (14%)
Money	0.69 ± 2.2 (33%)	0.32 ± 2.6 (41%)
Work	1.92 ± 2.2 (10%)	2.32 ± 2.7 (17%)
Play	1.04 ± 2.3 (27%)	1.62 ± 2.7 (24%)
Learning	2.75 ± 1.9 (6%)	2.51 ± 2.1 (11%)
Creativity	1.82 ± 2.0 (12%)	2.08 ± 2.0 (6%)
Helping	2.22 ± 1.9 (6%)	2.41 ± 3.1 (12%)
Love	2.88 ± 4.0 (21%)	3.41 ± 3.5 (14%)
Friends	2.96 ± 2.5 (5%)	3.51 ± 2.5 (8%)
Children	4.49 ± 2.2 (2%)	4.08 ± 3.0 (9%)
Relatives	3.67 ± 2.4 (7%)	3.08 ± 2.9 (11%)
Home	3.47 ± 2.5 (8%)	3.13 ± 3.0 (14%)
Neighborhood	3.67 ± 2.2 (4%)	2.92 ± 2.1 (3%)
Community	3.43 ± 2.1 (2%)	2.86 ± 1.9 (6%)

Data are expressed as Mean ± SD (% reporting dissatisfaction). QOLI, Quality of Life Inventory.

post-LTx caregivers, higher life satisfaction also was correlated with longer time since LTx ( $r = 0.42, p = 0.01$ ).

Mood

Relative to the normative sample, both pre-LTx and post-LTx caregivers had higher mean scores on the Depression–Dejection ( $t = 7.18, p < 0.0001$  and  $t = 4.82, p < 0.0001$ ), Anger–Hostility ( $t = 5.27, p < 0.0001$  and  $t = 2.40, p = 0.02$ ), and Fatigue–Inertia ( $t = 5.32, p < 0.0001$  and  $t = 2.75, p = 0.006$ ) scales of the POMS-SF (Table 5). Pre-LTx caregivers also had higher Tension–Anxiety ( $t = 5.1, p < 0.0001$ ) than the normative sample and more Anger–Hostility than a sample of bone marrow transplant

caregivers ( $t = 2.09, p = 0.04$ ). Post-LTx caregivers had higher Vigor–Activity ( $t = 2.03, p = 0.04$ ) than the normative sample and lower Tension–Anxiety scores than bone marrow transplant caregivers ( $t = 2.59, p = 0.012$ ).

Comparisons between pre- and post-LTx caregivers showed that pre-LTx caregivers had higher Tension–Anxiety ( $t = 3.44, p = 0.001$ ), while post-LTx caregivers had higher Vigor–Activity ( $t = 2.08, p = 0.04$ ). Overall, women ( $18.74 ± 16.6$ ) had higher Total Mood Disturbance scores than men ( $9.03 ± 10.5$ ),  $t = 2.35, p = 0.02$ . Higher Total Mood Disturbance scores were correlated with caregivers’ perceptions of poorer patient health ( $r = -0.28, p = 0.009$ ).

Caregiver strain and benefit

Mean total CSI scores were  $7.00 ± 3.9$  and  $7.89 ± 3.0$  for pre-LTx and post-LTx caregivers, respectively. These mean scores are at or above the clinical cutoff indicative of high caregiving strain (i.e., endorsement of ≥ seven items). Using this clinical cutoff score, 29 (59%) pre-LTx and 30 (81%) post-LTx caregivers were classified as having high caregiving strain. As noted in Fig. 1, the most common types of strain were having to make emotional adjustments, disturbed sleep, changes in personal plans, finding certain patient illness behaviors to be upsetting, and competing time demands. There were no significant differences between the pre- and post-LTx caregivers on the total caregiving strain score or individual strain items (all  $p$  values  $> 0.05$ ). Overall, more caregiving strain was associated with shorter relationship duration ( $r = -0.24, p = 0.3$ ) and less favorable ratings of the patient’s health ( $r = -0.31, p = 0.004$ ). Also, higher post-LTx caregiving strain was related to shorter time since transplantation ( $r = -0.42, p = 0.01$ ). The mean CSI score of caregivers in the first year following

Table 5. Profile of Mood States (POMS) means and standard deviations of pre- and post-LTx caregivers compared to those of published bone marrow transplant caregivers and a normative sample [Corrections made after online publication 23 February 2010]

	Pre-LTx caregivers (n = 49)	Post-LTx caregivers (n = 37)	Bone marrow transplant caregivers (n = 39) (16)	Normative sample (n = 1005) (11)
Tension–Anxiety	8.08 ± 4.3 <sup>a</sup>	4.86 ± 4.3 <sup>b</sup>	7.60 ± 4.9 <sup>a</sup>	4.30 ± 5.1 <sup>b</sup>
Depression–Dejection	7.90 ± 3.8 <sup>a</sup>	6.78 ± 4.3 <sup>a</sup>	8.81 ± 4.9 <sup>a</sup>	3.00 ± 4.7 <sup>b</sup>
Anger–Hostility	6.33 ± 4.0 <sup>a</sup>	4.78 ± 3.6 <sup>ab</sup>	4.50 ± 4.2 <sup>b</sup>	3.10 ± 4.2 <sup>c</sup>
Vigor–Activity	7.43 ± 4.4 <sup>a</sup>	9.57 ± 5.1 <sup>b</sup>	7.84 ± 4.1 <sup>ab</sup>	7.90 ± 4.9 <sup>a</sup>
Fatigue–Inertia	9.90 ± 5.5 <sup>a</sup>	8.05 ± 4.6 <sup>a</sup>	8.07 ± 5.9 <sup>a</sup>	5.40 ± 5.8 <sup>b</sup>
Confusion–Bewilderment	5.51 ± 2.6	4.51 ± 2.7	5.84 ± 4.0	4.50 ± 4.2
Total mood disturbance	28.47 ± 18.5	21.95 ± 18.1	23.84 ± 21.9	

Data are expressed as mean ± SD. In each row, values without a matching superscript differ significantly from each other ( $p < 0.05$ ). QOLI, Quality of Life Inventory.

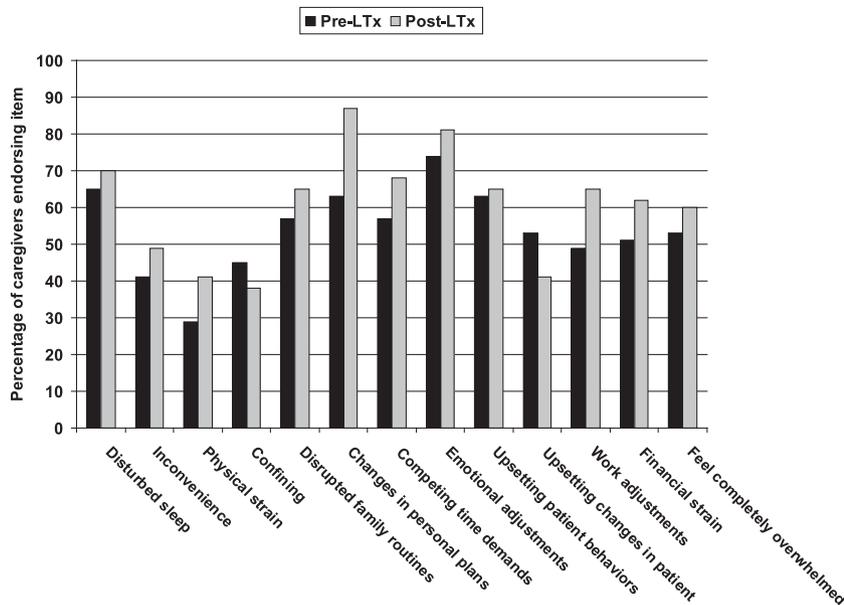


Fig. 1. Percentage of pre-LTx (n = 49) and post-LTx (n = 37) endorsing items on the Caregiver Strain Index.

transplantation ( $10.18 \pm 1.7$ ) was significantly higher than the mean score for those who were in the second post-operative year ( $7.33 \pm 2.8$ ) or beyond ( $6.36 \pm 2.2$ ) ( $F = 6.25$ ,  $p = 0.005$ ).

Mean total CBI scores were  $8.30 \pm 2.5$  and  $9.63 \pm 1.7$  for pre-LTx and post-LTx caregivers, respectively ( $t = 2.78$ ,  $p = 0.007$ ). The most commonly identified caregiving benefits were realizing what is important in life, giving emotional support to the patient, discovering one's own inner strength, and finding a new appreciation for the patient and what she/he is going through (Fig. 2).

#### Social intimacy

Both pre-LTx ( $70.94 \pm 10.9$ ) and post-LTx ( $72.73 \pm 8.2$ ) caregivers reported moderate levels of total social intimacy as measured by the MSIS ( $t = 1.30$ ,  $p = 0.20$ ). Social intimacy was associated with caregiver gender. Pre- and post-LTx female caregivers reported higher levels of both Frequency and Intensity, indicative of more favorable perceptions of social intimacy with the patient (all  $p$ s < 0.04).

#### Relationship between QOL, life satisfaction, mood, social intimacy, and caregiver strain/benefit

Table 6 shows the correlation matrix for the different outcome measures. Pre- and post-LTx caregivers were combined as few differences were identified on any of the measures. Higher caregiving strain was significantly correlated with lower mental quality of life, lower life satisfaction, and more mood disturbance. Higher caregiving benefit

and more life satisfaction were significantly associated with more social intimacy with the patient.

#### Discussion

Despite their importance in the transplant selection process and in optimizing post-transplant health outcomes, LTx caregivers have been the focus of very little empirical attention. This is the first study to simultaneously examine psychosocial outcomes and their correlates in a cross-sectional cohort of pre- and post-LTx spouse/partner caregivers. Overall, results suggest that caring for an adult both before and after LTx may have a negative impact on some aspects of the caregiver's QOL, life satisfaction, and mood. While the strain of caregiving is high, we also found some caregiving benefits that have implications for the provision of clinical services to LTx caregivers.

Adults typically assume many different roles in their lives (e.g., spouse, parent, and worker), and being a caregiver to someone waiting for or recovering from LTx represents an additional, perhaps unanticipated, role. For many caregivers, this responsibility may necessitate rearranging priorities, shifting roles and responsibilities, and redirecting emotional and physical energy. Clinically, the transplant community has long recognized that the frequency and intensity of caregiving activities may negatively impact the psychological health of some caregivers. Indeed, the majority of caregivers in our study reported that they had to alter personal plans, make work adjustments, and cope with frequent disruptions to family routines because of caregiving demands, and these stressors

Table 6. Correlation coefficient matrix showing the relationships between each of the study outcome measures (N = 86)

	SF-36 PCS	SF-36 MCS	QOLI	POMS	CSI	CBI	MSIS
Physical quality of life (SF-36 PCS)		-0.08 p = 0.49	0.30 p = 0.006	-0.20 p = 0.07	0.08 p = 0.47	-0.05 p = 0.65	-0.13 p = 0.25
Mental quality of life (SF-36 MCS)	-0.08 p = 0.49		0.38 p < 0.001	-0.75 p < 0.001	-0.47 p < 0.001	0.17 p = 0.12	0.27 p = 0.01
Total life satisfaction (QOLI)	0.30 p = 0.006	0.38 p < 0.001		-0.38 p < 0.001	-0.25 p = 0.02	0.12 p = 0.27	0.31 p = 0.004
Total mood disturbance (POMS)	-0.20 p = 0.07	-0.75 p < 0.001	-0.38 p < 0.001		0.37 p < 0.001	-0.20 p = 0.07	-0.10 p = 0.37
Caregiving strain (CSI)	0.08 p = 0.47	-0.47 p < 0.001	-0.25 p = 0.02	0.37 p < 0.001		-0.07 p = 0.51	-0.20 p = 0.06
Caregiving benefit (CBI)	-0.05 p = 0.65	0.17 p = 0.12	0.12 p = 0.27	-0.20 p = 0.07	-0.07 p = 0.51		0.42 p < 0.001
Total social intimacy (MSIS)	-0.13 p = 0.25	0.27 p = 0.01	0.31 p = 0.004	-0.10 p = 0.37	-0.20 p = 0.06	0.42 p < 0.001	

CBI, Caregiver Benefit Index; CSI, Caregiver Strain Index; MCS, Mental Component Summary; MSIS, Miller Social Intimacy Scale; PCS, Physical Component Summary; POMS, Profile of Mood States; QOLI, Quality of Life Inventory.

were associated with more mood disturbance, lower life satisfaction, and less social intimacy with the patient. These findings are similar to those reported in other transplant caregiver studies (5–7, 13, 16, 17).

Transplant programs often direct resources toward assisting pre-LTx caregivers in acclimating to the caregiving role and to enact the myriad associated tasks and responsibilities. This includes navigating the complexities of the patient’s physical health symptoms and treatments, the extensive transplant evaluation and monitoring processes, numerous outpatient clinic appointments, medication management, hospitalizations, and the psychological stress of uncertainty and fear. However, caregivers (and perhaps transplant staff) may expect LTx to eventually result in disengagement

from the caregiving role. Our data, however, suggest that caregiving strain and mood disturbances are just as prominent in the months and years after LTx as they were during the pre-LTx waiting period. While the restructuring of caregiving responsibilities may occur over time, the post-LTx onset of new health conditions (e.g., diabetes, malignancy), disease recurrence (e.g., hepatitis C), multiple outpatient appointments, and lifelong immunosuppression medication management may necessitate that the caregiver remain engaged for a longer time than anticipated. We found that caregiving strain was highest for those caregivers in the first year following LTx. However, it is important to emphasize that the caregiving strain of post-LTx caregivers who were beyond the first post-operative year mirrored those reported by

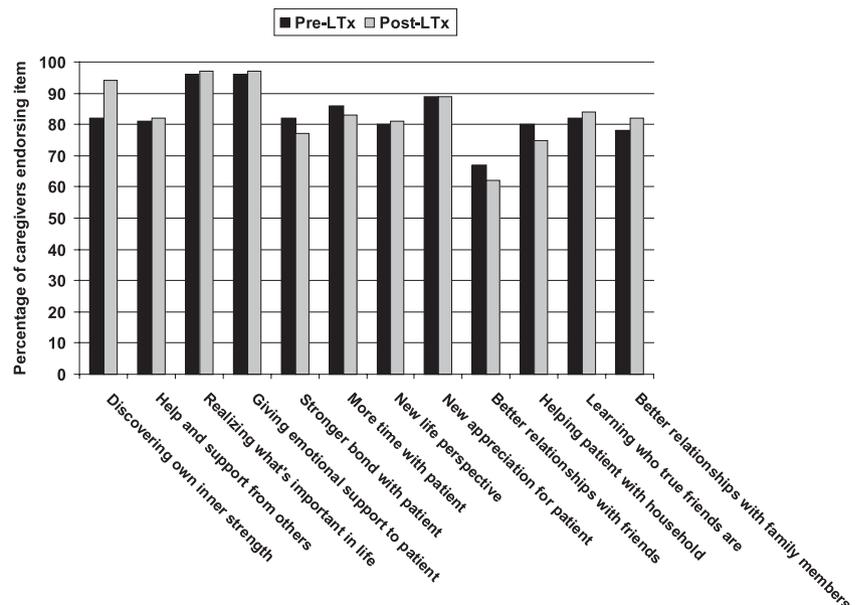


Fig. 2. Percentage of pre-LTx (n = 49) and post-LTx (n = 37) endorsing items on the Caregiver Benefit Index.

pre-LTx caregivers. Educating caregivers about the long-term nature of the caregiving responsibilities is important, as the burden and strain of this role may have lasting consequences for some caregivers and, possibly, some of the patients for whom they provide care.

Interestingly, we found that financial strain was higher in caregivers who were post- (61%) vs. pre- (51%) LTx, although this difference did not reach statistical significance. This was an unexpected finding because most of our LTx patients have the same insurance pre- and post-transplant and because Massachusetts requires all citizens to carry (and document) health insurance coverage. This finding mirrors the high financial stress reported by parents of pediatric transplant recipients (18) and by adult transplant recipients (19). Mothers of children undergoing transplantation reported more financial strain at one- and six-month post-transplant than during their pre-transplant evaluation (18). In a more recent study, Rodrigue et al. (19) found that 43% of LTx recipients felt that health problems related to transplantation caused financial problems for themselves personally or for their families. Also, half (51.2%) of LTx recipients reported less monthly income after transplant, relative to the year preceding transplant, and many patients used credit cards, personal savings, and investment accounts to pay for these unexpected post-LTx expenses. In general, transplant programs may underestimate the financial impact of chronic liver disease and eventual transplantation on families. Considerable resources are available to assist families through the pre-LTx process (e.g., transplant financial coordinators, social workers, and various private foundations), but some of our study participants noted that such resources are absent or less available in the months and years after LTx. The financial strain on families warrants further careful examination.

Study findings indicate that the caregiver's perceptions of the patient's physical health are important to consider when assessing caregiver functioning. Caregivers who perceived the patient's health to be poor were more likely to have lower mental QOL, lower life satisfaction, more mood disturbance, and higher caregiving strain. For pre-LTx caregivers, negative psychological outcomes may reflect, in part, the increased demands of caring for a patient who has worsening symptoms of end-stage liver disease, including encephalopathy, severe fatigue, sleep disturbances, and new activity restrictions (e.g., revocation of driver's license). Post-LTx caregiver functioning may be affected by transplant complications, disease recurrence, the patient's slower than expected recovery

of his or her pre-morbid level of functioning, or the cumulative effect of long-term care provision. In addition, prior research has shown that transplant caregivers have worse QOL outcomes when patients have fewer adaptive coping strategies, psychological distress, and worse QOL (20–22). Collectively, these findings underscore the potentially important association between patient (health status, coping resources, psychological status) and caregiver outcomes, and these should be evaluated in future prospective studies.

Importantly, we found that the overall physical QOL of caregivers was comparable to normative samples, and this finding is consistent with studies involving other transplant caregivers (6, 20, 23). Additionally, caregivers reported several benefits associated with this acquired role, including discovering one's own inner strength, a closer emotional connection to the patient, and strengthening relationship with others, among others. It is possible that those reporting many caregiving benefits are searching for justification for the considerable stress and strain they experienced while providing care for another person (i.e., cognitive dissonance theory) (24). Nevertheless, the identification of benefits in adversity and making meaning of challenging circumstances may be what sustains caregivers over the long haul of chronic liver disease, transplant waiting, and transplant survival. Cohen et al. (7) found that a higher sense of personal gain was associated with less depression in a small sample of LTx caregivers. Furthermore, we found that caregivers who perceived more benefits of caregiving had higher levels of social intimacy with the patient. These findings highlight the potential role that benefit-finding can play in attenuating the negative effects of caregiving. Interventions should include strategies that target not only the amelioration of caregiving distress but the maximization of caregiving benefits.

Future research is needed to identify why some caregivers appear less affected by caregiving demands, while others experience predominantly negative physical and psychological consequences. Perhaps the negative effects of caregiving are buffered by the availability and stability of an extended support network, one that can provide the caregiver with practical assistance, respite, and emotional support. As noted previously, benefit-finding also may mitigate against caregiving stress and burnout. Socioeconomic status and more financial resources also may attenuate the deleterious effects of caregiving, as has been shown by others (25). Caregivers with their own health care needs or who are also providing care to other family members (e.g., young children, elderly

parent) may be at higher risk for compromised psychological outcomes. These potential mediating variables warrant further investigation.

Some caution should be exercised when interpreting findings from this study, in light of a few methodological limitations. First, we used a cross-sectional design involving separate cohorts of pre- and post-LTx caregivers. Our pilot data, as well as those published by others, highlight the need for a prospective study in which changes in caregiver strain and psychological functioning can be evaluated over time. We are planning a multi-center, longitudinal evaluation of caregiver physical and mental health, although results will not be available for quite some time. Second, despite the reasonably good participation rate, our sample was relatively small and from a single transplant center, which limits the degree to which study findings can be generalized. Third, there is the possibility of a self-selection bias, in which caregivers who chose to participate in the study experienced more distress than those who did not take part, which would skew the data toward negative outcomes. Finally, we did not collect any data from the LTx patient. Future research should include information about the patient's physical and psychological health and their contributions to caregiving outcomes.

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### Conflicts of interest

There are no conflicts of interest to report.

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