

# Waiting for lung transplantation: quality of life, mood, caregiving strain and benefit, and social intimacy of spouses

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**Abstract:** Background: The emotional and physical well-being of lung transplant patients is enhanced by the availability and stability of a primary caregiver.

**Methods:** We describe the quality of life (QOL), mood, caregiving strain and benefits, and social intimacy of 73 lung transplant caregivers who completed the QOL Inventory, SF-36 Health Survey, Profile of Mood States, Caregiver Strain Index, Caregiver Benefit Index, and Miller Social Intimacy Scale.

**Results:** Clinically low QOL was reported by 17.8–35.6% of spouses. Relative to a normative sample, spouses reported significantly lower physical ( $z = 4.01$ ,  $p < 0.001$ ) and emotional ( $z = 7.01$ ,  $p < 0.001$ ) QOL. Over half (56.2%) had clinically elevated caregiving strain. Heightened physical strain (80.8%), inconvenience (79.5%), feeling confined (72.6%), feeling upset that patient has changed so much (69.9%) contributed most to caregiver strain, while discovering inner strength (60.3%), support from others (53.4%), and realizing what is important in life (42.5%) were noted caregiving benefits. Higher caregiving strain was associated with more mood disturbance ( $r = 0.42$ ,  $p < 0.001$ ), lower emotional QOL ( $r = -0.39$ ,  $p < 0.002$ ), lower social intimacy ( $r = -0.37$ ,  $p < 0.002$ ), and longer disease duration ( $r = 0.55$ ,  $p < 0.001$ ).

**Conclusion:** Spouses of patients awaiting lung transplantation may experience QOL deficits and high caregiver strain. Interventions to improve QOL and reduce caregiver strain are needed.

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\*For purposes of this study, spouses were defined as those individuals who self-identified as being in a legal marriage, common law marriage, or same-sex union.

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It is generally thought that the emotional and physical well-being of the transplant patient is enhanced by the availability and stability of a primary caregiver, usually the spouse or significant other. Caregivers 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 compliance with medications and lifestyle changes, communicate regularly with the transplant team, advocate for the patient, provide transportation to and from clinic visits, and provide ongoing emotional support to the patient, among other responsibilities. Consequently,

many transplant programs require that a full-time caregiver be available both prior to and in the months following transplantation (1, 2).

In caring for patients with end-stage pulmonary disease, caregivers may have to assume new roles and responsibilities, perhaps to the neglect of their own personal needs (3). Social and emotional isolation may occur as caregivers increasingly are confined to their homes to care for the patient (4). The nature of the patient–caregiver relationship may also change, which can lead to conflict, confusion, and interpersonal distancing (2, 3). The transplant waiting period may contribute to

heightened feelings of anxiety, depression, fear, and anger for caregivers, as well as compromised quality of life (QOL), as they prepare for the possibility of the patient's death vs. a prolonged life with a transplant (3–6). Heightened fatigued, mood instability, physical health problems, and relationship strain among caregivers may compromise the patient's adaptation throughout the transplant process and may also affect post-transplant outcomes.

Surprisingly, few studies have examined caregiver functioning in the setting of lung transplantation (4–8). In addition to the paucity of data regarding caregiver distress and QOL, little is known about the potential unexpected benefits that caregivers might experience during the pre-transplant phase. In an earlier study, we found that some caregivers of lung and liver transplant patients experienced benefits, including discovering inner strength, gaining new life perspective, and feeling wanted or needed (4). It is possible that finding benefit in caregiving may help to buffer feelings of caregiver stress and burden. Additional information about caregiver QOL, emotional distress, caregiver burden and benefits, and social intimacy could be useful in designing interventions to assist caregivers during the transplant waiting period.

The aims of this paper are fourfold. First, we describe the QOL, mood, caregiver strain and benefits, and social intimacy of spouses of adult patients awaiting lung transplantation. Second, we describe the proportion of spouses with low QOL, mood disturbance, and caregiver strain. Third, we examine whether the functioning of spouses differs significantly from that of published normative samples. Finally, we examine the relationships between spouse functioning, demographic characteristics, and the duration of the patient's illness.

## Patients and methods

### Participants and recruitment

All spouses\* of adult patients approved and wait-listed for lung transplantation between January 2003 and December 2004 were invited to participate in the study. They were contacted either in person during a transplant clinic appointment or by mail with a letter describing the purpose and nature of the study. Inclusion criteria were: spouse, identified primary caregiver of the patient, at least 18 yr old, resided with patient for at least 12 months subsequent to diagnosis of primary disease, ability to understand written and spoken English, and residential telephone service. Spouses completed study questionnaires

during the patient's routine transplant clinic appointment (56%), by mail (18%), or by telephone (26%). The University of Florida Institutional Review Board approved all study procedures.

### Measures

Spouses completed five questionnaires designed to measure QOL, mood disturbance, caregiver strain and benefit, and social intimacy. The QOL Inventory (9) (QOLI;  $\alpha = .83$  for study sample) includes 32 statements reflecting 16 domains of life to which respondents rate their relative importance and satisfaction. Domains include health, self-esteem, goals-and-values, money, work, play, learning, creativity, helping, love relationship, friendships, relationships with children, relationships with relatives, home, neighborhood, and community. Spouses use 3-point scales (0 = not important, 1 = important, 2 = extremely important) to rate how important each domain is to overall happiness and then use 6-point scales (–3 = very dissatisfied to +3 = very satisfied) to rate how satisfied they are with each area. A weighted 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 QOL. On the QOLI, the recommended cutoff for designating a low QOL is a raw score below 1.6 (9). The QOLI has good temporal stability (0.73 two-wk test-retest reliability), satisfactory internal consistency ( $\alpha = 0.79$  from standardization sample), good convergent validity (i.e., significantly correlated with other measures of life satisfaction and quality of well-being), and sensitivity to clinical treatment (9).

The SF-36 Health Survey (10) was also administered. The SF-36, which is widely used in transplantation, measures perceptions of general health-related QOL across several domains of physical and mental functioning, and it has repeatedly been shown to be very reliable and valid. In addition to several subscales, the SF-36 yields two summary scores – Physical Component Score (PCS;  $\alpha = 0.92$  from standardization sample) and Mental Component Score (MCS;  $\alpha = 0.89$  from standardization sample) (11).

The Profile of Mood States (12) (POMS;  $\alpha = 0.75$ – $0.89$  for study sample) includes self-descriptive adjectives to which respondents indicate (0 = not at all to 4 = extremely) the extent to which they have felt that way in the past week. The POMS yields a Total Mood Disturbance score and

six factor scores: Tension–Anxiety, Depression–Dejection, Anger–Hostility, Vigor–Activity, Fatigue–Inertia, and Confusion–Bewilderment. Higher scores indicate more mood disturbance. The POMS has good temporal stability (0.65–0.74 three-wk test–retest reliability), excellent internal consistency, good convergent validity with other measures of psychological distress, and sensitivity to change associated with psychotherapy (13, 14).

The Caregiver Strain Index (15) (CSI;  $\alpha = 0.87$  for study sample) measures the degree of strain felt by spouses in 13 areas. Respondents indicate whether they have experienced any strain by responding “yes” or “no” to each item. Research has shown that endorsement of seven or more items is indicative of clinically significant caregiver strain (15). The CSI has been shown to have excellent internal consistency and to be associated with caregiver physical and mental health (4, 15).

The Caregiver Benefit Index (CBI;  $\alpha = 0.80$  for study sample) was constructed for this study based on findings from one of our previous studies of transplant caregivers (4). Respondents were asked to indicate (“yes” or “no”) whether they find benefit as a caregiver in 12 different areas. These questions focused predominantly on benefit derived from helping the patient, spending time with the patient, personal growth, and interpersonal benefit.

Finally, the Miller Social Intimacy Scale (16) (MSIS;  $\alpha = 0.82$  for study sample) was used to assess perceived closeness between the spouse participants and the transplant patient. 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. Excellent test–retest reliability coefficients have been reported for two-month (0.96) and one-month (0.84) intervals, there is good evidence that the measure discriminates close from casual friends and happily married from distressed couples, and the MSIS can detect clinically meaningful change following psychological treatment (13, 16).

#### Statistical analysis

First, descriptive statistics were calculated to summarize the sociodemographic characteristics of the sample and the outcome measures. Second, the proportion of spouses with clinically significant scores on the outcome measures (QOL, caregiver strain) was calculated. Third, we calculated the proportion of spouses endorsing each of

the 13 CSI items to examine the nature of caregiver burden, as well as each of the 12 CBI items to assess perceived caregiving benefit. Fourth, QOL scores (QOLI raw score, SF-36 PCS, SF-36 MCS) were compared to a normative comparison sample using one sample *z*-tests. Fifth, bivariate correlations were calculated to assess the associations between caregiver strain/benefit and emotional distress. Finally, we used *t*-tests and correlation coefficients to determine whether spouse functioning varied as a function of gender or disease duration, respectively. The significance level was set at  $p < 0.05$  for all analyses. The SPSS for Windows statistical software package (Version 12.0; SPSS; Chicago, IL, USA) was used for all data analyses.

## Results

### Sociodemographic characteristics

Ninety-eight spouses were contacted for study participation, 86 consented to study participation (74% participation rate), and 73 completed all study questionnaires (15% drop-out rate). Sociodemographic characteristics are reported in Table 1. Spouses were predominantly White, high school graduates, and employed. There was relatively equal gender representation. The most common patient diagnosis was chronic obstructive pulmonary disease (COPD), with an average of six yr since initial diagnosis and nearly one yr on the transplant waiting list.

### QOL and caregiver strain: clinical elevations

Table 2 presents the means and standard deviations of the dependent measures. In our sample,

Table 1. Sociodemographic characteristics (n = 73)

Characteristic	
Age, years	48.3 ± 11.2
Sex, female	39 (53.4)
Race, white	66 (90.4)
Education, years	11.8 ± 2.6
Employed	45 (61.6)
Transplant candidate diagnosis	
COPD/emphysema	35 (48.0)
Pulmonary fibrosis	12 (16.4)
Alpha-1 antitrypsin deficiency	12 (16.4)
Cystic fibrosis	9 (12.3)
Other diagnoses	5 (6.9)
Disease duration, months	76.8 ± 45.5
Time on waiting list, days	362.7 ± 243.2

COPD, chronic obstructive pulmonary disease.  
Data are presented as mean ± SD or n (%).

Table 2. Spouse scores on dependent measures

Dependent measure	Mean ± SD
QOLI raw score	1.8 ± 1.2
SF-36 physical component summary	45.3 ± 9.6
SF-36 mental component summary	41.8 ± 10.3
POMS total mood disturbance	26.7 ± 9.2
CSI total score	6.8 ± 3.1
CBI total score	3.7 ± 2.0
MSIS total intimacy score	55.2 ± 17.2

QOLI, quality of life inventory; SF-36, SF-36 Health Survey; POMS, profile of mood states; CSI, Caregiver Strain Index; CBI, Caregiver Benefit Index; MSIS, Miller Social Intimacy Scale.

26 (35.6%) spouses had clinically low levels of life quality and satisfaction, as measured by the QOLI. Regarding caregiver strain, 41 (56.2%) spouses reported clinically significant levels of strain (score ≥7).

Nature of caregiver strain and benefit

Nine of 13 CSI items were endorsed by a majority of spouses (Table 3). Caregiver strain was especially prominent in the following areas: physical strain (80.8%), inconvenience (79.5%), feeling confined (72.6%), and upsetting to find that patient has changed so much (69.9%). Most spouses also reported difficulty with sleep, disrupted routines, patient behavior, feeling overwhelmed, and finances.

Two of 11 CBI items were endorsed by a majority of spouses (Table 4). Caregiver benefit most often occurred in the following areas: discovering inner strength (60.3%), support from others (53.4%), realizing what is important in life (42.5%), and giving emotional support to the

Table 3. Number (%) of spouses endorsing Caregiver Strain Index (CSI) item

CSI item	n (%)
It is a physical strain to care for the patient	59 (80.8)
It is inconvenient	58 (79.5)
It is confining	53 (72.6)
It is upsetting to find the patient has changed so much from former self	51 (69.9)
Some of the patient's behavior is upsetting to me	47 (64.4)
Sleep is disturbed	46 (63.0)
Adjustments in the family have been made because of disrupted routines	45 (61.6)
I have felt completely overwhelmed	41 (56.2)
It is a financial strain	37 (50.7)
I have had other demands on my time	36 (49.3)
I have had to make emotional adjustments	36 (49.3)
I have had to make work adjustments	33 (45.2)
I have made changes in personal plans	31 (42.5)

Table 4. Number (%) of spouses endorsing Caregiver Benefit Index (CBI) item

CBI item	n (%)
Discovering my own inner strength	44 (60.3)
Getting help and support from others	39 (53.4)
Realizing what is important in life	31 (42.5)
Giving emotional support to the patient	30 (41.1)
Stronger emotional bond with the patient	28 (38.4)
Spending more time with the patient	27 (37.0)
A new life outlook or perspective	20 (27.4)
New appreciation for the patient and what she/he is going through	19 (26.0)
Better relationships with friends	19 (26.0)
Helping the patient with household activities (like cooking, cleaning, yard work)	18 (24.7)
Learning who my true friends are	17 (23.3)
Better relationships with family members (other than the patient)	11 (15.1)

patient (41.1%). Relatively few spouses reported deriving any benefit from improved relationships with family members or friends, learning who one's true friends are, or gaining new appreciation for the patient's plight.

QOL of spouses vs. healthy normative sample

QOLI and SF-36 scores were compared to their standardization sample scores. The QOLI standardization sample comprised 798 non-clinical adults from throughout the USA (65% female, mean age = 36 yr, 70% White) (9). The SF-36 standardization sample comprised 1982 adults representing the general USA population (60% female, 84% White) (11). The QOLI mean raw score of spouses was significantly lower than that of the measure's standardization sample,  $z$ -test = 5.26,  $p < 0.001$ . The SF-36 PCS and MCS mean scores also were significantly lower than those of the measure's standardization sample,  $z$ -test = 4.01,  $p < 0.001$  and  $z$ -test = 7.01,  $p < 0.001$ , respectively.

Relationship between emotional distress and social intimacy with caregiver strain/benefit

Higher caregiver strain was associated with more overall emotional distress and less social intimacy between spouses and patients. Higher CSI scores were correlated with higher Total Mood Disturbance scores on the POMS ( $r = 0.42$ ,  $p < 0.001$ ) and with lower SF-36 MCS scores ( $r = -0.39$ ,  $p < 0.002$ ). Higher CSI scores also were associated with lower Total Intimacy Scores on the MSIS ( $r = -0.37$ ,  $p < 0.002$ ). Caregiver benefit was not significantly associated with emotional distress indices.

Caregiver functioning and relationship to gender and patient disease duration

There were no significant gender differences on any of the dependent measures ( $p > 0.05$ ). However, longer disease duration was associated with higher spouse emotional distress (POMS:  $r = 0.38$ ,  $p < 0.002$ ; SF-36 MCS:  $r = -0.42$ ,  $p < 0.001$ ) and more caregiver strain (CSI:  $r = 0.55$ ,  $p < 0.001$ ).

## Discussion

This study, one of only a few to examine caregiver functioning during the lung transplant waiting phase, yields four primary findings: (1) spouses reported compromised QOL relative to normative samples; (2) slightly more than half reported clinically significant elevations in caregiver strain; (3) some spouses derive benefit from their caregiving role; and (4) higher caregiver strain is associated with more emotional distress, less social intimacy between caregiver and patient, and longer disease duration.

On the surface, these findings are less encouraging than those reported by other researchers (4, 5). Meltzer and Rodrigue (4) reported much lower levels of caregiver strain in their study of 24 lung transplant caregivers. Claar et al. (5) found better overall adaptation and relatively low rates of depression (15%) and anxiety (2%) in a sample of 82 lung transplant caregivers. Differences between these studies and the present one may be explained, in part, by sociodemographic factors. Relative to previous studies, the present study cohort was younger, more gender balanced, and comprised spouses only. Perhaps spouses, more so than parents, adult children, and siblings, are more negatively impacted by the caregiving demands. Despite these study differences, findings across studies converge to suggest that lung transplant caregivers experience significant impairment in social functioning and those with high levels of caregiver strain are likely to be more emotionally distressed as well. Our findings also suggest that higher caregiver strain may contribute to social intimacy problems in the patient-caregiver relationship.

Two recent studies have shown that caregivers who use more active coping strategies are less likely to experience depression, anxiety, and lower QOL (5, 6). While caregiver benefits were not specifically examined in either of these studies, it is plausible that those who derive more personal growth and interpersonal benefits may be coping more adaptively to the high demands of caregiving. Despite

the burdens associated with transplant caregiving, some spouses may experience personal growth and interpersonal benefits as well. When developing interventions to assist caregivers throughout the transplant process, clinicians should consider identifying individual strengths or benefits to facilitate optimal psychological adaptation.

Collectively, findings from this study and others further highlight the need to develop effective interventions to reduce caregiver strain and emotional distress, especially during the pre-transplant waiting period. Perhaps most beneficial for transplant caregivers may be a multidimensional approach that provides some respite care, encourages participation in support groups, strengthens interpersonal relationships, helps caregivers find personal meaning from their experiences, and promotes the acquisition of coping strategies characterized by problem-solving and positive reappraisal. While interventions to improve coping skills and psychosocial functioning of caregivers have been shown to be effective with several different populations (17–19), their use has not been evaluated in the context of lung transplantation. Also, research is needed to further delineate the most effective timing for such interventions with caregivers, especially, considering the strong association between disease duration and spouse emotional distress. Moreover, there is some evidence that the psychological toll of caregiving may linger well beyond transplant surgery (7, 20). Our own anecdotal clinical experience suggests that caregivers respond well to receiving intervention services soon after the patient is listed for transplantation, with periodic “booster sessions” throughout the waiting period. We have also found that spouses derive some indirect psychological and QOL benefits when the transplant patient is receiving psychological services (13), which highlights the relevance to caregivers of also targeting improvements in patient life quality and psychological adaptation. Considering that patients and their caregivers may live a great distance from the transplant center, these highly specialized psychological and supportive resources may not exist in their local communities. Creative alternatives to supporting caregivers may be needed to efficiently and effectively deliver the services that are needed (19, 21).

The results of this study should be evaluated within the context of a few methodological limitations. First, while the participation rate was high, spouses were self-selected and findings may be biased toward those with less extreme levels of psychological distress. Second, as noted previously, this study was restricted to spouse caregivers and findings may be different with a more heterogeneous

group of caregivers that includes adult children, parents, siblings, extended family members, and friends. Third, findings should not be generalized beyond the sociodemographic characteristics of this single-center sample, which was not very ethnically diverse. Fourth, the cross-sectional nature of the study did not permit examining how caregiver adjustment changes throughout the entire transplant experience. Fifth, data were collected using several strategies – in clinic, by mail, by telephone – and it is possible that responses may vary based on these different contexts. Finally, in light of recent findings (6), it is possible that caregiver functioning is directly impacted by the coping responses and QOL of the patient for whom they are caring, something we did not measure in this study.

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