Caregivers of lung transplant candidates: do they benefit when the patient is receiving psychological services?

Background—We recently demonstrated that a targeted psychological intervention has quality of life, mood, and social intimacy benefits for patients awaiting lung transplantation.

Objective—To evaluate the impact of the patient's participation in treatment on caregiver functioning.

Design and Intervention—Caregivers of patients participating in a randomized clinical trial designed to compare 2 telephone-based psychological interventions completed outcome measures at baseline and at 1 and 3 months after patients completed treatment. Patients were randomized to receive either supportive therapy (emotional and educational support) or quality-of-life therapy (a cognitive-behavioral intervention that provided specific intervention strategies to boost happiness and satisfaction in life domains that compromise overall quality of life). Caregivers did not participate directly in the interventions.

Setting and Participants—Participants were 28 caregivers from a large lung transplant center in the southeastern United States.

Main Outcome Measures—Quality of life (Quality of Life Inventory), mood disturbance (Profile of Mood States-Short Form), and social intimacy (Miller Social Intimacy Scale).

Results and Conclusions—Caregivers reported higher quality of life and lower mood disturbance scores, and comparable social intimacy scores relative to the patients for whom they were caring. Caregivers whose patients received quality-of-life therapy reported vicarious gains in quality of life, mood disturbance, and social intimacy, relative to those whose patients received support therapy. Finally, the degree of change in patients' quality of life, mood disturbance, and social intimacy contributed significantly to predicting caregivers' functioning at the 3-month follow-up assessment. These findings suggest that telephone-based quality-of-life therapy has beneficial effects that extend beyond patients to their caregivers. (*Progress in Transplantation.* 2006;16:336-342)

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Lung transplantation offers adults with end-stage pulmonary diseases the potential for improved quality of life (QOL) and longer-term survival.[1-3] However, the long waiting time between transplant listing and transplant surgery often leads to further deterioration in physical health, emotional well-being, and QOL.[4-8] Recent clinical trials have shown that psychological interventions during this stressful period can lead to significant psychological, QOL, and interpersonal gains for patients. For instance, Napolitano et al[9] found that a brief cognitive-behavioral treatment program produced clinically meaningful QOL, psychological, and social support benefits for adults awaiting lung transplantation. More recently, Rodrigue et al[10] found that wait-listed lung transplant patients receiving a targeted psychological intervention showed significant improvements in QOL, mood disturbance, and interpersonal closeness compared to patients receiving general supportive therapy.

Many lung transplant programs require that patients have an identified primary caregiver before proceeding with transplant listing because that person is viewed as essential for the overall success of transplantation. Consequently, pretransplant evaluations usually include a formal assessment of the caregiver's availability, stability, and ability to provide emotional and practical

support for patients with declining physical health, limited mobility, and complex medical needs.[11] In light of the significance of the caregiver requirement for transplant listing, there is a surprising paucity of research on the impact of chronic lung disease and transplantation on family caregivers. Dew et al[12] identified several primary sources of caregiver burden for this population, including changes in roles and responsibilities at home, time constraints on work and leisure time activities, heightened worry and concern about the patient's health, social and emotional isolation, and financial stress. Moreover, researchers have found that the solid organ transplant waiting period can foster increased feelings of anxiety, depression, fear, anger, and/or social isolation.[13-17] Caregivers must prepare for the possibility of the patient's death as well as a prolonged life with a transplant. Poor physical health, sleep disturbances, elevated distress levels, declines in role performance, and lower QOL are associated with increased caregiver burden.

Psychological services designed to enhance emotional functioning and QOL are increasingly provided to patients awaiting lung transplantation. In a recent clinical trial,[10] we investigated the differential effects of 2 telephone-delivered psychological interventions—QOL therapy and supportive therapy (ST)—in improving QOL, mood disturbance, and social intimacy in lung transplant patients. We found that patients receiving QOL therapy showed significant QOL, mood disturbance, and social intimacy improvements compared to patients receiving ST. A secondary aim of the clinical trial was to evaluate the impact of the patient's participation in treatment on their caregiver's functioning.

The aims of this paper, therefore, are 4-fold. First, we describe the QOL, mood disturbance, and social intimacy levels of this cohort of caregivers. Second, we evaluate whether caregivers and patients differ significantly on these indices of adjustment, thus providing important information about the impact of disease and transplant waiting on the patient-caregiver system. Third, we examine whether the 2 interventions yield any systematic differences in caregiver functioning, that is, whether any differences in caregiver QOL, mood disturbance, or social intimacy between the 2 treatment groups mirror those found for patients. Finally, multivariate predictors of caregiver functioning are examined.

Methods
Study Context and Design

Between January 2003 and November 2003 we recruited adults who were listed for lung transplantation to participate in a study examining the differential effectiveness of 2 psychological interventions in attenuating psychological distress, improving QOL, and enhancing the relationship between patients and caregivers.[10] The study was a 2-group randomized trial with repeated measures (at baseline, 1 month, and 3 months).

Questionnaire answers and medical record data were collected.

Patients (n = 17) who received QOL therapy participated in weekly telephone sessions designed to improve QOL levels across multiple life areas (eg, self-esteem, goals and values, learning, relationships) that are essential to the patient's subjective well being.[18] In the first session, the therapist works with the patient to select 2 to 5 life areas that are designated by the patient as highly valued and essential to his or her subjective well being, but which have high levels of dissatisfaction. In subsequent treatment sessions, cognitive-behavioral strategies are implemented within each targeted area to facilitate change in the patient's subjective circumstances of the area (eg, problem solve to improve the situation), attitudes or perceptions of the area, standards of fulfillment for the area, and/or the relative importance placed on the area for overall happiness.

Examples of treatment strategies include writing about specific hurts, feelings, and wants (written emotional expression) relative to important personal relationships that have grown distant because of illness and then implementing a 3-step plan for increasing social contact and support; developing relaxation rituals (eg, progressive muscle relaxation, meditation, therapeutic massage); completing daily stress diaries that are reviewed in treatment so that effective coping strategies can be developed and implemented; challenging unhealthy core beliefs and replacing them with healthier beliefs; problem-solving ways to increase creativity and community connection despite physical limitations (eg, identifying appropriate volunteer activities and technology-assisted social activities); problem-solving attitudinal and physical barriers to recreation; building commitment and motivation to engage in health promoting behaviors; and reevaluating life goals and values by using a "life before" and "life after" transplantation technique. Consistent with this treatment model, patients also are assigned to complete various homework activities between sessions.

Patients (n = 18) receiving ST also participated in weekly telephone sessions that provided emotional and educational support. Support therapists provided patients with information about the transplant experience, listened actively to their concerns and worries, displayed a genuine interest in their life activities and well being, provided encouragement and reinforcement, and promoted the use of other support systems.[19] Within this context, additional treatment objectives included promoting a supportive therapist-patient relationship; facilitating and enhancing the patient's strengths, coping skills, and capacity to use environmental supports; and reducing the patient's subjective distress. The therapist's activity was determined by the patient's current state. Session topics included understanding the transplantation process, understanding medications and their effects, coping with illness and transplantation,

identifying and dealing with emotions, dealing with issues of death and dying, communicating with others, and navigating the healthcare system, among others.

Both interventions lasted 8 to 12 weeks and therapists were trained in the delivery of only 1 of the active treatments and delivered that treatment exclusively. The number of sessions varied on the basis of the number of life areas identified for intervention, patient comorbidities, and the need for some patients with breathing difficulties to have shorter (and therefore more) sessions. Telephone counseling was chosen as the service delivery mechanism because of the dispersion of patients throughout the region and their level of medical disability. The University of Florida Institutional Review Board approved all study procedures.

Caregiver Recruitment Procedures

Patients who met eligibility criteria were informed about the study at the time of a routine clinic visit or by telephone if a clinic visit was not imminent. All patients who agreed to participate in the study were told that the research team was also interested in assessing the QOL, mood disturbance, and social intimacy of their primary caregiver. We then either met with the primary caregiver or contacted him or her by telephone to provide information about the nature and purpose of the study and to request his or her participation. Study inclusion criteria for caregivers included at least 18 years of age, identified as the patient's primary caregiver during the wait-listed period, ability to read and understand English, and written informed consent.

Assessment Protocol

All questionnaires were completed by caregivers at home and mailed back to the research team in postage-paid envelopes. A research assistant who was unfamiliar with the interventions and blinded to patients' treatment condition retrieved the returned questionnaire data, scored the measures, and entered these data into a computer database.

Quality of Life. The Quality of Life Inventory (α =.83)[20] was used to assess the relative importance and satisfaction of 16 domains of life: health, self-esteem, goals and values, money, work, play, learning, creativity, helping, love relationships, friendships, relationships with children, relationships with relatives, home, neighborhood, and community. Caregivers used 3-point scales (0=not important, 1=important, 2= extremely important) to indicate the importance of each domain to their overall happiness and then used 6-point scales (-3=very dissatisfied to +3=very satisfied) to rate their level of satisfaction in each area. For each domain, a weighted satisfaction rating, a total raw score, and a standardized T score were calculated. Higher scores indicated a higher QOL. Temporal stability (r=

0.73, 2-week test-retest reliability), satisfactory internal consistency (α=.79), and good convergent validity (ie, significantly correlated with other measures of life satisfaction and QOL) were demonstrated.[20]

Mood Disturbance. The Profile of Mood States-Short Form (POMS-SF; α=.82-.91)[21] was used to measure current mood states. Using a 5-point scale (0= not at all to 4=extremely), caregivers read 30 self-descriptive adjectives and rate the extent to which they have felt that way in the past week. The POMS yields a total mood disturbance score and 6 factor scores: tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment. Higher scores indicate more mood disturbance. Temporal stability (r=0.65-0.74, 3-week test-retest reliability), high internal consistency (α=.87-.95), and good convergent validity with other measures of psychological distress have been documented.[22,23]

Social Intimacy. The Miller Social Intimacy Scale (MSIS; α=.79)[24] was used to measure the degree of perceived closeness between the caregiver and the transplant patient. The MSIS yields a total intimacy score and 2 intimacy subscale scores: frequency (eg, When you have leisure time how often do you choose to spend it with him or her?) and intensity (eg, How affectionate do you feel toward him or her?). Higher scores indicated greater intimacy. The MSIS has been shown to have high test-retest reliability (r=.96 at 2 months and r=.84 at 1 month) and good discriminant validity.[24]

Statistical Analysis

First, descriptive statistics were calculated to summarize the caregiver sample across all sociodemographic characteristics and primary assessment outcomes. Only the total scores for each of the 3 questionnaires were examined because of the small sample size and the need to limit the number of statistical tests (ie, reduce probability of type I error). Second, *t* tests were conducted to examine differences between caregivers and patients on the 3 primary outcome measures. Third, we evaluated whether there were differences in QOL, mood disturbance, and social intimacy between caregivers whose patients were assigned to the 2 treatment groups (ie, QOL therapy vs ST) and whether any gains made along these dimensions were maintained over time. We used repeated measures analyses of variance to explore treatment effects, time trends, and interactions between treatment and time on each outcome measure.

We included forced expiratory volume in 1 second (FEV_1) percent predicted, time on the waiting list, and number of treatment sessions as covariates in the analyses because of the potential impact of disease severity, waiting time, and amount of treatment received by the patient on caregiver functioning. For significant

Table 1 Demographic characteristics of caregivers by type of therapy received by patients

| Caregiver charactieristic | Total sample (N = 28) | Patient therapy | | Test statistic |
		Quality-of-life therapy (n = 13)	Supportive therapy (n = 15)	
Age, mean (SD), y	49.1 (12.1)	45.5 (10.3)	52.3 (13.1)	$t(26)=1.50$, $P=.15$
Female	8 (28.6)	5 (38.5)	3 (20.0)	Fisher exact test[†], $P=.41$
White	23 (82.1)	11 (84.6)	12 (80.0)	$\chi^2(2)=4.93$, $P=.18$
Married	22 (78.6)	9 (69.2)	13 (86.7)	$\chi^2(2)=3.40$, $P=.18$
Education, $\geq$ 12 y	26 (92.9)	12 (92.3)	14 (93.3)	$\chi^2(3)=0.61$, $P=.96$
Employed	20 (71.4)	9 (69.2)	11 (73.3)	$\chi^2(4)=3.47$, $P=.48$

*Values are expressed as number (percentage) unless otherwise indicated.
[†]Only P value is reported because Fisher exact test does not yield formal test statistic or critical value.

effects, t tests were calculated at the 2 posttreatment follow-up assessments, with Bonferroni correction for multiple comparisons (ie, α .05/2 = .025). Effect size estimates were reported as η_p^2 (partial eta squared) for multivariate effects and d (Cohen d) for t tests of the differences between the 2 groups. Fourth, linear regression analyses were performed to identify predictors of caregiver functioning at the 3-month follow-up assessment. We used an intent-to-treat approach for all analyses. Caregivers (n=3) with missing follow-up assessment data were included in the analysis by carrying forward their most recent assessment scores. SPSS version 11 (SPSS Inc, Chicago, Ill) was used for all statistical analyses.

Results
Characteristics of the Sample

Of the 35 lung transplant patients who were enrolled in the clinical trial, 28 had primary caregivers who agreed to participate in the study. Thirteen caregivers had patients in the QOL therapy condition and 15 caregivers had patients in the ST condition. Although all caregivers completed the baseline assessment, 1 did not complete either of the follow-up assessments (ST condition) and 2 did not complete the 3-month assessment (1 QOL therapy condition, 1 ST condition).

All but one of the participating caregivers was either the spouse or partner of the identified transplant patient. The caregivers had a mean age of 49.1±12.1 years and were predominantly male, white, at least high school educated, and employed. The patients for

whom they cared were diagnosed primarily with chronic obstructive pulmonary disease (50%) or pulmonary fibrosis (32%), and were on the transplant waiting list an average of 470.4 days (range 30-1800 days). There were no statistically significant differences between caregiver sociodemographics in the 2 treatment groups (Table 1).

Baseline Quality of Life, Mood Disturbance, and Social Intimacy: Caregivers and Patients

Baseline scores (means and SDs) on the 3 outcome measures for both caregivers and patients are reported in Table 2. Caregivers reported significantly higher QOL ($P=.001$) and lower mood disturbance ($P=.001$) than their transplant patient counterparts. There was no significant difference between these 2 groups on degree of social intimacy ($P=.20$). We also examined the QOL Inventory categorically, to assess the prevalence of clinically meaningful levels of QOL. The recommended cutoff for designating a low QOL is a T score below 43.[20] Although 19 patients (67.9%) had QOL Inventory scores that fell in this range, only 5 caregivers (17.9%) met criteria for low QOL ($P=.0003$).

Effects of Patient Treatment on Caregiver Functioning

There were no significant group differences on any of the caregiver outcome measures at baseline assessment. For QOL, there was a significant effect for Condition × Time (F=4.98, $P=.02$, $\eta_p^2=0.29$; Figure 1). Caregivers of patients assigned to the QOLT condition

Table 2 Caregiver and patient scores on baseline measures of quality of life, mood disturbance, and social intimacy

	Caregivers (N = 28)	Patients (N = 28)	Test statistic
QOLI T score, mean (SD)	49.04 (7.7)	41.0 (11.8)	$t=3.75$, $P=.001$, $d=0.81$
POMS total mood disturbance, mean (SD)	20.6 (9.7)	30.2 (11.9)	$t=3.72$, $P=.001$, $d=0.88$
MSIS total score, mean (SD)	58.1 (16.0)	55.5 (9.3)	$t=0.89$, $P=.40$, $d=0.20$

Abbreviations: MSIS, Miller Social Intimacy Scale; QOL Inventory, Quality of Life Inventory; POMS, Profile of Mood States-Short Form.
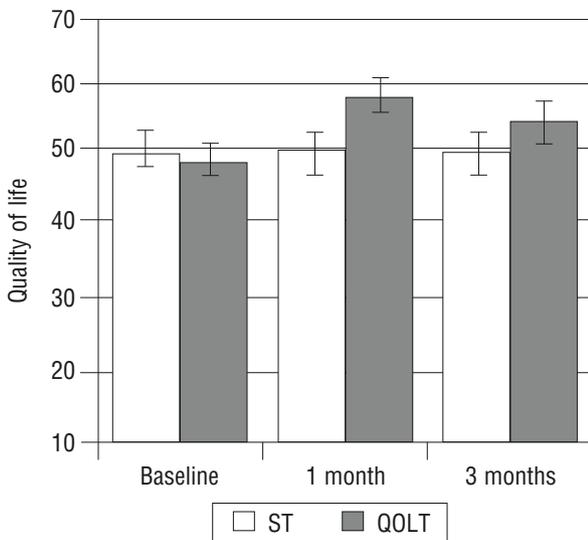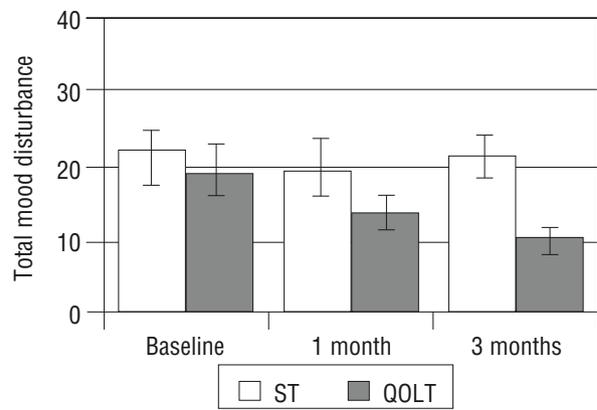
Abbreviations: QOLT, quality of life therapy; ST, supportive therapy.

Figure 1 Comparison of Quality of Life Inventory T scores (unadjusted), by type of therapy over time (error bars depict 95% confidence intervals)

had significantly higher QOLI scores at the 1-month follow-up compared with caregivers of ST patients ($t=2.3$, $P=.03$, $d=0.90$). A significant Condition × Time interaction effect (F=4.93, $P=.02$, $\eta_p^2=0.32$) was also found for total mood disturbance (Figure 2). Compared to those whose patients were in the ST condition, caregivers of patients assigned to the QOLT condition had significantly lower POMS-SF scores at the 3-month follow-up ($t=3.1$, $P=.005$, $d=1.18$). Finally, a significant Condition × Time interaction effect (F=12.10, $P=.0001$, $\eta_p^2=0.54$) was found for total Social Intimacy, with caregivers of QOLT patients reporting higher MSIS scores than caregivers of ST patients at both the 1-month ($t=2.5$, $P=.018$, $d=0.99$) and 3-month follow-ups ($t=2.4$, $P=.023$, $d=0.95$; Figure 3).

Multivariate Predictors of Caregiver Functioning

Linear regression modeling was used to identify predictors of caregiver functioning at the 3-month follow-up assessment. First, correlational analyses were conducted to examine relationships between hypothesized predictor variables and caregiver functioning. Possible predictor variables included caregiver demographic characteristics (age, sex), patient medical data (time on waiting list, FEV_1 percent predicted), the patient's randomized treatment condition, caregiver functioning (QOL, mood disturbance, and social intimacy) at the 3-month follow-up assessment, and patient change scores on the 3 primary outcome measures. Change scores were calculated as the difference between the patient's baseline and 3-month follow-up scores on each of the 3 measures. Only those variables that were significantly correlated with

Abbreviations: POMS-SF, Profile of Mood States Short Form; QOLT, quality of life therapy; ST, supportive therapy.

Figure 2 Comparison of POMS-SF total mood disturbance scores (unadjusted), by treatment condition over time (error bars depict 95% confidence intervals)
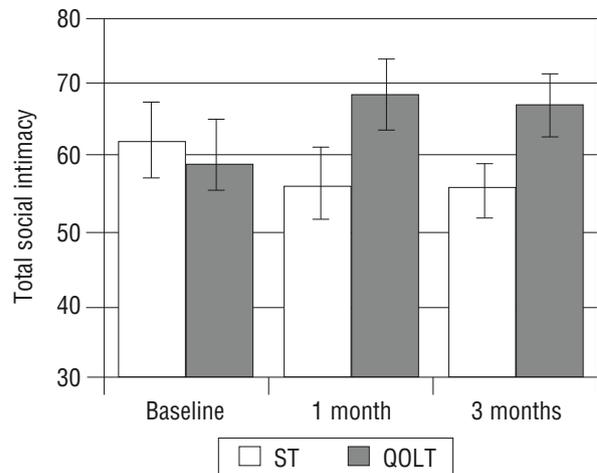
Abbreviations: MSIS, Miller Social Intimacy Scale; QOLT, quality-of-life therapy; ST, supportive therapy.

Figure 3 Comparison of the MSIS total social intimacy scores (unadjusted), by treatment condition over time (error bars depict 95% confidence intervals)

caregiver functioning at the 3-month assessment were included in the regression analyses.

All 3 caregiver regression models were statistically significant. Shorter transplant waiting time, lower caregiver mood disturbance, and more favorable change in patient QOL and social intimacy were all significant predictors of higher QOL Inventory scores (F=6.8, $P=.02$, $R^2=0.80$, 64% of variance predicted). Shorter transplant waiting time, lower FEV_1 percent predicted, patient assignment to QOL therapy, higher caregiver QOL, and more favorable change in patient QOL and mood disturbance were significant predictors of lower POMS-SF scores (F=4.6, $P=.04$, $R^2=0.63$, 39% of variance predicted). Finally, female gender, patient assignment to QOL therapy, higher caregiver QOL, and more favorable change in patient QOL significantly predicted higher MSIS scores (F=7.3, $P=01$, $R^2=0.74$, 55% of variance predicted).

Discussion

Many lung transplant programs require patients to identify a primary caregiver to assist them with their medical needs and activities of daily living throughout the waiting and posttransplant recovery periods.[11] However, researchers have documented relatively low levels of QOL, higher than expected affective distress, and social isolation among caregivers of patients awaiting solid organ transplantation.[13-17] We have previously reported on the effectiveness of a targeted psychological intervention for lung transplant patients during the waiting period.[10] The current study examined whether the psychological interventions as part of that trial had any impact on patients' identified caregivers.

Three findings are particularly noteworthy. First, caregivers reported higher QOL and lower mood disturbance, and comparable levels of social intimacy compared to the patients for whom they were caring. Second, caregivers whose patients received QOL therapy reported vicarious gains in QOL, mood disturbance, and social intimacy, compared to those whose patients received ST. Third, the degree of change in patients' QOL, mood disturbance, and social intimacy contributed significantly to predicting caregivers' functioning at the 3-month follow-up assessment.

Few would argue that caregivers' QOL and emotional functioning are affected by the stress associated with caring for medically compromised patients awaiting lung transplantation. Therefore, it can be argued that the potential QOL benefits associated with transplantation extend both to the patients and to their primary caregivers, that is, most commonly, the spouses. Nearly 18% of caregivers in this study reported clinically significant decrements in QOL at the time of baseline assessment. Although it is possible that the strain of caring for someone with worsening medical status is contributing most to lower QOL levels, we did not conduct a thorough assessment of the caregivers' own health status. Therefore, it is possible that caregivers' QOL is negatively affected by their own decline in physical health. Dew et al,[25] for instance, found that many caregivers experienced worsening of physical health and either significant weight gain or loss in the first year after heart transplantation.

Most importantly, the results of this study demonstrate that caregivers can be affected vicariously via a targeted psychological intervention delivered to the patient. In particular, caregivers of patients who received QOL therapy showed improvements in QOL, mood disturbance, and social intimacy. Multivariate analyses further showed that such gains in caregiver QOL and psychological functioning were often associated with improvements in patients' QOL and psychological functioning from baseline to follow-up assessment. This is consistent with recent findings indicating that patients' coping resources and QOL are especially critical in predicting caregiver well being.[26]

The obvious clinical implication of these findings is that QOL therapy, unlike supportive interventions, may have significant benefits for the patient-caregiver system, even when the caregiver is not actively involved in the intervention. Given the relatively short follow-up period in this study, it is not possible to determine how long such benefits last, but the findings suggest that patient improvement in QOL, mood disturbance, and social intimacy through active psychological treatment (especially QOL therapy) may ease the deleterious psychological effects of caregiving.

The benefits that caregivers derive from the QOL therapy intervention may occur through 1 or more pathways. One of the common treatment goals identified by patients in the QOL therapy condition was the improvement of interpersonal relationships. By working therapeutically on relationship skills, patients may develop more effective strategies to improve communication and to enhance intimacy with their spouses. Second, QOL therapy encourages patients to focus their energy on deriving more satisfaction from those aspects of life that they find meaningful. This necessitates that they shed, to some degree, the sick role that has consumed them for many months or years by focusing more on other aspects of living. For caregivers, watching patients develop a renewed commitment to living (vs waiting passively for a transplant) may have significant psychological benefits. Third, psychological services for patients awaiting transplantation have some unintended respite benefits for caregivers, especially for those with high perceived burden.

Our findings also indicate that shorter duration on the transplant waiting list has positive benefits for caregiver QOL and mood disturbance. As waiting time increases for patients, caregivers may feel more burden and strain, and their ability to pursue their own life goals, to maintain social relationships, and to remain psychologically stable may become increasingly difficult. In light of this finding, it is possible that the new lung allocation system,[27] in which patients are less likely to be placed on the waiting list early to accrue time, could have some benefit for the long-term psychological functioning of caregivers.

Conclusion

Findings from this study suggest that QOL therapy provides an opportunity to improve the lives both of patients awaiting a lung transplant and their primary caregivers. Mood disturbance and social intimacy benefits for caregivers may last as long as 3 months following the patient's completion of psychological treatment. Although caregivers of QOL therapy patients showed improvements in QOL at both follow-up assessments, their scores were not statistically dif-

Rodrigue et al

ferent from caregivers of ST patients. This is likely due to the small sample size, because the effect size (Cohen d) for the QOL difference at the 3-month assessment was 0.60, which is in the moderate range. Moreover, the treatment effects were derived from a telephone-based delivery method, rather than more traditional face-to-face counseling. Perhaps face-to-face QOL therapy services that also involve the caregiver may yield even stronger QOL, psychological, and relationship benefits.

Limitations

There are a few methodological limitations to this study. First, the sample size is small and recruitment occurred at only 1 transplant center. Clearly, there is a need to examine QOL therapy benefits both for patients and caregivers in the context of a larger, multisite study. Second, minorities were not well represented in this study, which certainly limits the degree to which these findings can be generalized to a more ethnically diverse population. Third, as previously noted,[10] QOL therapy patients received, on average, 1 treatment session more than ST patients, which may have contributed to the sustained caregiver benefits observed in this study. These limitations notwithstanding, this study provides evidence for caregiver benefits associated with QOL therapy for lung transplant patients. Finally, as a cautionary note, these data should not be interpreted to mean that caregivers themselves should not be the primary focus of psychological interventions because they derive benefit from the patient's participation in such treatment. Indeed, we strongly support the call for more clinical trials designed to evaluate the effectiveness of caregiver-based interventions.[28,29]

Acknowledgments

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