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A M E R I C A N C O L L E G E O F
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Psychological Functioning and Quality of Life in Lung Transplant Candidates and Recipients*

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Objective: The purpose of this study was to examine the psychological functioning and quality of life (QOL) of lung transplant candidates and recipients.

Methods: The following measures were completed by 36 lung transplant candidates (the pretransplant group [PRE]) and 73 recipients (the posttransplant group [POST]): the Rand-36 Item Health Survey 1.0 (RAND-36), visual analog scale of overall QOL (OQOL), Brief Symptoms Inventory (BSI), Derogatis Sexual Functioning Inventory (DSFI), Hospital Anxiety and Depression Scale (HAD), Rosenberg Self-Esteem Scale (RSES), and Body Cathexis Scale (BC).

Results: Compared to the PRE, POST patients had significantly better scores on the following measures: RAND-36 total, physical health, role limitations due to physical health, general health, vitality, and social functioning subscales (all $p < 0.0001$); visual analog scale of OQOL ($p < 0.0001$); BSI ($p < 0.05$); BC ($p < 0.05$); HAD anxiety ($p < 0.05$) and depression ($p < 0.0001$); and RSES ($p < 0.05$). Despite better scores, some areas did not differ between the PRE and the POST, and many patients continued to experience impairments in psychological functioning. Specifically, the RAND-36 emotional health and role limitations due to emotional health subscale scores did not differ between the PRE and the POST and they remained lower than published norms. A significant proportion of patients in both groups (44% of PRE patients and 28% of POST patients) had borderline or clinical levels of anxiety (ie, the HAD). Finally, PRE and POST mean scores were significantly lower than published norms on the RSES ($p < 0.05$) and the body image scale of the DSFI ($p < 0.05$).

Conclusions: Although lung transplant recipients have better general, physical, and psychological health than their pretransplant counterparts, the present research suggests that both groups experience impairment in several areas of psychological functioning. Future research into the QOL of the lung transplant population should be aimed at recognizing, intervening, and improving patients' psychological and emotional well-being. (CHEST 2000; 118:408–416)

Key words: anxiety; body satisfaction; depression; lung disease; lung transplantation; quality of life; self-esteem; sexual functioning

Abbreviations: ANOVA = analysis of variance; BC = Body Cathexis Scale; BOS = bronchiolitis obliterans syndrome; BSI = Brief Symptoms Inventory; DSFI = Derogatis Sexual Functioning Inventory; HAD = Hospital Anxiety and Depression Scale; HRQOL = health-related quality of life; 6MWT = 6-min walk test; NS = not significant; OQOL = overall quality of life; PRE = pretransplant group; POST = posttransplant group; QOL = quality of life; RAND-36 = Rand-36 Item Health Survey 1.0; RSES = Rosenberg Self-Esteem Scale

In evaluating the efficacy of health-care interventions, researchers are now examining quality of life (QOL) and return to full functional capacity, in

addition to objective measures of physical health. Within the lung transplant literature, several studies have found that transplantation is associated with improvements in the QOL of patients with end-stage lung disease.^{1–14} More specifically, transplantation results in increased overall QOL (OQOL) and energy level, fewer physical and role limitations, as well as improved mental health, social functioning, and health perceptions.^{3–11} There is also research that documents a decrease in disease-related symptoms and treatment-related side effects following transplantation.¹⁵

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Despite these demonstrated improvements, QOL in lung transplant patients is only beginning to be explored. Issues regarding the methodology and accuracy of previous measurements of QOL bring into question the validity of prior findings.¹⁶⁻¹⁸ Most studies have used single generic measures of health-related QOL (HRQOL),^{3,4,6-9,12} and those that have used multiple measures are limited by relatively small sample sizes.^{5,10,14} Since authors have focused their discussions on the dramatic improvements in QOL after transplantation, areas of health that are unimpaired in the pretransplant period have not been defined and there is little discussion of the ongoing limitations in health that exist after transplantation. Similarly, few studies have explored other domains of QOL that may be affected in this population that are not included in generic measures of HRQOL.^{5,11,15} Finally, studies have relied mainly on professionals' opinions of what is important to patients, despite evidence that there may be a significant discrepancy between patients' and physicians' perspectives regarding important determinants of QOL.^{16,17} Accurately assessing QOL involves capturing all areas of life that are impaired, distinguishing those from areas that are not impaired, validly and reliably measuring the various domains in order to detect changes that occur with intervention, as well as incorporating patients' views.^{16,18}

The importance of examining QOL accurately emerges from research indicating that QOL predicts survival in lung transplant recipients, even after controlling for disease severity.¹⁹ Pretransplantation psychological factors such as anxiety have been found to be predictive of posttransplant QOL, pulmonary symptoms, and mental health.¹⁵ Careful measurement of QOL in this population would allow for the most appropriate and effective interventions to be put into place, and ultimately for maximum physical and psychological functioning to be attained.

Thus, the main purpose of this study was to comprehensively examine QOL in lung transplant candidates and recipients. Specifically, the first objective was to examine whether other domains of QOL (*ie*, anxiety, depression, psychological symptoms, self-esteem, body satisfaction, sexual functioning) are impaired in this group and whether they are responsive to change in transplant status. Secondly, in addition to studying absolute changes in QOL, this study aimed to examine more closely areas of QOL that are impaired before and after transplantation. Finally, this study aims to examine, through qualitative measures, overall QOL and the subjective importance of the various domains of QOL assessed before and after transplantation.

Study Population

Between July 1996 and September 1998, all patients on the active waiting list and those who received a lung transplant at The Toronto Hospital were considered eligible for participation in the study. Excluded from the study were those patients who were < 6 months from the date of the transplant and those who were currently hospitalized or receiving IV medications for a medical illness or complication of their lung transplant. The study was approved by The Toronto Hospital executive committee for research on human subjects, and all study participants gave written informed consent.

Procedures

Following an information session in which the study was introduced to patients in the transplantation program, all eligible patients were contacted by telephone and questionnaires were mailed to those agreeing to participate. All questionnaires were self-administered. Each package included a consent form, a stamped return envelope, and a cover letter explaining the study and addressing issues of confidentiality. Follow-up telephone calls were made to address any questions or concerns. A proportion of women in this study had participated in a pilot study that did not include the OQOL visual analog measure or the subjective questionnaire. Supplemental packages including these items were mailed to participants within 2 months of their initial participation in the study.

Demographic Questionnaire

Demographic variables, including underlying pulmonary disease, age, marital status, race, weight, height, and time since transplantation, were collected. The presence or absence of bronchiolitis obliterans syndrome (BOS) was noted among transplant patients.

Pulmonary Function Measures

Patient charts were reviewed to obtain the FEV₁ and 6-min walk test (6MWT) scores completed at the time closest to the date that patients completed their questionnaire. Percent-predicted FEV₁ was used for comparisons between subgroups.

Definition of QOL

For the purpose of this study, QOL was defined as a person's perception and/or satisfaction with their physical and general health, as well as with the psychological, social, and emotional aspects of their life.^{16,17} QOL can be divided into two broad categories: OQOL and HRQOL.¹⁶ The former is typically measured using visual analog scales and incorporates both health-related (*eg*, physical, social, functional and emotional well-being) and nonhealth-related (*eg*, employment, spirituality, family and friends, and other life circumstances) factors to yield a global assessment of patients' QOL. HRQOL, on the other hand, refers more specifically to health status or the degree to which aspects of patients' physical, social, functional, and emotional well-being are impacted by their health.

Measures of QOL

As the purpose of the current study was to comprehensively evaluate QOL, we included a comprehensive measure of

HRQOL (the Rand-36 Item Health Survey 1.0 [RAND-36]) and a measure of OQOL (a visual analog scale). The operational components of HRQOL included social, emotional, physical, disease-specific symptoms, and treatment-related side effects, general health perceptions, changes and limitations in roles and activities of daily living, most of which are measured in the RAND-36. However, in order to comprehensively examine all domains of HRQOL in this patient population, particularly some components of the psychological domain of HRQOL that may not be captured by traditional HRQOL measures, we included several other measures.^{5,16-18} Specifically, measures of body satisfaction (Body Cathexis Scale [BC]), body image (body image subscale of the Derogatis Sexual Functioning Inventory [DSFI]), self-esteem (Rosenberg Self-Esteem Scale [RSES]), sexual functioning (DSFI), anxiety and depression (Hospital Anxiety and Depression Scale [HAD]), psychological and psychiatric symptoms (Brief Symptoms Inventory [BSI]), and patients' subjective assessment of their QOL (visual analog scale) were added to the battery. These measures are described in further detail below.

HRQOL

RAND-36: The RAND-36²⁰ assesses eight health concepts: (1) limitations in physical activities because of health problems (physical); (2) limitations in social activities because of physical or emotional problems (social); (3) limitations in usual role activities because of physical health problems (role physical); (4) bodily pain (pain); (5) general mental health (emotional); (6) limitations in usual role activities because of emotional problems (role emotional); (7) energy and fatigue (vitality); and (8) general health perceptions (general health). The measure has been standardized on 2,546 patients with chronic medical conditions, and published norms are available.^{20,21} An earlier version, the Medical Outcome Study Health Survey-20, was utilized in a study of quality of life in lung transplant recipients.⁴ The newer version is more comprehensive and has improved validity. In the current study, a total HRQOL score was calculated by adding the *T* scores for all eight subscales.

Psychological and Psychiatric Functioning

Depression and Anxiety: The HAD is a 14-item questionnaire designed for the assessment of depression and anxiety in physically ill patients.²² As opposed to other depression scales, the HAD focuses on psychological symptoms rather than somatic symptoms of depression, which often overlap with physical disease symptomatology. For this reason, it is more appropriate for use with individuals who have concurrent general medical illnesses. A total score on each scale of ≥ 11 has been reported to correspond with a clinical diagnosis of anxiety or depression; a score of 8 to 10 is borderline, while ≤ 7 is considered nonclinical or normal. This self-assessment scale has been found to be a reliable instrument for detecting states of depression and anxiety in a hospital medical outpatient clinic setting.²²

Psychological and Psychiatric Symptoms

The psychological/psychiatric symptoms subscale of the DSFI is a distinct psychometric instrument (the BSI), which assesses the degree to which a person experiences 53 physical, psychological, and psychiatric symptoms.²³ Participants are asked to circle the number that best describes how much each symptom has distressed or bothered them in the last 2 weeks on 5-point Likert-type scales, ranging from 1 (not at all) to 5 (extremely). Of particular interest to the present study are such items as difficulty concentrating, insomnia, panic, depressed mood, nausea, and shortness of breath. Higher scores indicate more symptomatology.

Body Satisfaction

The BC was used to measure body satisfaction in this study.²⁴ The measure contains 46 items that assess the degree of a person's satisfaction with various parts or processes of the body. The patient is asked to rate satisfaction with each of the body parts on a 5-point Likert-type scale, ranging from 1 (have strong feelings and wish change could somehow be made) to 5 (consider myself fortunate). Higher scores indicate greater body satisfaction. This scale has been utilized to assess body image and psychosocial adjustment in individuals with multiple sclerosis, mastectomies, and lung transplants.^{11,25,26} The published norms for this measure are based on a sample of men and women college students.²⁴ Split-half reliability coefficients are satisfactory at 0.83.²⁴

Body image was also assessed using the body image subscale of the DSFI (see below). This measure contains 15 5-point Likert-type questions, ranging from 1 (not at all true of me) to 5 (extremely true of me). The questions relate to the person's subjective appraisal of the attractiveness of their overall body and various body parts. Higher scores indicate better body image.

Self-esteem

The RSES is a widely used instrument and has well-researched validity and reliability.²⁷ Rosenberg²⁷ reported a coefficient of reproducibility of 0.92 in a sample of senior high school students. Silber and Tippett²⁸ found a test-retest coefficient of 0.85 for 28 college students over a 2-week period. The RSES demonstrates good convergent validity with other measures of self-esteem.^{28,29} This questionnaire has been used to assess self-esteem in several medical clinical populations, including people with diabetic retinopathy and tuberculosis.^{30,31} The RSES has also been utilized to assess adjustment to illnesses such as cancer, endometriosis, and osteoporosis.³²⁻³⁴ Higher scores on the scale reflect better self-esteem. A study of 50 women with endometriosis served as a clinical sample with which to compare our mean scores.³³

Sexual Functioning

The DSFI is a comprehensive self-report measure of sexual functioning.²³ As the measure was not administered through the usual interview format, and due to the highly sensitive nature of certain questions, only five subtests were utilized: drive, psychological symptoms, body image, sexual satisfaction, and overall sexual satisfaction. Scaled scores from each subtest of the DSFI are combined to calculate an overall score. Higher scores on the total DSFI or its subscales indicates better functioning. The scale has been used to assess sexual dysfunction in female patients with gynecologic cancer, Hodgkin's disease, diabetes, and end-stage lung disease.^{11,35-37} Comparisons were made using the percentile rank and *T* scores obtained from a norm sample of healthy adults.²³ Percentile ranks differ for men and women.

To supplement this questionnaire, men were asked about their ability to attain an erection or ejaculate through two 4-point Likert-like items, ranging from 1 (always able) to 4 (never able), included in the demographic questionnaire.

OQOL

OQOL was assessed using a visual analog scale asking patients to indicate their OQOL on a scale from 0 to 100. Zero represented the worst possible QOL, whereas 100 represented the best possible QOL. This measure is comparable to other visual analog scales, such as the EuroQol, which has been used to assess

QOL in other populations.³⁸ Visual analog scales have the advantage of increasing response rates to QOL questionnaires and allowing patients to include an assessment of aspects of QOL not directly related to their medical condition.³⁹

Subjective Assessment of Importance of Various Domains of QOL

Using the major themes of the measures that were administered, we developed a list of 12 domains of QOL and asked patients to rate their importance. The domains included the following: (1) limitation in physical activities; (2) limitations in social activities; (3) degree of bodily pain; (4) feelings of anxiety; (5) feelings of depression; (6) limitations in activities of daily living; (7) energy level/fatigue; (8) beliefs regarding personal health; (9) self-esteem; (10) satisfaction with sexual relationships; (11) sexual functioning; and (12) changes in the body/body image. The scales ranged from 1 (not important at all) to 5 (extremely important). A domain of QOL was considered to be an important determinant of QOL if the patient rated it as at least a 3 (3 = somewhat important). Finally, in order to assess if there were other aspects of QOL that had not been captured by our questionnaires, patients were asked to list the 10 factors that were most important to their QOL.

Data Analysis

Data are expressed as absolute numbers and mean \pm SD. Subjects were classified into a pretransplant group (PRE) and a posttransplant group (POST). For continuous variables, a series of one-way analysis of variance (ANOVA) tests were used for comparison of means. The χ^2 statistic was used for comparison of proportions for categorical data and for scores on Likert-type scales. Similar analyses were conducted to examine gender differences on the major outcome variables. Despite differences in proportions of men and women (see Results), comparisons between the PRE and the POST were not weighted for gender because analyses found no differences between male and female patients on the major outcome variables. To determine if age and time since transplantation were significant covariates with the major outcome variables, all ANOVAs were repeated controlling for age and time since transplantation. As these analyses did not reveal any significant effect of age or time since transplantation on the outcome variables, these variables were not controlled in subsequent analyses. All analyses for the major outcome measures were repeated, controlling for BOS status. For comparisons of mean scores with published norms on the major outcome measures, *T* scores were calculated manually using a *t* test. The following equation for calculating the *T* score was used: $T = [(\text{mean score of our sample}) - (\text{mean score of norm population})] / \text{SE of our sample}$. A score > 2 indicated a significant difference between the groups. For some measures, scores are also expressed as percentiles, which reflects the percentage of people in a norm sample scoring at or below a specific score. For the purpose of this study, a percentile rank of ≤ 25 was considered below average for that group.

As it was hypothesized in a previous study that gender differences may exist on certain domains of QOL, scores on all of the major outcomes were compared between men and women using ANOVA.¹¹ Because of the small sample size and small number of men in the PRE, gender comparisons were limited to the POST. All other data were considered statistically significant at $p < 0.05$.

RESULTS

Participants

During the recruitment time, a total of 180 patients were eligible to participate in the study. Of these, 109 patients (61%) completed the questionnaires. Reasons for not completing questionnaires included the following: current hospitalization ($n = 2$), not interested in participating ($n = 27$), inability to fill out questionnaire due to language barrier ($n = 4$), and no reason given ($n = 38$). Of the respondents, 36 patients (33%) were in the PRE and 73 patients (67%) were in the POST.

Demographic Data

The characteristics of the PRE and the POST are shown in Table 1. The majority of patients in each group had COPD or cystic fibrosis as their underlying disease. A combined χ^2 analysis revealed no difference in the proportions of all disease types between the groups. However, comparing each disease category separately revealed significantly more patients with emphysema in the POST ($p < 0.05$).

Table 1—Demographic Characteristics of Patients*

Characteristics	PRE (n = 36)	POST (n = 73)
Age n, yr	45 \pm 14	48 \pm 12
Time since transplant, mo	0	44 \pm 29
BMI n, kg/m ²	23 \pm 5†	25 \pm 4†
FEV ₁ , % predicted	44 \pm 30‡	83 \pm 36‡
6MWT	392 \pm 123‡	606 \pm 132‡
Underlying disease		
COPD/emphysema	9 (25)†	35 (48)†
Cystic fibrosis	9 (25)	13 (18)
Primary pulmonary hypertension	3 (8)	7 (10)
Idiopathic pulmonary fibrosis	7 (19)	7 (10)
Other diagnoses§	8 (22)	11 (15)
Marital status		
Married or cohabitating	21 (58)	48 (66)
Gender		
Female	30 (83)†	38 (52)†
Race		
White	32 (89)	69 (95)
Black	0	1 (1)
Other	4 (11)	3 (4)

*Data are presented as mean \pm SD or No. (%). Percentages may not add up to 100 due to rounding. BMI = body mass index.

†Significant at $p < 0.05$.

‡Significant at $p < 0.0001$.

§For the PRE, other diagnoses included congenital heart disease/Eisenmenger's syndrome ($n = 2$), Sjögren's syndrome ($n = 1$), pulmonary embolism/pulmonary hypertension ($n = 1$), and not recorded ($n = 4$). For the POST, other diagnoses included sarcoidosis ($n = 1$), asbestosis ($n = 1$), scleroderma ($n = 1$), lymphangiomyomatosis ($n = 1$), bronchiectasis ($n = 1$), bronchiolitis obliterans ($n = 1$), eosinophilic granuloma ($n = 1$), bronchiolitis ($n = 1$), and not recorded ($n = 3$).

The proportion of women was significantly higher in the PRE ($p < 0.05$). There were significant differences in the mean body mass index between the PRE and the POST ($23 \pm 5 \text{ kg/m}^2$ vs $35 \pm 4 \text{ kg/m}^2$, respectively; $p < 0.05$). For the POST, the mean time since transplantation was 44 ± 29 months (range, 6.0 to 119.8 months). Two patients in the PRE were on the waiting list for a second lung transplant. Eleven POST patients had a current diagnosis of BOS. With respect to immunosuppressive medications, all 73 POST patients used prednisone, 64 used azathioprine, 64 used cyclosporine, 8 used tacrolimus, and 8 used methotrexate.

Pulmonary Function Tests

As seen in Table 1, FEV₁ percent predicted in the POST was nearly double that of the PRE ($p < 0.0001$). Likewise, significant differences in 6MWTs existed between the groups ($p < 0.0001$).

OQOL

As seen in Table 2, ratings of OQOL were significantly higher in the POST compared to the PRE.

HRQOL

RAND-36: As shown in Table 2, significant differences were found between the PRE and the POST on most subscales of the RAND-36, including total HRQOL, physical, role physical, general health, vitality, and social. Conversely, there were several domains in which the two groups did not differ

Table 2—Test Scores for Measures of QOL for PRE and POST Patients

Measures	PRE (n = 36)	POST (n = 73)
RAND-36		
Physical	41 ± 6†	55 ± 8†
Emotional	48 ± 9	51 ± 10
Role physical	44 ± 7†	53 ± 10†
Role emotional	49 ± 11	50 ± 10
Pain	49 ± 11	51 ± 9
General health	43 ± 7†	54 ± 9†
Vitality	43 ± 8†	53 ± 9†
Social	44 ± 9†	53 ± 9†
Total HRQOL	361 ± 37†	419 ± 58†
OQOL	58 ± 20†	77 ± 17†
BC	3.3 ± 0.4*	3.5 ± 0.4*
HAD		
Anxiety	7 ± 3*	6 ± 3*
Depression	6 ± 3†	3 ± 3†
RSES	21 ± 4*	24 ± 4*

*Significant at $p < 0.05$.

†Significant at $p < 0.0001$.

significantly, including emotional, role emotional, and pain.

Compared with published norms, the PRE had significantly lower standardized *T* scores on all of the RAND-36 domains except for the pain and role emotional subscales. On these latter two subscales, scores were below published norms, but not statistically so. POST *T* scores were equal to or significantly higher than norms for patients with chronic illnesses, with the exception of the emotional and role emotional subscales, which were significantly below published norms ($p < 0.05$).

Psychological and Psychiatric Functioning

Anxiety and Depression: There were statistically significant differences between the PRE and the POST on the anxiety and depression subscales of the HAD, although mean scores were in the nonclinical range for both groups (Table 2).²² Clinically significant depression was present in two PRE patients (6%) and one POST patient (1%). Four PRE patients (11%) and three POST patients (4%) had clinically significant anxiety. χ^2 analyses revealed no significant differences in the proportion of patients in the PRE or the POST with clinical depression or anxiety ($p =$ not significant [NS]). There were, however, significant differences between the groups in the proportion of patients with either borderline or clinical depression. The proportion of PRE and POST patients with a score ≥ 8 was 25% ($n = 9$) vs 8% ($n = 6$), respectively ($p < 0.05$). There were no significant differences between the groups in the proportion of patients with borderline or clinical anxiety; there were 16 PRE patients (44%) and 20 POST patients (28%) with an anxiety subscale score ≥ 8 ($p =$ NS).

Psychological and Psychiatric Symptoms

An ANOVA revealed significant differences between the groups on the BSI subtest of the DSFI, with the PRE having significantly higher scores. Both groups were significantly below published norms. For the PRE, the mean score was at the 2nd percentile for men and at the 10th percentile for women; in the POST group, men and women scored at 12th and 24th percentiles, respectively.

Body Satisfaction

As seen in Table 2, an ANOVA revealed a significant difference between PRE and POST patients in BC scores, with higher scores in the POST ($p < 0.05$). However, the mean scores for both groups were comparable to values obtained from a nonclinical group of college men (3.4 ± 0.4) and

women (3.5 ± 0.4),²⁴ with the exception of men in the PRE who had a significantly lower scores. In contrast, PRE and POST percentile scores for all subjects on the body image subtest of the DSFI were well below average (*ie*, \leq 5th percentile).

Self-esteem

An ANOVA revealed significantly higher scores in the POST on the RSES ($p < 0.01$). Again, in comparison with the mean of a published clinical sample (32.17 ± 5.89), both the PRE and POST means were significantly lower.³³

Sexual Functioning

No significant difference emerged in mean scores between the PRE and the POST on any of the five sexual functioning subscales of the DSFI. More specifically, both groups were in the average range (*ie*, percentiles ≥ 25) in terms of satisfaction with sexual functioning, overall sexual satisfaction, and affectivity in comparison to a clinical sample of healthy adults. However, percentile scores for the “drive” subtest were below average in the PRE and the POST for the women only. An ANOVA confirmed a trend toward a significant difference in the drive subscores between men and women in the PRE ($p = 0.056$) and in the POST ($p = 0.058$).

There was no significant difference between the PRE and the POST in terms of the proportion of men who hardly ever or were never able to obtain an erection (20% vs 27%, $p = \text{NS}$) or ejaculate (20% vs 15%, $p = \text{NS}$).

Subjective Assessment of Importance of Various Domains of QOL

Patients’ subjective ratings of the importance of various domains of QOL are shown in Table 3. Each of the 12 domains assessed in the study were classified as important by at least 60% of patients in both the PRE and the POST. Significantly more patients in the POST than in the PRE rated sexual functioning and satisfaction with sexual relationships as important to their QOL. A significantly higher proportion of patients in the PRE than in the POST rated beliefs about health, changes in their body, energy level, and social functioning as important to their QOL.

Patients were asked to supplement the questionnaires with a list of areas they believed to be most important to their QOL. Most of the domains listed had been formally measured in this study. Additional areas that were listed by patients as being important determinants of their QOL but that had not been measured included the following: (1) concern about future health and life expectancy; (2) ability to

Table 3—Proportion of PRE and POST Patients Reporting Various Domains as Important Determinants of QOL*

QOL Domains	PRE (n = 32)	POST (n = 52)
Anxiety	71	68
Depression	68	65
Body changes	100†	79†
Self-esteem	94	92
		0
Beliefs about health	100†	87†
Energy level	100†	89†
Limitations due to emotional problems	59	65
Limitations due to physical problems	97	90
Pain	63	69
Social functioning	100†	75†
Sexual functioning	60†	86†
Satisfaction with sexual relationships	69†	88†

*A domain of QOL was considered important if the subject indicated a score of ≥ 3 on a 5-point Likert-type subjective rating scale (1 = not important at all, to 5 = extremely important). Data are presented as percent.

†Significant at $p < 0.05$.

continue working or obtain formal education; (3) personal growth, including spirituality; (4) ongoing need for medication and frequent medical visits; (5) overall outlook on life; and (6) ability to contribute to society and give to others.

Analyses Controlling for BOS

Eleven POST patients had a current diagnosis of BOS. Comparison of POST patients with and without BOS on all of the major outcome measures revealed significant differences only in terms of depression ($p < 0.001$) and OQOL ($p < 0.05$). All PRE and POST comparisons were repeated, omitting patients with BOS from the POST. Controlling for BOS did not change any of the original findings. Specifically, there were still no significant differences in emotional health and role limitations due to emotional health in the PRE and the POST, and scores were lower than published norms. In addition, the proportion of PRE and POST patients with borderline or clinical anxiety did not differ.

Gender Differences

There were no differences between women and men in the POST on any of the other outcome measures aside from the 6MWT scores (495 ± 152 vs 636 ± 136 , respectively; $p < 0.001$)

DISCUSSION

The purposes of this study were to comprehensively examine QOL in patients before and after lung

transplant and to examine psychological functioning. All pretransplant and posttransplant patients were compared on multiple QOL measures, and their level of functioning was compared to available population norm data. In order to validate the findings, patients were asked to rate the importance of the various QOL domains measured in the study. Findings revealed that although lung transplant recipients had better general, physical, and psychological health than their pretransplant counterparts, when compared to population norms, both groups had more concerns in terms of anxiety, self-esteem, and depression. This study provides evidence that while the physical and health-related aspects of patients' health status clearly improved after transplantation, the psychological and emotional health of transplant recipients continues to be negatively affected.

More specifically, the findings of this study revealed that in addition to an expected large improvement in pulmonary function and exercise tolerance, POST patients had better physical, social, and general health functioning than PRE patients, and had more body satisfaction, higher self-esteem, and higher ratings of their OQOL. Likewise, POST patients reported fewer psychological/psychiatric symptoms and were less likely to have borderline or clinical levels of anxiety or depression. Conversely, in the POST, emotional health and role limitations due to emotional health were not significantly higher and the scores on these two domains were significantly below the means of patients with stable chronic illnesses. Second, the frequency of psychological and psychiatric symptoms, although reduced, was still > 75% of the nonclinical comparison sample. Third, the proportion of patients with borderline or clinical levels of anxiety or depression remained high in both groups. One fourth of the PRE and 8% of the POST had borderline or clinical depression, and 44% of PRE and 28% of POST patients had borderline or clinical anxiety. Finally, both body image and self-esteem scores were significantly below published norms.

This study supports the findings of previous research showing significant improvement in many domains of QOL after transplantation.¹⁻¹⁴ Although seemingly inconsistent, our results highlight previous research findings indicating ongoing areas of concern for lung transplant recipients. These areas of difficulty were likely not emphasized in light of the improvements in general health. For example, Cohen and colleagues¹⁵ found no significant differences between transplant candidates and recipients in terms of anxiety, behavioral and emotional control, role limitations due to emotional health and internal locus of control. Similarly, although Gross and colleagues⁵ found significant improvements in most

domains of HRQOL in their cross-sectional study, their small longitudinal sample revealed no significant improvement in social functioning, role functioning, or mental health following transplantation. Through a larger sample and a further level of comparison (*ie*, population norms), our study adds to previous research indicating few changes and ongoing concerns in emotional and psychological areas of functioning.

The present results are important in light of an emerging literature demonstrating the prognostic implications of emotional health and QOL.^{15,19,40,41} A study by Squier and colleagues¹⁹ revealed that patients on the waiting list for lung transplantation who scored in the upper median of HRQOL scores survived significantly longer than those with lower QOL and that the baseline measurement of QOL was a prospective predictor of survival in all patients. Similarly, Cohen and colleagues¹⁵ found that pretransplant anxiety and other psychological factors predicted posttransplant QOL. The role of anxiety in predicting QOL directly and survival indirectly underscores the importance of examining psychological factors further and of including them in intervention strategies.

The findings of this study underscore the importance of comprehensively assessing multiple domains of QOL in the lung transplant population. Although this study supports previous findings of improvement in many domains of QOL after lung transplantation,¹⁻¹⁴ careful study of several domains uncovered significant difficulties relative to general and clinical populations. While the more generic measure of HRQOL (*ie*, RAND-36) was sensitive and indicated no improvement in emotional health when there was none, the use of multiple measures allowed for a more accurate and comprehensive assessment of the factors responsible for poor emotional well-being. Poor body image, self-esteem, and significant psychological/psychiatric symptoms (particularly anxiety) were found in the POST. These factors may be responsible for poorer than normal HRQOL and OQOL domains discovered in the POST patients. Future research should expand on the present findings by exploring the interplay among the various domains of functioning and QOL, and future practice might include generic as well as specific clinical measures of QOL supplemented by patient input.

The finding of below-average emotional and psychological health of lung transplant patients has important implications for this patient group. From a general health perspective, the evidence indicates that lung transplantation is meeting its goals of improving HRQOL. However, since emotional health is below expected levels, improving QOL in these patients will

require more allocation of resources to address the psychological needs of transplant patients. Such resources should be aimed at maximizing emotional health during the pretransplant period and continuing support after transplantation. While many individuals at our center were already involved in support groups, the current findings suggest that it may be necessary to initiate other interventions, such as more individualized therapies (*eg*, cognitive behavioral therapy) or medications.^{3,42} Such a strategy includes more active inquiry and assessment of current psychological status as well as an exploration of body image, self-esteem, and anxiety symptoms.

The reason for ongoing psychological difficulties in lung transplant patients is not completely understood and should be further researched. Although their health status has improved, the ongoing uncertainty, unpredictability, and feelings of lack of control patients have over their lives and future may continue to raise levels of anxiety and affect emotional health.³ Many patients have undergone and continue to experience significant life stresses, including unemployment, financial strain, and hospitalizations.^{3,43,44} As a result, many never completely resume their previous roles and struggle to find meaning and purpose in their lives. Others have ongoing physical symptoms (*eg*, patients with superimposed infection or bronchiolitis obliterans), which increase their likelihood of psychiatric symptoms and unsatisfactory QOL.^{5,45–47} The finding in this study that even patients without bronchiolitis obliterans had lower-than-average QOL suggests that there may be several potential factors that contribute to a decreased QOL after the operation.

Limitations must be considered in interpreting the results. First, the cross-sectional study design limits our ability to draw conclusions about actual changes in health status after transplantation. Second, the comparison with population norms is tentative and the two groups may have many other unknown factors that distinguish them (*eg*, cohort effects). However, this study represents the largest study examining the QOL of lung transplant patients to date, and the sample size of 109 makes this a representative sample of transplant patients.

In conclusion, although lung transplant recipients have better general, physical, and psychological health than their pretransplant counterparts, the present research suggests that pretransplant and posttransplant patients experience below-average psychological functioning. Future research into the QOL of the lung transplant population should be aimed at recognizing, intervening, and improving patients' psychological and emotional well-being.

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