

# Quality of life in caregivers providing care for lung transplant candidates

**Context**—Caregivers are essential members of the health care team who provide care, valued at more than \$250 billion each year, to millions of persons who require assistance with health and daily care. Patients with respiratory diseases who are waiting for a lung transplant are required to have an identified caregiver. The caregivers are rarely studied.

**Objective**—To explore the relationships among the health status of caregivers of lung transplant candidates, caregivers' reaction to caregiving, and caregivers' perceived quality of life.

**Design**—This descriptive study examined the quality of life of lung transplant caregivers from a multidimensional perspective.

**Setting and Participants**—Twenty-nine dyads of lung transplant candidates and their caregivers were recruited from a Midwestern medical center.

**Measures**—Data were collected by self-report: caregivers completed the Quality of Life Index, SF-12 health survey, Profile of Mood States-Short Form, and the Caregiver Reaction Assessment.

**Results**—Caregivers reported favorable levels of quality of life, physical health, and mood during the pretransplant waiting phase. However, problem areas for caregivers during this time included fatigue, depression, and the financial impact of the transplant. Data analyses indicated that depression, caregiver general health, impact on finances, and lack of family support had the greatest effect on caregivers' quality of life. Nurses are urged to recognize the role of caregivers in the transplant process, ask about and listen to caregivers' needs, and include caregivers in the plan of care. (*Progress in Transplantation*. 2009;19:142-152)

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An estimated 21% or 44.4 million Americans over 18 years old provide unpaid care to an adult.<sup>1</sup> The aging population and the advances in health care that allow people with chronic illness to live long lives have made the issue of caregiving a national health care priority. The National Institute of Nursing Research work group on caregiving reported that an estimated 4.1 million adults aged 21 to 64 years need assistance with activities of daily living, 6.8 million persons aged 65 years and over have mobility or self-care limitations, and more than 30 million persons who need assistance after acute care are discharged from hospitals annually.<sup>2</sup> According to Arno,<sup>3</sup> the value of services provided by caregivers in the United States, more than \$300 billion each year, exceeds the cost of expenses from homecare and nursing home services combined. Thus, caregivers are essential members of the health care team, providing approximately 80% of the homecare

services in the United States for family members who are elderly or have chronic or acute illness.<sup>4</sup>

Studies of caregiving<sup>5-7</sup> have largely been conducted in populations of caregivers for dementia patients; however, studying caregiver quality of life (QOL) within other populations of patients living with diseases that are equally prevalent and disabling is also important. In particular, caregivers in lung transplantation are a unique population because the patients' illness necessitates both acute and chronic care. For this reason, these patients are required to have adequate caregiver support before they can be listed for a lung transplant; such support is required for assistance in the home, as well as transportation to tests and appointments.<sup>8,9</sup>

Once the decision is made that the patient needs a lung transplant, the caregiver and patient undergo a lengthy evaluation process and are placed on a waiting list until a suitable donor organ is procured. According

to the Organ Procurement and Transplantation Network,<sup>10</sup> the number of persons waiting for lung transplantation is approximately 2098. The waiting time for lung transplant patients can be lengthy with high mortality rates, because of the limited number of donated organs. According to the Organ Procurement and Transplantation Network, of the 2098 candidates currently waiting for a lung transplant, 13% have already waited between 1 and 2 years, 27% have waited 2 to 5 years, and 24% have waited more than 5 years.

Although patients are generally comforted by the care provided by a caregiver, studies of caregivers indicate that caregiving can be physically and psychologically demanding, adversely affecting the caregiver's QOL. A caregiver's impaired health status and/or poor QOL can then adversely affect the quality of care that the caregiver provides.<sup>11-15</sup> Nursing can be influential in advocating for a healthy working partnership between families and professionals to ensure the best outcome for caregivers and patients awaiting lung transplantation. The assessment of QOL from the perspective of the lung transplant candidate and caregiver can provide a basis for nurses to develop strategies to support caregivers.

The purpose of this study was to investigate caregivers' QOL as perceived by caregivers of lung transplant candidates while waiting for a transplant. The study examined differences between caregivers within subgroups based on demographic characteristics and the relationships among the caregiver's health status, the caregiver's reaction to caregiving, and the caregiver's perceived QOL.

## Review of the Literature

The bulk of the studies of QOL in lung transplantation have focused strictly on patients' outcomes,<sup>16-21</sup> yet there is growing interest in research focusing on the QOL among caregivers of lung transplant patients. This review includes studies of the caregiver experience in lung transplant patients and specifically includes caregiver QOL as an outcome variable.<sup>14,15,22-31</sup>

The experience of caregiving in transplantation has been described as a life put on hold by several researchers.<sup>22,24,25,31</sup> Before transplant, caregivers reported feelings of isolation,<sup>22,32</sup> uncertainty,<sup>24-26,33</sup> and fears of the patient's death while waiting.<sup>26</sup> Caregiver strain related to inconvenience and surprise that the patient's health had changed so much has been reported.<sup>30,31</sup> Other factors that may influence caregivers during the pretransplant phase include the burden of taking over responsibilities that once belonged to the patient,<sup>26-28,34</sup> while at the same time relinquishing some activities, such as social interaction and employment, in order to immerse oneself in the care of the patient.<sup>25,28,34,35</sup> Worsening disease severity or health status of the patient had a negative influence on the caregiver's QOL,<sup>27,30,36,37</sup> and the caregiver's physical and mental health status

was related to the caregiver's QOL.<sup>15,27,38</sup> In one study,<sup>30</sup> QOL of lung transplant caregivers was reported as poorer than that in normative samples.

Interestingly, in several studies,<sup>31,32,37,38</sup> caregivers reported a positive effect from maintaining employment outside the home even when it increased the number of responsibilities for the caregiver and took the caregiver away from caring for the patient. Other positive effects of the caregiving experience include discovering one's own inner strength<sup>30</sup> and strengthening the bond between the caregiver and the patient.<sup>30,31</sup>

Although progress has been made in understanding the experience of caregiving in this population, gaps in the literature remain. Mental health of the caregiver is often reported as a general or summary score<sup>4,27</sup>; only a few studies have measured particular mood states such as depression and anxiety. Claar et al<sup>28</sup> reported a minimal incidence of depression or anxiety in caregivers of lung transplant candidates. In addition, few of the reviewed studies<sup>28,30</sup> included a measure of caregiver burden, although studies from other populations suggest a relationship between caregiver reaction and QOL.<sup>39-41</sup>

This study was designed to address some of the gaps identified and is intended to serve as a catalyst for future research. The conceptual definition of QOL that guided this study was from Ferrans and Powers<sup>42(p249)</sup>: "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her." Caregivers for the proposed study were operationally defined according to what person the patient identified as the one person relied on for assistance in care; therefore, the sample intentionally included parents, adult children, spouses, and others. The theoretical framework for this study was the Roy Adaptation Model,<sup>43</sup> as it provides a multidimensional approach to the evaluation of caregiver QOL, including the positive and negative consequences of caregiving.<sup>44</sup> Perception of QOL was examined by using 2 methodologically different measures of QOL, including an overall global interpretation of QOL and a multidimensional perspective of QOL.

## Methods

A descriptive correlational design with survey methods was used for this study. The setting was a Midwestern medical center and its outpatient clinics. The convenience sample consisted of 29 dyads of caregivers and lung transplant candidates. Subjects met the following inclusion criteria: (1) 18 years of age or older; (2) able to read, write, and understand English; and (3) willing to participate and to sign an informed consent form. The lung transplant candidate was actively waiting on the lung transplant list at the specified medical center, and the caregiver was identified as a primary caregiver by the lung transplant candidate.

## Procedure

Approval was obtained from the participating medical center's institutional review board. All lung transplant candidates and caregivers signed an informed consent form before participating in the study. Potential subjects, including lung transplant candidates and their caregivers, were invited to participate in the study by way of an informational letter from the lung transplant medical director. Approximately 1 week after the letter was mailed, each lung transplant candidate was contacted by telephone to arrange a meeting with the primary researcher. During the initial telephone call, the lung transplant candidate was asked to "identify the one person that you rely on for assistance in care." For most of the lung transplant dyads, a meeting with the lung transplant candidate and caregiver was scheduled to coincide with an upcoming clinic appointment. During this meeting, the study was described and informed consent was provided to the lung transplant candidate and caregiver. Dyads unable to complete the questionnaires at the clinic were given a prepaid self-addressed stamped envelope to return the questionnaire after completing it at home.

The lung transplant candidates and caregivers were explicitly asked to complete the surveys individually without discussing their responses with each other. If the questionnaires were not returned within 10 days of the clinic appointment, participants received a follow-up reminder telephone call. Caregivers of 4 lung transplant candidates who were participating were not able to attend the clinic meeting. For these participants, the study purpose was described and the informed consent form for the lung transplant candidate was completed at the clinic appointment, then the lung transplant candidate was contacted by telephone for participation. The caregiver's signed informed consent form and questionnaire were returned in a prepaid self-addressed stamped envelope.

During the initial telephone call, we identified 7 lung transplant candidates who did not have an upcoming appointment but were willing to participate in the study and preferred to receive the booklets in the mail. The study was described to the lung transplant candidate over the telephone, and a convenient time for a follow-up call was established. Then a packet with the informed consent form and questionnaires was mailed to the lung transplant candidate and his or her identified caregiver. Each of these lung transplant candidates and caregivers received a follow-up telephone call to verify receipt of the study packet and answer any questions. The lung transplant candidate and caregiver were instructed to complete their booklets individually without sharing their responses. These dyads' questionnaires were self-administered and returned in a prepaid self-addressed stamped envelope.

## Instruments

The caregiver of the lung transplant candidate completed the generic Quality of Life Index (QLI), Caregiver Reaction Assessment (CRA), SF-12 Health Survey version 2 (SF-12), and Profile of Mood States-Short Form (POMS-SF). Completion of all instruments took approximately 20 to 30 minutes.

The generic version III of the QLI<sup>45,46</sup> is a 66-item instrument used to quantify subjective QOL by measuring satisfaction with and importance of 33 items. Subjects rate items on a 6-point Likert-type scale for satisfaction and importance. The possible range of scores for overall QOL and the subscales health and functioning, psychological/spiritual, socioeconomic, and family is 0 to 30. High scores indicate good perceived QOL, whereas low scores reflect poor perceived QOL.

Adequate internal consistency reliability of the total score and subscales has been reported.<sup>45,46</sup> Reliability for this sample yielded a Cronbach  $\alpha$  for the total tool of 0.90 and from 0.67 to 0.90 for subscales.

The CRA<sup>47</sup> is a self-administered 24-item multidimensional instrument that measures 5 independent dimensions of caregiver burden: impact on health, caregiver esteem, impact on schedule, impact on finances, and lack of family support. Extensive reliability and validity testing has demonstrated good internal consistency and stability as well as content, construct, and concurrent validity.<sup>47-50</sup> Using a 5-point scale, respondents indicate their level of agreement with various statements about their feelings regarding caregiving in the past month. Scores for the positive esteem scale range from 1 to 5, a higher score reflects greater esteem and less perceived burden; for the scales schedule, health, finances, and lack of family support, scores also range from 1 to 5, but higher scores represent levels of greater perceived burden. Internal consistency in this sample, measured with Cronbach  $\alpha$  was 0.77, 0.86, 0.86, 0.79, and 0.92 for the subscales of impact on health, caregiver self-esteem, impact on schedule, impact on finances, and lack of family support, respectively.

The SF-12 version 2<sup>51</sup> was used to measure the mental and physical health function of the lung transplant caregivers. Subjects respond to 12 items about health views and functional limitation on a 5-point scale. Additionally, general health is rated from 1 (excellent) to 5 (poor). Adequate reliability has been reported.<sup>51</sup> For this study, 3 summary scores were analyzed: the single general health item, the physical component summary, and the mental component summary. A score above or below 50 was considered above or below normative values.<sup>51</sup>

The POMS-SF<sup>52</sup> was used in this study to measure the psychological affect and mood of caregivers and lung transplant candidates. The instrument contains 37 items; subjects respond to questions about how they have felt during the past week on a 5-point

Likert-type scale.<sup>53</sup> Scores for the POMS-SF can be calculated for a total mood disturbance score and for each of the 6 factors: tension-anxiety (tension), depression-dejection (depression), anger-hostility (anger), vigor-activity (vigor), fatigue-inertia (fatigue), confusion-bewilderment (confusion). The total score can range from -24 to 124; a higher score represents more negative mood. The POMS-SF factor scores each have a different range: tension (0-24), depression (0-32), anger (0-28), vigor (0-24), fatigue (0-20), and confusion (0-20); higher scores also represent greater disturbance for that factor. However, for the vigor factor, a higher score represents greater energy. Good internal consistency for the short form has been reported.<sup>52</sup> Internal consistency of the POMS-SF total score and factor scores in this study was adequate as measured with Cronbach  $\alpha$ : total mood disturbance,  $\alpha = 0.887$ ; tension,  $\alpha = 0.799$ ; depression,  $\alpha = 0.892$ ; anger,  $\alpha = 0.765$ ; vigor,  $\alpha = 0.859$ ; fatigue,  $\alpha = 0.899$ ; and confusion,  $\alpha = 0.821$ .

Demographic characteristics of the caregivers for lung transplant candidates were collected by using a self-report survey and included date of birth, sex, ethnic background, employment status, socioeconomic status, and relationship to the lung transplant candidate. Demographic characteristics of the lung transplant candidates were collected by using a self-report survey and included date of birth, sex, ethnic background, employment status, socioeconomic status, date of symptom onset, and the length of time spent on the transplant waiting list. The lung transplant candidate's respiratory diagnosis, date he or she was listed for transplant, and percent predicted of the most recent measure of forced expiratory volume in 1 second were collected from the medical record.

## Analysis

Data were analyzed only if both the caregiver and candidate completed and returned the questionnaires. Data collected on the QLI, CRA, SF-12, and POMS-SF were first analyzed for a normal distribution. Independent sample *t* tests were used to examine differences between subgroups based on the demographic characteristics of the caregiver. Pearson correlation was used to show relationship between the study variables. Variables that were significantly correlated with the caregivers' total QLI score at a level less than 0.05 were added into a forced entry multiple regression to identify predictors of caregiver QOL. All analyses were performed with Statistical Package for the Social Sciences (SPSS) version 12.0.<sup>54</sup>

## Results

### Sample Characteristics

Thirty-seven lung transplant candidates and their caregivers were eligible for study inclusion during the

recruitment period. Twenty-nine dyads participated, for a response rate of 78%. Reasons given for not participating included the following: patients received their transplant before they returned their booklets ( $n = 4$ ), patient-caregiver dyads were too overwhelmed to participate ( $n = 2$ ), a patient-caregiver dyad who never returned their booklets ( $n = 1$ ), and a patient who died before returning the booklet ( $n = 1$ ).

All sample characteristics are presented in Table 1. The mean (SD) ages of the caregivers (50.43 [12] years) and the lung transplant candidates (52.7 [11] years) were similar. Most caregiver respondents were white wives who were living with the lung transplant candidate. The lung transplant candidates' top clinical diagnoses were emphysema (41.4%) and pulmonary fibrosis (41.4%). Although most of the caregivers were working either full- or part-time, only 8 of the lung transplant candidates were working at the time of data collection, and more than half (55.2%) were receiving disability income because of limitations due to their disease. The lung transplant candidates had been waiting for transplantation from 2 days to 31.6 months (mean, 9 months; median, 8.7 months) at the time of data collection.

### Survey Results

*QLI.* Survey instrument scores are reported in Table 2. The mean caregivers' total score on the QLI was 22.81 (SD, 4.5; range of QLI scale went from 0-30, with 30 representing highest perceived QOL), with mean subscale scores from 21.99 to 23.94. Caregivers' lowest score was on the health and functioning subscale, and the highest reported score was on the social and economic subscales.

The 5 items ranked by caregivers as most satisfying were (1) ability to take care of yourself without help, (2) children, (3) friends, (4) ability to take care of family responsibilities, and (5) faith in God. The 5 items ranked as least satisfying to caregivers were (1) sex life, (2) amount of worries in your life, (3) personal appearance, (4) family's health, and (5) the amount of energy you have for everyday activities.

An examination of the importance rankings for individual items revealed that caregivers, on average, considered all items to be moderately or very important. The lowest importance mean item score was reported for sex life; in contrast, the items ranked as most important were (1) ability to take care of yourself without help, (2) children, (3) how well you can take care of your financial needs, (4) family's health, and (5) the amount of energy you have for everyday activities.

*SF-12.* General health of caregivers as scored on the SF-12 was reported as just slightly above the normative value of 50. Caregivers also scored above the normative value for physical function (mean, 53.10; SD, 8.9), and only slightly below the normative value

Table 1 Sample demographics for caregivers and lung transplant candidates

Characteristic	Group	Caregiver		Lung transplant candidate	
		No.	%	No.	%
Sex	Male	10	34	13	45
	Female	19	66	16	55
Relationship to patient	Spouse	20	69	NA	NA
	Parent	3	10	NA	NA
	Sibling	1	3	NA	NA
	Child	3	10	NA	NA
	Other (friend)	2	7	NA	NA
Living arrangement	With transplant candidate	22	76	NA	NA
	Not with transplant candidate	7	24	NA	NA
Respiratory diagnosis	Emphysema	NA	NA	12	41
	Pulmonary fibrosis	NA	NA	12	41
	Cystic fibrosis	NA	NA	2	7
	Other	NA	NA	3	10
Education <sup>a</sup>	<High school	0	0	4	14
	High school	8	29	6	21
	Some college	11	39	11	38
	College or graduate degree	9	32	8	28
Marital status	Married	27	93	21	72
	Divorced/separated/widowed	0	0	6	21
	Single	2	7	2	7
Ethnicity	White	23	79	23	79
	African American	5	17	5	17
	Asian	1	3	1	3
Work status	Full-time	23	79	5	17
	Part-time	2	7	3	10
	Homemaker	1	3	0	0
	Student	1	3	1	3
	Disabled	0	0	16	55
	Retired	2	7	4	14
Annual household income, <sup>a</sup> \$	<25 000	0	0	5	19
	25 000-50 000	7	26	7	26
	50 001-75 000	5	19	4	15
	75 001-100 000	9	33	8	30
	>100 000	6	22	3	11
Age, mean (SD)		28	50.43 (12.3)	29	52.72 (10.8)
No. of months since diagnosis, mean (SD)		NA	NA	29	83.5 (90)
No. of days on wait list, mean (SD)		NA	NA	29	276 (242)
Forced expiratory volume in 1 second, % predicted, mean (SD)		NA	NA	29	32.76 (18.4)

<sup>a</sup> Incomplete data.

Abbreviation: NA, not applicable.

for mental health function (mean, 48.8; SD, 8). On a scale of 1 (excellent) to 5 (poor) for the item of general health, 64.3% of caregivers rated their health as very good or excellent.

*POMS-SF.* As reported on the POMS-SF, this sample of caregivers reported a wide range of mood (-24 to 52) with a mean score for total mood disturbance of 12.03 (see Table 3 for complete results). The factors that negatively affected mood scores ranged from the highest, fatigue (mean, 6.7; SD, 4.5), to lowest, depression (mean, 3.65; SD, 3.6). This sample of

caregivers scored their level of vigor as fairly good with a mean of 12.17 (SD, 4.9).

*CRA.* Caregiver reaction mean scores of 2.05, 2.60, and 2.19 demonstrate that these caregivers were moderately affected in the areas of health, schedule, and finances, respectively. In contrast, the mean score for caregivers on the esteem subscale (4.29) was very close to the maximum score of 5, representing high self-esteem. The mean score on the lack of family support subscale (1.98) was fairly low, indicating that family support was present for these caregivers.

Table 2 Scores on the quality of life index for 29 caregivers and 29 lung transplant candidates <sup>a</sup>

Scale or subscale	Caregivers	Lung transplant candidates
Quality of Life Index total score		
Mean (SD)	22.81 (4.5)	17.2 (3.8)
Median (range)	21.87 (14.55-29.79)	16.64 (10-24.5)
Health and functioning		
Mean (SD)	21.99 (5.0)	12.55 (4.7)
Median (range)	22.5 (12.9-29.5)	11.93 (3.9-22.1)
Social and economic		
Mean (SD)	23.94 (4.5)	21.29 (4.7)
Median (range)	24.36 (14.57-30)	21.1 (11.9-29)
Psychological/spiritual		
Mean (SD)	22.71 (5.0)	19.04 (4.8)
Median (range)	22.43 (11.57-30)	20.07 (11.4-29.1)
Family		
Mean (SD)	23.59 (5.3)	24.08 (4.7)
Median (range)	22.8 (14.3-30)	25.12 (13.2-30)

<sup>a</sup> Possible range of scores, 0 to 30.

Item frequencies from the CRA revealed that these caregivers felt positive about their experience of caring for a lung transplant candidate. In response to the statement whether the caregivers "feel privileged to care for [the lung transplant candidate]," 82.2% responded that they agreed or strongly agreed. Furthermore, in the response to the items "caring for [the lung transplant candidate] is important to me," and "I enjoy caring for [the lung transplant candidate]," more than 82% of caregivers responded that they agreed or strongly agreed.

In contrast, 30% of this sample either agreed or strongly agreed with the statement "I have eliminated things from my schedule since caring for [the lung transplant candidate]" and 47% of this sample agreed with the statement "My activities are centered around care for [the lung transplant candidate]." Related to the financial impact of caregiving, 15% responded that they agreed or strongly agreed with the statement:

"Caring for [the lung transplant candidate] has put a financial strain on the family." Statements that reflected the impact on health showed that 14% of caregivers responded that they agreed or strongly agreed with the statement: "My health has gotten worse since I've been caring for [the lung transplant candidate]," and 22% agreed with the statement: "Since caring for [the lung transplant candidate], it seems like I'm tired all of the time."

#### Subgroup Comparisons

Independent *t* tests were used to examine subgroup differences for the sample of caregivers. These tests included group comparisons for gender (male, *n* = 10; female, *n* = 17), respiratory diagnosis of the lung transplant candidate (emphysema, *n* = 12; pulmonary fibrosis, *n* = 12; other, *n* = 5), and relationship (spouse, *n* = 20; other, *n* = 9). No significant differences were found between groups tested on characteristics of

Table 3 Scores on the Profile of Mood States-Short Form for 29 caregivers and 29 lung transplant candidates

Factor	Possible score <sup>a</sup>	Caregivers		Lung transplant candidates	
		Mean (SD)	Median (range)	Mean (SD)	Median (range)
Total mood disturbance	-24 to 124	12.03 (20.3)	13 (-24 to 52)	23.52 (21.5)	21 (-17 to 102)
Tension	0-24	5.48 (3.8)	5 (0-13)	7.31 (5.1)	7 (0-21)
Depression	0-32	3.65 (3.6)	3 (0-12)	6.65 (6.2)	5 (0-32)
Anger	0-28	4.55 (4.8)	3 (0-20)	4.6 (5.4)	3 (0-25)
Vigor	0-24	12.17 (4.9)	12 (5-24)	8.62 (4.8)	8 (2-23)
Fatigue	0-20	6.7 (4.5)	7 (0-16)	10.07 (4.8)	9 (0-20)
Confusion	0-20	3.83 (3.9)	3 (0-13)	3.48 (4.1)	2 (0-18)

<sup>a</sup> Possible range of scores for total score and each factor.

respiratory diagnosis or relationship for QLI, SF-12, POMS-SF, or CRA. Significant differences were found between male and female caregivers on the POMS-SF factors of tension ( $P = .02$ ) and confusion ( $P = .03$ ). However, Bonferroni correction for multiple  $t$  tests indicated that significance levels needed to be adjusted to .02. With this correction, only the difference between sexes for tension was statistically significant; male caregivers reported higher levels of tension than female caregivers reported.

### Regression of Caregiver QOL

Multiple hierarchical regression was performed to investigate the relationship of the independent variables: SF-12 general health, POMS factors, and CRA subscales with the dependent variable: total caregiver QLI. Based on significant correlations and using a 2-step approach, the dependent variable total caregiver QLI was forced entered into a regression with each of the independent variables representing mood state and caregiver reaction. In model 1, the 6 independent variables included 5 factors of the POMS-SF (tension, depression, anger, vigor, and fatigue) and the general health item from the SF-12. In model 2, the 4 independent variables were 4 subscales of the CRA: caregiver self-esteem, lack of family support, impact on health, and impact on finance. Then, using the results from models 1 and 2, a final regression was run including the independent variables with significant ( $P < .05$ ) beta weights and moderate partial correlations ( $r_p > 0.4$ ).

Model 1 explained 78% of the variance of overall QOL ( $F = 13.334$ ,  $P < .001$ ); the variables depression and general health contributed a significant amount of unique variance to the model. Model 2 also explained a moderate level of the variance of QOL, 59% ( $F = 8.251$ ,  $P < .001$ ); 2 variables contributed a significant amount of variance to the model: lack of family and impact on finance. Both of these models confirmed a significant relationship between overall caregiver QOL and the independent variables. However, a single model was desired that was consistent with the theoretical model and the parameters for sample size.

In the final regression model, the variables of depression, impact of finance, general health, and lack of family explained 79% of the variance of caregiver QOL ( $F = 21.8$ ,  $P < .001$ ). The final model explained only 0.01 increase in the explained variance of QOL from model 1, yet yielded a larger  $F$  value than model 1 ( $F = 13.33$  vs 21.87) and was more parsimonious because it had fewer independent variables; thus, the final model was considered the best fitting.

### Discussion

The combination of instruments used in this study portrays a multidimensional perspective of caregiver

QOL. Overall, the caregivers reported favorable levels of QOL, health status, and mood state. Even so, some areas were found to be challenging for these caregivers: fatigue, depression, and the impact of transplantation on finances. Areas that were found to be challenging were also found to have a close association to caregiver QOL.

### Caregiver QOL

In general, caregiver QOL was positive. These findings are consistent with findings from a study of caregivers of heart transplant candidates (mean, 21.1; SD, 2.9)<sup>12</sup> and caregivers of heart failure patients (mean, 20.11; SD, 7.6).<sup>55</sup> Conversely, Kurz<sup>14</sup> reported that a combined sample of 9 dyads of caregivers and heart and lung transplant candidates reported lower QOL (mean, 16.14; SD, 3.4) than that reported for this sample; one possible explanation for this discrepancy was the small sample size. Positive findings for these caregivers were also found for the components of QOL, including physical and mental health function and mood state.

Consistent with the findings of positive QOL, most caregivers in this study reported their general health as very good to excellent, as measured with the single general health item on the SF-12. In addition, using the SF-12 physical component summary score, caregiver health function was reported as better than the normative value. These findings are similar to those of Meltzer and Rodrigue,<sup>24</sup> who reported that the caregivers of lung transplant patients reported values on the SF-36 within normal limits. Yet, a more recent study by Rodrigue and Baz<sup>20</sup> found that caregivers' total scores for the SF-36 were poorer than the standardization sample. The finding of essentially normal values for physical and general health in this study may be related to the fact that these individuals are screened for functional capacity by a social worker before being identified as the patient's primary caregiver. Furthermore, caregivers often disregard concern for their own health because of their devotion to the candidate.

The caregivers in this study reported positive levels of general health; however, 15% of the sample responded that their health had gotten worse since caring for the lung transplant candidate. Those caregivers that reported a larger impact on health also reported poorer QOL. The length of time that these caregivers had been providing care for the lung transplant candidate was not measured in this study; however, candidates had been listed for transplant anywhere from 4 days to 30 months. The variability in the length of time these caregivers had been providing care may account for the perceived change in health.

In contrast to the findings of high QOL and general health scores for these caregivers, mental component summary scores on the SF-12 were below the population

mean of 50. The range of scores of mental health, also demonstrated that some caregivers had much lower scores (as much as 2 standard deviations from the mean), indicating poor mental health. This wide range of scores was also demonstrated for the total mood disturbance score on the POMS; caregivers on average did not report mood disturbance. Yet, as evidenced by the large standard deviation, the caregiver scores showed great variability. The findings from these 2 instruments suggest that neither an overall score of mood disturbance nor a summary mental health score may be sensitive enough to describe the mental health of these caregivers. A more specific measure, labeled caregiver self-esteem, was provided by the subscale of the CRA; caregiver scores averaged 4.29 on a scale of 1 to 5, suggesting positive levels of self-esteem in this sample, similar to those reported by Scott,<sup>55</sup> who found similar self-esteem scores. Item responses from the CRA also confirmed the findings of positive self-esteem in this study.

### Challenging Aspects of QOL for Caregivers of Lung Transplant Candidates

In general, measurement scores from this investigation suggest that the caregivers had good QOL, typical general health, and positive self-esteem. However, mean values on total tool scores may not tell the whole story. Qualitative findings in heart and lung transplantation suggest that caregivers report burden from taking over responsibilities that once belonged to the patient, while at the same time relinquishing activities such as social interaction in order to provide care for the transplant candidate.<sup>22,25,26,33,35</sup> Item responses and subscale scores in this study shed light on negative aspects of caregiving during the lung transplant waiting phase that may influence caregiver QOL. According to the strength of the evidence from this study, areas of concern for these caregivers included: fatigue, depression, and the impact of transplantation on finances.

*Fatigue.* Fatigue has not been measured as an independent variable in any other published studies of caregivers for lung transplant candidates. Caregivers in this study scored fatigue as the highest negative mood factor out of tension, depression, anger, and confusion. Validation of this reported fatigue was found on the CRA, with 23% of caregivers responding that they agreed or strongly agreed with the statement "Since caring for [the lung transplant candidate], it seems like I'm tired all the time."

Considering the level of fatigue reported in these caregivers, it is somewhat incongruent that relatively high levels of vigor were also found. The vigor factor is scored in the opposite direction of the other factors, so that higher scores of vigor represent better mood

and higher perceived levels of energy. Similar to these findings, vitality as measured with the SF-36 was reported as better than normative values in 2 studies of caregivers of lung transplant candidates.<sup>27,28</sup> Caregivers' reports of high levels of vigor, however, do not negate their reported fatigue. It may be that even if the caregiver feels worn out and exhausted, he or she stays active and can be cheerful at the same time. Perhaps caregivers feel that they must stay active because they are working and taking on added responsibilities related to caregiving. Kurz and Cavanaugh<sup>22</sup> reported in a qualitative study that 4 of 13 well spouses of lung transplant candidates felt exhausted, but still maintained an active life by continuing to work while taking on additional household jobs. Item frequencies from the CRA revealed a similar dichotomy; 23% of caregivers reported feeling tired all the time, yet over 80% of caregivers responded positively to "caring makes me feel good" and "I enjoy caregiving."

*Depression.* The mean scores for depression reported by this sample of caregivers, as measured by the POMS-SF, were relatively low. However, of a possible score of 32, the caregiver scores ranged from 0 to 12, suggesting that the mean score may not be representative of this sample. Depression yielded the strongest significant correlation to caregiver QOL (total QLI) and the dimensions of QOL for caregivers in this study; caregivers with higher levels of depression also had poorer overall QOL. Martensson et al<sup>13</sup> reported a significant relationship between depression and the mental health summary on the SF-12 in 48 spouses of patients with heart failure. Studies in the caregiving literature often use depression as the dependent variable of study because it is so important in caregiver populations.<sup>11,56,57</sup> In this study, depression was highly negatively correlated with overall QOL, indicating a strong relationship between the 2 variables.

*Financial Burden.* Caregivers in this study reported moderate levels of financial burden related to their caring for a lung transplant candidate. The impact on finances was significantly and negatively correlated with overall QOL and the dimensions of QOL. This finding was supported in a previous study,<sup>30</sup> where 50% of a sample of lung transplant caregivers reported the transplant process as a financial strain. Similarly, financial stressors were listed among the top 10 stressors on a transplant stress scale in a study of caregivers of heart transplant candidates,<sup>58</sup> and the burden of finances was discussed by 100% of the spouses in a qualitative study in heart transplantation.<sup>36</sup> It is important to recognize that the financial burden of transplantation is considerable, particularly after transplant as the medications that must be taken for the transplant patient to survive are very costly.

### Differences Between the Sexes

Differences were found between the male and female caregivers for measures of tension and confusion; specifically, male caregivers reported significantly higher levels of tension than female caregivers reported. All the male caregivers in this study were working full time, which is consistent with reports of male caregivers of elderly care recipients.<sup>1,59</sup> Possibly, the male caregivers had increased tension because of having full-time responsibilities at work in addition to caring for a lung transplant candidate. Not only could this cause increased tension, but it could also lead to the increase in confusion, characterized on the POMS by an inability to concentrate, forgetfulness, and uncertainty about things. Still, it is not entirely clear why the female caregivers also working full time showed lower levels of tension and confusion than did the male caregivers. In studies with mostly female caregivers, work was cited as a form of respite, or a way to concentrate on something else instead of the responsibilities at home.<sup>32,37,38</sup>

For this investigation, 90% of the male caregivers were spouses of the lung transplant candidate, whereas only 56% of the women were spousal caregivers. Studies of caregivers for the elderly and related populations have demonstrated that spouses spend significantly more time providing care than others, such as adult children, and siblings; spousal caregivers also report more burden than children caring for their elderly parents report.<sup>60</sup> The differences found between the sexes could be related to these male spousal caregivers facing the possible loss of their mate. In one study,<sup>61</sup> mortality increased in caregiver spouses whose elderly partner was hospitalized, with male spouses having a higher risk of death than female spouses. The differences between the sexes found in this study are not clearly understood, and additional research in a similar population with larger sample sizes is warranted.

### Relationships Among Health Status, Reaction to Caregiving, and Caregiver QOL

The best statistical model of the relationships among caregiver variables accounted for 79% of the variance of caregiver QOL, with depression explaining the most unique variance, and impact on finances and general health contributing about half as much unique variance. In a sample of dyads of 20 heart failure patients and 18 family caregivers, caregiver mental health and caregiver esteem were identified as significant predictors of caregiver QOL, accounting for 49% of the variance.<sup>55</sup> Another study by Rodrigue et al<sup>29</sup> showed that after 3 months of the patient receiving psychological QOL therapy, 64% of the variance of caregiver QOL was positively associated with a favorable change in the patient's QOL, lower caregiver mood disturbance, shorter transplant waiting time, and social intimacy.

The results of this study differ from those of Scott<sup>55</sup> and Rodrigue et al,<sup>29</sup> in that caregiver esteem or patient QOL did not explain a unique amount of variance of QOL. Rather, a negative component of caregiver reaction, impact on finance, explained a unique amount of variance of QOL in this investigation.

### Conclusions

#### Limitations

The findings of this research investigation must be considered within the confines of certain limitations. The cross-sectional design limited the examination of caregivers to the time before transplantation. Considering the practical constraints of the data collection time, all lung transplant candidates and their caregivers were recruited for study inclusion regardless of the length of time the candidate had already spent on the waiting list. Although the length of waiting time was not related to the independent or dependent variables, the small sample may have masked a significant effect and its impact. Furthermore, the variables chosen for inclusion were based on the caregiving literature, but other variables may contribute to caregiver QOL. The sample characteristics and small size limit the generalizability of the findings. The caregiver sample characteristics, including being white and well-educated with a higher than average income, may be representative of the lung transplant population; however, caution is advised in relating these findings to other caregiving populations demographically. Most subgroup comparisons did not reach statistical significance, which may be related to the small group sizes.

#### Implications for Nursing Practice

The findings from this descriptive study contribute unique information to nursing science about the QOL of caregivers for lung transplant candidates. Results of this study highlight the fact that patients do not experience the process of transplantation in isolation. In fact, transplant nurse coordinators who interact frequently with lung transplant patients and their caregivers may be the group who find these results most useful. Transplant nurses are integral to the team because they are the one stable group of health care providers who initiate and maintain a relationship with the patient-caregiver dyad throughout the pre-transplant phase. The transplant nurse can recognize that the caregiver may have individual needs that are distinct from the patient's needs. It would be ideal for the transplant nurse to meet with the caregiver individually, even for a brief conversation while the patient is completing necessary testing in the clinic. Such an encounter would provide caregivers an opportunity for open communication with the transplant nurse, who can then address the caregiver's personal concerns or the caregiver's concerns related to

the patient. Another way to acknowledge the individual needs of the caregivers is to inform them of support groups designated for caregivers of transplant patients, or Web sites that provide information about aspects of their role. Overall, nurses are urged to ask about and listen to the needs of the caregivers, to develop plans of care that include the caregiver, and to assure caregivers of the importance of the caregiving role in the transplant process.

### Future Research

Nurse researchers can use these study findings to guide future QOL studies in transplantation. Because no other studies of caregivers of lung transplant candidates have considered the association between depression and caregiver QOL, replication is needed to substantiate the findings of the levels of depression for lung transplant candidates and caregivers, as well as the relationship between depression and caregiver QOL. Larger sample sizes are needed to examine caregiver subgroup differences based on sex, respiratory diagnosis, and relation to the lung transplant candidate. Using more than 1 site for data collection may be one way to enable the recruitment of a larger sample. Longitudinal designs with measurement periods before and after transplantation are also needed to examine changes over time.

In summary, this study provides an important contribution to the nursing literature. The combination of instruments used in this study was designed to portray a multidimensional perspective of the caregiver QOL. Caregivers reported positive self-esteem, enjoyment of their role, and overall favorable levels of QOL, general health, and mood state. Despite these positive findings, the areas found to be problematic for these caregivers include fatigue, depression, and the financial impact of transplantation. Finally, the independent variables of depression, general health, impact on finances, and lack of family support accounted for 79% of the variance of caregiver QOL. Depression explained the most significant amount of variance and largest association with caregiver QOL.

It is important for nurses to remember that the patient and caregiver undergo the process of waiting for lung transplant together. Future research is necessary to confirm the findings of this study and to design interventional research useful for improving the QOL of the lung transplant candidate-caregiver dyad.

### Financial Disclosures

None reported.

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