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# Quality of Life and Meaning of Illness of Women With Lung Cancer

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**Purpose/Objectives:** To describe the quality of life (QOL) of women with non-small cell lung cancer (NSCLC) and examine relationships of demographic, clinical, health status, and meaning of illness (MOI) characteristics to QOL.

Design: Descriptive, cross-sectional survey.

Setting: In-person interviews in homes or research offices.

**Sample:** 217 women with NSCLC ( $\geq$  6 months and  $\leq$  5 years since diagnosis,  $\overline{X}$  = 2 years); 19% of the women had advanced disease. The mean age was 65 years.

**Methods:** Assessments of QOL with cancer-specific (QOL Scale-Patient Version) and generic (Short Form-36) self-reports, health status (i.e., number and type of comorbid conditions, presence of depressed mood using the Center for Epidemiologic Studies—Depression Scale, smoking status), and MOI (positive and negative perceptions).

Main Research Variables: QOL, health status, MOI, and demographic and clinical characteristics.

**Findings:** Serious disruptions in psychological and social aspects of QOL were common. Depressed mood, negative conceptualizations of MOI, and younger age explained 37% of the variance of global QOL and were correlated with poorer physical, psychological, and social dimensions of QOL. Thirty-six percent reported negative ascriptions of MOI; 35% experienced depressed mood; more than 75% reported distress with their diagnosis, family distress, and impact of sexual function as lowering their QOL; and 67% reported comorbid conditions, the most common being chronic obstructive pulmonary disease (31%).

**Conclusions:** Women with lung cancer experience a range of disruptions in QOL, and more than a third associate lung cancer with negative meaning. Younger age, depressed mood, and number of comorbid diseases are risk factors for negative QOL.

**Implications for Nursing:** These findings support the importance of assessing the QOL, MOI, and health status of women with lung cancer even after treatment is completed. Younger women may be at higher risk for disruptions.

Information about patients' quality of life (QOL) can be important to healthcare providers in identifying anticipated areas of distress (Montazeri, Milroy, Hole, McEwen, & Gillis, 2003). Despite the incidence of lung cancer among

## **Key Points...**

- ➤ Lung cancer has been the leading cause of cancer death for women since 1987; however, information guiding assessment and interventions to support quality of life (QOL) is limited.
- ➤ Most women reported numerous serious disruptions in psychological and social well-being and viewed their illness as a challenge.
- ➤ Depressed mood, negative conceptualizations of the meaning of illness, and younger age were predictive of poorer global, physical, psychological, and social QOL.
- ➤ The number of comorbid conditions, with the most common being chronic obstructive pulmonary disease, was related directly to physical QOL.

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women, information about the QOL of women living with this disease is limited. Lung cancer has been the major cause of cancer-related death and morbidity in women, surpassing breast cancer in 1987, and rates continue to increase (Patel, Bach, & Kris, 2004). In 2004, lung cancer accounted for 25% of all female cancer deaths—more deaths than breast, ovarian, and uterine cancers combined (Centers for Disease Control and Prevention [CDC], 2002a, 2002b; Jemal et al., 2004). Disturbing evidence from a recent lung cancer screening trial suggests that women who smoke are more susceptible to lung cancer than men (Henschke & Miettinen, 2004); therefore, as incidence increases, obtaining information about QOL in women with lung cancer is essential in devising interventions to prevent or reduce distress.

#### Literature Review

#### **Quality of Life and Lung Cancer**

QOL is a multidimensional phenomenon that can be influenced by the experience of living with lung cancer (Cooley, 1998; Gralla & Moinpour, 1995; Zieren, Muller, Hamberger, & Pichlmaier, 1996). The experience of living with a potentially fatal illness such as lung cancer can have negative and positive influences on physical, psychological, social, and spiritual dimensions of daily living (Zebrack, 2000). In comparison with patients with other cancer types, patients with lung cancer report the greatest amount of psychological distress (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Disruptions in QOL are important to monitor during the entire continuum of the disease, from diagnosis to treatment, during recovery and rehabilitation, and living with advancedstage disease. Although QOL data frequently are obtained in clinical trials for advanced lung cancer, information is limited about QOL after the initial diagnosis and treatment when individuals continue to live with the disease and are faced with the possibility of recurrence and metastasis. Few researchers have reported QOL during the postoperative phase or among long-term survivors (Dales et al., 1994; Mangione et al., 1997; Montazeri, Gillis, & McEwen, 1998; Sarna et al., 2002).

Data from female survivors of cancer indicate that women have significantly poorer scores on physical, psychological, and social components of QOL but higher ratings of spiritual well-being (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995). The QOL and demands of illness experienced by women with lung cancer may be different than men because of competing household, childcare, and other role-related demands (Sarna, 1993a, 1993b). In the only known study specifically focused on the QOL of women with lung cancer, the most common serious disruptions were fatigue, difficulty in household chores, and worry about the ability to care for oneself (Sarna, 1993b).

A variety of factors affecting the QOL of patients with lung cancer have been suggested, including clinical, demographic, and health status characteristics. The meaning of illness (MOI) also has been suggested to influence the way that women with cancer perceive their QOL (Degner, Hack, O'Neil, & Kristjanson, 2003; Wallberg et al., 2003). To date, MOI has not been explored in women with lung cancer. In part because of the stigma (Chapple, Ziebland, & McPherson, 2004) and the disease severity of lung cancer, negative conceptualizations of illness may be more likely in women with lung cancer than women with breast cancer and may be negatively related to QOL.

#### **Clinical Characteristics**

Lung cancer characteristics, especially metastasis, may affect QOL (Montazeri et al., 1998). These disease-related variables may be different for women compared to men. For example, women often are diagnosed after a shorter history of smoking, have less tobacco-related comorbidity, and have increased incidence of adenocarcinoma histology (Ouellette, Desbiens, Emond, & Beauchamp, 1998; Patel et al., 2004). Lung cancer generally is diagnosed at an advanced stage, and overall survival mirrors the stage of disease at diagnosis; for example, if in an advanced stage at diagnosis, African American and Caucasian women have a 13.5% and 16.6% five-year survival, respectively, whereas 16% of all women diagnosed with localized disease have a 52.5% survival rate (Ries et al., 2000). The presence of metastatic disease is associated with increased symptoms and decreased QOL (Cooley, 1998; Cooley, Short, & Moriarty, 2002; Sarna, 1993a). Although side effects of treatment may decrease QOL in the short term, the positive benefits in the long term may improve QOL. In addition, length of time since diagnosis may affect QOL because survivors adjust to living with a chronic disease (Maliski, Sarna, Evangelista, & Padilla, 2003).

#### **Demographic Characteristics**

A variety of demographic characteristics have been linked with QOL and lung cancer. Previous study findings of QOL in women with lung cancer (Sarna, 1993b) indicate that significantly greater disruptions occurred in younger women. In addition, being married has been linked with better QOL among patients with lung cancer (Ganz, Lee, & Siau, 1991), but this relationship was not supported in a report of disease-free lung cancer survivors (Sarna et al., 2002). Differences in race have been reported with higher QOL among non-Caucasian lung cancer survivors (Sarna et al.).

#### **Health Status**

In addition to a cancer diagnosis, chronic physical and mental illnesses have the potential to affect all aspects of QOL; however, they rarely are reported in QOL studies of people with cancer. In 60 women with advanced non-small cell lung cancer (NSCLC), comorbid disease was associated with more severe symptoms (Sarna & Brecht, 1997). Although not all women with lung cancer have a history of smoking, tobacco-induced comorbidity may be more common among those affected with this disease (Tammemagi, Neslund-Dudas, Simoff, & Kvale, 2004). Including lung cancer, almost 9 million Americans were affected by tobacco-attributed conditions in 2002 (CDC, 2003). Among current and former smokers, these chronic conditions include chronic bronchitis (35%), emphysema (24%), heart attack (19%), other cancers (12%), and stroke (8%) (CDC, 2003).

Self-reported depressed mood has the potential to affect evaluations of QOL. Passik et al. (1998) suggested that health-care professionals underestimate depression among people with cancer, which affects an estimated 25%. Depression has been reported among patients diagnosed with lung cancer, especially those with advanced-stage disease, at rates higher than the general population (Ginsburg, Quirt, Ginsburg, & MacKillop, 1995; Hopwood & Stephens, 2000; Montazeri et al., 1998), and has been linked to decreased survival (Buccheri, 1998; Faller, Bulzebruck, Drings, & Lang, 1999; Ganz et al., 1991). Akechi, Okamura, Nishiwaki, and Uchitomi

(2001) reported that psychiatric disorders among 129 patients with unresectable NSCLC included nicotine dependence (67%) and major depression (5%). Women with NSCLC reported more psychological symptoms than men (Hopwood & Stephens, 1995). Even among survivors of NSCLC, depression has been reported. Uchitomi et al. (2000) found that 6% of 223 patients with NSCLC had minor or major depression three months after thoracotomy. Sarna et al. (2002) reported that 22% of disease-free survivors had depressed mood.

Former and continued tobacco use has the potential to affect multiple aspects of QOL after a diagnosis of cancer. A diagnosis of lung cancer can be a strong motivation to quit smoking, and in comparison to other smokers, individuals with lung cancer have been reported to have increased quit rates (Cox, Patten, et al., 2002; Cox, Sloan, et al., 2002). Women with lung cancer appear to have even higher quit rates than men with lung cancer (Gritz, Nisenbaum, Elashoff, & Holmes, 1991).

#### Meaning of Illness

The positive or negative attribution of a cancer diagnosis has been postulated to be an important factor influencing QOL (Degner et al., 2003). Degner et al. developed an MOI instrument, which was tested in a study of 1,012 Canadian women with breast cancer. In that study, the majority of the participants selected categories associated with positive MOI. Those who selected negative MOI were more likely to have late-stage disease, be younger, and have poorer emotional well-being. No differences were found in time since diagnosis, type of treatment, or level of education. Minimal change was reported in ascriptions of MOI in a three-year follow-up.

## **Conceptual Framework**

A multidimensional QOL framework, including physical, psychological, social, and spiritual dimensions, provided the conceptual underpinnings for this study (Ferrell, Dow, & Grant, 1995). QOL was viewed as dynamic and influenced by the experience of living with lung cancer (Gralla & Moinpour, 1995; Zieren et al., 1996). In this study, demographic and clinical characteristics, health status (comorbid disease, depressed mood, tobacco use), and MOI were hypothesized as factors that might influence perceptions of QOL.

## **Purpose**

The purposes of this article are to (a) describe the QOL among women living with a diagnosis of NSCLC, (b) describe the ascriptions of MOI, and (c) explore the demographic, clinical, health status, and MOI correlates of QOL. This article reports baseline data from a prospective six-month study. The following research questions were addressed.

- What is the QOL of women after a diagnosis of lung cancer?
- What are the health status characteristics (number of comorbid conditions, depressed mood, tobacco use) of women with lung cancer?
- What meaning do women attribute to their lung cancer diagnosis?
- Controlling for time since diagnosis, to what extent are demographic, clinical, health status, and MOI characteristics related to QOL?

In this study, the researchers hypothesized that women with negative connotations of MOI, poorer health status (comorbid disease, depressed mood, current smoking), and metastatic disease would have lower ratings of QOL.

## Methods

#### Design

A prospective, cross-sectional, descriptive design was used to describe the QOL of women who had been diagnosed with NSCLC. To enhance the generalizability of the findings, data collection sites in the western, eastern, and southern regions of the United States were selected for recruitment of women from a range of socioeconomically, ethnically, and geographically diverse populations. The study was approved by the institutional review board at the University of California, Los Angeles, and at each of the participating institutions (Yale University; University of Alabama at Birmingham; University at Buffalo, State University of New York; Medical College of Georgia). Multiple clinical sites were used for recruitment within each region. To ensure compliance with the standard procedure, the principal investigator visited each site and facilitated communication among the team with techniques described by Cooley et al. (2003), including frequent conference calls, e-mails, and a newsletter.

#### Sample and Setting

Women were eligible to participate if they had been diagnosed at least six months and less than five years prior to study entry. This lag time after diagnosis was purposeful in that it allowed the researchers to focus on the range of experiences of women living with lung cancer, including the recovery period after active treatment. Only women with a histologically or cytologically proven diagnosis of NSCLC, as verified by the treating physician, tumor registry, or medical record, were eligible to participate. Women who had experienced a recurrence of lung cancer or a second primary lung cancer were eligible. Exclusion criteria included diagnosis with small cell lung cancer or other types of cancer involving the lung (e.g., mesothelioma, lung metastasis, carcinoid).

In total, 353 women were screened for study participation. Of these, 313 (89% of those screened) were eligible, and 231 (74% of those eligible) agreed to participate; 217 completed data for the outcome variables and therefore are the subjects of this report.

#### Instruments

Quality of life: QOL was assessed by a cancer-specific and a generic QOL instrument. This allowed the researchers to compare the findings with those of other patients with cancer; because some of the participants potentially were cured of their cancer, a measure was used that allowed for comparison of the findings with the general population of women with chronic illness. The 41-item QOL Scale-Patient Version (QOL-Patient) was used as a cancer-specific measure of QOL (Ferrell & Dow, 1997; Ferrell, Dow, & Grant, 1995). Sarna et al. (2002) validated this instrument in a population of lung cancer survivors. Participants responded to questions based on their experience of how cancer affected their QOL (i.e., "based on your life at this time"). Individual items use a Likert-type scale ranging from 0–10 and are comprised of four subscales (physical, social, psychological, and spiritual

well-being). The QOL-Patient total score (average across all items) and the four QOL-Patient subscale scores were used as outcomes. Possible subscale scores range from 0–10. Transformations were performed on items such that higher scores indicate better QOL for all of the items. The reliability (Cronbach's alpha) for this sample ranged from 0.71–0.91 for all subscales and for the global score.

The multidimensional **Short Form-36 Item** (**SF-36**) Rand Version 1.0 was used as a generic measure of QOL (Hays & Morales, 2001). This 36-item self-report evaluates eight concepts (physical functioning, bodily pain, role limitations caused by physical health, role limitations caused by emotional problems, emotional well-being, social functioning, vitality and fatigue, and general health perceptions). The time frame for all items is within the past four weeks. Using scores from individual scales, a physical component score (PCS) from physical functioning, role-physical, bodily pain, and general health scales and a mental component score (MCS) from vitality, social functioning, role-emotional, and mental health scales were determined. These standardized scores range from 0–100, with higher scores indicating better QOL. These summary measures can be compared with percentile scores for the general female population (Ware, Kosinski, & Dewey, 2000; Ware, Kosinski, & Keller, 1994). The SF-36 has well-established reliability and validity and has been reported to be sensitive to changes after thoracic surgery for NSCLC (Mangione et al., 1997). Cronbach's alpha coefficient of the SF-36 for this study was 0.95.

Meaning of illness: MOI was assessed according to Degner et al.'s (2003) description. Eight cards with individual statements describing illness as positive (i.e., a challenge or a value), negative (i.e., an enemy, a terrible loss that can not be replaced, a punishment, or a weakness), or other meaning (i.e., relief, strategy, or write-in comments) were placed all at once before the participant. Each woman was asked to select the card that best matched her view of her illness. This instrument has been used to evaluate perceptions of illness in women with cancer (Wallberg et al., 2003). Comparisons of positive and negative response categories across a six-month data collection period for this sample of women with lung cancer revealed that this was a stable and reliable measure. Percent agreement was 79%, 77%, and 84% for positive MOI categories and 63%, 59%, and 62% for negative MOI categories (kappa < 0.001) at baseline to three months, three months to six months, and baseline to six months, respectively.

Health status: Health status was evaluated in several ways. The presence of comorbid diseases was assessed by a valid and reliable self-report using a list of conditions from the well-established Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987; Elixhauser, Steiner, Harris, & Coffey, 1998; Katz, Chang, Sangha, Fossel, & Bates, 1996). In this article, the frequency of specific conditions is described and the total number of conditions was used in the analysis. This procedure was used in a study of survivors of lung cancer (Sarna et al., 2002) and a study of the impact of comorbid conditions on lung cancer survival (Tammemagi et al., 2004).

Tobacco history and current smoking status were obtained through self-report and biochemical verification. Survey questions were based on items from the **Behavioral Risk Factor Survey** (CDC, 2000) and the **Fagerstrom Test for Nicotine Dependence** (Fagerstrom, 1978; Fagerstrom & Schneider, 1989). Biochemical validation of smoking status was per-

formed at the time of the interview using a urine sample and cotinine dipstick (Nicometer, Jant Pharmacal Corporation, Ventura, CA) to confirm reliability of the self-report (Parker et al., 2002; SRNT Subcommittee on Biochemical Verification, 2002). Patients who reported not smoking were reclassified as smokers if they scored positive for cotinine (i.e., 2 or higher out of 6) on the dipstick.

Depressed mood was considered a comorbid condition and assessed using the Center for Epidemiologic Studies-Depression Scale (CES-D) (Lewisohn, Seeley, Roberts, & Allen, 1997; Radloff, 1977; Radloff & Teri, 1986). Total scores range from 0-60, with scores greater than 15 indicating potential depression. This instrument has been used to evaluate depressive symptoms in patients with cancer (Hann, Winter, & Jacobsen, 1999) and has acceptable reliability and validity. Discrimination between healthy and clinical samples has been reported (Lewisohn et al.). A cut-off point for the CES-D score was used to group women with (i.e., scores  $\geq 16$ ) and without (scores < 16) depressed mood. This dichotomous grouping was used in the analysis rather than the total score because of the overlap of some items in the CES-D with items in the QOL instruments. The Cronbach's alpha for the CES-D in this sample was 0.87.

Demographic and clinical variables: Demographic data (i.e., age, marital status, race or ethnicity, educational level, employment status, living arrangements) were collected on a self-report survey. Height and weight (with participants fully clothed) were measured at the time of the interview using a standardized protocol, and body mass index (i.e., weight in kilograms divided by height in meters<sup>2</sup>) was calculated because weight can be affected by disease and treatment (Evangelista, Sarna, Brecht, Padilla, & Chen, 2003). Height was measured using a metal ruler (Stanley Model 33-158, New Britain, CT) at baseline. Weight was assessed using an electronic strain gauge scale with a digital reading. Body mass index was considered a continuous variable and categorized in quartiles (20, 20–25, 26-30, and > 30). Patients with a body mass index of 26 or more were considered overweight, and more than 30 were considered obese (Flegal, Carrol, Kuczmarski, & Johnson, 1998).

Clinical characteristics assessed via the medical record included the NSCLC histology, stage of disease at diagnosis, time since diagnosis, and type and extent of treatment. Because of potential changes in disease status since initial diagnosis, investigators evaluated the extent of disease at the interview as local (stage 1), regional (presence of lymph nodes, stage II or III), or advanced (presence of metastasis, stage IV) based on medical information and self-report. For women who had undergone surgical treatment, the extent of surgery was described. The presence and type (chemotherapy, radiation therapy) of current treatment status also were assessed.

#### **Procedure**

Potential participants were recruited via materials approved by the institutional review board, including letters, flyers in oncology offices, and advertisements. Several strategies were used for recruitment, including identification of potential participants through tumor registries as well as through thoracic surgical, medical, and radiation therapy oncology practices. Direct appeals to women with NSCLC through institutional review board-approved newspaper advertisements and television and radio announcements were used at some sites (Cooley et al., 2003). A telephone script was used to ensure that consistent

information was provided about the study. Information about the clinical characteristics of lung cancer and its treatment was obtained from medical records. Interviews occurred in the subjects' homes or in research offices, and participants were paid \$25 for their time and effort.

#### Data Analyses

Analysis included descriptive statistics, as appropriate, to provide a profile of the sample and variables. To examine the prevalence of the most serious QOL disruptions (reported by ≥ 20% of the participants), responses to individual items from the QOL-Patient questionnaire rated as stressful (0 with the anchor "most distressing" to 4 on a 10-point scale) were rank ordered by subscale. Similarities between the scores on the generic QOL measure (SF-36 PCS and MCS) and the normative values for women aged 55–64 years were examined (Ware et al., 2000).

As a preliminary screen, the bivariate associations of each of the potential demographic, clinical, health status, and MOI predictors with QOL outcomes were examined. Analysis of variance methods or chi-square was used to determine discrete predictors (e.g., smoking status), and Pearson or Spearman (rank order) correlations were used for continuous predictors (e.g., age).

Variables that were related at least modestly to some of the QOL subscales in the preliminary analyses were included in the regression analysis. Stepwise regression, with time since diagnosis entered first, was used to examine multivariate models for each of the QOL outcomes (QOL-Patient global score and subscales, and the SF-36 PCS and MCS). Dummy variables for this analysis included demographics (race [non-Caucasian = 0, Caucasian = 1], married or partnered [no or yes]) and health status (depressed mood [no = 0, yes = 1], current smoker [no = 0, yes = 1]), and clinical variables (advancedstage disease [no = 0, yes = 1]). MOI statements were grouped as positive or negative (0 = negative, 1 = positive). All statistical procedures were conducted at the University of California, Los Angeles, according to a schema developed by the investigators and principal statistician. All questionnaires were reviewed for completeness. A random sample of 20% of the data was doubleentered and assessed for reliability. Because of the primary focus on exploration, no statistical adjustment for multiple tests was performed; thus, conservative interpretation is suggested. Statistical analysis was carried out using SPSS® (SPSS Inc., Chicago IL, version 11.5), and alpha was set at 0.05.

#### Results

#### Demographic, Clinical, and Health Status Characteristics

The description of the sample, including demographic and health status characteristics, is provided in Table 1. The majority had at least one comorbid condition (n = 146, 67%): 30% (n = 64) had only one condition, 18% (n = 38) had two, 11% (n = 23) had three, and 10% (n = 21) had four to six other illnesses. The most common comorbid conditions were chronic obstructive pulmonary disease (n = 68, 31%), heart disease (n = 34, 16%), rheumatoid arthritis (n = 34, 16%), asthma (n = 31, 14%), and stomach ulcers (n = 25, 12%). Twenty-four (20%) participants reported a history of other cancers: skin (n = 11), breast (n = 9), colon (n = 3), and cervical (n = 1). The majority (76%) of these cancers were diagnosed prior

Table 1. Descriptive Statistics of Demographic and Health Status Characteristics

Characteristic	$\overline{\mathbf{X}}$	SD	Range
Age (years)	65.00	12.00	33.0-89.0
Years of education	13.00	3.00	6.0-24.0
Number of comorbid diseases	1.38	1.38	0.0-6.0
CES-D	12.97	9.75	0.0 - 45.0
Body mass index	27.62	6.07	16.7–46.4
Characteristic	n		%
Age (≥ 65 years)	124		57
Race			
Caucasian	184		85
African American	23		11
Asian or Pacific Islander	3		1
Other	7		3
Ethinicity			
Of Hispanic origin	3		1
Geographic location			
East	87		40
West	76		35
South	54		25
Religion			
Protestant	122		56
Catholic	67		31
Jewish	20		9
Other	8		4
Marital status			
Married	104		48
Widowed	59		27
Separated or divorced	43		20
Never married	11		5
Living arrangements			
Alone	78		36
With others	139		64
Currently employed	53		24
Depressed mood			
≥ 16 (CES-D score)	76		35
Smoking status			
Former	160		74
Current	29		13
Never	28		13

N = 217

CES-D—Center for Epidemiologic Studies-Depression

to the lung cancer diagnosis. Most of the participants (54%) were overweight (body mass index > 26), including 30% who were obese (body mass index > 30). Eighty-seven percent (n = 189) of the participants had a history of smoking, and 99% of those women who were smoking at the time of diagnosis (n = 120) tried to quit at diagnosis, but only 57% were able to do so. Thirty-five percent (n = 76) reported a CES-D score of 16 or more, indicating depressed mood. Lung cancer disease and treatment characteristics are displayed in Table 2.

#### Quality of Life

The mean QOL scores (QOL-Patient scores and SF-36 PCS and MCS) are displayed in Table 3. The most distressing QOL disruptions reported in each of the QOL-Patient subscales are shown in Table 4. At least half of the respondents rated seven items in the psychological QOL subscale as most distressing.

Table 2. Descriptive Statistics of Clinical Characteristics

Characteristic	n	%
Type of non-small cell lung cancer		
Adenocarcinoma	168	77
Squamous	27	12
Large cell	8	4
Other	14	6
Time since diagnosis		
$\overline{X}$ = 24 months	_	_
SD = 16 months	_	_
Range = 6-60 months	-	_
< 1 year	69	32
1–2 years	65	30
> 2 years	83	38
Stage at interview		
Local	105	48
Regional	71	33
Advanced (metastasis)	41	19
Surgical treatment	177	82
Type of surgery		
Lobectomy	129	73
Wedge resection	36	20
Pneumonectomy	10	6
Other	2	1
Presence of recurrence	25	12
Undergoing treatment	28	13
Chemotherapy	24	11
Radiation	2	1
Chemotherapy and radiation	2	1

N = 217

*Note.* Because of rounding, not all percentages total 100.

In descending order of frequency, these were distress with diagnosis, fear of metastasis, fear of diagnostic tests, distress with treatment, fear of recurrence, anxiety, and fear of second cancer. In the social subscale, two items were rated distressing by more than 75%: impact on sexual function and distress with family. Uncertainty was rated as most distressing by the majority of women in the spirituality subscale. No items in the physical subscale were distressing to the majority of women.

#### Meaning of Illness

Table 5 displays the frequency of ascriptions of MOI. Most participants (63%) reported positive meanings, with 53%

reporting "illness as a challenge" as the best descriptor of their lung cancer.

#### Correlates of Quality of Life

Age, race, marital status, presence of metastasis, number of comorbid conditions, current smoking status, depression, and MOI were found to be related at least modestly to some of the QOL subscales. Thus, QOL outcomes were regressed on these variables using several models. The results of the stepwise regressions, with time since diagnosis as a covariate, are displayed for the QOL-Patient global score, each of the QOL-Patient subscale scores, and the SF-36 PCS and MCS in Table 6. Depressed mood, negative MOI, and younger age were significant correlates of poorer QOL in most of the models. Presence of metastasis contributed to poorer QOL in the social subscale, and 37% of the variance in global QOL was related to depressed mood, negative conceptualizations of MOI, and younger age.

#### Discussion

The findings of this study provide important information about the issues and concerns of women living with lung cancer and provide direction for the development of future interventions. Women in this study had similar complaints of serious fatigue and pain as did disease-free survivors (Sarna et al., 2002) and women with lung cancer (Sarna, 1993a) in two other studies. However, in the current study, women with lung cancer had substantially more disruptions in psychological well-being, especially relative to their distress about their disease and treatment as well as fears about metastasis or recurrence. Moreover, most indicated that the impact of their disease on sexual functioning and family distress seriously affected their social well-being. The SF-36 PCS and MCS averages (40.57 and 49.6, respectively) were substantially lower than the 50th percentile normative scores for older adults (PCS = 49.86, MCS = 54.34) (Ware et al., 1994), but they were similar to the physical QOL ratings for male and female disease-free survivors (PCS = 41.5) and emotional QOL ratings (MCS = 51.96) (Sarna et al.).

As anticipated, health status was related strongly to physical QOL. More than two-thirds of the participants had at least one comorbid condition, and chronic obstructive pulmonary disease was most prevalent (31%). This might be expected in a group where most were former or current

Table 3. Descriptive Statistics of Quality-of-Life Scores

Quality-of-Life Instrument	$\overline{\mathbf{X}}$	SD Range		Possible Range	
Quality of Life-Survivor <sup>a</sup>					
Global score	6.27	1.42	1.53-9.07	0-10	
Physical subscale	7.73	1.59	2.00-10.00	0-10	
Spiritual subscale	6.48	2.06	1.00-10.00	0-10	
Social subscale	6.35	0.35	0.63-10.00	0-10	
Psychological subscale	5.57	1.85	0.44-9.56	0-10	
Short Form-36 <sup>a</sup>					
Mental component score	49.60	10.68	17.47-69.29	0-100	
Physical component score	40.57	10.74	14.90-64.59	0-100	

N = 217

<sup>&</sup>lt;sup>a</sup> A lower score indicates poorer quality of life.

Table 4. Frequency and Mean Item Scores of Most Distressing Items on Quality-of-Life Scale-Patient Version Subscales

Quality-of-Life Subscales	%	$\overline{\boldsymbol{X}}^{b}$	SD
Psychological well-being			
Distress with diagnosis	76	2.1	2.9
Fear of metastasis	69	3.3	2.8
Diagnostic tests	62	3.9	2.6
Distress with treatment	59	3.8	3.4
Recurrence	53	4.2	3.6
Anxiety	51	4.7	2.4
Fear of second cancer	50	4.4	3.6
Change in self-concept	40	5.7	3.3
Change in appearance	39	5.8	3.3
Distress since treatment	30	6.3	3.2
Lack of control	23	6.7	3.0
Problems with concentration	23	6.5	2.7
Feeling useless	23	6.7	2.7
Social well-being			
Impact on sexual function	77	4.4	2.3
Distress with family	77	2.6	2.5
Interfere with activities at home	30	6.2	3.2
Financial burden	28	6.7	3.6
Interfere with employment	26	7.2	4.0
Feelings of isolation	21	7.6	3.2
Spiritual well-being			
Uncertainty	54	4.5	3.5
Spirituality not important	33	6.0	3.9
Spirituality less important	21	6.8	3.5
Physical well-being			
Sleep disruption	29	7.1	3.0
Fatigue	27	5.9	2.9
Pain	22	6.6	2.9

N = 217

smokers. Despite the fact that the majority had early-stage disease, more than a third of the participants had depressed mood. The number of comorbid conditions and depressed mood was related to lower physical QOL. Other researchers also reported possible depression in patients with curative disease (Myrdal, Valtysdottir, Lambe, & Stahle, 2003; Sarna et al., 2002; Uchitomi et al., 2000). Additionally, being unmarried was related to lower functioning in the PCS, and younger age was related to lower QOL-Patient scores. Surprisingly, none of the clinical variables was significant.

Thirteen percent of the participants continued to smoke, but smoking status, as reported by others, was not correlated to QOL (Myrdal et al., 2003); however, the sample of continuing smokers was small. Almost all of the women who smoked tried to quit at diagnosis. Cessation can reduce lung cancer recurrence, reduce the risk of second primary disease, and increase survival, and patients with lung cancer generally have a higher quit rate than patients with other cancers (Cox, Africano, Tercyak, & Taylor, 2003; Cox, Patten, et al., 2002; Cox, Sloan, et al., 2002). Even for patients with advanced-stage disease, cessation can provide psychological as well as physical benefits (Garces & Hays, 2003).

Although not a significant correlate of QOL in this study, the number of women who could be categorized as over-

weight or obese was more than anticipated. Information is limited about weight among cancer survivors, but weight loss is an indication of poor prognosis for patients with advanced lung cancer. However, in a sample of long-term lung cancer survivors, 51% were overweight, including 16% in the obese category, with a 7% mean weight gain after diagnosis (Evangelista et al., 2003). More study is needed to determine the prevalence of being overweight in this population and how it affects health status. Being overweight may be a consequence of decreased activity caused by decreased pulmonary function or other conditions related to lung cancer and its treatment.

As expected, depressed mood contributed to explanations of poorer psychological well-being. Negative meaning of illness and younger age also were significant factors related to poorer QOL. Thirty-six percent of the women described MOI in negative terms, which was substantially more than the 12% reported by a sample of women with breast cancer (Degner et al., 2003). Similar to Degner et al.'s findings, 53% reported "challenge" as the single most commonly selected descriptor of MOI. Lung cancer may be viewed as a disease associated with guilt from tobacco use, but only 7% viewed their diagnosis as a punishment in this study. However, a greater percentage (18%) of women with lung cancer, as compared to the 8% of women with breast cancer, viewed their cancer as an "enemy." Cultural differences may exist in the interpretations of words and meanings associated with a cancer diagnosis (Wallberg et al., 2003). Degner et al. suggested that the positive MOI expressed by a majority of women with breast cancer reflected a determination to fight the disease. This same resolve also was seen in the responses of the majority of women with lung cancer in this sample.

A qualitative study of 45 patients with lung cancer in the United Kingdom (no information was given on gender) revealed that many participants reported a stigma and blame associated with lung cancer because of the link of the disease to smoking (Chapple et al., 2004). This was felt by some to negatively affect their interactions with healthcare professionals and access to care. The current study did not address the issues that might have affected MOI. Further exploration of the psychological mechanisms involved in characterizing cancer for patients with lung cancer and the impact of that characterization on overall QOL is needed.

Similar to findings of lung cancer survivors (Sarna et al., 2002), being non-Caucasian was correlated with higher levels of spiritual QOL, along with positive MOI. Depressed mood

Table 5. Frequency of Attributions of Meaning of Illness

Meaning of Illness	n	%
Positive meaning	137	63
A challenge	115	53
A value	22	10
Negative meaning	77	36
An enemy	40	18
A loss	16	7
A punishment	14	7
Weakness	7	3
Other meaning	3	1
Relief	3	1

N = 217

<sup>&</sup>lt;sup>a</sup> Most distressing ranged from 0-4 on a 0-10 scale, with 0 being the worst possible.

<sup>&</sup>lt;sup>b</sup> A lower item score indicates poorer quality of life.

Table 6. Summary of Seven Models Regressing Quality-of-Life Scores on Selected Variables Controlling for Time Since Diagnosis

Regression Model	b	t	р	Adjusted R <sup>2</sup>	F (1, 216)
Quality-of-Life Scale–Patient Version					
<ul> <li>Global</li> </ul>				0.370*	32.649
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.475	-8.708	0.001		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.269	4.923	0.001		
- Age	0.176	3.241	0.001		
<ul> <li>Social subscale</li> </ul>				0.351*	24.385
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.394	-7.111	0.001		
- Age	0.306	5.525	0.001		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.170	3.075	0.002		
<ul> <li>Presence of metastasis<sup>c</sup></li> </ul>	-0.154	-2.798	0.006		
Psychological subscale				0.305*	24.718
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.427	-7.447	0.001		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.237	4.135	0.001		
- Age	0.175	3.056	0.003		
Physical subscale				0.251*	15.464
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.347	-5.739	0.001		
<ul> <li>Number of diseases</li> </ul>	-0.176	-2.881	0.004		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.134	2.227	0.027		
- Age	0.201	3.351	0.001		
Spiritual subscale				0.140*	8.054
<ul> <li>Whether Caucasian<sup>d</sup></li> </ul>	-0.219	-3.414	0.001		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.199	3.116	0.002		
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.171	-2.682	0.008		
- Age	-0.150	-2.333	0.021		
Short Form-36					
Mental component score				0.320	51.823
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.569	-10.098	0.001		
Physical component score				0.181	10.573
<ul> <li>Depressed mood<sup>a</sup></li> </ul>	-0.216	-3.425	0.001		
<ul> <li>Number of diseases</li> </ul>	-0.206	-3.221	0.001		
<ul> <li>Meaning of illness<sup>b</sup></li> </ul>	0.171	2.721	0.007		
<ul> <li>Marital status<sup>e</sup></li> </ul>	0.134	2.146	0.033		

N = 217

Note. Independent variables entered in regression were time since diagnosis, marital status, age, race, smoking status, number of comorbid diseases, metastasis, depressed mood, and meaning of illness.

and older age were related to lower spiritual QOL. The spiritual and existential aspects of living with a diagnosis of lung cancer deserve further study. The finding that depression is the strongest predictor of most dimensions of QOL is similar to findings in a report of long-term survivors of NSCLC (Sarna et al.). This study also corroborates the importance of psychosocial rather than physical concerns identified as priorities in a study of 80 people newly diagnosed with lung cancer (Hill, Amir, Muers, Connolly, & Round, 2003). In the current study, the findings of the power of MOI conceptualizations support those of Degner et al. (2003) and Wallberg et al. (2003) in which negative conceptualizations of MOI were significant predictors of poorer QOL.

Demographic characteristics, other than age, did not clearly define a group at high risk for disruptions in QOL. Younger age was related to lower global, physical, psychological, and social QOL. This study's sample included women as young as 33 years. Because no reports of the QOL concerns specifically address these young women living with lung cancer, further study is needed. Surprisingly, the presence of metastatic disease was not a significant correlate of most aspects of QOL. However, the subsample of those with advanced-stage disease was small. The presence of metastasis, along with depressed mood, negative MOI, and younger age contributed to the model of lower social QOL. The impact of advanced-stage disease on the social network is clearly understandable.

The larger percentage of women with early-stage disease as compared to the normal distribution of stage of lung cancer limits the generalizability of these findings to women with lung cancer who have advanced-stage disease. Because the focus was on women after the initial phase of diagnosis and

<sup>\*</sup> p < 0.0001

a Center for Epidemiologic Studies-Depression Scale score: < 16 = 0 (not depressed), ≥ 16 = 1 (depressed)

<sup>&</sup>lt;sup>b</sup> Meaning of illness categories: negative = 0, positive = 1

<sup>°</sup> Presence of metastasis: 0 = no metastasis. 1 = metastasis

d Race: 0 = non-Caucasian, 1 = Caucasian

<sup>&</sup>lt;sup>e</sup> Marital status: 0 = unmarried. 1 = married

treatment, women who were diagnosed with advanced-stage disease may have been too ill or unwilling to participate. Additionally, the approved institutional review board sampling strategy as described by Cooley et al. (2003) may have negatively affected recruitment of women with more advanced-stage disease.

This study's hypothesis that women with negative MOI, poorer health status, and metastatic disease would have lower QOL scores was supported partially. Depressed mood, MOI, and age consistently were related to global, physical, psychological, social, and spiritual QOL. Depressed mood was the strongest correlate of all aspects of QOL except the spiritual subscale. Depressed mood and negative MOI were related to lower QOL in all dimensions.

## **Implications**

In this cross-sectional sample, despite the relatively small number of participants with advanced-stage disease, many women with NSCLC had concerns about their QOL and had symptoms of depression. Assessment of emotional and physical well-being in women with lung cancer needs to continue even after treatment is completed. An experimental computer-based intervention to provide education and support for patients newly diagnosed with cancer, including 29 patients with lung cancer, demonstrated that intensive telephone and in-person support over an 18-week period resulted in improved mental health and less depression (Kozachik et al., 2001; Rawl et al., 2002). In that study, no significant gender differences were found, but differences in response to the intervention by diagnostic group were not reported. Such a proactive support intervention deserves further study on the long-term consequences of living with lung cancer. However, in another report from this study that focused on newly diagnosed patients with pain and fatigue, the participants with lung cancer, in comparison with other newly diagnosed patients, received the least benefit in symptom relief (Given et al., 2002). Future studies need to combine interventions that address symptom and emotional distress in this population.

This study's findings suggest that assessment of MOI provides additional information about the experience of lung cancer among women just as it did among women with breast cancer. Negative conceptualizations of illness can be addressed by exploring feelings about the disease, including stigmas and perceived blame related to a smoking history. Helping current or former smokers to understand the addictive properties of cigarettes as well as the targeting of women by the tobacco industry (U.S. Department of Health and Human Services, 2001) may be helpful. Patients who never have smoked also report this stigmatization (Chapple et al., 2004). Providing opportunities for social support for women with lung cancer to share their stories about the meaning and impact of lung cancer and to normalize their experiences may be important in assessing psychological distress. Brief questions to detect negative views may be one strategy used in screening at-risk patients who require additional assessment.

In conclusion, this study provides important QOL information about an understudied group, women with lung cancer. Women at particular risk for disruptions in QOL appear to have a depressed mood, a negative view of their illness, and comorbid conditions in addition to being younger. To the authors' knowledge, this is the first study to report the relationship between the conceptualization of MOI and appraisals of QOL in women with lung cancer. Future research is needed to profile changes in QOL disruptions during the trajectory of lung cancer and to compare and contrast male and female QOL responses to determine whether different support strategies are warranted.

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