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Lung cancer stigma, depression, and quality of life among ever and never smokers

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Abstract

Purpose—In 2010, lung cancer is expected to be the leading cause of cancer death in both men and women. Because survival rates are increasing, an evaluation of the effects of treatment on quality of life (QOL) is an important outcome measure. In other diseases, stigma is known to have a negative impact on health status and QOL and be amenable to intervention. This is the first study to compare levels of lung cancer stigma (LCS) and relationships between LCS, depression, and QOL in ever and never smokers.

Method—A total of 192 participants with a self-report diagnosis of lung cancer completed questionnaires online.

Results—Strong associations in the expected directions, were found between LCS and depression ($r = 0.68$, $p < 0.001$) and QOL ($r = -0.65$, $p < 0.001$). No significant differences were found in demographic characteristics or study variables between ever smokers and never smokers. A simultaneous multiple regression with 5 independent variables revealed an overall model that explained 62.5% of the total variance of QOL ($F5,168 = 56.015$, $P < 0.001$).

Conclusions—After removing age, gender, and smoking status, depression explained 22.5% of the total variance of QOL ($F4,168 = 100.661$, $p < 0.001$). It is expected that depression and LCS would share some of the explanation of the variance of QOL, the correlation between LCS and depression is 0.629 ($p < 0.001$), however, LCS provides a unique and significant explanation of the variance of QOL over and above that of depression, age, gender, and smoking status, by 2.1% ($p < 0.001$).

Keywords

Lung Cancer; Smoking; Stigma; Depression; Quality of life; Oncology

Introduction

In the United States, lung cancer is the leading cause of cancer death in both men and women with over 219,000 cases in 2009 (Jemal et al., 2009). Lung cancer is expected to account for 15% of new cases of cancer in men and 14% in women. Although overall survival remains low, changes in treatment and patient management have increased the numbers of long term lung cancer survivors (Janne et al., 2002). Because survival rates are increasing, an evaluation of the effects of treatment on quality of life (QOL) is an important

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outcome measure (Jemal et al., 2009; Montazeri et al., 2001). In the future, population growth and aging will significantly increase the number of long term lung cancer survivors (Sugimura & Yang, Apr, 2006).

In HIV, cancer, and other diseases, stigma is known to have a negative impact on health status. In a study of health and disability among cancer survivors, lung cancer survivors experienced significantly poorer general health status and more psychological problems than patients with other types of cancer (Hewitt et al., 2003). Early work by Chapple et al. (Chapple et al., 2004) found that whether lung cancer patients smoked or not, they felt stigmatized because their disease is so strongly associated with smoking. There are no previous quantitative studies on the association of lung cancer stigma with health outcomes. The purpose of this study was to compare the levels of lung cancer stigma and the relationship between lung cancer stigma (LCS) to depression and QOL among individuals who have ever smoked and those who have never smoked (ever or never smokers). It was hypothesized that a positive relationship would exist between LCS and depression and an inverse relationship would be found between LCS and QOL. In addition, after accounting for the effects of depression, LCS would make a significant independent contribution to the percentage of explained variance in QOL regardless of smoking status in a sample of lung cancer patients.

Theoretical framework

Perceived stigma refers to the anticipation or fear of discrimination and an awareness of negative attitudes and actions related to a specific condition (Van Brakel, 2006). Health related stigma (HRS) is a specific type of perceived stigma that is defined as a personal experience characterized by exclusion, rejection, blame, or devaluation which results from anticipation of an adverse judgment. This judgment is based on an enduring feature of identity conferred by a health problem or health related condition. The judgment is medically unwarranted and may adversely affect health status (Weiss and Ramakrishna, 2006). HRS is well characterized in people with HIV/AIDS (Fife and Wright, 2000). Higher levels of HRS are associated with depression, limited social support, and decreased treatment adherence (Kalichman et al., 1999; Berger et al., 2001). Based on a conceptual model of perceived stigma, Berger et al (Berger et al., 2001) developed the items for the HIV Stigma scale. This model was adapted to guide the development of the Cataldo Lung Cancer Stigma Scale (CLCSS) (Cataldo et al., 2011). The perceived stigma of lung cancer occurs in the context of two factors: a person's perception of societal attitudes toward both smoking and lung cancer and one's personal knowledge of having lung cancer. Perceived stigma associated with having lung cancer is conceptualized as the person's awareness of their lung cancer as it relates to actual or potential social disqualification, limitations in opportunities, and negative changes in social identity. Perceived stigma can lead to several negative outcomes including: increased levels of psychosocial symptoms (e.g. decreased self esteem, anxiety, depression) and increased physical symptom severity. HRS ascribed to controllable factors (e.g., drug abuse) elicits a greater negative reaction than stigma ascribed to uncontrollable factors (e.g., genetics) (Lebel and Devins, 2008; Weiner et al., 1988). Lung cancer is often associated with smoking cigarettes. Although there is an increase in the number of lung cancer patients who have never smoked cigarettes, more than 80% of all lung cancer patients have a history of smoking (Jemal et al., 2009). Because smoking is a proven cause of lung cancer, it is perceived to be a controllable factor that can be associated with HRS (Weiner et al., 1988) Fig. 1.

Smoking stigma

The increased social unacceptability of smoking has had a major impact on the prevalence of smoking in the United States (Alamar and Glantz, 2006). The denormalization of tobacco

has had a dramatic impact on smoking behaviors. However, a consequence of this denormalization is that smokers have become social pariahs. How policies such as smoke free air laws and social norms drive this social unacceptability is only recently being studied. Stuber et al. found that white smokers with higher education level perceived more smoker stigma than Black and Latino smokers with less education. Social norms, especially disapproval expressed by family and friends, contributed to the formation of smoker stigma (Stuber et al., 2008). Other factors that contribute to the stigmatization of smokers, include: perceptions of smoking as a choice not an addiction; fear that second hand smoke harms children; and perceptions that smokers are less educated (Stuber et al., 2008, 2009).

LCS

Anecdotal and qualitative evidence suggests that stigma is an important factor in the care of lung cancer patients (Chapple et al., 2004). Whether they smoked or not, lung cancer patients reported stigmatization from clinicians, as well as family members and friends, because the disease is strongly associated with smoking. Only two studies have tangentially addressed lung cancer stigma. One study explored shame and blame among lung cancer patients (LoConte et al., May 2008) and one examined perceived stigma with a single measure to assess a patient's sense of being stigmatized or blamed with the assessment of agreement to the statement: 'People judge me for my type of cancer'. (Else-Quest et al., 2009) While LCS is known to impact both patients and family care givers, its full impact has been unknown because until recently, a valid and reliable measure of LCS did not exist. In our previous work, the HIV Stigma Scale (Berger et al., 2001) was revised to measure HRS in patients with lung cancer (Cataldo et al., 2011).

LCS and depression

Compared to other types of cancer, lung cancer patients experience the greatest amount of psychological distress (Zabora et al., Jan–Feb 2001) and are at higher risk for psychosocial problems during and after treatment (Carlsen et al., 2005). In an investigation of the variation in distress among 14 cancer diagnoses, while the prevalence of psychological distress varied across cancers, it was highest in lung cancer at (43.4%) (Zabora et al., Jan–Feb 2001). In addition, one out of four persons with lung cancer experience periods of depression or other psychosocial problems during their treatment (Carlsen et al., 2005). In one study, at the time of diagnosis, 23% of 129 lung cancer patients were depressed and 16% were anxious. After 3 months, 30% had died or were terminally ill, the remaining 82 patients, 44% were depressed (Montazeri et al., 2001). A U.K. study found the prevalence of depression was 43% among 352 small cell and 21% among 366 patients with non-small cell lung cancer. The prevalence of anxiety was 43% and 25% respectively (Hopwood and Stephens, 2000). Prior to this study the effects of stigma on lung cancer patient outcomes were unknown.

LCS and QOL

Higher QOL scores are associated with increased survival in lung cancer patients (Ruckdeschel and Piantadosi, 1994; Ganz, 1994; Buccheri et al., 1995). Lung cancer survivors do not experience the same level of QOL as other cancer survivors (Sugimura & Yang, Apr, 2006). Montazeri found that pre-diagnosis rating of QOL was the most significant predictor of the length of survival even after adjusting for known prognostic factors (Montazeri et al., 2001). A significant consequence of HRS is a decrease in QOL (Van Brakel, 2006). However, the relationship between LCS and QOL in lung cancer patients has not been systematically investigated because a valid stigma scale was not available.

Study aims and hypotheses

The specific aims and hypotheses for this study are to: 1) Investigate the relationship of LCS with depression and QOL. It is expected that there will be a positive relationship between LCS and depression and an inverse relationship with LCS and QOL among lung cancer patients; and 2) Explore whether LCS has a unique contribution to the explanation of QOL after controlling for age, gender, smoking status and depression. It is expected that LCS will have a unique and significant contribution to QOL after controlling for covariates.

Methods and design

This descriptive cross sectional study evaluated the relationships between LCS, depression, and QOL. All procedures were reviewed by the UCSF IRB for protection of human subjects and the sample was recruited online. Postings of an active link to the study's homepage were established on web sites frequented by potential study participants, including, LUNGevity, American Lung Association, Lung Cancer Alliance, and American Cancer Society-Cancer Survivor Network. Web-based, online data collection creates opportunities to conduct research among difficult to access populations. However, special consideration was given to how the study would be advertised and how the data were collected to insure high quality data, privacy protection, and validity of findings (Cantrell and Lupinacci, 2007). When constructed with the right controls, (i.e. encryption), participant anonymity is enhanced (Ahearn, 2005). As recommended in the literature, (Rhodes et al., 2003) support was elicited from the website administrators to advertise the study. All instruments, including the demographic questionnaire and the consent form, were formatted into an individual active HTML web page with encryption using www.surveymonkey.com. SurveyMonkey© uses multiple layers of security to make sure that data remains private and secure. They use a third-party firm to conduct daily audits of their security, and the data resides behind the latest in firewall and intrusion prevention technology. We contracted for an extra service so that the data were collected in a totally encrypted environment (Survey Monkey, 2009).

The online survey was reviewed by the site administrators before posting. The posting included an introduction to the study, HIPAA regulations and pledge of anonymity, the researcher's contact information, and a direct link to the questionnaires. The posting made participants aware of any potential risks that exist in data security violation associated with providing online information and that submission of the completed questionnaires implies that they have read the consent form and that they consent to participate in the study. The internet data were properly secured when stored on a computer and a password accessed server. Data were collected as a spreadsheet and remained anonymous with no information linking questionnaires to participants.

Measures

Smoking status

An ever smoker was defined as someone who had smoked at least 100 cigarettes in a lifetime, a never smoker was defined as someone who smoked less than 100 cigarettes, and a former smoker was measured by number of pack years, but not currently smoking. A current smoker was defined by number of packs smoked a day within the last week and number of pack years.

Lung cancer stigma

The CLCSS was found to be a reliable and valid measure with a sample of people with lung cancer (Cataldo et al., 2011). The CLCSS scale potential range of scores was 46–184 (higher score means more stigma), actual range was 51–178, mean score was 120.31 (SD = 30.36).

The scale has 31 items, each item is rated on a 4-point Likert-type scale (strongly disagree, disagree, agree, and strongly agree), with higher values indicating greater agreement with the item. Using the Flesch-Kinkaid Index, the CLCSS is worded at a 4th grade reading level (Indianapolis MacMillan Computer Publishing, 1990). The Cronbach's a for the total scale was 0.96 and the Cronbach's a for the subscales: stigma/shame, social isolation, discrimination, and smoking subscales were 0.97, 0.98, 0.95, and 0.75 respectively.

Depression

The Center for Epidemiologic Studies-Depression (CES-D) is a 20-item scale that was expected to correlate positively with stigma. The CES-D is a valid and reliable tool that is widely used for self-ratings of depression in clinical populations, including people with cancer and people with HIV/AIDS (Hoover et al., 1993). Participants responded using a 4-point scale (0–3), that yielded total scores of 0–80, higher scores indicate greater depression. For this study, the range was 0–58 and the Cronbach's a was 0.95.

Quality of life

The Quality of Life Inventory (QOLI) developed by Ferrell and colleagues (Ferrell et al., 1989) is a 33-item instrument that measures four dimensions of QOL in cancer patients (i.e., symptoms, social concerns, psychological well-being, and physical well-being) and was expected to correlate negatively with stigma. The participant responded to each item on the QOL inventory by circling a number from 0 (not at all positive) to 10 (extremely positive). Subscale scores and a total QOL were calculated. The reliability of this tool was determined to be 0.94 in a sample of 435 patients undergoing treatment for cancer. (Miaskowski & Dibble,) This tool has been tested for content validity using a panel of experts in oncology and pain management. The content validity index was 0.90. Construct and concurrent validity were reported (Ferrell et al., 1989). The Cronbach's a for the total scale for this study was 0.94 and the subscales ranged from 0.78 to 0.89.

Data analysis

Descriptive statistics were used to describe the demographic characteristics, smoking status, level of depression, CLCSS, and QOL (Tables 1 and 2). Smoking status was classified as current, former, or never smoker. No significant differences in all demographic and study variables were found between the former and current smokers. Therefore, these two categories were collapsed into ever smoker, defined as someone who smoked >100 cigarettes in a lifetime. Likelihood ratio Chi-square and Independent sample t-tests were used to compare the ever smoker and never smokers on all demographic characteristics and other variables. A simultaneous multiple regression was used to simultaneously test and model 5 independent variables (age, gender, smoking status, depression, and LCS) with QOL.

Results

Sample

A total of 190 participants with a self-report diagnosis of lung cancer completed questionnaires online. Participants ranged in age from 20 to 88 years (mean age = 55.05 years); 56% were men; 73.8% were partnered and only 14% of the sample lived alone. Almost 96% had 12 years of education or greater. The majority of the participants were Caucasian (85%), 8% Asian, 2% African American, and 5% other minority. Eighty percent of the sample were either current or former smokers (ever smokers) and 55% met the CES-D criteria for depression (total score >16). There were no significant differences in demographic measures or study variables between never and ever smokers.

LCS severity, depression, and QOL

The means, standard deviations, and ranges for the study variables are given in Table 2. The participants ($n = 190$) reported a mean stigma level of 102.6 (SD = 31), (possible range = 46–184); never smokers ($n = 39$) reported a mean of 99.5 (SD = 30.8) and ever smokers ($n = 151$) a mean of 103.7 (SD = 31.2). The cutoff score for a diagnosis of depression is total score >16, mean CES-D depression scores for the total sample ($n = 190$) was 18.97 (SD = 14.0) for ever smokers 19.27 (SD = 12.5), and for never smokers 18.42 (SD = 13.5). Mean QOL scores for the total sample ($n = 185$) was 5.59 (SD = 1.66), for ever smokers 5.52 (SD = 1.72), and for never smokers 5.83 (SD = 1.44). Two-tailed t-tests for LCS, depression, and QOL revealed no significant difference between ever smokers and never smokers ($p > 0.05$).

Hypotheses

The first hypothesis was supported: There a positive relationship between LCS and depression, and an inverse relationship between LCS and QOL was found. The results in Table 3 reveal strong Pearson product-moment correlations in the expected directions of 0.679 ($p < 0.001$) for LCS and depression and −0.650 ($p < 0.001$) for LCS and QOL.

The second hypothesis was supported: After accounting for the effects of age, gender, smoking status, and depression, LCS had a significant and unique contribution to the explanation of QOL. (Table 4). A simultaneous multiple regression with 5 independent variables revealed an overall model that explained 62.5% of the total variance of QOL ($F_{5,168} = 56.015$, $P < 0.001$). Depression explained 22.5% of the total variance of QOL ($F_{4,168} = 100.661$, $p < 0.001$). It was expected that depression and LCS would share some of the explanation of the variance of QOL; the correlation between LCS and depression was 0.629 ($p < 0.001$). However, LCS provided a unique and significant explanation of the variance of QOL over and above that of depression, age, gender, and smoking status, by 2.1% ($p < 0.001$). There were no significant differences found between the ever and never smokers ($p > 0.05$) on demographic or study variables.

Discussion

The important findings in this study are that regardless of whether or not a person with lung cancer has ever smoked, LCS has a strong positive relationship with depression and a strong inverse relationship with QOL. After controlling for gender, age, smoking status, and depression, LCS made a small but significant and unique contribution to the explanation of the variance in the QOL in a sample of lung cancer patients. This study supports the premise that perceived stigma among lung cancer patients, whether they smoked or not, can lead to negative outcomes including: increased levels of depression and diminished QOL.

There are several limitations to this study, the convenient online sample was a national sample that allowed us to reach a hard to reach population, with 38 states represented. However, this sample did not reflect the general lung cancer population. This sample was, younger, more Caucasian, more educated, and from a higher SES than the usual population of lung cancer patients. Because of the nature of online data, clinical information about the sample (i.e., diagnosis, stage of disease, treatment) was limited.

This study supports the previous qualitative work of Chapple and colleagues (Chapple et al., 2004), whether they smoked or not, lung cancer patients report stigmatization from friends and clinicians, because the disease is strongly associated with smoking. Stigma, in part, stems from the fact that smokers have become a marginalized part of society (Stuber et al., 2008). The denormalization of smoking has been a very effective tobacco control strategy. However, an untoward consequence of this approach is the stigmatization of smokers (Stuber et al., 2008) and the tendency to blame the victim. The association of smoking with

lung cancer has negative consequences for lung cancer patients. Because smoking is a proven cause of lung cancer, whether patients are smokers or never smokers, smoking is perceived to be a controllable factor and a behavior associated with lung cancer stigma (Weiner et al., 1988). Several factors that contribute to the marginalization of smokers include: perceptions of smoking as a choice not an addiction; discrimination perpetrated against smokers through no smoking policies, and perceptions that smokers are less educated (Stuber et al., 2008). Another factor that contributes to lung cancer stigma is the initial, very public battle by scientists and public health advocates versus the tobacco industry that smoking is bad for your health. Lung cancer was the standard bearer of that argument and the first disease to be directly linked with smoking cigarettes. Lung cancer has shared the public lime light with smoking for several decades. Recently, with the development of the lung cancer stigma scale, the empirical evidence is building, that whether or not lung cancer patients were ever smokers, they experience significant levels of perceived stigma. Because stigma has a strong significant correlation with increased depression and diminished quality of life, education about coping strategies to deal with stigma need to be incorporated into the care of lung cancer patients.

The mean CES-D score for this sample was 18.97 (54.9% of the total sample); using the >16 cutoff score, over half of this sample was depressed. Previous studies have shown that prevalence of depression among lung cancer patients has varied from 23% to 44% 3, (Carlsen et al., 2005). The depression levels in this sample may be due to the online population. The possibility exists that this sample sought out an online support group because of depression. However, as a result of a lung cancer diagnosis, patients often experience increased psychological distress (Bottorff et al., 2009; Henoch et al., 2007; McBride et al., 2003; Sarna et al., Jan 2005). Because lung cancer patients experience more psychological distress than other cancer patients, stigma intervention and mood management needs to be an essential aspect of treatment. Lung cancer patients need to be evaluated and treated for stigma and mood disorders throughout their treatment course.

Higher QOL scores are associated with increased survival in lung cancer patients (Ruckdeschel and Piantadosi, 1994; Ganz, 1994; Buccheri et al., 1995) A pre-diagnosis rating of QOL has been found to be the most significant predictor of the length of survival even after adjusting for known prognostic factors (Montazeri et al., 2001) Lung cancer survivors do not experience the same length or quality of life as other cancer survivors (Sugimura & Yang, Apr, 2006) In this study, after controlling for age, gender, and smoking status, LCS explained 2.1% ($p < 0.001$) of the variance over and above the 22.5% ($p < 0.001$) explained by depression. A significant consequence of LCS is a disruption in QOL (Van Brakel, 2006). Therefore, prevention and or treatment of LCS could significantly impact on the quality of life for lung cancer patients.

The next stages of research should include: further examination of the multiple dimensions of lung cancer stigma in a larger, more diverse and representative sample; investigation of the character and magnitude of stigma and the relationships with symptom burden and QOL over time; and investigations of the impact of the stigmatization of lung cancer on the family members of patients with lung cancer. There is an urgent need to develop effective interventions to prevent and decrease LCS because it affects both patients and families and can contribute to strained relationships at a time when connectedness is needed. Effective stigma interventions could help both patients and family members manage and integrate the cancer illness experience into their everyday life.

Acknowledgments

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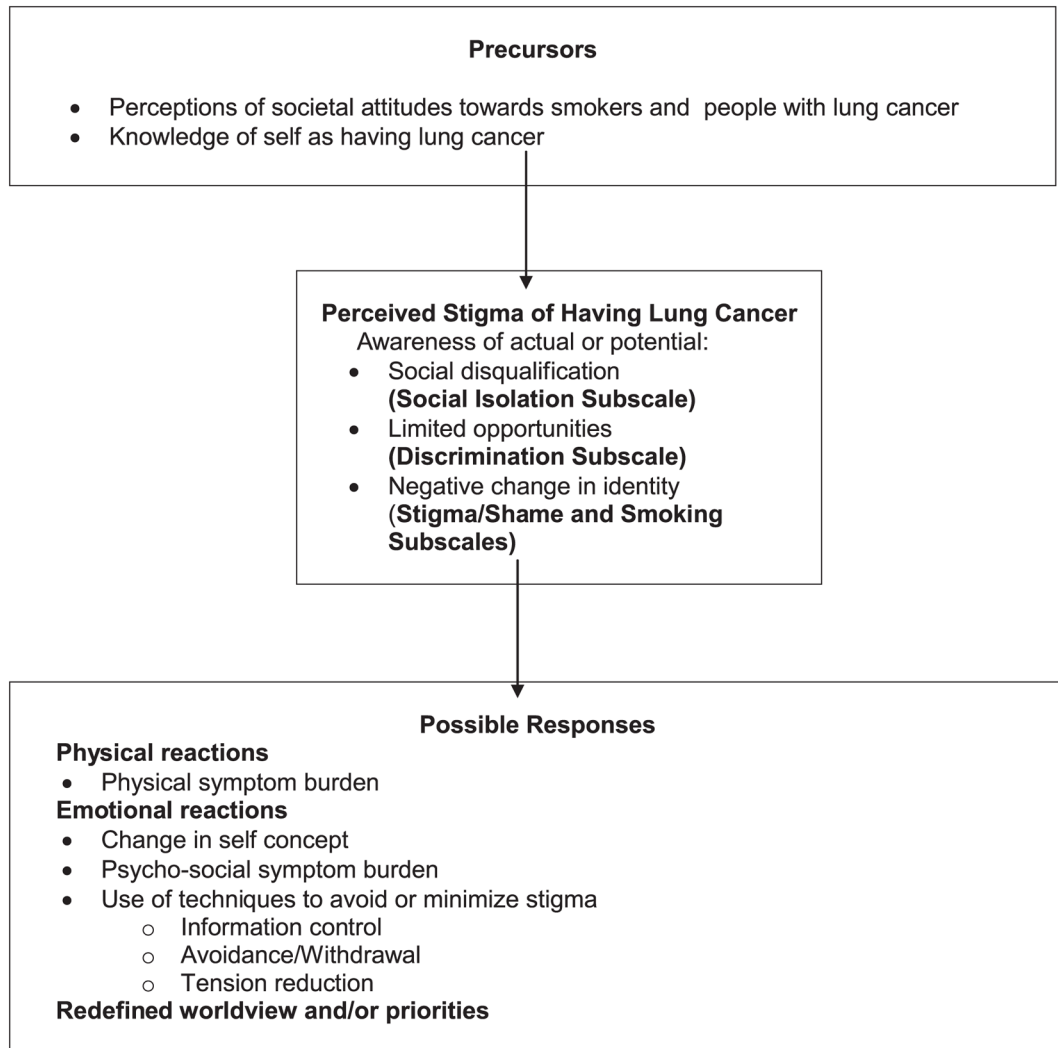
Fig. 1.
Model of Health Related Stigma in people with lung cancer (adapted from Berger et al. 2001).

Table 1

Descriptive statistics of Demographics and Health Status $N = 190$.

Characteristics	Ever smokers $N = 151$			Never smokers $N = 39$		
	X̄	SD	Range	X̄	SD	Range
Age (Years)	55.52	12.81	20–88	53.72	16.71	24–81
Years of Education	15.32	4.48	9–57	14.58	3.93	6–23
Characteristics	n		%	n		%
Race						
Caucasian	130		86.7%	32		86.5%
African American	3		2.0%	0		0%
Asian or Pacific Islander	12		8.0%	4		10.8%
American Indian	0		0%	1		2.7%
Hispanic	3		2.0%	0		0%
More than one ethnicity	2		1.3%	0		0%
Marital Status						
Married	98		65.3%	31		79.5%
Living with Intimate Partner	10		6.7%	0		0%
Widowed	10		6.7%	2		5.1%
Separated or divorced	26		17.3%	4		10.3%
Never Married	6		4.0%	2		5.1%
Depressed Mood						
>16 (CESD Score)	78		57.4%	17		48.6%
Smoking Status						
Ever (>100 cigs/life)	151		79.5%			
Current	21		13.8%			
Ex Smokers	130		86.2%			
Never (<100 cigs/life)	39		20.5%			

Table 2

Descriptive statistics for Lung Cancer Stigma, LCS subscale scores, Depression, and Quality of Life for ALL, EVER SMOKERS, and NEVER SMOKERS.

N = 190

Instrument	$\bar{X}$			SD			Range of scores			Possible Range of Scores
Smoking Status	All	Ever	Never	All	Ever	Never	All	Ever	Never	
Lung Cancer Stigma (LCS) ($n = 181$)	102.6	103.7	69.76	20.22	20.28	20.19	34–121	34–121	34–112	0–155
Stigma/Shame ($n = 178$)	20.86	21.28	19.25	7.69	7.70	7.70	10–40	10–40	10–37	0–50
Social Isolation ($n = 181$)	19.39	19.52	19.31	7.33	7.31	7.44	9–36	9–36	9–34	0–45
Discrimination ($n = 181$)	12.18	12.11	12.59	3.80	3.75	3.92	5–20	5–20	5–20	0–25
Smoking ($n = 180$)	14.89	15.05	14.19	2.95	2.93	2.96	7–20	7–20	8–19	0–25
Depression CES-D ($n = 171$)	18.96	19.27	18.43	14.07	14.30	13.50	0–58	0–58	0–48	0–80
QOL ($n = 180$)	5.56	5.51	5.72	1.66	1.72	1.39	0.83–9.24	83–9.24	2.70–8.24	0–10

A higher score indicates increased Stigma, Depression, and Quality of Life.

Table 3

Pearson product-moment correlation for Lung Cancer Stigma, Depression, and QOL for smokers and non smokers.

ALL (*n* = 180)		
Scale	**LCS (*n* = 180)**	**CES-D (*n* = 171)**
1. Lung Cancer Stigma (LCS)	–	–
2. Depression (CES-D)	0.687[**]	–
3. Quality of Life (QOL)	−0.645[**]	−0.824[**]
EVER SMOKERS (*n* = 144)		
1. Lung Cancer Stigma (LCS)	–	–
2. Depression (CES-D)	0.687[**]	–
3. Quality of Life (QOL)	−0.671[**]	−0.834[**]
NEVER SMOKERS (*n* = 36)		
1. Lung Cancer Stigma (LCS)	–	–
2. Depression (CES-D)	0.685[**]	–
3. Quality of Life (QOL)	−0.500[**]	−0.784[**]

[**] $p < 0.001$.

Table 4

Simultaneous multiple regression summary table: the effect of Lung Cancer Stigma on QOL among lung cancer patients controlling for age, gender smoking status, and depression.

Source	R^2	beta	R^2 change	df	F	p
Overall	0.625			5,168	56.015	<0.001
Age		0.064	0.003	5,168	1.26	0.262
Gender		0.070	0.005	5,168	2.17	0.143
Smoking Status		0.029	0.001	5,168	0.37	0.543
Depression		0.613	0.225	5,168	100.66	<0.001
LCS		0.208	0.021	5,168	9.32	<0.001