



Published in final edited form as:

Oncol Nurs Forum. 2011 January 1; 38(1): E46–E54. doi:10.1188/11.ONF.E46-E54.

Measuring Stigma in People With Lung Cancer: Psychometric Testing of the Cataldo Lung Cancer Stigma Scale

Janine K. Cataldo, RN, PhD[Assistant professor],

Department of Physiological Nursing–Gerontology, University of California, San Francisco

Robert Slaughter, PhD[Director],

Office of Research and Information Technology in the School of Nursing, University of California, San Francisco

Thierry M. Jahan, MD[Associate Professor of Medicine],

Bonnie J. and Anthony Addario Endowed Chair in Thoracic Oncology in the Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco

Voranan L. Pongquan, RN, MPH[Master's student], and

School of Nursing, University of California, San Francisco

Won Ju Hwang, RN, MPH[Doctoral student]

School of Nursing, University of California, San Francisco

Abstract

Purpose/Objectives—To develop an instrument to measure the stigma perceived by people with lung cancer based on the HIV Stigma Scale.

Design—Psychometric analysis.

Setting—Online survey.

Sample—186 patients with lung cancer.

Methods—An exploratory factor analysis with a common factor model using alpha factor extraction.

Main Research Variables—Lung cancer stigma, depression, and quality of life.

Findings—Four factors emerged: stigma and shame, social isolation, discrimination, and smoking. Inspection of un-rotated first-factor loadings showed support for a general stigma factor. Construct validity was supported by relationships with related constructs: self-esteem, depression, social support, and social conflict. Coefficient alphas ranging from 0.75–0.97 for the subscales (0.96 for stigma and shame, 0.97 for social isolation, 0.9 for discrimination, and 0.75 for smoking) and 0.98 for the 43-item Cataldo Lung Cancer Stigma Scale (CLCSS) provided evidence of reliability. The final version of the CLCSS was 31 items. Coefficient alpha was recalculated for the total stigma scale (0.96) and the four subscales (0.97 for stigma and shame, 0.96 for social isolation, 0.92 for discrimination, and 0.75 for smoking).

Conclusions—The CLCSS is a reliable and valid measure of health-related stigma in this sample of people with lung cancer.

Implications for Nursing—The CLCSS can be used to identify the presence and impact of lung cancer stigma and allow for the development of effective stigma interventions for patients with lung cancer.

Lung cancer is the leading cause of cancer deaths in men and women in the United States (Centers for Disease Control and Prevention, 2010). Compared to patients with other types of cancer, patients with lung cancer experience the greatest amount of psychological distress (Else-Quest, LoConte, Schiller, & Hyde, 2009; Holland et al., 2010; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) and have a higher risk for psychological distress during and after treatment (Akin, Can, Aydiner, Ozdilli, & Durna, 2010; Carlsen, Jensen, Jacobsen, Krasnik, & Johansen, 2005). Psychological distress is a strong predictor of lung cancer mortality (Hamer, Chida, & Molloy, 2009).

Health-related stigma (HRS) is a perceived stigma that has been defined as a personal experience characterized by exclusion, rejection, blame, or devaluation that results from anticipation of an adverse judgment. This judgment is based on an enduring feature of identity conferred by a health issue; the judgment is medically unwarranted and may adversely affect health status (Weiss & Ramakrishna, 2006). HRS has been associated with an increase in the stress associated with illness and contributes to psychological, physical, and social morbidity (Major & O'Brien, 2005). HRS has been extensively studied in patients with HIV and AIDS, mental illness, epilepsy, and physical disability (Van Brakel, 2006), but not in patients with lung cancer.

Stigma in lung cancer is based on the belief that the patient's behavior was the cause of the cancer (i.e., by smoking). Few studies have examined the presence of HRS in patients with lung cancer or its effect on patient outcomes because tools to measure lung cancer stigma did not exist (Van Brakel, 2006). In one study of the meaning of illness, women with lung cancer experienced a range of disruptions in quality of life (QOL), and more than a third of the sample associated lung cancer with negative meaning (Sarna et al., 2005). The purpose of this study was to psychometrically develop and evaluate an instrument to measure stigma as perceived by patients with lung cancer.

Background

Health-Related Stigma

HRS refers to a perceived stigma that is both a trait and the outcome of being known to possess that trait (Heijnders & Van Der Meij, 2006). The effects of perceived stigma depend on whether patients hold themselves or if others hold the patients responsible for the disease and whether the disease leads to serious disability, disfigurement, lack of control, or disruption of social interactions (LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). The association of stigma with HIV and AIDS has been well established. Stigma in people with HIV is associated with emotional distress, anxiety, depression, poor self-esteem, limited sources of social support, relationship issues, concealment of disease after prognosis, poor adherence to treatment, increased disability, and diminished QOL (Berger, Ferrans, & Lashley, 2001; Stutterheim et al., 2009; Ware, Wyatt, & Tugenberg, 2006). Lung cancer can conjure a similar attribution of blame as that found with HIV or AIDS because lung cancer often is associated with smoking cigarettes (Marlow, Waller, & Wardle, 2010).

Conceptual Framework

Based on a conceptual model of perceived stigma, Berger et al. (2001) developed the items for the HIV Stigma Scale. This model was adapted to patients with lung cancer and was used to guide the development of the Cataldo Lung Cancer Stigma Scale (CLCSS). 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 a personal knowledge of having lung cancer (see Figure 1). 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 psychosocial symptom burden and increased physical symptom burden. Although HRS has not been measured in patients with lung cancer, findings from one qualitative study suggest that this patient population often feels “victimized” or excluded by support systems, which results in strained social relationships (Greene & Banerjee, 2006).

HRS ascribed to controllable factors (e.g., smoking) elicits a greater negative reaction than stigma ascribed to uncontrollable factors (e.g., genetics) (Hegarty & Golden, 2008; Lebel & Devins, 2008). In HIV and other diseases, the negative effects of HRS appear to be related to the level of responsibility that the patient assigns to his or her disease (Raleigh, 2010). Lung cancer can conjure up a similar attribution of blame as that found with HIV (Greene & Banerjee, 2006). Although HIV often is associated with homosexuality and IV drug use, lung cancer is associated with smoking cigarettes. Whether patients are smokers or not, because smoking is a proven cause of lung cancer, it is perceived to be a controllable factor and a behavior that can be associated with lung cancer stigma (Lebel & Devins, 2008).

Tobacco Smoking and Stigma

The effects of HRS are related to the level of responsibility that a patient assigns to his or her disease. A greater negative reaction occurs when factors that contribute to a disease, such as smoking, can be associated with HRS (LoConte et al., 2008). Stigmatization of patients with lung cancer is, in part, a consequence of the demoralization of tobacco smoking (Bayer & Stuber, 2006; Bell, Salmon, Bowers, Bell, & McCullough, 2010). Smokers have become a marginalized part of society (Stuber, Galea, & Link, 2008); current and former smokers have identified several factors that contribute to the perception of stigmatization in smokers: perceptions of smoking as a choice and not an addiction, fear that secondhand smoke harms children, discrimination perpetrated against smokers through no-smoking policies, and low education levels associated with smokers (Stuber et al., 2008).

Cancer and Stigma

Stigma has been found to be related to a deficit in knowledge about cancer, disease prevention, and risk (Rosman, 2004). Several studies indicate that patients with cancer feel stigmatized because of their disease (Wilson & Luker, 2006). The reasons for stigmatizing patients with cancer are many, but, if the patient is of the same age and gender of the healthcare provider, the perception of similarity is likely, and a tendency exists to attribute the disease to the patient’s characteristics, personality, and lifestyle to reduce the personal threat to the provider (Greene & Banerjee, 2006). Stigma related to disease has been identified as a significant barrier to health promotion (Corrigan & Watson, 2007).

Lung Cancer Stigma

Whether they smoked or not, patients with lung cancer have reported stigmatization (Chapple, Ziebland, & McPherson, 2004). Patients with lung cancer have a high risk for psychological issues after diagnosis and treatment (Carlsen et al., 2005). In a study of cancer-related stigma by Else-Quest et al. (2009), patients with lung cancer were more likely than patients with breast or prostate cancer to report internal causal attributions for their cancer. Blame often has been cited as a major stressor of having lung cancer (Carmack et al., 2008; Marlow et al., 2010).

Because of the lack of a valid and reliable measure, empiric evidence of lung cancer stigma is limited. A qualitative study by Chapple et al. (2004) found that patients with lung cancer experience guilt and shame as a result of the stigmatization of lung cancer as a self-induced disease. Although stigma has not been measured in patients with lung cancer, findings from

one study suggest that these patients often feel victimized or excluded by support systems, which results in strained social relationships (Greene & Banerjee, 2006). In addition, patients may fear the loss of health insurance and employment as a result of disclosure of their cancer diagnosis (Greene & Banerjee, 2006; Wilson & Luker, 2006).

Methods

Design and Procedures

This was an exploratory study using a convenience sample and a self-administered questionnaire. The study procedures and materials were approved by the university institutional review board. Participants received a \$10 gift card.

Sample Recruitment

The sample was recruited online. 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 ensure high-quality data, privacy protection, and validity of findings (Cantrell & Lupinacci, 2007). When constructed with the right controls (i.e., encryption), participant anonymity is enhanced, decreasing social response set and researcher-influenced bias (Rhodes, Bowied, & Hergenrather, 2003; SurveyMonkey®, 2009). As recommended in Rhodes et al. (2003), support was elicited from the Web site administrators in advertising the study to increase the response rate, data fields were designated as optional or not optional, and all instruments and the consent form were formatted into an individual active HTML Web page with encryption. Because of the sensitivity of the data, a contract was made with SurveyMonkey for an extra service that allowed for data collection in a totally encrypted environment. Postings of an active link to the study's home page were established on Web sites frequented by potential study participants, including LUNGeivity, American Lung Association, Lung Cancer Alliance, and the American Cancer Society's Cancer Survivor Network.

The first draft of the online survey was reviewed for edits by the site administrators before posting. The posting included an introduction to the study, Health Insurance Portability and Accountability Act 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 existed in data security violations associated with providing online information, and that submission of the completed questionnaires implied that they had read the consent form and that they consented 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 and participants.

Instruments

Cataldo Lung Cancer Stigma Scale—Seven experts in stigma from the disciplines of sociology, psychology, oncology, and nursing were asked to serve as content reviewers. Berger et al.'s (2001) model of perceived stigma in people with HIV was modified for use in patients with lung cancer. According to the procedure recommended by Lynn (1986), reviewers were asked to evaluate how well each of the items tapped the concept of stigma in people with lung cancer in terms of an item's clarity and relevance to the concept of stigma. Items rated as not relevant or needing major revision were rejected. Reviewers also were asked to judge the comprehensiveness of the item pool and were invited to suggest new items or content areas to fill any gaps they perceived. Items rejected by more than one of the seven reviewers were discarded or rewritten. Of the 45 items in the CLCSS submitted to content experts in the first round, eight were discarded. The 37 remaining items were

retained unchanged or were revised slightly to improve clarity. Nine additional items were submitted to the reviewers and then added to the 37 remaining items for a total of 46 items. Each stigma item was measured using a four-point Likert-type scale ranging from 1 (strongly disagree) to 4 (strongly agree). Reading level, using the Flesch-Kinkaid Index (Software Q, 1990), was assessed and found to be at the fifth-grade level.

Self-esteem—The **Rosenberg Self-Esteem Scale (RSES)** was used to measure self-esteem. Respondents rated each of the 10 self-esteem items on a four-point scale. The possible scores ranged from 10–40, with higher scores indicating higher self-esteem. A wide variety of analyses have supported the RSES’s validity (Wiley, 1989). The RSES has demonstrated consistent acceptable internal consistency reliability (coefficient alphas of 0.72–0.87). For the current sample, the coefficient alpha for the RSES was 0.89.

Depression—The **Center for Epidemiological Studies–Depression Scale (CES-D)** is a valid and reliable tool that has been widely used for self-ratings of depression in clinical populations, including people with cancer and people with HIV and AIDS (Hoover et al., 1993). Participants were rated on a four-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). The overall score was calculated by summing the ratings of 20 items, so the possible range of score was 0–60. Higher scores indicated greater depression. A score of 16 or higher is generally used to indicate depression. For the current sample, the coefficient alpha for the CES-D was 0.91.

Social support and social conflict—The **Social Support indices** from the Multicenter AIDS Cohort Coping and Change Study (O’Brien, Wortman, Kessler, & Joseph, 1993) were used to measure perceived availability of support and social conflict. To complete the social support scales, respondents were asked to consider their experiences during the preceding month. Scores on each index ranged from 0–1, with higher scores indicating higher levels of the measured concept. Published psychometric data on the indices for people at risk for HIV infection reported alphas of 0.78–0.89 (Berger et al., 2001). Four of the five indices were used in the current study; coefficient alpha was 0.95 for the availability index, 0.78 for the validation index, 0.82 for the subjective social integration index, and 0.84 for the social conflict index.

Quality of life—The **Quality of Life Inventory**, a 41-item cancer-specific QOL instrument, was used (Ferrell, Wisdom, & Wenzl, 1989). This instrument was previously validated in a population of patients with lung cancer (Sarna et al., 2002). Participants responded to questions based on their experience of how cancer affected their QOL. Individual items were rated on a Likert-type scale (ranging from 0–10) comprised of four subscales (physical, social, psychological, and spiritual) with a coefficient alpha of 0.94.

Results

Sample

The convenience sample in this study consisted of 186 patients with lung cancer (all types and stages) who were aged 20 years or older (see Table 1). The average age was 55 years (SD = 13.7, range = 20–88), 70% were female, and 79% reported that they either smoke or have smoked in the past. No significant correlations were noted for demographics and study variables. To test for adequacy of sample size, the authors examined the correlation matrix using the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (MSA) (Kaiser, 1981) and the Bartlett Sphericity Test (Dziuban & Shirkey, 1974) and found that both supported factorability. The Kaiser-Meyer-Olkin MSA is a measure of the size of partial correlations among variables and is a good indicator of factorability when the MSA is greater than 0.7.

The MSA in this study was 0.96 ($p < .001$). The Bartlett Sphericity Test assesses the degree to which a correlation matrix is an identity matrix, which would make factoring inappropriate. Because the Bartlett Sphericity Test in this study was statistically significant ($p < .001$), the authors were able to conclude that the correlation matrix is not an identity matrix, suggesting that factor analysis is appropriate.

Construct Validity: Factor Analysis of the Cataldo Lung Cancer Stigma Scale

All stigma items were completed in 186 of the 200 questionnaires returned. To evaluate construct validity, an exploratory factor analysis was performed to determine the underlying structure of the CLCSS. A common factor model with alpha factor extraction was used (Ferketich & Muller, 1990). Alpha extraction generates its factors by finding the item groupings with maximum internal consistency, which makes it an appropriate choice for instrument development (Gorusch, 1983).

Initially, 46 lung cancer stigma items were submitted for factor analysis. The unrotated first factor loadings were examined to ensure that all items loaded on a global stigma factor. All items loading at least 0.35 on the global factor were retained, as were items loading at least 0.35 on two or more factors. Two items were eliminated because they did not meet the retention criteria and one factor had only one item. This resulted in a CLCSS with 43 items. The factor loadings for the four retained and varimax rotated factors are presented in Table 2. The variance explained by the four-factor solution was 57%.

Factor 1. Stigma and shame subscale—The first factor consisted of 19 items with loadings ranging from 0.41–0.81. Two items loaded greater than 0.7 on the first factor. These items were related to the patient’s personal sense of stigma and shame and addressed the perceived consequences of other people knowing. Nine of the other items loading on this factor had moderate loadings (0.4 or greater), and 11 of the items also had moderate loadings on at least one other factor.

Factor 2. Social isolation subscale—Thirteen items loaded on the second factor in the structure matrix with loadings ranging from 0.48–0.81. Five items loaded greater than 0.7 on the second factor. This factor was termed “social isolation subscale,” in keeping with the most salient items that addressed losing social supports. Four items had loadings of greater than 0.4 on another factor.

Factor 3. Discrimination subscale—Six items loaded on the third factor in the structure matrix with loadings ranging from 0.44–0.7. One item loaded greater than 0.7 on the third factor. The most salient item (0.7) was the statement, “People with lung cancer are treated like outcasts.” Other items referred to feeling judged and discriminated against. Four items had loadings of 0.4 or more on another factor.

Factor 4. Smoking subscale—Four items loaded on the fourth factor in the structure matrix with loadings ranging from 0.35–0.7. One item loaded greater than 0.7 on the fourth factor. The most salient item (0.7) was the statement, “Lung cancer is viewed as a self-inflicted disease.” The items most correlated with this factor referred to lung cancer being considered a smoking-caused disease, even if the patient had never smoked or stopped smoking years ago.

Development of Subscales and Total Score

Kaiser’s (1981) eigenvalue greater than one criterion was employed to decide on the number of components to extract, and a component loading cutoff of 0.35 was used to decide whether an item loaded on a specific component (Nunnally & Bernstein, 1994). Items were

inspected for high coefficients or loadings and were then used in subscale scores. Subscales were formed from all items loading 0.35 or better on each factor. When an item loaded at that level on more than one factor, it was included in each of the corresponding subscales; five items were included in three of the four subscales because they loaded well on three factors. Twenty items were assigned to more than one subscale. Forty-three items among all 46 items were assigned to at least one of the four subscales; three items remained unloaded. This resulted in a factor solution containing 43 items. Subscale reliability cutoff was set at greater than 0.7 (Nunnally & Bernstein, 1994).

Criterion-Related Validity: Correlations With Related Measures

Criterion-related validity was assessed by examining the relationship of the instrument with measures of related constructs: self-esteem, depression, aspects of social support, social conflict, and QOL (see Table 3). Construct validity was supported by correlations being in predicted directions with other instruments. As expected, self-esteem scores correlated negatively with the total stigma score and all subscale scores; self-esteem had the strongest negative correlation with the smoking subscale score. Similarly, higher levels of depression were associated with higher levels of overall stigma, as well as higher levels for each of the subscales. Social support availability and validation and subjective social integration and QOL showed similar patterns: moderate negative correlations with the total stigma score and with the stigma and shame, social isolation, and discrimination subscale scores and slightly weaker negative correlations with the smoking subscale score. Social conflict, by contrast, was positively related to the total stigma score and all subscale scores.

Reliability: Internal Consistency Reliability

Coefficient alpha for the total lung cancer stigma scale with 43 items was 0.98. Coefficient alphas calculated for the four subscales provide evidence of internal consistency reliability (see Table 4). To decrease patient burden and to further address the issue of adequate sample size, the CLCSS was shortened to 31 items. Twelve items that correlated with other items at 0.8 or greater and appeared to be conceptually redundant were eliminated. Coefficient alpha was recalculated for the 31-item stigma scale (0.96), and the four subscales ranged from 0.75–0.96.

Discussion

In this study, the CLCSS is a reliable and valid instrument that measures HRS in patients with lung cancer. The four factors that emerged in this analysis are reflected in the four subscales: stigma and shame, social isolation, discrimination, and smoking. These subscales reflect a conceptual linkage with the phenomenon of perceived stigma of having lung cancer in the Berger et al. (2001) model of HRS. The linkages are social disqualification (social isolation subscale), limited opportunities (discrimination subscale), and negative change in identity (stigma and shame and smoking subscales).

As a result of a lung cancer diagnosis, patients often experience increased psychological distress (Bottorff, Robinson, Sullivan, & Smith, 2009; Gritz, Dresler, & Sarna, 2005; Henoeh, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007; McBride et al., 2003). Previous studies have shown that prevalence of depression among patients with lung cancer has ranged from 23%–55% (Carlsen et al., 2005; Cataldo, Jahan, & Pongquan, 2011; Montazeri, Milroy, Hole, McEwen, & Gillis, 2001). Stigma most likely plays an important role in the psychological distress of patients with lung cancer.

A significant consequence of HRS is a disruption in QOL (Van Brakel, 2006), and QOL is a strong predictor of survival in patients with lung cancer (Balduyck, Hendriks, Lauwers, Nia,

& Van Schil, 2009; Qi et al., 2009). Lung cancer survivors do not experience the same length or QOL as other cancer survivors (Sugimura & Yang, 2006). Stigma may be part of the explanation. In Cataldo, Jahan, and Pongquan (2011), the authors found that lung cancer stigma explained 11% of the variance of QOL ($p < 0.001$), over and above the 69% explained by depression.

Although this online sample represented 38 states, it did not reflect the general lung cancer population. Most participants were Caucasian, women, had higher levels of completed education, and fell into wealthier classifications. This may represent a lung cancer population that has access to the Internet. Also, because of the nature of online data, clinical information on the sample (diagnosis, stage of disease, and treatment) was limited.

Future research should include additional psychometric testing of the CLCSS in a larger, more diverse sample with clinical data, investigation of the effect of lung cancer stigma on patient outcomes (i.e., mood, treatment choice, help-seeking behavior, treatment adherence, disability, morbidity, and mortality), and development of an effective stigma intervention.

As treatment for lung cancer becomes more aggressive and successful, the early detection and intervention for psychological distress becomes increasingly more important for patients with lung cancer (Holland et al., 2010; Lynch, Goodhart, Saunders, & O'Connor, 2010). This article highlights lung cancer stigma as an important psychosocial issue faced by patients. Because stigma is associated with poorer health status, higher levels of depression, and diminished QOL, including an assessment of stigma in clinical practice is important (Cataldo et al., 2011). In other diseases, stigma has been amenable to intervention; the development of the CLCSS provides the opportunity to identify and measure the experience of lung cancer stigma and to develop effective interventions. For people experiencing stigma from an HIV and AIDS diagnosis, effective interventions have consisted of three components: education about the disease, skills building for coping with the stigma, and counseling and support (Brown, Macintyre, & Trujillo, 2003). The authors of the current study are pilot testing a lung cancer stigma intervention with these three components.

Feeling stigmatized causes a fear of rejection, limits the use of potential social support, and is associated with depression, poor treatment adherence, poor health, and shortened survival. Therefore, a sensitive measure of lung cancer stigma will allow for the identification of individuals who feel stigmatized and could benefit from intervention. The prevention and treatment of stigma can have a significant impact on the overall health and QOL of patients with lung cancer.

Acknowledgments

This research was supported by a California Tobacco-Related Disease Research Program Grant (16RT-0149) and a National Institute of Nursing Research Grant (NR011934-01).

References

- Akin S, Can G, Aydiner A, Ozdilli K, Durna Z. Quality of life, symptom experience, and distress of lung cancer patients undergoing chemotherapy [Epub ahead of print]. *European Journal of Oncology Nursing*. 2010
- Balduyck B, Hendriks J, Lauwers P, Nia PS, Van Schil P. Quality-of-life evolution after lung cancer surgery in septuagenarians: A prospective study. *European Journal of Cardio-Thoracic Surgery*. 2009; 35:1070–1075.10.1016/j.ejcts.2009.01.050 [PubMed: 19286388]
- Bayer R, Stuber J. Tobacco control, stigma, and public health: Rethinking the relations. *American Journal of Public Health*. 2006; 96:47–50.10.2105/AJPH.2005.071886 [PubMed: 16317199]

- Bell K, Salmon A, Bowers M, Bell J, McCullough L. Smoking, stigma and tobacco “denormalization:” Further reflections on the use of stigma as a public health tool. A commentary on Social Science and Medicine’s Stigma, Prejudice, Discrimination, and Health Special Issue. *Social Science and Medicine*. 2010; 70:795–799.10.1016/j.socscimed.2009.09.060 [PubMed: 20044187]
- Berger B, Ferrans C, Lashley F. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing and Health*. 2001; 24:518–529.10.1002/nur.10011 [PubMed: 11746080]
- Bottorff J, Robinson C, Sullivan K, Smith M. Continued family smoking after lung cancer diagnosis: The patient’s perspective [Online exclusive]. *Oncology Nursing Forum*. 2009; 36:E126–E132.10.1188/09.ONF.E126-E132 [PubMed: 19403440]
- Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*. 2003; 15:49–69.10.1521/aeap.15.1.49.23844 [PubMed: 12627743]
- Cantrell M, Lupinacci P. Methodological issues in online data collection. *Journal of Advanced Nursing*. 2007; 60:544–549.10.1111/j.1365-2648.2007.04448.x [PubMed: 17973718]
- Carlsen K, Jensen A, Jacobsen E, Krasnik M, Johansen C. Psychosocial aspects of lung cancer. *Lung Cancer*. 2005; 47:293–300.10.1016/j.lungcan.2004.08.002 [PubMed: 15713512]
- Carmack C, Badr H, Lee J, Fossell F, Pisters K, Gritz E. Lung cancer patients and their spouses: Psychological and relationship functioning within one month of treatment initiation. *Annals of Behavioral Medicine*. 2008; 36:129–140.10.1007/s12160-008-9062-7 [PubMed: 18797978]
- Cataldo JK, Jahan TM, Pongquan VL. Lung Cancer Stigma, Depression and Quality of Life Among Ever and Never Smokers. *European Journal of Oncology Nursing*. July 30.2011 DOI:10.016/jejon.2011.06.008.
- Centers for Disease Control and Prevention. United States cancer statistics: 1999–2006 cancer incidence and mortality data. 2010. Retrieved from <http://www.cdc.gov/uscs>
- Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *BMJ*. 2004; 328:1470–1475. [PubMed: 15194599]
- Corrigan P, Watson A. The stigma of psychiatric disorders and the gender, ethnicity, and education of the perceiver. *Community Mental Health Journal*. 2007; 43:439–458.10.1007/s10597-007-9084-9 [PubMed: 17876705]
- Dziuban C, Shirkey E. When is a correlation matrix appropriate for factor analysis? Some decision rules. *Psychological Bulletin*. 1974; 81:358–361.10.1037/h0036316
- Else-Quest N, LoConte N, Schiller J, Hyde J. Perceived stigma, self-blame, and adjustment among lung, breast, and prostate cancer patients. *Psychology and Health*. 2009; 24:949–964.10.1080/08870440802074664 [PubMed: 20205038]
- Ferketich S, Muller M. Factor analysis revisited. *Nursing Research*. 1990; 39:59–62.10.1097/00006199-199001000-00012 [PubMed: 2294518]
- Ferrell B, Wisdom C, Wenzl C. Quality of life as an outcome variable in the management of cancer pain. *Cancer*. 1989; 63:2321–2327.10.1002/1097-0142(19890601)63:11<2321::AID-CNC R2820631142>3.0.CO;2-T [PubMed: 2720579]
- Gorusch, R. Factor analysis. 2. Hillsdale, NJ: Lawrence Erlbaum Associates; 1983.
- Greene K, Banerjee S. Disease-related stigma: Comparing predictors of AIDS and cancer stigma. *Journal of Homosexuality*. 2006; 50:185–209.10.1300/J082v50n04_08 [PubMed: 16723345]
- Gritz E, Dresler C, Sarna L. Smoking, the missing drug interaction in clinical trials: Ignoring the obvious. *Cancer, Epidemiology, Biomarkers, and Prevention*. 2005; 14:2287–2293.10.1158/1055-9965.EPI-05-0224
- Hamer M, Chida Y, Molloy G. Psychological distress and cancer mortality. *Journal of Psychosomatic Research*. 2009; 66:255–258.10.1016/j.jpsychores.2008.11.002 [PubMed: 19232239]
- Hegarty P, Golden A. Attributional beliefs about the controllability of stigmatized traits: Antecedents or justifications of prejudice? *Journal of Applied Social Psychology*. 2008; 38:1023–1044.10.1111/j.1559-1816.2008.00337.x
- Heijnders M, Van Der Meij S. The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychology, Health and Medicine*. 2006; 11:353–363.10.1080/13548500600595327

- Henoch I, Bergman B, Gustafsson M, Gaston-Johansson F, Danielson E. The impact of symptoms, coping capacity, and social support on quality-of-life experience over time in patients with lung cancer. *Journal of Pain and Symptom Management*. 2007; 34:370–379.10.1016/j.jpainsymman.2006.12.005 [PubMed: 17616335]
- Holland J, Andersen B, Breitbart W, Compas B, Dudley M, Fleishman S, Zevon MA. Distress management. *Journal of the National Comprehensive Cancer Network*. 2010; 8:448–485. [PubMed: 20410337]
- Hoover D, Saah A, Bacellar H, Murphy R, Visscher B, Anderson R, Kaslow RA. Signs and symptoms of “asymptomatic” HIV-1 infection in homosexual men. *Journal of Acquired Immune Deficiency Syndromes*. 1993; 6:66–71. [PubMed: 8417176]
- Kaiser H. A revised measure of sampling adequacy for factor-analytic data matrices. *Educational and Psychological Measurement*. 1981; 41:379–381.10.1177/001316448104100216
- Lebel S, Devins G. Stigma in cancer patients whose behavior may have contributed to their disease. *Future Oncology*. 2008; 4:717–733.10.2217/14796694.4.5.717 [PubMed: 18922128]
- LoConte N, Else-Quest N, Eickhoff J, Hyde J, Schiller J. Assessment of guilt and shame in patients with non-small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical Lung Cancer*. 2008; 9:171–178.10.3816/CLC.2008.n.026 [PubMed: 18621628]
- Lynch J, Goodhart F, Saunders Y, O’Connor S. Screening for psychological distress in patients with lung cancer: Results of a clinical audit evaluating the use of the patient distress thermometer [Epub ahead of print]. *Supportive Care in Cancer*. 2010
- Lynn M. Determination and quantification of content validity. *Nursing Research*. 1986; 35:382–385.10.1097/00006199-198611000-00017 [PubMed: 3640358]
- Major B, O’Brien L. The social psychology of stigma. *Annual Review of Psychology*. 2005; 56:393–421.10.1146/annurev.psych.56.091103.070137
- Marlow L, Waller J, Wardle J. Variation in blame attributions across different cancer types. *Cancer, Epidemiology, Biomarkers, and Prevention*. 2010; 19:1799–1805.10.1158/1055-9965.EPI-09-1298
- McBride C, Pollak K, Garst J, Keefe F, Lyna P, Fish L, Hood L. Distress and motivation for smoking cessation among lung cancer patients’ relatives who smoke. *Journal of Cancer Education*. 2003; 18:150–156.10.1207/S15430154JCE1803_08 [PubMed: 14512262]
- Montazeri A, Milroy R, Hole D, McEwen J, Gillis C. Quality of life in lung cancer patients: As an important prognostic factor. *Lung Cancer*. 2001; 31:233–240.10.1016/S0169-5002(00)00179-3 [PubMed: 11165402]
- Nunnally, J.; Bernstein, I. *Psychometric theory*. New York, NY: McGraw-Hill; 1994.
- O’Brien K, Wortman C, Kessler R, Joseph J. Social relationships of men at risk for AIDS. *Social Science and Medicine*. 1993; 36:1161–1167.10.1016/0277-9536(93)90236-W [PubMed: 8511645]
- Qi Y, Schild S, Mandrekar S, Tan A, Krook J, Rowland K, Sloan JA. Pretreatment quality of life is an independent prognostic factor for overall survival in patients with advanced stage non-small-cell lung cancer. *Journal of Thoracic Oncology*. 2009; 4:1075–1082.10.1097/JTO.0b013e3181ae27f5 [PubMed: 19546817]
- Raleigh Z. A biopsychosocial perspective on the experience of lung cancer. *Journal of Psychosocial Oncology*. 2010; 28:116–125. [PubMed: 20391069]
- Rhodes S, Bowied D, Hergenrather K. Collecting behavioral data using the World Wide Web: Considerations for researchers. *Journal of Epidemiology Community Health*. 2003; 57:68–73.10.1136/jech.57.1.68 [PubMed: 12490652]
- Rosman S. Cancer and stigma: Experience of patients with chemotherapy-induced alopecia. *Patient Education and Counseling*. 2004; 52:333–339.10.1016/S0738-3991(03)00040-5 [PubMed: 14998604]
- Sarna L, Brown J, Cooley M, Williams R, Chernecky C, Padilla G, Danao LL. Quality of life and meaning of illness of women with lung cancer [Online exclusive]. *Oncology Nursing Forum*. 2005; 32:E9–E19.10.1188/05.ONF.E9-E19 [PubMed: 15660139]
- Sarna L, Padilla G, Holmes C, Tashkin D, Brecht M, Evangelista L. Quality of life of long-term survivors of non-small-cell lung cancer. *Journal of Clinical Oncology*. 2002; 20:2920–2929.10.1200/JCO.2002.09.045 [PubMed: 12089220]

- Software Q. Right writer [v.4.0]. Indianapolis, IN: MacMillan Computer Publishing; 1990.
- Stuber J, Galea S, Link B. Smoking and the emergence of a stigmatized social status. *Social Science and Medicine*. 2008; 67:420–430.10.1016/j.socscimed.2008.03.010 [PubMed: 18486291]
- Stutterheim S, Pryor J, Bos A, Hoogendijk R, Muris P, Schaalma H. HIV-related stigma and psychological distress: The harmful effects of specific stigma manifestations in various social settings. *AIDS*. 2009; 23:2353–2357. [PubMed: 19741478]
- Sugimura H, Yang P. Long-term survivorship in lung cancer: A review. *Chest*. 2006; 129:1088–1097.10.1378/chest.129.4.1088 [PubMed: 16608961]
- SurveyMonkey®. Online software and questionnaire tool. 2009. Retrieved from http://www.surveymonkey.com/Home_Reasons.aspx
- Van Brakel W. Measuring health-related stigma: A literature review. *Psychology, Health and Medicine*. 2006; 11:307–334.10.1080/13548500600595160
- Ware N, Wyatt M, Tugenberg T. Social relationships, stigma, and adherence to antiretroviral therapy for HIV/AIDS. *AIDS Care*. 2006; 18:904–910.10.1080/09540120500330554 [PubMed: 17012079]
- Weiss M, Ramakrishna J. Stigma interventions and research for international health. *Lancet*. 2006; 367:536–538.10.1016/S0140-6736(06)68189-0 [PubMed: 16473134]
- Wiley, R. Measures of self-concept. Lincoln, NE: University of Nebraska Press; 1989.
- Wilson K, Luker K. At home in hospital? Interaction and stigma in people affected by cancer. *Social Science and Medicine*. 2006; 62:1616–1627.10.1016/j.socscimed.2005.08.053 [PubMed: 16198466]
- Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology*. 2001; 10:19–28.10.1002/1099-1611(200101/02)10:1<19::AID -PON501>3.0.CO;2-6 [PubMed: 11180574]

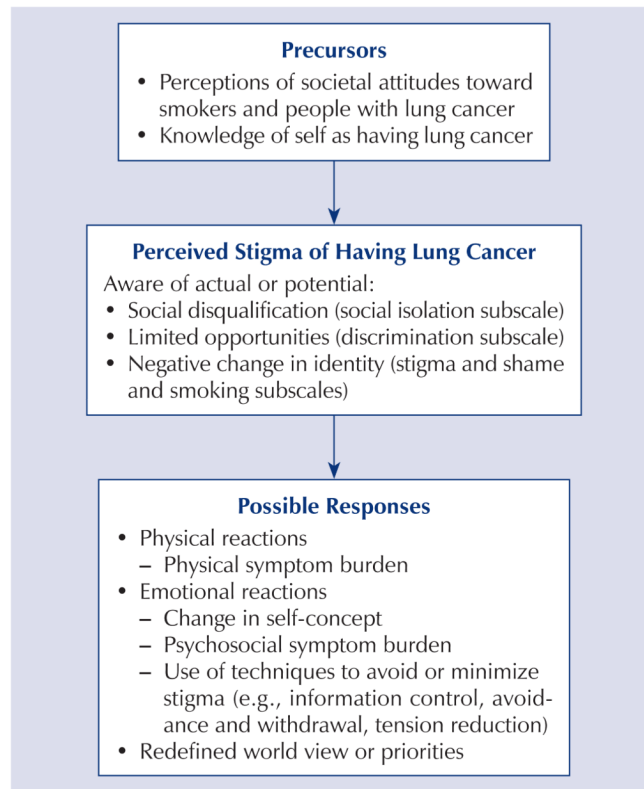


Figure 1. Model of Health-Related Stigma in Patients With Lung Cancer

Note. From “Measuring Stigma in People With HIV: Psychometric Assessment of the HIV Stigma Scale,” by B. Berger, C. Ferrans, and F. Lashley, 2001, *Research in Nursing and Health*, 24, p. 520. Copyright 2001 by John Wiley and Sons. Adapted with permission.

Table 1

Characteristics by Smoking Status

Variable	Smokers (N = 151)		Nonsmokers (N = 39)	
	n	%	n	%
Age (years)				
20–34	10	7	8	21
35–44	19	13	4	10
45–54	38	25	5	15
55–64	38	25	9	23
65 or older	42	28	13	32
Missing data	4	3	–	–
Education				
High school or less	26	17	6	15
Some college	52	35	6	15
Four-year college or higher	73	48	26	67
Missing data	–	–	1	3
Gender				
Male	42	28	13	33
Female	109	72	26	67
Race or ethnicity				
Asian or Pacific Islander	12	8	4	10
White, non-Hispanic	130	86	32	82
Hispanic	3	2	–	–
Other	5	3	1	3
Missing data	1	1	2	5
Income (\$)				
Less than 30,000	41	27	10	26
31,000–70,000	64	42	14	36
More than 70,000	42	28	15	38
Missing data	4	3	–	–
Work status				
Employed	65	43	15	38
Unemployed	84	56	23	59
Missing data	2	1	1	3
Marital status				
Married	108	72	31	79
Nonmarried	42	28	8	21
Missing data	1	1	–	–

Note. Because of rounding, not all percentages add up to 100.

Table 2

Factor Loadings of the Stigma Items

Statement	Factor			
	1	2	3	4
1. I feel guilty because I have lung cancer. ^a	0.814	–	–	–
2. I work hard to keep my lung cancer a secret. ^a	0.761	0.407	–	–
3. Having lung cancer makes me feel like I'm a bad person. ^a	0.678	0.382	0.343	–
4. I'm very careful whom I tell I have lung cancer. ^a	0.666	0.387	–	–
5. I feel I'm not as good as others because I have lung cancer. ^a	0.655	0.378	–	–
6. I worry people who know I have lung cancer will tell others.	0.645	0.461	–	–
7. Having lung cancer makes me feel unclean. ^a	0.636	0.42	0.433	–
8. In many areas of my life, no one knows I have lung cancer.	0.616	0.351	–	–
9. I feel set apart, isolated from the rest of the world. ^a	0.613	0.449	0.418	–
10. I told people close to me to keep my lung cancer a secret.	0.608	0.489	–	–
11. Telling someone I have lung cancer is risky.	0.604	0.307	0.398	–
12. People's attitudes make me feel worse about myself.	0.594	–	0.316	–
13. As a rule, telling others has been a mistake.	0.588	0.57	–	–
14. My lung cancer diagnosis was delayed because I put off going to the doctor. ^a	0.56	0.304	–	–
15. I regret having told some people that I have lung cancer.	0.551	0.539	0.344	–
16. Having lung cancer in my body is disgusting to me.	0.513	–	0.407	–
17. Some told me lung cancer is what I deserved for smoking. ^a	0.488	0.436	–	–
18. My lung cancer diagnosis was delayed because my healthcare provider did not take my "smoker's cough" seriously. ^a	0.475	0.4	–	–
19. Smokers could be refused treatment for lung cancer. ^a	0.41	–	–	–
20. I have lost friends by telling them I have lung cancer. ^a	0.341	0.807	–	–
21. I stopped socializing with some because of their reactions. ^a	0.328	0.767	–	–
22. People have physically backed away from me. ^a	0.359	0.747	–	–
23. People I care about stopped calling after learning that I have lung cancer. ^a	0.394	0.737	–	–
24. People seem afraid of me because I have lung cancer. ^a	0.362	0.709	0.312	–
25. People who know tend to ignore my good points.	0.441	0.698	–	–
26. People avoid touching me if they know I have lung cancer. ^a	0.486	0.677	–	–
27. Some people don't want me around their children once they know.	0.466	0.675	–	–
28. People avoid you because lung cancer is associated with death. ^a	–	0.62	0.339	0.35
29. Some people who know have grown more distant. ^a	0.393	0.615	0.346	–
30. Knowing, they look for flaws in your character.	0.355	0.58	0.328	–
31. I was hurt how people reacted to learning I have lung cancer. ^a	0.368	0.509	0.402	–
32. I worry about people discriminating against me. ^a	0.452	0.484	0.427	–
33. People with lung cancer are treated like outcasts. ^a	–	–	0.701	0.379
34. Most people believe a person with lung cancer is dirty. ^a	0.354	0.326	0.59	–

Statement	Factor			
	1	2	3	4
35. Most people think a person with lung cancer is disgusting.	0.341	0.436	0.565	–
36. Most are uncomfortable around someone with lung cancer. ^a	–	0.47	0.498	–
37. I worry that people may judge me when they learn I have lung cancer. ^a	0.448	–	0.45	0.343
38. People with lung cancer lose jobs when employers learn. ^a	0.306	0.415	0.435	–
39. Lung cancer is viewed as a self-inflicted disease. ^a	–	–	–	0.704
40. Others assume that a patient's lung cancer was caused by smoking, even if he or she never smoked. ^a	–	–	–	0.697
41. Others assume that a patient's lung cancer was caused by smoking, even if he or she had stopped smoking years ago. ^a	–	–	–	0.663
42. Some people act as though it is my fault that I have lung cancer. ^a	–	0.369	–	0.455
43. Healthcare providers don't take "smoker's cough" seriously. ^a	–	0.329	–	0.349

^aItems retained for the revised 31-item scale.

Table 3
Correlations of Other Measures With the Cataldo Lung Cancer Stigma Scale Total and Subscales

Measure	Subscale			
	Total LCS	Stigma and Shame	Social Isolation	Smoking
CES-D	0.616*	0.608*	0.574*	0.565*
QOL inventory	-0.618*	-0.603*	-0.569*	-0.325*
RSES	-0.723*	-0.738*	-0.701*	-0.227*
Social conflict	0.619*	0.606*	0.607*	0.237*
SS-Availability	-0.547*	-0.542*	-0.551*	-0.434*
SS-Validation	-0.512*	-0.479*	-0.503*	-0.441*
Subjective Integration	-0.627*	-0.604*	-0.631*	-0.556*

* p = 0.01 level (two-tailed)

CES-D—Center for Epidemiological Studies–Depression Scale; LCS—lung cancer stigma; QOL—quality of life; RSES—Rosenberg Self-Esteem Scale; SS—Social Support indices

Table 4

Reliability Coefficients for the Cataldo Lung Cancer Stigma Scale (CLCSS) and Subscales

Subscale	43-Item Scale		31-Item Scale	
	Coefficient α	n	Coefficient α	n
Discrimination	0.946	6	0.916	5
Smoking	0.748	5	0.748	5
Social isolation	0.98	13	0.958	10
Stigma and shame	0.974	19	0.968	11
Total CLCSS	0.981	43	0.964	31