

# Exploring Stigma Among Lung Cancer Survivors: A Scoping Literature Review

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**PROBLEM IDENTIFICATION:** Lung cancer survivors face many challenges that affect their quality of life and survival. A growing concern is the layered effect of stigma related to cigarette smoking and the perceived life-threatening diagnosis of lung cancer. This experience may affect lung cancer survivors' physical, psychological, and social well-being, negatively influencing their quality of life.

**LITERATURE SEARCH:** CINAHL®, PubMed®, PsycINFO®, and Web of Science were searched from January 2000 through August 2017, using combinations of four keywords: *lung cancer*, *lung neoplasm*, *stigma*, and *smoking*.

**DATA EVALUATION:** Extracted data included research aims, design, method, analytical approach, sample size, gender, ethnicity/race, setting, stigma measure, smoking status, and major results.

**SYNTHESIS:** Of 163 studies initially identified, 30 (19 quantitative, 8 qualitative, 2 theoretical reviews, and 1 mixed method) were included. Quantitative studies were analyzed by statistical significance and relevant findings. Thematic analysis was used to evaluate qualitative studies.

**IMPLICATIONS FOR RESEARCH:** Future research should focus on the development and testing of tailored and multilevel interventions to support the management of stigma and lessen the negative impact it has on quality of life, with special considerations for vulnerable subpopulations.

**KEYWORDS** lung cancer; stigma; smoking; scoping review; psychometrics

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Lung cancer is the second leading cause of cancer among adults, accounting for 27% of all cancer deaths in the United States (American Cancer Society [ACS], 2018; American Lung Association [ALA], 2018). Because of advances in screening practices, early detection, and improved treatments, lung cancer survival rates continue to slowly improve (ACS, 2018; de Moor et al., 2013). In 2018, the one- and five-year survival rates for lung cancer were 50% and 18%, respectively, up from 37% and 15% in 2013 (ACS, 2018; ALA, 2018).

The Institute of Medicine (2013) reported that 14 million cancer survivors lived in the United States in 2012 and estimated that number to increase to 18 million by 2022. Survivorship is defined as the time from diagnosis to the end of life; the increasing number of cancer survivors, including lung cancer survivors, warrants examination of the challenges these survivors face, particularly stigma in the lung cancer population.

Stigma is “an undesirable stereotype leading people to reduce the bearer from a whole and usual person to a tainted, discounted one” (Goffman, 1986, p. 3). Health-related stigma is the perception of possessing a trait that produces an unfavorable health outcome. For lung cancer, the health-related stigma is a perception that individuals diagnosed with lung cancer must be tobacco users, because tobacco use is the leading cause of lung cancer (Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011). Cigarette smoking is viewed as a poor life choice, and individuals who make this choice are perceived as being responsible for their lung cancer diagnosis (Cataldo et al., 2011; Lehto, 2014). This perception stems from the U.S. Department of Health, Education, and Welfare (1964) report that heightened public awareness of the effects of tobacco use and its link to chronic illnesses. Subsequent reports have validated that groundbreaking finding and revealed more concerns regarding

tobacco use that affect nonsmokers (U.S. Department of Health and Human Services, 2014). Pervasive antismoking initiatives have denormalized smoking, leading to smokers being blamed for diseases with which their behavior is linked (Bayer, 2008; Gielen & Green, 2015; Peretti-Watel, Legleye, Guignard, & Beck, 2014).

Lung cancer survivors experience higher levels of psychological distress in comparison to other cancer survivors (Brown Johnson et al., 2015; Chambers et al., 2012; Chambers, Morris, et al., 2015; Chapple, Ziebland, & McPherson, 2004; Gonzalez & Jacobsen, 2012; Hamann et al., 2014). Stigma is thought to lead to further psychological distress, social isolation, and negative effects on physical and functional well-being (Brown Johnson et al., 2015; Cataldo et al., 2011; Chambers et al., 2012; Chambers, Baade, et al., 2015; Gonzalez & Jacobsen, 2012; Hamann et al., 2014).

Although there is an acknowledgment of the negative ramifications related to lung cancer stigma, there are scant studies addressing possible interventions for oncology healthcare providers to assist with alleviating the widespread effect stigma imposes on lung cancer survivors. To date, existing research has evaluated lung cancer stigma and the impact it has on physical, social, and psychological challenges experienced by survivors. The examination of existing literature will not only assist with enhancing the conceptualization of lung cancer stigma but also identify gaps and provide suggestions for oncology practice and future research. The authors chose a scoping review to provide this direction. This review captures emerging knowledge, identifies areas where scientific advancement is needed, and assists with future development of interventions applicable to oncology practice that will mitigate stigma-induced distresses and improve quality of life (QOL).

## Methods

Using the process delineated by Arksey and O'Malley (2005), a scoping review was conducted of the stigma experience among lung cancer survivors. The five-step process involves the following:

- Identifying the research question
- Identifying relevant studies
- Selecting the studies
- Charting the data
- Summarizing the data and reporting results

Following this process, pertinent research questions were identified and are as follows:

- How is lung cancer stigma measured?

- How can we fully describe the stigma lung cancer survivors face?
- How does lung cancer stigma affect survivors' overall QOL?

Existing research was delineated by the measures of lung cancer stigma, the scope and depth of stigma among adult lung cancer survivors, and the impact it has on QOL. Existing research was categorized and summarized. Clarification of the conceptual definition and identification of research gaps were reported, and suggestions of future paths for research were recommended (Peters et al., 2015).

## Identification of Relevant Research Studies

CINAHL®, PubMed®, PsycINFO®, and Web of Science were used to identify research studies that were published from January 2000 through August 2017. Searches included four keywords (*lung cancer* or *neoplasm*, *stigma*, and *smoking*) in various combinations.

Keywords could appear in the title, abstract, or body of the article. For an article to be included, it had to be published in English and in a peer-reviewed journal. The inclusion criteria also required that sample participants be aged 18 years or older and be survivors of small cell or non-small cell lung cancer. Studies included had to examine an outcome variable associated with lung cancer stigma, such as smoking status, depressive symptoms, and QOL. Studies that did not consider stigma associated with lung cancer as one of their aims were excluded from the review. Studies using both qualitative and quantitative research methodologies were included.

A search across all four databases yielded 163 articles. Duplicate articles ( $n = 114$ ) and non-research articles, commentary articles, and theoretical reviews ( $n = 48$ ) were excluded. After making these exclusions, 30 relevant publications remained and were included in the review (see Table 1). Existing research was delineated, categorized, and summarized by the study methods, measures of lung cancer stigma, scope and depth of stigma among adult lung cancer survivors, and impact on QOL.

## Data Extraction, Analysis, and Synthesis

Evaluated data included research aims, design, method, analytical approach, sample size, gender, ethnicity/race, setting, stigma measure, smoking status, and major results. Studies aimed to define internal, external, and perceived stigma and understand the health consequences and QOL impact that stigma has on lung cancer survivors.

**TABLE 1. Lung Cancer Stigma Study Review**

| Study and Location                            | Design and Aim   | Methods  | Participants  | Findings   |
|---|--|--|---|--|
| Brown & Cataldo, 2013<br>(United States)      | Qualitative; to explore the experience of female long-term lung cancer survivors in the context of lung cancer stigma and examine how participants discursively adhere to or reject stigmatizing beliefs   | Exploratory 1-on-1 and group interviews focused on diagnosis, experience with HCPs, experience of attitudes toward lung cancer, changes in social network, and experience with stigma                            | N = 8; 100% women; 63% ever smokers   | Participants experienced stigma in interactions with HCPs and expressed displeasure with how they were identified; conflict between rejecting and assuming stigma relative to diagnosis; expressed that stigma interferes with an ideal patient-provider relationship  |
| Brown Johnson et al., 2014<br>(United States) | Quantitative; to investigate lung cancer stigma, anxiety, depression, and QOL among ever and never smokers   | Descriptive cross-sectional study; correlational analyses and hierarchical multiple regression were performed using multiple surveys for anxiety, depression, and QOL; CLCSS                                     | N = 149; 75% women and 25% men; 93% Caucasian and 7% non-Caucasian; 80% ever and 20% never smokers                    | Significant negative relationships between QOL, anxiety, and depression, and significant negative relationship between lung cancer stigma and QOL; significant associations with stigma and 3 of 4 QOL subscales (physical, psychological, and social well-being); smoking status did not affect stigma, depression, or QOL. |
| Carter-Harris & Hall, 2014<br>(United States) | Psychometric analysis; to investigate dimensionality of the original CLCSS in patients with lung cancer, to evaluate internal consistency reliability of the original CLCSS, and to shorten the CLCSS using exploratory factor analysis and reliability indicators | Self-reported written surveys followed by semistructured interviews; principal component analysis used to assess dimensionality followed by exploratory factor analysis; reliability tested using Cronbach alpha | N = 94; 62% women and 38% men; 83% Caucasian and 17% African American; 68% ever and 32% never smokers                 | 3 factors identified: shame and blame, social isolation, and discrimination; scale decreased from 31 to 21 items with internal consistency of 0.93 (compared to 0.95 for the 31-item scale).   |
| Carter-Harris et al., 2014<br>(United States) | Quantitative; to examine relationships among demographic variables, healthcare system distrust, lung cancer, stigma, smoking status, and timing of medical care  | Cross-sectional, correlational study using self-reported surveys followed by semistructured interview; CLCSS used to measure stigma  | N = 93; 62% women and 38% men; 83% Caucasian and 17% African American; 32% current, 35% former, and 32% never smokers | Associations present among time from symptom onset to medical help, healthcare system distrust, lung cancer stigma, smoking status, income, ethnicity, and social desirability. Stigma was a significant predictor of increased time from symptom onset to seeking medical help.   |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location                           | Design and Aim   | Methods   | Participants  | Findings   |
|--|--|---|---|--|
| Cataldo et al., 2011<br>(United States)      | Psychometric analysis; to develop and evaluate an instrument to measure perceived stigma of individuals with lung cancer   | Exploratory online survey for factor analysis for construct validity; correlations to establish criterion-related validity and measure internal consistency reliability of CLCSS  | N = 186; 70% women and 30% men; 86% Caucasian, 8% Asian, 2% Hispanic, and 3% other; 79% current and 21% nonsmokers  | Authors validated the scale developed to measure stigma components. 4 subscales identified: shame/stigma, social isolation, discrimination, and smoking; associations between perception of stigma and depression, QOL, social support and conflict, and self-esteem                                   |
| Cataldo et al., 2012<br>(United States)      | Quantitative; to examine the relationship of lung cancer stigma, depression, and QOL and to explore the impact of stigma on QOL, adjusting for age, gender, smoking status, and depression | Online questionnaire examining the association between self-reported stigma and depression and QOL, with comparison between participants with lung cancer who were smokers and nonsmokers using CLCSS   | N = 190; 56% men and 43% women; 85% Caucasian, 2% African American, 8% Asian or Pacific Islander, 2% Hispanic, 1% American Indian, and 1% more than one ethnicity; 80% ever and 21% never smokers | Positive relationship between stigma and depression; inverse relationship between stigma and QOL; stigma significantly contributed to the explanation of QOL; small difference between ever and never smokers  |
| Chambers et al., 2012<br>(NA)                | Systematic review; to assess the influence of stigma and nihilism on lung cancer care QOL and psychosocial well-being  | Search guided by stigma and treatment outcomes, psychosocial outcomes, and public health impact; assessed stigma or nihilism and included an outcome of interest relative to survival, delayed presentation, treatment adherence or refusal, patterns of care, psychological distress, psychological help seeking, or QOL         | 15 articles reviewed and discussed (7 qualitative and 8 quantitative)   | Stigma has an adverse effect on psychosocial well-being and QOL. Felt, perceived, and enacted stigma was experienced by many with lung cancer. No clear indication was found of nihilism in association with stigma.   |
| Chambers, Baade, et al., 2015<br>(Australia) | Quantitative; to describe the impact of stigma on psychological distress and QOL of patients with lung cancer  | Cross-sectional survey examining psychological distress and QOL after lung cancer diagnosis; health-related stigma, social constraints, and illness appraisals assessed as predictors of adjustment outcomes; surveys measured psychological distress, QOL, social constraints, and stigma (using CLCSS); hierarchical regression | N = 151; 52% men and 48% women; 72% born in Australia and 28% other; specific race/ethnicity not reported; 83% ever and 17% never smokers   | An increase of stigma, shame, and discrimination was associated with increased anxiety. A higher level of shame related to stigma was associated with increased depression. An association between stigma and shame/distress was established. Stigma and shame had a significant association with QOL. |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location                         | Design and Aim  | Methods   | Participants  | Findings   |
|--|---|---|---|--|
| Chambers, Morris, et al., 2015 (Australia) | Mixed methods; to test the acceptability of a focused cognitive behavioral intervention targeting stigma for a group of patients with lung cancer   | 6-week telephone self-help intervention; stigma, QOL, depression, and cancer-related distress measured prior to intervention for baseline and in months after study began; interview completed at 3 months to assess intervention acceptability; CLCSS measured stigma.   | N = 25; 88% women and 12% men; race/ethnicity not reported; 28% current, 52% former, and 20% never smokers  | Overall stigma score decreased at the second time point; the subscale of discrimination did not have a substantial change. Psychological outcomes improved. Stigma was a theme identified from the interviews postintervention.  |
| Chapple et al., 2004 (United Kingdom)      | Qualitative; to explore the perception of stigma among patients with lung cancer  | 1-on-1 interviews focused on the perception of the cause of illness and how others reacted to the diagnosis   | N = 45; gender not reported; 98% White British and 2% Indian; smoking status not reported   | Stigma was felt and enacted within the sample. These feelings may deter participants from seeking support and assistance. Participants expressed anger that they were blamed for acquiring the disease.  |
| Criswell et al., 2016 (United States)      | Psychometric analysis; to evaluate Cancer Responsibility and Regret Scale   | Factor analysis of the scale, which measures the constructs of medical stigma, personal responsibility, and regret; correlational design to compare measures among never, former, and current smokers   | N = 213; 56% women and 44% men; 80% Caucasian and 18% other; 18% current, 66% former, and 16% never smokers   | Current and former smokers had higher personal responsibility and regret than never smokers. All smoking statuses reported medical stigma with very little difference between current/former and never smokers; greater medical stigma was associated with worsening psychological functioning.  |
| Else-Quest et al., 2009 (United States)    | Quantitative; to assess patients' experience of stigma and self-blame after diagnosis of breast, lung, and prostate cancer, and to explore stigma, shame, and self-blame relative to psychological adjustment | Bivariate and multivariate correlation examining differences between groups; hierarchical regression examining mediation between self-blame and perceived stigma; perceived stigma measured with Perceived Cancer-Related Stigma (nonvalidated instrument) developed by the authors; causal attribution evaluated using thematic content analysis | 96 of 172 participants had lung cancer; 51% men and 49% women; 94% Caucasian, 3% African American, 2% Native American, and less than 1% Hispanic; 92% current or former smokers | A strong correlation existed between self-blame, self-esteem, and perceived stigma for all participants. Participants (all cancers) who reported internal attribution had higher self-blame, lower self-esteem, higher anxiety, and higher depression. Participants with lung cancer reported more internal attribution and behavioral cause of disease. |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location   | Design and Aim  | Methods   | Participants   | Findings  |
|--|---|---|--|---|
| Gonzalez & Jacobsen, 2012<br>(United States)                         | Quantitative; to examine the possible association between perceived stigma related to a lung cancer diagnosis and depressive symptomatology   | Correlational analysis from a questionnaire and self-reported measures assessing perceived stigma, depressive symptomatology, and chart review; Social Impact Scale–Stigma was used.              | N = 95; 59% women and 41% men; 93% Caucasian and 7% non-Caucasian; 16% current, 72% former, and 13% never smokers  | Perceived stigma degree significantly related to depressive symptoms; poorer social support, more avoidant coping, and more dysfunctional attitude significantly related to more depressive symptoms  |
| Gonzalez et al., 2015<br>(United States)                             | Quantitative; to examine diagnosis concealment and its association with stigma, social anxiety and avoidance, coping strategies, support systems, anxiety and depression, and self-esteem | Correlational design to evaluate demographics and clinical variables with concealment of diagnosis; hierarchical regression analysis to predict concealment; Social Impact Scale–Stigma was used. | N = 117; 50% men and 50% women; 82% Caucasian and 18% non-Caucasian; 78% ever and 22% never smokers  | Strong association between concealment and internalized shame; anxiety, depression, cancer-specific distress, social avoidance, and self-esteem not associated with concealment   |
| Hamann et al., 2014<br>(United States)                               | Qualitative; to explore a conceptual model for lung cancer stigma   | Individual interviews and focus group discussions to explore and describe the perception of lung cancer survivors   | Interviews (N = 42 of 65): 52% women and 48% men; 64% Caucasian, 29% African American, 5% Asian or Pacific Islander; and 2% American Indian or Alaska Native; 24% current, 50% former, and 26% never smokers; focus group (N = 23 of 65): 52% men and 48% women; 70% Caucasian, 22% African American, and 9% Asian or Pacific Islander; 17% current, 48% former, and 35% never smokers | Perceived stigma pervasive throughout entire sample, manifesting as devaluation and negative appraisal; internalized stigma affected by smoking history; long-term quitters and never smokers experienced less internalized stigma; stigma-related consequences seen as adaptive and maladaptive; participants recognized the need for intervention to promote adaptive consequences. |
| Hamann et al., 2018<br>(United States)                               | Psychometric analysis; to evaluate newly developed Lung Cancer Stigma Inventory   | Exploratory factor analysis on phase 3 participants of this study; 25-item survey developed and validated   | N = 231; 64% women and 36% men; 79% Caucasian and 14% African American; 8% current, 65% former, and 26% never smokers  | Internal consistency = 0.89; convergent validity (CLCSS) $r = 0.58$ ; 3 factors: internal stigma, perceived stigma, and constrained disclosure  |
| Jeong et al., 2016<br>(United States, United Kingdom, and Australia) | Metasynthesis; to explore and synthesize the experience of stigma among lung cancer survivors in qualitative studies  | Review of qualitative studies using the process according to Sandelowski and Barroso (2007)   | 7 qualitative studies  | Themes: experiencing some distance from surrounding world, experiencing self-made distance between the disease and oneself, the disease experience causing social isolation and loneliness, and lack of supportive care   |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location                       | Design and Aim  | Methods  | Participants  | Findings  |
|--|---|--|---|---|
| Lebel, Castonguay, et al., 2013 (Canada) | Quantitative; to examine cancer-related stigma, determinants, and psychosocial impacts in lung and head and neck cancer survivors   | Self-reported questionnaires for correlations among stigma, behavioral self-blame, disfigurement, illness intrusiveness, benefit finding, distress, and subjective well-being and sociodemographic and medical variables; hierarchical multiple regression to predict impact of stigma on distress and well-being; stigma by cancer site, age, self-blame, and disfigurement; measured stigma with 13-item subscale from Explanatory Model Interview Catalogue | 107 of 206 participants had lung cancer; 60% women and 40% men; 12% current, 79% former, and 8% never smokers; race/ethnicity not reported            | Lung cancer survivors had higher self-blame and higher stigma than head and neck cancer survivors. Self-blame did not predict stigma. Stigma correlated significantly and positively with distress and negatively with well-being.                              |
| Lebel, Feldstain, et al., 2013 (Canada)  | Quantitative; to examine cancer-related stigma, determinants, and psychosocial impacts in lung and head and neck cancer survivors and the relationship to positive health changes   | Correlational analysis examining the associations among positive health changes, sociodemographic, and medical variables; hierarchical multiple regression used to examine the predicted power of stigma, self-blame, age, radiation treatment, and smoking status in relationship to positive health changes; 13-item subscale from Explanatory Model Interview Catalogue to measure perceived stigma   | 107 of 206 participants were lung cancer survivors; 60% women and 40% men; 12% current, 79% former, and 8% never smokers; race/ethnicity not reported | In comparison to other cancer survivors, lung cancer survivors experienced higher levels of stigma and self-blame and fewer positive health changes. Behavioral self-blame significantly predicted adoption of positive health changes, whereas stigma did not. |
| Lehto, 2014 (United States)              | Qualitative; to describe the lung cancer experience in relation to perceived stigmatization, smoking behaviors, and illness causes, and to discuss these findings relative to the role of the nurse as a patient advocate | Focus group interviews discussed patient perceptions of lung cancer challenges and adaptation issues   | N = 11; 55% women and 45% men; 100% Caucasian; smoking status not reported  | Emergent themes included societal attitudes, institutional practices and experiences, negative thoughts and emotions, actual stigmatization experiences, smoking cessation, personal choices versus addiction, and causal attributions.                         |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location                       | Design and Aim   | Methods  | Participants  | Findings   |
|--|--|--|---|--|
| Liu et al., 2016<br>(China)              | Qualitative; to describe experiences of lung cancer survivors in China relative to stigma and coping strategies  | Exploratory study using semistructured individual interviews to obtain data and analyze  | N = 17; 59% men and 41% women; race/ethnicity not reported; smoking status not reported   | 3 themes: stigma sources; experience of stigma, perceived discrimination, and social isolation; and coping with stigma   |
| LoConte et al., 2008<br>(United States)  | Quantitative; to evaluate guilt and shame in patients with non-small cell lung cancer in comparison to breast and prostate cancer  | Repeated-measures surveys at 3 time points using means to evaluate between participants; multivariate analysis of covariance; stigma measured with Perceived Cancer-Related Stigma (nonvalidated instrument) and State Shame and Guilt Scale | N = 96; 51% men and 49% women; 94% Caucasian, 2% African American, 1% Native American, and 1% Hispanic; 12% current, 80% former, and 8% never smokers                             | Those with lung cancer had higher perceived stigma than those with breast and prostate cancer. Smokers had a higher level of shame and guilt, anxiety, and depression, regardless of cause. Guilt and shame did not increase or decrease over the 3 time points for all cancers.                                       |
| Rowland et al., 2016<br>(United Kingdom) | Qualitative; to explore QOL and support experiences among individuals with advanced lung cancer  | Semistructured interviews were analyzed using interpretative phenomenologic analysis.  | N = 9; 67% men and 33% women; 67% former and 33% current smokers; race/ethnicity not reported   | Illness effect on QOL depended on how physical tasks were done. Coping strategies varied. Medical support communication was challenged; smoking status predicted this at times. Participants acknowledged etiology.  |
| Scott et al., 2015<br>(Australia)        | Qualitative; to evaluate stigma as a barrier to seeking medical attention from the perspective of the lung cancer survivor and HCPs  | Semistructured interviews  | N = 20; 60% men and 40% women; race/ethnicity not reported; 65% former and 35% never smokers  | Survivors reported stigmatization and blame for acquiring disease secondary to tobacco and that antismoking ads perpetuate the stigma. HCPs indicated a sense of responsibility on survivors partly because of smoking.  |
| Shen et al., 2015<br>(United States)     | Quantitative; to examine post-traumatic growth among lung cancer survivors as a potential buffer against the relationship between stigma and psychological distress, and to examine how these relationships differed by the timing of quitting smoking | Hierarchical linear regression using multiple surveys on psychological distress stigma, post-traumatic growth, and demographics; Shame and Stigma Scale  | N = 141; 62% women and 38% men; 95% Caucasian and 3% African American; 70% former prediagnosis smoking quitters, 30% former postdiagnosis smoking quitters, and 20% never smokers | Stigma significantly associated with psychological distress; high levels of post-traumatic growth among prediagnosis quitters, but higher stigma associated with higher psychological distress; in postdiagnosis quitters, stigma associated with higher psychological distress at low levels of post-traumatic growth |

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**TABLE 1. Lung Cancer Stigma Study Review (Continued)**

| Study and Location                    | Design and Aim  | Methods   | Participants  | Findings   |
|---------------------------------------|---|---|---|--|
| Shen et al., 2016<br>(United States)  | Quantitative; to evaluate patient-provider communication and its association with lung cancer stigma                                  | Secure electronic portal surveys or paper-based version; CLCSS measured stigma; bivariate correlations and multivariate regression assessed association and significance of stigma, patient-provider communication, and smoking status.   | N = 231; 64% women and 36% men; 79% Caucasian and 14% African American; 9% current, 65% former, and 26% never smokers                                   | Good patient-provider communication is associated with lower stigma. Age and marital status were significantly associated with stigma. No association was found between smoking status and lung cancer stigma.   |
| So et al., 2017<br>(South Korea)      | Psychometric analysis; to evaluate reliability and construct validity of the Korean Cancer Stigma Scale (adapted from CLCSS)          | Exploratory factor analysis and construct validity performed  | 50 of 247 participants had lung cancer; 60% of the 247 were women and 40% of the 247 were men; race/ethnicity not reported; smoking status not reported | Factors identified: social isolation, distancing/avoidance, discrimination, guilt, attribution, and lack of medical support  |
| Tod et al., 2008<br>(United Kingdom)  | Qualitative; to evaluate delayed reporting of lung cancer symptoms  | Individual interviews using framework analysis for interpreting data  | N = 20; 60% men and 40% women; race/ethnicity not reported; 40% current, 45% former, and 15% never smokers  | Participants stated that symptoms were varied and nonspecific. Participants generally lacked knowledge regarding symptoms, diagnosis, and treatment. Shame and guilt, fear, and stoicism were experienced.   |
| Weiss et al., 2017<br>(United States) | Quantitative; to understand lung cancer survivors' experiences and attitudes toward stigma, self-blame, and medical care satisfaction | Telephone and online surveys administered to evaluate perceived stigma, self-blame, and satisfaction of care; correlational design used to assess associations with these factors and demographic characteristics; nonvalidated, 63-item survey developed by Health Communication Company | N = 174; 52% men and 48% women; 91% Caucasian and 9% other; 19% current, 68% former, and 13% never smokers  | Stage III participants (43% of all in study) indicated a high level of perceived stigma from society as a whole; low correlation between stigma and self-blame; current and former smokers were more likely to report self-blame, and smoking history was strongly correlated with stigma. |
| Yang et al., 2014<br>(China)          | Psychometric analysis; to test reliability and validity of the Chinese version of CLCSS for lung cancer survivors                     | Exploratory factor analysis; correlational design for construct validity; Cronbach alpha for reliability  | N = 117; 74% men and 26% women; race/ethnicity not reported; smoking status not reported  | Negative association between all stigma factors and self-esteem; positive association between all stigma factors and depression  |

CLCSS—Cataldo Lung Cancer Stigma Scale; HCP—healthcare provider; NA—not applicable; QOL—quality of life  
**Note.** An ever smoker is one who currently smokes or smoked in the past.

## Results

### Reviewed Studies

The four earliest studies were published from 2004 through 2009; the remaining 26 were published after 2011. A majority of studies ( $n = 17$ ) were conducted in the United States. Others took place in Australia ( $n = 3$ ), the United Kingdom ( $n = 3$ ), Canada ( $n = 2$ ), China ( $n = 2$ ), and Korea ( $n = 1$ ). The remaining two studies were literature reviews, one a systematic review and the other a meta-analysis. The U.S.-based studies evaluated lung cancer stigma in three different regions: the Northwest, Midwest, and Southeast. Study designs included analysis of covariates, correlational analysis, factor analysis, multiple linear regression, and repeated measures with interventions. Study participants were generally homogeneous in terms of Caucasian ethnicity and age range of 60–65 years.

The studies' aims included understanding the impact on QOL experienced by lung cancer survivors, specifically depression, guilt, shame, caregiver support, and patient-provider communication from the survivors' perspectives. Not all studies reported smoking status of the participants. Studies that did reported a higher incidence of stigma among current and former smokers. Eight studies (Brown & Cataldo, 2013; Chapple et al., 2004; Hamann et al., 2014; Lehto, 2014; Liu et al., 2016; Rowland et al., 2016; Scott, Crane, Lafontaine, Seale, & Currow, 2015; Tod, Craven, & Allmark, 2008) used an exploratory approach with a qualitative design. This allowed researchers to capture participants' perspectives on stigma, societal attitudes toward smoking and lung cancer, challenges related to stigma, and positive and negative results from the experience of stigma. In the included quantitative studies, investigators used survey instruments to measure lung cancer stigma, anger, anxiety, causal attribution, depression, QOL, self-blame, timing of medical help, diagnosis concealment, and patient-provider communication (Brown Johnson, Brodsky, & Cataldo, 2014; Carter-Harris & Hall, 2014; Carter-Harris, Hermann, Schreiber, Weaver, & Rawl, 2014; Cataldo et al., 2011, 2012; Chambers, Baade, et al., 2015; Criswell, Owen, Thornton, & Stanton, 2016; Else-Quest, LoConte, Schiller, & Hyde, 2009; Gonzalez & Jacobsen, 2012; Gonzalez et al., 2015; Hamann, Shen, Thomas, Craddock Lee, & Ostroff, 2018; Lebel, Castonguay, et al., 2013; Lebel, Feldstain, et al., 2013; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008; Shen et al., 2015; Shen, Hamann, Thomas, & Ostroff, 2016; So, Chae, & Kim, 2017; Weiss et al., 2017; Yang, Liu, Yang, Ji, & Li, 2014). One

systematic review (Chambers et al., 2012) assessed lung cancer stigma and its association with nihilism, health-related outcomes, and public health programs and included studies with medical professionals as participants along with studies focused on support programs. A meta-synthesis (Jeong, Jeong, & So, 2016) explored the experience of stigma among lung cancer survivors. Because of this review's broad aims, seven qualitative research studies were included.

### Instruments Measuring Stigma

To evaluate lung cancer stigma among survivors, researchers measured stigma and related constructs with six instruments across the 30 studies (see Table 2). The Cataldo Lung Cancer Stigma Scale (CLCSS) was used in nine studies. This 31-item instrument was adapted from Berger's HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001; Cataldo et al., 2011). The four factors that emerged from this instrument (stigma and shame, social isolation, discrimination, and smoking) represent perception, blame and shame from others, the feeling of social strain and judgment, and the responsibility of acquiring the disease. Carter-Harris and Hall (2014) conducted a psychometric analysis of this instrument and reduced the number of items to 21.

LoConte et al. (2008) developed a six-item scale, the Perceived Cancer-Related Stigma Scale, derived from qualitative data obtained from lung cancer survivors' focus group discussions. This instrument assessed self-blame, guilt, shame, and embarrassment among lung, breast, and prostate cancer survivors. Gonzalez and Jacobsen (2012) and Gonzalez et al. (2015) used the Social Impact Scale to measure the perception of stigma in relation to social rejection, financial insecurity, internalized shame, and social isolation. This scale assessed stigma in cancer populations and individuals diagnosed with HIV/AIDS. Shen et al. (2015) adapted the head and neck cancer Shame and Stigma Scale (SSS) for lung cancer survivors. The SSS assessed stigma, regret, and feelings of guilt and regret related to cigarette smoking.

The Lung Cancer Stigma Inventory (LCSI) was developed by Hamann et al. (2018). This 25-item instrument was derived from the conceptual model of lung cancer stigma developed by Hamann et al. (2014). Three subscales emerged: perceived stigma, internalized stigma, and constrained disclosure. LCSI was psychometrically evaluated and had adequate internal consistency and convergent validity with related constructs. Lebel, Castonguay, et al. (2013) and Lebel, Feldstain, et al. (2013) both used

**TABLE 2. Instruments Assessing Lung Cancer Stigma**

| Instrument                             | Study                 | Dimensionality  | Scoring   | Methods  | Reliability<br>Coefficient Alpha   | Validity  |
|--|-----------------------|---|---|--|--|---|
| Cancer Responsibility and Regret Scale | Criswell et al., 2016 | EFA yield, 3 domains: personal responsibility, regret, and medical stigma   | Balanced 23-item, 7-point Likert-type scale   | Factor analysis, correlational analysis, and multiple linear regression  | Personal responsibility = 0.84, regret = 0.64, and medical stigma = 0.71   | Construct validity with Pearson correlation with measure from similar constructs  |
| Cataldo Lung Cancer Stigma Scale       | Cataldo et al., 2011  | EFA yield, 4 domains: stigma and shame, social isolation, discrimination, and smoking                                   | Balanced 31-item Likert-type 4-point scale ranging from 1 (strongly agree) to 4 (strongly disagree) | Psychometric testing: internal consistency, construct validity, and criterion validity; additional analysis includes correlations and multiple regression                              | Total scale = 0.96; for each domain: stigma and shame = 0.97, social isolation = 0.97, discrimination = 0.92, and smoking = 0.74 | Criterion-related validity supported by correlation; predicted association direction with similar constructs: depression, QOL, social support, social conflict, and self-esteem |
| Explanatory Model Interview Catalogue  | Weiss et al., 1992    | 13-item subscale adapted from interview to questionnaire  | Balanced 13-item Likert-type 4-point scale based on agreement                                       | Correlational and hierarchical multiple regression   | 0.82   | Not assessed  |
| Lung Cancer Stigma Inventory           | Hamann et al., 2018   | EFA yield, 3 factors: internalized stigma, perceived stigma, and constrained disclosure                                 | Balanced 25-item Likert-type 5-point scale ranging from 1 (not at all) to 5 (extremely)             | Preliminary psychometric testing; internal consistency; test-retest correlation and convergent validity  | 0.89; test-retest correlation $r = 0.91$   | Convergent validity with Cataldo Lung Cancer Stigma Scale was $r = 0.58$  |
| Perceived Stigma Scale                 | LoConte et al., 2008  | Not assessed  | Balanced 6-item Likert-type 5-point scale ranging from 1 (strongly agree) to 5 (strongly disagree)  | Repeated measures of stigma, guilt, and shame  | 0.75   | Not assessed  |
| Shame and Stigma Scale                 | Kissane et al., 2011  | EFA yield for original scale, 4 domains: shame with appearance, sense of stigma, regret and speech, and social concerns | Balanced 20-item Likert-type 5-point scale ranging from 1 (never) to 5 (all the time)               | Internal consistency for lung cancer adaption; bivariate correlations with stigma and other related variables and hierarchical linear regression among stigma, anxiety, and depression | Total (2 domains) = 0.81; internal stigma domain = 0.77; perceived stigma domain = 0.79  | Construct validity with preliminary psychometric testing with Pearson correlation with similar constructs   |

*Continued on the next page*

**TABLE 2. Instruments Assessing Lung Cancer Stigma (Continued)**

| Instrument          | Study               | Dimensionality   | Scoring                                    | Methods   | Reliability<br>Coefficient Alpha | Validity   |
|---------------------|---------------------|--|--|---|----------------------------------|--|
| Social Impact Scale | Fife & Wright, 2000 | Factor analysis yield, 4 domains: social rejection, financial insecurity, internalized shame, and social isolation | Balanced 24-item Likert-type 4-point scale | Correlational design and hierarchical linear regression | 0.95                             | Construct validity tested previously and established |

EFA—exploratory factor analysis; QOL—quality of life

the Explanatory Model Interview Catalogue. This semistructured interview was adapted into a 13-item questionnaire that explored stigma and illness disclosure and social rejection related to stigma. To date, there are two instruments (CLCSS and LCSII) to evaluate lung cancer stigma that have been psychometrically tested and proven to have adequate reliability and validity.

#### Definitions of Lung Cancer Stigma

The work of Goffman (1986) has been the most commonly used conceptualization of health-related stigma. His work laid the foundation for the initial conceptualization of stigma. He defined stigma as “an attribute that is deeply discrediting,” where the attribute in question is different from the normal status quo (Goffman, 1986, p. 3). A cancer diagnosis is often stigmatized because of a general misunderstanding or fear of cancer (Daher, 2012). Stigma can increase when a particular lifestyle or behavior is linked to the cancer (Cataldo et al., 2011; Lehto, 2014), such as lung cancer and cigarette smoking (ALA, 2018; Dela Cruz, Tanoue, & Matthay, 2011). Although Goffman (1986) provided the foundation, researchers have given meaningful but also different definitions and descriptions of lung cancer stigma. This is true even though associated constructs are in alignment with all descriptions and definitions of stigma and the overall effects it has on QOL among lung cancer survivors.

**Internal, external, and perceived stigma:** Chapple et al. (2004), Hamann et al. (2014), Lebel, Feldstain, et al. (2013), and Shen et al. (2016) described stigma as having both internal (felt) and external (enacted) components. Felt stigma is internal to the survivor, like feelings of shame and guilt (Chapple et al., 2004; Lebel, Feldstain, et al., 2013). Qualitative studies by Chapple et al. (2004), Hamann et al. (2014), and Tod

et al. (2008) reported that participants felt shame and guilt, which negatively affected seeking health care, social interaction, and support. Internalized feelings may manifest as negative outcomes, such as social isolation and depression. Enacted stigma is external to but directed toward the patient; it is stigma from others that produces an action (reaction or behavior), such as discrimination, blame, or social rejection (among other negative behaviors) (Chapple et al., 2004; Gonzalez & Jacobsen, 2012). Stigma also has been characterized as a perception that is felt both by the survivor and others (Brown Johnson et al., 2014; Cataldo et al., 2011, 2012; Criswell et al., 2016; Gonzalez et al., 2015). Perceived stigma is the negative association that survivors believe others have toward them and their cancer diagnosis (Brown & Cataldo, 2013; Cataldo et al., 2011; Chambers, Baade, et al., 2015; Lehto, 2014).

The current study concludes that lung cancer stigma is a threefold complex concept that involves survivors’ perceptions, survivors’ internalized feelings, and feelings and actions of others toward survivors. There is often interplay among felt, enacted, and perceived stigma, amplifying or reinforcing the other stigmas. For example, lung cancer survivors are aware that others may believe that their cancer is self-inflicted through tobacco use, holding the patient responsible for the diagnosis. The anticipated blame, discrimination, and social rejection may lead to a sense of internal shame (Cataldo et al., 2011; Lehto, 2014).

#### Health Consequences of Stigma

Of the studies that reported smoking status ( $n = 23$ ), lung cancer survivors felt some sense of responsibility for their disease, regardless of their smoking status (Brown & Cataldo, 2013; Cataldo et al., 2011, 2012;

Else-Quest et al., 2009; Gonzalez et al., 2015; Shen et al., 2015). Current smokers experienced a higher level of guilt, shame, anxiety, and depression in comparison to former and never smokers (Cataldo et al., 2012; Else-Quest et al., 2009; LoConte et al., 2008). Former and current smokers also experienced a higher level of depression and anxiety in comparison to individuals with breast, colon, lung, stomach, cervical, and head and neck cancers (Lebel, Castonguay, et al., 2013; Lebel, Feldstain, et al., 2013; So et al., 2017). Further validation was reported (Cataldo et al., 2011, 2012; Gonzalez & Jacobsen, 2012) where there was a statistically significant strong positive association between stigma and depression in a study of lung cancer survivors. Brown Johnson et al. (2014) found significant statistical associations among lung cancer stigma, depression, and anxiety. Chambers, Morris, et al. (2015) introduced a cognitive behavioral intervention focused on lung cancer stigma in their pilot intervention study. They reported higher levels of depression, anxiety, and stigma preintervention, which significantly decreased postintervention.

Stigma affects psychological challenges and complicates patient-provider communication (Brown & Cataldo, 2013; Brown Johnson et al., 2014, 2015; Cataldo et al., 2011; Chambers, Baade, et al., 2015; Gonzalez & Jacobsen, 2012; Hamann et al., 2014; Lehto, 2014; Shen et al., 2015; Yang et al., 2014). Brown and Cataldo (2013) explored the experiences of women with lung cancer and found that lung cancer stigma negatively affected the patient-provider relationship. Other studies reported strong associations between the presence of stigma and adverse outcomes of depression, anxiety, self-esteem, QOL, and patient-provider communication (Brown Johnson et al., 2014; Cataldo et al., 2012; Chambers, Baade, et al., 2015; Gonzalez et al., 2015; Gonzalez & Jacobsen, 2012; Lehto, 2014; Yang et al., 2014). Researchers also found that perceived and internalized stigma altered patients' communication with their friends, families, and healthcare providers (Brown & Cataldo, 2013; Chapple et al., 2004; Hamann et al., 2014; Lehto, 2014).

In their qualitative studies, Tod et al. (2008) and Scott et al. (2015) reported that blame, fear, and stigma all delayed seeking medical care. Carter-Harris et al. (2014) reported that lung cancer stigma was predictive of increasing the time to seeking care for lung cancer symptoms, which prolonged the time to diagnosis of lung cancer. Studies have reported that many lung cancer survivors are afraid of others' reactions to their diagnosis (LoConte et al., 2008; Tod et al., 2008). Reactions of others may include discrimination by

family, friends, and healthcare providers, which led some to conceal their diagnosis (Cataldo et al., 2011; Hamann et al., 2014; Shen et al., 2015). Gonzalez et al. (2015) found that internalized shame was a factor for those who did not disclose their diagnosis in comparison to those who did. Internalized shame and nondisclosure are two factors that validate the intertwining of the constructs related to lung cancer stigma. In addition, survivors reported experiencing feelings of isolation from friends and family as well as feelings of loneliness (Cataldo et al., 2011; Hamann et al., 2014). Gonzalez and Jacobsen (2012) evaluated depressive symptomology, including social support and its relationship with stigma. They reported an inverse relationship between social support and stigma experienced by participants in their research study ( $n = 95$ ).

## Discussion

This scoping review presents the results of 30 peer-reviewed studies that investigated stigma and lung cancer. The studies concentrated on the perspective of survivors and on the physical, psychological, and social influences on stigma. The findings present varied definitions of lung cancer stigma in terms of how this health-related stigma is experienced among survivors. Chapple et al. (2004) presented a foundational conceptualization that encompassed enacted stigma of others and internal and perceived feelings of lung cancer survivors. It is important to note that lung cancer stigma is a combination of awareness of social identity and survivors' personal identity, which, in turn, leads to the awareness of potential negative actions of others. This combination may result in negative consequences for the survivors. Hamann et al. (2014) captured this in their conceptual model, which led to an instrument to measure the constructs of perceived/felt and internalized/self-stigma. Hamann et al.'s (2014) model with the incorporation of adaptive and maladaptive consequences contributed to this conceptualization.

Lung cancer stigma stems from the link between cigarette smoking and the disease itself. LoConte et al. (2008) found that current or former smokers with lung cancer experienced a higher level of guilt, shame, and perceived stigma in comparison to women with breast cancer and men with prostate cancer. However, there is an association of lung cancer stigma among those who are never smokers. Cataldo et al. (2012) found a small difference in perceived stigma, depression, and QOL among ever and never smokers. This indicates that individuals with lung cancer experience

altered QOL outcomes and depression, regardless of their history with tobacco use.

Self-blame and guilt may affect the decision to seek and the timeliness of seeking medical care (Carter-Harris et al., 2014). Although lung cancer survivors cannot control others' perceptions or behaviors, perceived stigma negatively affects their self-evaluation, internalizing the stigma. Gonzalez et al. (2015) and Webb and McDonnell (2018) found that some lung cancer survivors concealed their diagnosis from family, friends, and acquaintances. Concealment of a chronic illness linked with stigma fosters a lack of support and social isolation. This may lead to further devaluation of self and increase psychological challenges that may already exist among these survivors (Quinn, Weisz, & Lawner, 2017). Good healthcare provider communication has a direct impact on the level of internalized and perceived stigma. Communication between providers and survivors is vital for management of lung cancer, and positive communication identifies and supports the needs of lung cancer survivors. The quality and quantity of positive and beneficial communication between a healthcare provider and a survivor is associated with decreased lung cancer stigma (Shen et al., 2016). When survivors perceive blame, responsibility, or fatalism, positive communication is hindered. This may lead to delay in seeking medical assistance when needed and conceal symptoms that need assessment and management.

Although this review summarizes and synthesizes substantial evidence of lung cancer stigma, knowledge gaps remain. Certain subpopulations of lung cancer survivors are underrepresented. African Americans, Pacific Islanders, and Native Americans have higher incidence and mortality rates among all populations diagnosed with lung cancer (ACS, 2018). Only five studies had samples with adequate African American representation (Carter-Harris et al., 2014; Criswell et al., 2016; Gonzalez et al., 2015; Hamann et al., 2014; Shen et al., 2016). No study had adequate representation of Pacific Islanders and Native Americans. Never smokers, who constitute 20% of individuals diagnosed with lung cancer (ACS, 2018), were not adequately represented in half of the studies. Further research is needed involving vulnerable populations, given the increased risk of negative outcomes for those living with lung cancer.

This scoping literature review focused on stigma from the viewpoint of lung cancer survivors; however, exploration of the perceptions of family members, friends, caregivers, and healthcare providers is needed. A better understanding of how stigma affects family

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## KNOWLEDGE TRANSLATION

- Lung cancer stigma is a barrier that affects the physical, mental, and social well-being of a growing population of lung cancer survivors.
  - Stigma is associated with feelings of self-blame, anger, regret, and guilt, along with the perception of shame, discrimination, and blame from others, which influence timeliness of seeking medical care and may alter patient-provider relationships.
  - Healthcare providers should be aware of the evidence that strong patient-provider communication is associated with decreased lung cancer stigma.
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members, friends, and caregivers may assist with developing strategies to support and help survivors moderate stigma, which would improve survivors' QOL. Another area that warrants investigation is the influence of antismoking campaigns, both on survivors' internalization of lung cancer stigma and perceptions of family, friends, and healthcare providers.

Lung cancer stigma affects a growing population of cancer survivors. Advancing knowledge about stigma can improve the care and QOL of this population. Developing effective education programs, awareness campaigns, and interventions can assist lung cancer survivors with the negative consequences of stigma.

## Limitations

To the authors' knowledge, this is the first scoping review to synthesize evidence from quantitative and qualitative studies relative to lung cancer survivors and stigma. For this reason, a scoping review was conducted rather than a systematic review or metasynthesis. This review evaluated research on lung cancer stigma, determined the extent and type of research conducted to date, and identified gaps in this research area (Arksey & O'Malley, 2005). Despite best efforts to uncover all relevant literature, the authors cannot disregard the possibility that some studies may not have been identified. Lastly, the authors did not limit this review to a specific methodology. The diversity of methods may have interfered with the ability to make accurate inferences related to lung cancer stigma.

## Implications for Nursing

Oncology nurses play a significant role in the lives of lung cancer survivors and their family members and friends. To provide patient-centered care, it is essential for oncology nurses to understand the harmful impact of stigma. Developing strategies to



promote meaningful communication with providers is essential for survivors and their family members, friends, and caregivers. In clinical settings, oncology nurses can advocate for improved communication and an evaluation of stigma to assist with planning individualized care. Advocating for the development and implementation of interventions that target outcomes related to decreasing physical and psychological burdens and social isolation is warranted. Although instruments have been developed for the evaluation of lung cancer stigma, more research is needed to develop practical strategies to measure these constructs and develop interventions to minimize negative effects.

## Conclusion

Additional investigations examining lung cancer stigma are imperative to improve patient-centered health care and QOL for lung cancer survivors. Research should focus on capturing specific experiences of stigma among subpopulations and amass the formative data that support the development of tailored interventions for the most vulnerable subpopulations of lung cancer survivors. Such data will assist with decreasing the experience and consequences of stigma for all lung cancer survivors.

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