

Development of a Short Version of the Cataldo Lung Cancer Stigma Scale

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### **Background and Significance**

The purpose of this study was to develop a psychometrically sound shortened version of an existing measure of lung cancer stigma for use by researchers and clinicians. Lung cancer stigma is an influential variable in the timing of help-seeking behavior in individuals with symptoms suggestive of lung cancer (Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Else-Quest, LoConte, Schiller, & Hyde, 2009). Lung cancer is the deadliest cancer worldwide with an estimated 1.6 million new diagnoses and 1.4 million deaths annually (Bray, Ren, Masuyer, & Ferlay, 2012) and a five-year relative survival rate of 16% (ACS, 2013).

Cancer-related stigma has historically evolved from a fear of suffering and death (Muzzin, Anderson, Figueredo, & Gudelis, 1994; Stahly, 1989). For lung cancer, the perception of the disease has been shaped by tobacco abuse resulting in a stigma surrounding the disease (Chapple, Ziebland, & McPherson, 2004). Individuals with lung cancer frequently experience a perceived stigma related to their diagnosis regardless of their smoking status (Cataldo et al., 2011). Current smokers, former smokers, and never smokers have reported stigmatization from healthcare providers, family members, and friends because lung cancer is so strongly associated with smoking (Cataldo, Jahan, & Pongquan, 2012). Therefore, stigma related to lung cancer is important to explore in clinical and research settings. Lung cancer patients are frequently diagnosed at an advanced stage (Ferlay et al., 2010; Jemal et al., 2011), and patient burden with survey completion may be higher. A short measure of lung cancer stigma is needed to reduce patient burden.

## Review of Literature

Stigma has long been associated with illnesses that were either poorly understood, poorly defined, lacked effective treatment, and frankly invoked fear within a population (Lebel & Devins, 2008; Stutterheim et al., 2011; Weiss & Ramakrishna, 2006). The stigma associated with lung cancer is one of tobacco use blame and self-blame of the individual's own behavior (Bell, Salmon, Bowers, Bell, & McCullough, 2010; Cataldo et al., 2011; Chapple et al., 2004; Else-Quest et al., 2009). Whether or not an individual smokes, he or she frequently perceives stigmatization from healthcare providers, friends, and family members because the disease is strongly associated with smoking (Cataldo et al., 2012).

The Cataldo Lung Cancer Stigma Scale (CLCSS) has been used to measure self-perceived lung cancer stigma in outpatient lung cancer patients (Cataldo et al., 2011), in lung cancer patients with depression (Cataldo et al., 2012), and in lung cancer patients exploring the relationship of lung cancer stigma to patient distress and individual quality of life (Lee & Kim, 2011). Although the instrument is written at the Flesch-Kinkaid Index fifth-grade reading level (Cataldo et al., 2011), the length of the instrument (31 items) may be burdensome to individuals with lung cancer. A shortened version of the CLCSS would be a valuable tool for use by researchers working with a study population of lung cancer patients as well as clinicians to assess lung cancer-related stigma in their patients. The specific aims of this study were to: (a) investigate the dimensionality of the original CLCSS in a sample of lung cancer patients; (b) evaluate the internal consistency reliability of the original CLCSS; and (c) shorten the CLCSS using exploratory factor analysis and reliability indicators.

## **Methods**

### **Design**

Data for this secondary analysis were collected in a cross-sectional study of outpatient lung cancer patients. The original study explored the influence of healthcare system distrust, lung cancer stigma, and smoking status on the timing of help-seeking behavior in individuals with symptoms suggestive of lung cancer.

### **Sample and Setting**

The sample consisted of outpatients with all four stages of lung cancer. Participants (N = 94) were recruited from December 2012 to February 2013 from two sites in Louisville, Kentucky: (a) an outpatient thoracic oncology clinic in an urban, academic medical center; and (b) an outpatient radiation oncology clinic in a private community-based hospital. Individuals were eligible for enrollment into the study if they were age 22 or older, able to speak and understand English, diagnosed with lung cancer as the primary site of cancer, and had knowledge of their lung cancer stage.

### **Measure**

Lung cancer stigma was measured using the 31-item CLCSS. Cataldo and colleagues (2011) developed the CLCSS to measure perceived stigma in lung cancer patients. The CLCSS was derived from the HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001) because of similarities in experience of perceived self-infliction of the disease process (Cataldo et al., 2011). Cataldo et al. (2011) used the conceptual model of perceived stigma from the HIV Stigma Scale (Berger et al., 2001) to adapt a model of health-related stigma in patients with lung cancer for development of the CLCSS. The conceptual model served as a guide noting “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" (Cataldo et al., 2011, p. E47). The CLCSS was modified for use in a sample of lung cancer patients. Content validity of the original scale was ensured by the inclusion of experts on stigma from psychology, sociology, oncology, and nursing. If an item was rejected by more than one of the seven reviewers, it was discarded or rewritten resulting in a reduction of the original 45-item scale to 37 items. Nine additional items were developed, reviewed, and accepted by the content experts resulting in a 46-item scale initially. The CLCSS is based upon a 4-point Likert scale anchored by 1 (*strongly disagree*) and 4 (*strongly agree*).

Psychometric testing of the original scale was conducted with 186 lung cancer patients (Cataldo et al., 2011). Construct validity was supported and involved exploratory factor analysis which revealed four underlying subscales: (a) stigma and shame, (b) social isolation, (c) discrimination, and (d) smoking. The four-factor solution explained 57% of the variance. According to Stevens (2009), greater than 50% cumulative explained variance is considered 'excellent' in factor analysis. Using an eigenvalue greater > 1 criterion for the subscales and a loading cutoff of .35, 43 of the 46 items were retained. Criterion-related validity was supported by examining the relationship of the 43-item instrument with the pre-identified related constructs (Cataldo et al., 2011): self-esteem (measured using the Rosenberg Self-Esteem Scale; Wiley, 1989), depression (measured using the Center for Epidemiologic Studies-Depression Scale; Hoover et al., 1993), social support and social conflict (both measured using the Social Support indices; O'Brien, Wortman, Kessler, & Joseph, 1993), and quality of life

(measured using the Quality of Life Inventory; Ferrell, Wisdom, & Wenzl, 1989). Internal consistency reliability was assessed with Cronbach's alpha and was noted to be .98. The Cronbach's alphas for the four subscales were: .97 (stigma and shame), .98 (social isolation), .95 (discrimination), and .75 (smoking).

The original CLCSS was then shortened to a 31-item lung cancer stigma scale to decrease patient burden after it was determined the scale could be shortened while maintaining an adequate internal consistency reliability (Cataldo et al., 2011). The 31-item, 4-point Likert scale has a range from 31 (reflecting low levels of lung cancer stigma) to 124 (reflecting high levels of lung cancer stigma). In the factor analysis for the original scale by Cataldo et al. (2011), there were six scale items noted with double factor loadings: *Some told me lung cancer is what I deserved for smoking* (.49 factor loading on component 1, .44 factor loading on component 2); *My lung cancer diagnosis was delayed because my healthcare provider did not take my "smoker's cough" seriously* (.48 factor loading on component 1, .40 factor loading on component 2); *Most are uncomfortable around someone with lung cancer* (.47 factor loading on component 2, .50 factor loading on component 3); *I worry that people may judge me when they learn I have lung cancer* (.45 factor loading on component 1, .45 factor loading on component 3); *People with lung cancer lose jobs when employers learn* (.42 factor loading on component 2, .44 factor loading on component 3); and *Healthcare providers don't take "smoker's cough" seriously* (.33 factor loading on component 2, .35 factor loading on component 4). One scale item – *I worry about people discriminating against me* – had a triple factor loading of .45 on component 1, .48 on component 2, and .43 on component 3. In addition to double loadings, the scale item – *Healthcare providers don't*

*take “smoker’s cough” seriously* – had low factor loadings of .33 on component 2 and .35 on component 4 using a cutoff loading of .40. Finally, component 3 – the discrimination subscale – only had one strong primary loading of .70 (*People with lung cancer are treated like outcasts*). The double and triple loadings, low loadings, and solitary loading on a single component supported the need for further psychometric analysis of the dimensionality of the scale and provided a rationale for considering a shorter version of the 31-item CLCSS.

The CLCSS is a relatively new instrument and, to date, has been used in two published studies. Cataldo, Jahan, and Pongquan (2012) used the CLCSS to examine lung cancer stigma in lung cancer patients with depression; Lee and Kim (2011) used the CLCSS to examine the relationships of lung cancer stigma, distress, and quality of life in lung cancer patients. Both studies supported the reliability and validity of the instrument.

### **Procedure**

The university institutional review board and review committees at both recruitment sites approved the study. Data were collected in-person using a self-administered survey in the clinic prior to an oncology visit. Data were analyzed using the Statistical Program for Social Sciences software version 20.0 (SPSS, 2012).

Dimensionality of the 31 items of the CLCSS was evaluated using principal components analysis. To assess the suitability of the data for factor analysis, Bartlett’s test for sphericity and the Kaiser-Meyer-Olkin (KMO) statistic were used. Eigenvalues greater than 1 were examined first but those located above the elbow on the scree plot were used to make the final determination of the number of factors to retain for rotation.

Reliability statistics including Cronbach's alpha, corrected item-total correlations, and alphas-if-item-deleted were used for scale and subscale refinement. Principal components analysis with varimax rotation was performed.

## **Results**

### **Sample Characteristics**

Characteristics of the sample are summarized in Table 1. The majority of participants were female, married, and age 60 years or older. More than three-fourths had advanced stage lung cancer.

### **Psychometric Testing of the Original CLCSS**

#### **Dimensionality.**

Cronbach's alpha for the 31 items was .95, indicating excellent internal consistency reliability but potential item redundancy. Three principal components analyses were run. The significant Bartlett's test of sphericity ( $p < .001$ ) and the high KMO index (.87) indicated that the data were appropriate for this analysis. On the basis of the scree plot, one primary component emerged explaining 50% of the variance. Four other components had eigenvalues greater than 1. These components explained an additional 9%, 7%, 5%, and 4% of the variance. In examining the component matrix, 23 items loaded strongly on the first component, three items loaded strongly on the second component, and one item loaded strongly on the fourth component. The third component did not have any strong loadings; four items double loaded. After further examination of the scree plot, three factors were retained for rotation. Nine items had double loadings and one item had low loadings on all three components (See Table 2). Items were eliminated if they had double loadings (defined as a minimum of .32;

Tabachnick & Fidell, 2001). These 10 items were excluded and a final principal components analysis with varimax rotation of three factors was run with the remaining 21 items (see Table 3). All items loaded strongly on either the first, second or third component. No double loadings were noted. Items loading on each factor were examined and the three factors were named. Factor 1 – shame and blame– had eight loadings that ranged from .60 to .83. Factor 2 – social isolation– had nine loadings that ranged from .47 to .88. Factor 3 – discrimination – had four primary loadings that ranged from .74 to .94. The three factors explained 68% of the item variance.

#### **Internal consistency reliability.**

Table 4 provides a summary of the reliability coefficients of the original CLCSS and subscales and the shortened version of the CLCSS and subscales. All three subscales of the shortened version had strong internal consistency reliability. The item with the lowest corrected item-total correlation (.37) was *My lung cancer diagnosis was delayed because my healthcare provider did not take my “smoker’s cough” seriously.* For the revised CLCSS, the corrected item-total correlations for Factor 1 (shame and blame subscale) ranged from .58 to .86, Factor 2 (social isolation subscale) ranged from .37 to .85, and Factor 3 (discrimination subscale) ranged from .70 to .89. There were moderate intercorrelations among the subscales: .69 between shame and blame and social isolation; .47 between shame and blame and discrimination; and .44 between social isolation and discrimination. All intercorrelations were statistically significant ( $p < .001$ ).

## Discussion

In this study, we examined the psychometric properties of the original CLCSS (Cataldo et al., 2011) and developed a short version for use by researchers and clinicians working with lung cancer patients. In a sample of lung cancer patients, the original CLCSS had excellent internal consistency reliability but potential item redundancy. The original scale contains 31 items and evidence to support reliability and validity (Cataldo et al., 2011; Cataldo et al., 2012; Lee & Kim, 2011). By examining the dimensionality of the original CLCSS, we were able to shorten the scale to 21 items and improve the practicality of the instrument's use in research and clinical practice. The shorter version will also reduce lung cancer patient burden with questionnaire completion.

In our sample, internal consistency reliability of the three subscales of the short version were strong and ranged from .89 to .92; all scale items strongly loaded onto only one factor. Cronbach's alpha for the total 21-item scale (.93) demonstrated strong evidence of internal consistency reliability of the short measure in this sample of lung cancer patients.

From a clinical standpoint, the subscales of the short version of the CLCSS offer an opportunity to tailor lung cancer stigma assessment and interventions. For example, if an individual lung cancer patient is a never smoker and scores high on the social isolation subscale but low on the smoking and shame and blame subscales, interventions can be tailored to focus on the social isolation aspect of a lung cancer diagnosis. Future research should be focused on validation of the short version of the CLCSS and its subscales.

## **Limitations**

The average age of a lung cancer patient is 71 years (ACS, 2013). The average age of the participants in this study was 62 years. Younger individuals may perceive stigma differently than their older counterpart. In addition, sample size may be a weakness. Although the sample size was sufficient for factor analysis, future studies testing the psychometric properties of the shortened version of the CLCSS should use larger samples.

## **Conclusion**

Lung cancer stigma is an important phenomenon experienced by many lung cancer patients. Perceived stigma in individuals with lung cancer can serve as a barrier to healthcare help-seeking behavior, treatment adherence, and social support. The 21-item version of the CLCSS had strong evidence of reliability. In comparison to the original CLCSS, this short version may decrease patient burden and be more applicable to clinicians; however, future research is needed to further examine its psychometric properties.

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Table 1

*Characteristics of the Persons with Lung Cancer (N = 94)*

Variable	n	%
Age (years)		
44 – 49	7	7
50 – 59	32	34
60 – 69	35	37
70 – 79	17	18
80 or older	3	.03
Education		
Less than high school	3	3
High school graduate	38	40
Some college	20	21
College graduate or higher	33	35
Gender		
Male	36	38
Female	58	62
Ethnicity		
Caucasian	78	83
African-American	16	17
Work Status		
Employed Full-Time	23	25
Employed Part-Time	7	7
Self-Employed	3	3
Unemployed	12	13

Variable	n	%
Retired	49	52
Income		
Less than \$25,000	17	18
\$25,000 - \$50,000	31	33
Greater than \$50,000	46	49
Smoked 100 Cigarettes in Lifetime		
Yes	64	68
No	30	32
Smoker at Diagnosis		
Yes	31	33
No	33	35
Lung Cancer Stage at Diagnosis		
Stage 1	7	7
Stage 2	14	15
Stage 3	29	31
Stage 4	44	47

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

Table 2

*Factor Loadings of the Original CLCSS Items with Principal Components Analysis with Varimax Rotation (N = 94)*

Item	Factor <sup>a</sup>		
	I	II	III
1. Having lung cancer makes me feel like I'm a bad person.*	<b>.81</b>	.19	.27
2. I'm very careful whom I tell I have lung cancer.*	<b>.80</b>	.37	.19
3. Having lung cancer makes me feel like I'm a bad person.*	<b>.80</b>	.33	.13
4. I work hard to keep my lung cancer a secret.*	<b>.79</b>	.33	.10
5. I feel I'm not as good as others because I have lung cancer.*	<b>.77</b>	.02	.14
6. I feel set apart, isolated from the rest of the world.*	<b>.76</b>	.18	.22
7. Smokers could be refused treatment for lung cancer.*	<b>.64</b>	.11	.18
8. People with lung cancer lose jobs when employers learn.*	<b>.55</b>	.15	.19
9. Some people who know have grown more distant.*	.24	<b>.87</b>	.13
10. I was hurt how people reacted to learning I have lung cancer.*	.33	<b>.83</b>	.04
11. I stopped socializing with some because of their reactions.*	.29	<b>.78</b>	.06
12. People avoid you because lung cancer is associated with death.*	.39	<b>.75</b>	.18
13. People I care about stopped calling after learning that I have lung cancer.*	.38	<b>.74</b>	.21
14. People have physically backed away from me.*	.18	<b>.68</b>	.39
15. Most people are uncomfortable around someone with lung cancer.*	.24	<b>.57</b>	.36
16. Some told me lung cancer is what I deserved for smoking.*	.22	<b>.48</b>	.39
17. My lung cancer diagnosis was delayed because my	-.26	<b>.42</b>	.32

Item	Factor <sup>a</sup>		
	I	II	III
healthcare provider did not take my “smoker’s cough” seriously.*			
18. Others assume that a patient’s lung cancer was caused by smoking, even if he or she never smoked.*	.20	-.02	<b>.90</b>
19. Others assume that a patient’s lung cancer was caused by smoking, even if he or she had stopped smoking years ago.*	.20	.03	<b>.89</b>
20. Lung cancer is viewed as a self-inflicted disease.*	.15	.28	<b>.77</b>
21. Some people act as though it is my fault that I have lung cancer.*	.29	.23	<b>.75</b>
22. People seem afraid of me because I have lung cancer.	<b>.66</b>	<b>.60</b>	.15
23. I worry about people discriminating against me.	<b>.66</b>	<b>.59</b>	.00
24. Most people believe a person with lung cancer is dirty.	<b>.63</b>	<b>.61</b>	.15
25. People avoid touching me if they know I have lung cancer.	<b>.62</b>	<b>.61</b>	.26
26. I worry that people may judge me when they learn I have lung cancer.	<b>.61</b>	<b>.55</b>	-.04
27. People with lung cancer are treated like outcasts.	<b>.60</b>	<b>.57</b>	.31
28. I have lost friends by telling them I have lung cancer.	<b>.58</b>	<b>.60</b>	.10
29. I feel guilty because I have lung cancer.	<b>.55</b>	<b>.42</b>	.06
30. Healthcare providers don’t take “smoker’s cough” seriously.	.13	<b>.51</b>	<b>.55</b>
31. My lung cancer diagnosis was delayed because I put off going to the doctor.	.34	.17	.25

<sup>a</sup> Factor I = Shame and Blame

Factor II = Social Isolation

Factor III = Discrimination

\* Items retained for the shortened CLCSS

Table 3

*Factor Loadings for the Shortened Version – Cataldo Lung Cancer Stigma Scale (N = 94)*

Item	Factor <sup>a</sup>		
	I	II	III
1. Having lung cancer makes me feel unclean.	<b>.83</b>	.19	.23
2. I'm very careful whom I tell I have lung cancer.	<b>.82</b>	.36	.15
3. I feel I'm not as good as others because I have lung cancer.	<b>.80</b>	.03	.13
4. I feel set apart, isolated from the rest of the world.	<b>.80</b>	.20	.17
5. Having lung cancer makes me feel like I'm a bad person.	<b>.79</b>	.32	.13
6. I work hard to keep my lung cancer a secret.	<b>.78</b>	.30	.12
7. Smokers could be refused treatment for lung cancer.	<b>.71</b>	.21	.10
8. People with lung cancer lost jobs when employers learn.	<b>.60</b>	.17	.11
9. Some people who know have grown more distant.	.28	<b>.88</b>	.03
10. I was hurt how people reacted to learning I have lung cancer.	.34	<b>.82</b>	-.03
11. I stopped socializing with some because of their reaction.	.27	<b>.76</b>	.06
12. People avoid you because lung cancer is associated with death.	.42	<b>.75</b>	.10
13. People I care about stopped calling after learning that I have lung cancer.	.38	<b>.75</b>	.17
14. People have physically backed away from me.	.21	<b>.72</b>	.34
15. Most people are uncomfortable around someone with lung cancer.	.24	<b>.59</b>	.33
16. Some told me lung cancer is what I deserved for smoking.	.30	<b>.54</b>	.29

Item	Factor <sup>a</sup>		
	I	II	III
17. My lung cancer diagnosis was delayed because my healthcare provider did not take my “smoker’s cough” seriously.	-.17	<b>.47</b>	.16
18. Others assume that a patient’s lung cancer was caused by smoking, even if he or she never smoked.	.16	.05	<b>.94</b>
19. Others assume that a patient’s lung cancer was caused by smoking, even if he or she had stopped smoking years ago.	.15	.09	<b>.94</b>
20. Lung cancer is viewed as a self-inflicted disease.	.15	.35	<b>.75</b>
21. Some people act as though it is my fault that I have lung cancer.	.28	.28	<b>.74</b>

<sup>a</sup> Factor I = Shame and Blame  
Factor II = Social Isolation  
Factor III = Discrimination

Table 4

*Reliability Coefficients for the Original Cataldo Lung Cancer Stigma Scale and Subscales and the Shortened Version – Cataldo Lung Cancer Stigma Scale and Subscales (N = 94)*

Scale/Subscale	Number of Items	Range of	
		Item-Total Correlations	Coefficient alpha
Total CLCSS	31	.24 - .76	.95
Stigma and Shame	11	.12 - .79	.85
Social Isolation	10	.71 - .85	.96
Smoking	5	.54 - .81	.89
Discrimination	5	.54 - .84	.85
Total Short Version-CLCSS	21	.24 - .76	.93
Shame and Blame	8	.58 - .86	.92
Social Isolation	9	.37 - .85	.89
Discrimination	4	.70 - .89	.91