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Lung Cancer Stigma as a Barrier to Medical Help-Seeking Behavior: Practice Implications

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Abstract

Purpose—The purpose of this study was to examine the relationship of perceived lung cancer stigma and timing of medical help-seeking behavior in symptomatic individuals.

Data sources—A convenience sample was recruited from an academic thoracic oncology clinic and community hospital-based outpatient radiation center in a large city in the southeastern United States. This descriptive, cross-sectional study used survey methodology and semi-structured interviews to examine the relationship of perceived lung cancer stigma and delayed medical help-seeking finding a statistically significant positive correlation. Additional examination revealed positive correlations between the stigma and shame, social isolation, and smoking-related stigma subscales and delay. The discrimination-related subscale was not associated with delay. In addition, smoking status was not related to perceived lung cancer stigma.

Conclusions—Findings support an association between lung cancer stigma and delayed medical help-seeking behavior. Therefore, lung cancer stigma is a potential barrier to timely medical help-seeking behavior in lung cancer symptoms, which can have important patient outcome implications.

Implications for practice—As primary care nurse practitioners, awareness that lung cancer stigma exists for patients is essential regardless of smoking status and efforts to decrease this barrier to timely healthcare are important.

Lung cancer kills more people than breast, colorectal, pancreatic, and prostate cancers combined regardless of gender or ethnicity (ACS, 2014). Lung cancer patients feel stigmatized reporting the highest levels of stigma and related psychological distress compared to all other cancers (Cataldo & Brodsky, 2013). In the United States, there will be an estimated 224,210 new cases and 159,260 lung cancer related deaths in 2014 (ACS, 2014). Lung cancer-related mortality is directly related to stage at diagnosis and most are diagnosed at an advanced stage (Luo, Chen, Narsavage, & Ducatman, 2012). Individuals with Stage III and IV lung cancers have five-year survival rates of 5% and 1% respectively. Although individuals may be asymptomatic when diagnosed, many individuals do experience symptoms. An alarming proportion of symptomatic patients report varying degrees of delayed medical help-seeking behavior (Levealahti, Tishelman, & Ohlen, 2007).

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When an individual has symptoms suggestive of lung cancer but waits to seek medical evaluation, lung cancer can advance exponentially (Salomaa, Sallinen, Hiekkänen, & Liippo, 2005). Perceived lung cancer stigma is a potential barrier to timely evaluation in symptomatic individuals. As primary care providers, nurse practitioners are frequently the first contact patients have with the healthcare system and are poised to address this important patient outcomes issue.

Stigma has historically been conceptualized by the seminal work of Goffman (1974) as “an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one” (p. 11). Lung cancer’s strong association with smoking has resulted in perceptions of self-infliction and subsequent stigma (Chapple, Ziebland, & McPherson, 2004). Stigmatized individuals suffer shame, an altered identity, and an associated blame (Engebretson, 2013). In fact, a lung cancer diagnosis can invoke similar attribution of blame as that seen with HIV/AIDS (Marlow, Waller, & Wardle, 2010). Over the past decade, the social stigma of smoking has become pronounced leading to negative attitudes held by both smokers and non-smokers (Raleigh, 2010). Further, stigmatization from healthcare providers, family, and friends may be perceived by lung cancer patients regardless of the individual’s smoking status because the disease is so strongly associated with smoking (Cataldo, Jahan, & Pongquan, 2012). Because timely medical help-seeking behavior is critical in the lung cancer diagnostic process, the purpose of this study was to examine the relationship of perceived lung cancer stigma and timing of medical help-seeking behavior in symptomatic individuals.

Methods

Design

This descriptive, cross-sectional study assessed the correlation between perceived lung cancer stigma and timing of medical help-seeking behavior in symptomatic individuals. While the idea of medical help-seeking behavior in lung cancer symptoms is not new, exploring the relationship of perceived lung cancer stigma and medical help-seeking behavior has not been addressed in the current literature.

Theoretical Foundation

The “Model for Understanding Delayed Presentation with Breast Cancer” was the theoretical foundation for this study (Bish, Ramirez, Burgess, & Hunter, 2005). Bish and colleagues developed the model after exploring empirical evidence that suggested delayed medical help-seeking behavior was influenced by multiple complex interactions including sociodemographic, clinical, cognitive and behavioral variables. Specifically, sociodemographic variables (e.g. age, ethnicity, socioeconomic status, and access to medical care) influence knowledge and symptom appraisal, which influence attitudes to help seeking and disclosure of symptoms. Ultimately, these variables influence an individual’s intention to seek help and subsequent medical help-seeking behavior. In this study, perceived lung cancer stigma is conceptualized as a variable that influences both disclosure of symptoms and attitudes to medical help-seeking behavior.

Setting

Participants were recruited from an academic thoracic oncology clinic and a community hospital-based outpatient radiation center in Louisville, Kentucky. At both recruitment sites, the setting was a private exam room within the clinic.

Procedures

Participant Recruitment and Screening

The University of Louisville Institutional Review Board, Clinical Scientific Review Committee at the James Graham Brown Cancer Center, and the Nursing Research Committee at Baptist Healthcare reviewed and approved the study prior to recruitment. All participants gave written informed consent prior to data collection. Inclusion criteria included diagnosis of non-small cell lung cancer as the primary site of cancer and knowledge of stage at diagnosis. Only adult (age 22 and older), English-speaking patients were invited to participate. A convenience sample of 93 participants was recruited from the 94 eligible participants. Study recruitment took place from December 2012 to February 2013. The researcher worked with clinic nursing staff to identify potential participants at the start of each clinic day. All (N = 94) were approached by the lung oncologist, nurse practitioner, or nurse during a follow-up appointment and introduced to the study opportunity. If the potential participant was interested in receiving further information, the researcher was invited into the exam room to explain the study fully and answer all questions. The researcher was not employed by either recruitment site. Informed consent was obtained and data collected.

Data Collection

Data were collected using survey methodology and a semi-structured interview. The 31-item four-point Likert style Cataldo Lung Cancer Stigma Scale (CLCSS) is a survey developed by Cataldo and colleagues (2011) to measure perceived lung cancer stigma in people with lung cancer with components that focus on stigma and shame, social isolation, discrimination, and smoking. Statements such as “I feel guilty because I have lung cancer”; “My lung cancer diagnosis was delayed because my healthcare provider did not take my smoker’s cough seriously”; and “Others assume that a patient’s lung cancer was caused by smoking, even if he or she never smoked” comprise the CLCSS (Cataldo et al., 2011). Participants were asked to respond to each statement with either strongly agree, agree, disagree, or strongly disagree. Timing of medical help-seeking behavior was defined as the number of days between the first symptom(s) and the time the individual called their primary care provider to seek evaluation for those symptoms. For the purposes of this paper, the number of days was used in the analyses. The qualitative analysis will be reported separately and is not included in this paper. Timing data was gathered retrospectively as self-report. Although few individuals had difficulty recalling initial symptoms and associated dates, for those that did, key event mapping was used in which recall was enhanced using a calendar and reference to common and participant specific dates and times of the year (Molassiotis, Wilson, Brunton, & Chandler, 2010). Using G*Power 3.14, a sample of 93 provided a power of 0.72 to identify a medium effect size (Cohen’s $d = 0.3$) using three groups and a .05 level of significance (Faul, Erdfelder, Lang, & Buchner, 2009).

Data Analysis

Data were analyzed using the Statistical Package for Social Sciences (IBM Corp, 2012). Descriptive statistics, Pearson product-moment correlations, and one-way analysis of variance were employed to evaluate the data. The criterion for statistical significance was p .05 for all statistical tests.

Results

Sample Characteristics

The majority of participants were Caucasian, female, educated, and insured. The mean age of the sample was 62 years ($SD = 8.7$). The ethnic representation of the sample closely mirrored that of the geographic location with 77 (82.8%) Caucasian and 16 (17.2%) African-American participants. Most participants were advanced stage; 29 (31.2%) were Stage III and 43 (46.2%) were Stage IV at diagnosis. A full description of sample characteristics can be found in Table 1.

Timing of Medical Help-Seeking Behavior

Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. The variable, timing of medical help-seeking behavior, was positively skewed. A log transformation was applied and resolved the violation to the assumption of normality. The median number of days reported between the first symptom(s) and the time the individual called their primary care provider to seek evaluation for those symptoms was 41 days. Participants reported a range of 0 to 366 days to seek medical evaluation.

Perceived Lung Cancer Stigma

Total perceived lung cancer stigma scores were measured with the CLCSS in which total scores range from 31–124. Higher scores reflect higher levels of perceived lung cancer stigma. Total perceived lung cancer stigma in this sample ranged from 31–98 (mean 68.6; SD 11.5) and the scale Cronbach's alpha was .95 consistent with excellent internal consistency reliability. The CLCSS is comprised of four subscales: (1) stigma and blame; (2) social isolation; (3) discrimination; and, (4) smoking. Stigma and blame subscale scores range from 11–34; the mean stigma and blame subscale scores in this sample were 23.6 (SD 4.2). Social isolation-related stigma subscale scores range from 10–30; the mean social isolation-related stigma scores in this sample were 20.1 (SD 3.95). Discrimination-related stigma subscale scores range from 5–16; the mean discrimination-related stigma scores in this sample were 10.4 (SD 2.0). Smoking-related stigma subscale scores range from 5–20; the mean smoking-related stigma scores in this sample were 14.5 (SD 3.1).

The relationship between the total and subscale stigma scores and timing of medical help-seeking behavior in symptoms suggestive of lung cancer were investigated using the Pearson product-moment correlation coefficient. There was a small, positive correlation between total perceived lung cancer stigma scores and timing of medical help-seeking behavior, $r = .27$, $n = 93$, $p = .01$, with high levels of perceived lung cancer stigma associated with an increased number of days to seek medical help for symptoms suggestive

of lung cancer. In addition, the relationship between the individual stigma-related subscales of the CLCSS and timing of medical help-seeking behavior were examined to understand the descriptive data more completely. There were small, positive correlations noted individually between the stigma and blame, social isolation, and smoking-related subscales and timing of medical help-seeking behavior (see Table 2). However, there was not a statistically significant relationship between the discrimination-related stigma subscale and timing of medical help-seeking behavior, $r = .18, p = .09$.

We also examined the difference in perceived lung cancer stigma scores by smoking status. A one-way between-groups analysis of variance was conducted to explore the impact of smoking status at lung cancer diagnosis on perceived lung cancer stigma, as measured by the total CLCSS scores. Participants were classified as never smokers, former smokers, or current smokers by self-report. There was no statistically significant difference at the $p < .05$ level in total perceived lung cancer stigma scores for the three smoking status groups: $F(2, 90) = .14, p = .87$.

Conclusions

Perceived lung cancer stigma was associated with delays in medical help-seeking behavior. When perceived lung cancer stigma was examined using the CLCSS subscales, the constructs of importance were shame and stigma, social isolation, and smoking-related stigma. Most importantly, perceived lung cancer stigma scores did not differ by smoking status.

Discussion

Although timing of medical help-seeking behavior ranged widely from immediate medical help-seeking behavior (0 days) to lengthy delays (366 days), the median of 41 days suggests symptomatic individuals are waiting to seek medical evaluation for symptoms of concern. Patient delay has been defined as three months or longer in other cancers (Bish et al., 2005). However, given the high mortality related to lung cancer, defining patient delay in lung cancer by the same three-month measure may not be appropriate. Individuals with symptoms suggestive of lung cancer should be evaluated promptly.

Perceived lung cancer stigma in patients that have symptoms suggestive of lung cancer can serve as a critical barrier to timely medical help-seeking behavior. When an individual becomes aware of a symptom of concern but delays seeking evaluation because of the fear of feeling stigmatized, lung cancer has the potential to advance. As primary care providers, nurse practitioners are key in the assessment and diagnosis of symptoms that may ultimately be lung cancer. It is imperative for primary care nurse practitioners to address lung cancer stigma in practice to combat this barrier to timely medical help-seeking behavior.

Lung cancer stigma is a national health issue with multiple layers of complexity. This important public health issue must be addressed from individual-, provider- and system-level perspectives. Some practical recommendations that may begin to address lung cancer stigmatization include (1) provider self-awareness; (2) education (patient, public and policy leader); (3) community engagement; and, (4) patient advocacy.

Because lung cancer stigma is so deeply rooted in society, providers are not immune to the subtle negative assumptions related to individuals with lung cancer that can negatively impact the patient-provider relationship. This societal entrenchment of stigma surrounding lung cancer necessitates provider self-awareness to begin to address this problem. Lung cancer is not a smoker exclusive disease. While tobacco cessation is important and screening for lung cancer in high-risk, long-term smokers is essential, the historical evolution of smoking and lung cancer has led to the unfortunate stigmatization of the deadliest cancer in the world. It is essential to increase awareness in the primary care community that lung cancer stigma exists with patients regardless of smoking status. Increased awareness will challenge providers to reassess their assumptions that may negatively and unknowingly impact the patient-provider relationship in the clinical setting. Self-awareness as a provider of negative assumptions related to lung cancer can positively impact future patient-provider encounters.

Lung cancer-related stigma arises from a belief that a person caused his or her own cancer (i.e. from smoking). A key to combat lung cancer-related stigma is to educate patients, and by doing so the public, about common lung cancer symptoms (i.e. persistent or increased cough, fatigue, chest discomfort, unexplained weight loss, hemoptysis), risk factors and prevalence of lung cancer in never and former smokers. By educating patients about non-smoking related risk factors such as radon and occupational environmental exposure, we can start to address the myth of lung cancer as a smoker exclusive disease and indirectly address self-infliction blame.

Further, community engagement of the issue of lung cancer is paramount. While most lung cancer patients are diagnosed at an advanced stage, there are lung cancer survivors. Often, the general public is not aware because they do not routinely see the face of lung cancer. A concerted effort needs to prominently engage lung cancer survivors in community events to raise awareness about lung cancer in order to fight its related stigma. For example, highlighting a lung cancer survivor during a local community outreach effort on cancer awareness will serve to promote education, awareness, and give a relatable face to lung cancer.

Finally, as nurse practitioners, it is our responsibility to be educated about the disease and educate others, but to also advocate for lung cancer patients and a reduction in its associated stigma. On a broader level, we are uniquely poised to educate state and federal policy leaders on the need for increased resources for lung cancer research. Policy leaders must know this issue is important to the nurse practitioner community. Resources specific to targeting lung cancer stigma in addition to prevention, early detection, and treatment are key. It is critical to acknowledge that current healthcare system constraints imposed by policy may hinder efforts to employ ideal practice making patient advocacy in this area essential. In order to move the agenda of decreasing lung cancer stigma forward, health policy must be shaped by healthcare providers for meaningful healthcare change to occur.

Limitations

As with all studies, this study is not without limitations. The greatest limitation involves the potential for recall bias. Data was collected retrospectively regarding symptom awareness and the time from symptom onset to medical help-seeking behavior. Key event mapping was used to increase the accuracy of recall. Although most participants did not have difficulty recalling specific symptoms and time periods, key event mapping was successful in those that needed assistance. In addition, the relatively small sample size of 93 participants limited power reached for this study and the ability to generalize. Future studies should be performed with a larger sample to assess replication of findings. Finally, the average age of study participants was nearly a decade younger than the average lung cancer patient in the United States. Younger individuals may perceive lung cancer stigma differently than older individuals. Future studies should aim to recruit a sample representative in age of the national lung cancer patient population.

Implications

When patients perceive lung cancer stigma, they may not seek help in a timely manner with initial symptoms. Delayed medical help-seeking behavior may result in an advanced stage lung cancer diagnosis, which is associated with a decreased prognosis secondary to decreased treatment options. With the recent release of lung cancer screening guidelines for high-risk patients by the United States Preventive Services Task Force (Moyer, 2013), perceived lung cancer stigma may negatively impact screening participation. Decreased screening participation secondary to lung cancer stigma may be associated with more advanced stage diagnoses compared to the potential for earlier stage diagnosis discovered by screening participation. Lung cancer stigma can also affect the patient-provider relationship which can compromise trust in other health-related areas such as seeking medical evaluation for other symptomatic conditions, adhering to healthcare recommendations, and keeping scheduled follow-up appointments. Going forward, primary care nurse practitioners will be an integral component of a public health awareness effort and paradigm shift related to perceived lung cancer stigma and its impact on patient outcomes.

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Table 1

Sample Characteristics of Study Participants

Variable	Study Participants N=93 (%)
Gender	
Male	35 (37.6)
Female	58 (62.4)
Ethnicity	
Caucasian	77 (82.8)
African-American	16 (17.2)
Education	
Less than High School	3 (3.2)
High School Graduate	37 (39.8)
Some College	20 (21.5)
College Graduate or Higher	33 (35.5)
Marital Status	
Not Married/Separated	33 (35.5)
Married	60 (64.5)
Employment Status	
Employed	26 (28.0)
Unemployed/Retired	67 (72.0)
Insurance Status	
Medicare/Medicaid	41 (44.0)
Private Health Insurance	40 (43.0)
Uninsured	12 (12.9)
Stage at Diagnosis:	
Stage I	7 (7.5)
Stage II	14 (15.1)
Stage III	29 (31.2)
Stage IV	43 (46.2)
Smoker at Diagnosis	
Yes	30 (32.3)
No	63 (67.7)
Smoking Status	
Never Smoker	30 (32.3)
Former Smoker	33 (35.5)
Current Smoker	30 (32.3)
Do you now smoke?	
Every Day	6 (6.5)
Some Days	4 (4.3)
Not at All	53 (57.0)
How long since last smoked regularly?	
Within the past month	12 (12.9)

Variable	Study Participants N=93 (%)
Within the past 3 months	3 (3.2)
Within the past 6 months	5 (5.4)
Within the past year	4 (4.3)
Within the past 5 years	8 (8.6)
Within the past 10 years	10 (10.8)
10 years or more	21 (22.6)
Packs per day (PPD) of current smokers at diagnosis	
Less than 1 PPD	5 (5.4)
1 PPD	12 (12.9)
1.5 PPD	1 (1.1)
2 PPD	10 (10.8)
3 PPD	2 (2.2)

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Table 2

Correlations, means and standard deviations on subscale values

Measure	Mean	SD	<i>r</i>
Stigma and Blame	23.6	4.20	.26*
Social Isolation	20.1	3.95	.23*
Smoking	14.5	3.10	.23*
Discrimination	10.4	2.00	.18

*
p < .05

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