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Lung Cancer Stigma: Associated Variables and Coping Strategies

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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

Lung Cancer Stigma: Associated Variables and Coping Strategies

by

Kevin R. Criswell

A dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

September 2016

Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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It is with great pride that I finally finish this milestone towards completing the requirements for my doctoral degree. That being said, my pride is tempered by the love and support of my friends, family, and mentors. I especially want to thank my wife for her understanding and her patience as I am certain I have contributed to clutter in our living space when I had research articles strewn around my workspace.

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played various roles in helping me reach the point to where I am ready to defend such a large project as a dissertation!

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ABBREVIATIONS

ACS	American Cancer Society
EORTC QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders third ed., revised
CES-D	Centers for Epidemiological Studies Depression
LLUMC	Loma Linda University Medical Center
COH	City of Hope Medical Center
PC	Project Coordinator
IRB	Internal Review Board
DT	Distress Thermometer
SF-36	Medical Outcomes Study Short Form
ADLs	Activities of Daily Living
MSAS-SF	Memorial Symptom Assessment Scale-short form
SCNS	Supportive Care Needs Survey
CRRS	Cancer Responsibility and Regret Scale
ANOVA	analysis of variance
CIs	confidence intervals
APA	American Psychological Association
LCA	Lung Cancer Alliance
NSCLC	non-small cell lung cancer
SCLC	small cell lung cancer
HIV	human immunodeficiency virus

AIDS	acquired immunodeficiency syndrome
SSCI	Stigma Scale for Chronic Illness Short Form

ABSTRACT OF THE DISSERTATION

Lung Cancer Stigma: Associated Variables and Coping Strategies

by

Kevin R. Criswell

Doctor of Philosophy, Graduate Program in Clinical Psychology
Loma Linda University, September 2016
Dr. Jason E. Owen, Chairperson

Lung cancer stigma is a burgeoning area of literature, yet two important questions remain unanswered: a) What are the associations between lung cancer stigma and psychosocial outcomes across lung cancer survivors with different smoking histories and b) how would lung cancer survivors describe their experience of coping strategies they utilize to cope with lung cancer stigma. This dissertation presents two studies that seek to answer the above-mentioned questions: a) a quantitative study that describes the rates of Personal Responsibility, Regret, and Medical Stigma and the associations between the above-mentioned constructs and psychosocial outcomes; and b) a qualitative study of coping strategies that lung cancer survivors reported utilizing in response to lung cancer stigma. Results from the quantitative study suggest that, while current and former smokers report significantly greater rates of Personal Responsibility and Regret when compared to never smokers, smoking status did not significantly affect the level of Medical Stigma reported by lung cancer survivors. The most common themes extracted from the qualitative data were coping strategies involving education, avoidance, support, helping others, acceptance, and assertive communication. Further research is needed to investigate exactly how lung cancer stigma relates to psychosocial outcomes As future interventions geared towards lung cancer stigma are developed and tested, it will be

important to a) measure lung cancer stigma and its associated constructs (e.g., regret, guilt/shame, personal responsibility) with instruments that are firmly rooted in testable theoretical frameworks, b) track psychosocial outcome variables and their changes as a result of the treatment response via the intervention, c) and observe any differences in how stigma variables (e.g., perceived stigma and internalized stigma) might be associated differently with outcome variables and change over time differently depending on smoking history (e.g., comparing outcomes between ever vs. never smokers).

CHAPTER ONE

BACKGROUND AND SIGNIFICANCE

Brief Introduction to the Dissertation

This dissertation is a collection of two studies aimed at addressing the issue of lung cancer stigma. Lung cancer survivors not only experience a greater rate of psychosocial issues and mortality in comparison to other cancer types (Else-Quest et al., 2008; LoConte et al., 2008; Zabora et al., 2001), they also anticipate (Chappel et al., 2004) and may actually experience (Gonzalez & Jacobsen, 2010) stigma from the general public as well as healthcare professionals. In comparison to prostate (LoConte et al., 2008), breast (LoConte et al., 2008), and head and neck cancers (Lebel et al., 2013), individuals with lung cancer have reported higher levels of perceived stigma. Higher levels of stigma have been associated with higher levels of depressive symptoms (Gonzalez & Jacobsen, 2010) and lower levels of quality of life (Cataldo et al., 2012; Gonzalez & Jacobsen, 2010) in lung cancer survivors. Also, qualitative studies suggest that lung cancer stigma may contribute to later diagnosis of lung cancer because some individuals who smoke fear differential medical treatment (Chappel et al., 2004). Although the negative psychosocial impact of stigma and its contribution to the high rate of lung cancer mortality have been demonstrated in the literature, no interventions have been developed to address the effects of lung cancer stigma (Chambers et al., 2012). Currently, gaps in lung cancer stigma literature include a) an understanding of associations between psychosocial outcomes and perceived stigma from healthcare professionals and b) coping strategies that lung cancer survivors utilize to cope with perceived stigma. Therefore, the aims of this dissertation are to a) quantitatively analyze associations between perceived stigma from healthcare professionals, b) to qualitatively analyze themes of coping strategies that lung cancer survivors utilize in response to perceived stigma, and c) to design a brief module for use by lung cancer survivors who experience stigma. Two studies (each described individually in subsequent chapters) will be described in this dissertation, each one addressing a separate aim. Development of the interactive module will be informed by results from the results of the studies addressing aims A and B as well as the existing literature.

Epidemiology of Lung Cancer

According to the American Cancer Society (ACS), lung cancer is projected to be responsible for more deaths than any other cancer type in 2013 in the United States, causing 159,480 deaths, or more than a quarter (27%) of all deaths attributable to cancer (ACS, 2013). It is also projected that lung cancer will be the second-most-diagnosed cancer type in men and women (228,190 lung cancer cases, combined sexes), behind prostate cancer (238,590 cases) and breast cancer (232,340 cases). Lung cancer is most often diagnosed at more advanced stages of the disease; 85% of lung cancer cases are diagnosed at advanced stages (i.e., the tumor has spread beyond the primary tumor site) whereas only 15% are diagnosed at a localized stage (ACS, 2013). As a consequence of the majority of lung cancer cases diagnosed at later stages, the five-year survival rate for all stages combined is 16% (ACS, 2013). Five-year relative survival rates by cancer spread is 52% (localized), 25% (regional), and 4% (distal; ACS, 2013). However, one-year survival rates have shown modest increases: 37% in 1975-1979 and 44% in 2005-

2008. The increase in survival rates has been attributed to improvements in medical treatment techniques (ACS, 2013).

Lung cancer diagnoses have trended differently for men and women. Although males have been diagnosed with lung cancer more often compared to females since the earliest recorded data, mortality rates have shown greater declines for males compared to females (Jemal et al., 2008), 2.8% per year and 1.0% per year, respectively, during the period 1991-2009 (ACS, 2013). Incidence rates for lung cancer (between 2005 and 2009) are greater in males (65.7 out of 100,000) compared to females (39.6 out of 100,000; ACS, 2013). In males during 2013, it is projected that lung cancer will be diagnosed in 118,080 men and will be attributed to 87,260 deaths, greater in number of deaths than prostate (29,720), colon and rectum (26,300), and pancreatic (19,480) cancers combined (ACS, 2103). In females during 2013, it is projected that lung cancer will be diagnosed in 110,110 women and will be attributed to 72,220 deaths, greater in number of deaths than breast (39.620) and colon and rectum (24,530) cancers combined (ACS, 2013).

Risk factors for lung cancer include environmental, genetic and medical, and behavioral factors (ACS, 2013). The best-known risk factor for contracting lung cancer is inhalation of cigarette smoke. Individuals can either voluntarily smoke cigarettes (attributable to about 90% of lung cancer cases; Alberg & Samet, 2003) or inhale cigarette smoke second-hand from others' smoking (attributable to about 3,400 deaths due to lung cancer in never smokers; Centers for Disease Control and Prevention, 2010). Other environmental risk factors include inhalation of asbestos, radon gas, metals (chromium, cadmium, arsenic), radiation, smog, and talcum powder.

Psychosocial Issues in Lung Cancer

In addition to high physical symptom burden (Sanders et al., 2010), high levels of psychosocial concerns exist in those living with lung cancer. In a large multisite national study, Zabora et al. (2001) found that individuals with lung cancer reported the highest prevalence of clinically significant distress (43% out of n = 629 lung cancer survivors) compared to all other cancer types (N = 4,496). Graves et al. (2007) found an even higher prevalence rate, reporting that nearly 62% of lung cancer survivors experienced clinically significant distress. Many lung cancer survivors also experience poor quality of life, with at least two studies showing decreasing quality of life over time (Naughton et al., 2002; Slotman et al., 2009). Although no generally accepted methods of determining clinical cutoffs for low quality of life currently exist, Slotman et al. (2009) attempted to quantify clinically relevant decreases in quality of life (i.e., decrease of at least 20 points over time according to the EORTC QLQ-C30); rates of clinically significant decreases in quality of life domains were as follows over a three-month period: 28.7% for global health status, 30.3% for role functioning, 16.5% for cognitive functioning, and 17.0% for emotional functioning.

Psychiatric illness has also been reported at high rates in lung cancer survivors. Depression has been reported in 4.7-38.9% (Gonzalez & Jacobsen, 2010; Hopwood & Stephens, 2000; Kurtz, Kurtz, Stommel, Given, & Given, 2002; Nakaya et al., 2006; Uchitomi et al., 2003) of those with lung cancer, and the prevalence of anxiety disorders has been estimated to vary between 25-43% of lung cancer survivors (Buchanan, Milroy, Baker, Thompson, & Levack, 2010; Myrdal et al., 2003; Tchekmedyian, Kallich, McDermott, Fayers, & Erder, 2003). The large range of depression rates has been attributed to differences in measurements of depressive symptoms (Carlsen et al., 2005), specifically in authors utilizing the Structured Clinical Interview for the *DSM-III-R* (Nakaya et al., 2006; Uchitomi et al., 2003) compared to authors using other depressive symptom scales (e.g., the Centers for Epidemiological Studies Depression [CES-D]; Gonzalez & Jacobsen, 2010). Regardless of these differences in measurement, clinically-significant levels of depression and anxiety appear to be consistently higher in those with lung cancer relative to other cancer types, as evidenced by the greatest number of psychiatric referrals being made for lung cancer survivors compared to other cancer types (Akechi et al., 2001).

Fatigue is one of the most common symptoms reported by cancer survivors, and lung cancer is no exception. Fatigue has been conceptualized as a distressing and subjective feeling of lack of energy, tiredness, and loss of physical strength, and it is typically conceptualized as having both psychological and physical etiologies. An estimated 50-66% of lung cancer survivors report significant concerns related to fatigue (Hung et al., 2011; Okuyama et al., 2001; Stone, Richards, A'Hern, & Hardy, 2000). Undergirding the significance of fatigue in this population is its associations with other psychosocial outcomes; lung cancer survivors with higher levels of fatigue has been associated with lower levels of quality of life (Franceschini, Jardim, Fernandes, Jamnik, & Santoro, 2013), higher levels of distress (Carlson, Waller, Groff, & Bultz, 2013), lower levels of sleep quality (Akyuz, Ugur, Elcigil, 2013), and higher levels of anxiety and breathlessness (Chan, Richardson, & Richardson, 2013).

Cigarette Use and Psychosocial Concerns of Those with Lung Cancer

Public health campaigns have effectively convinced the general public that "smoking causes cancer," but the smoking history of those living with lung cancer is often more complex. Specifically, lung cancer survivors may be considered "current smokers" (smoking at the time of the study), "former smokers" (quit smoking before the start of the study, typically years or decades prior to their diagnosis), or "never smokers" (smoked less than 100 cigarettes during their lifetimes; Subramanian & Govindan, 2010). Thus, there are really three (or more) distinct groups of those living with lung cancer: those that have a lengthy history of smoking, unabated by their diagnosis; those who quit long before or shortly after their diagnosis; those with exposure to high levels of second-hand smoke; and those have had very little exposure to tobacco smoke. Typically, samples of lung cancer survivors are comprised mostly of former smokers (37-80.2%), followed by current (11.5-50%) and never (8.3-13%; Balduyck et al., 2011; Gonzalez & Jacobsen, 2010; LoConte et al., 2008). However, the size of former and current smoking groups may actually fluctuate given that smoking relapse rates in lung cancer survivors post-treatment are between 30-60% (Pinto, Eakin, & Maruyama, 2000; Walker, Larsen, Zona, Govindan, & Fisher, 2004). Although there is a dearth of literature highlighting psychosocial differences between lung cancer survivors who have never smoked and those who have smoked, available evidence suggests that a history of depression (Hopenhayn, Christian, Christian, Studts, & Mullet, 2013) and cancer-related anxiety (Simmons et al., 2013) contributes to relapse in smoking after a period of abstinence in lung cancer survivors. These findings are significant given that available evidence suggests that abstaining from smoking, even after smoking for several years, can contribute to greater quality of life and higher survival rates compared to those who continue to smoke (Hopenhayn et al., 2013). Also, the literature appears to be divided on the impact of stigma on lung cancer survivors who never smoked and those with a smoking history; one study demonstrated that stigma was significantly greater in those with a smoking history (Gonzalez & Jacobsen, 2010), while another study reported no statistical differences in levels of reported stigma between those who never and ever smoked (Cataldo et al., 2012). This discrepancy may be due to differences in sampling strategies and in measures of self-reported stigma.

Stigma: Definition and Brief History Related to Medical Illness

Stigma has been defined by Goffman (1963) as occurring when others consider one to be undesirable due to possessing a certain attribute. As early as 2004 (Chappel et al.), stigma associated with a diagnosis of lung cancer has been identified in the literature. Presumably spurred on by the U.S. Surgeon General's report in 1964 (Advisory Committee to the Surgeon General of the Public Health Service) as well as media campaigns aimed at decreasing the smoking of cigarettes, lung cancer has become inextricably tied to smoking behavior in the minds of the general public (Holland, Kelly, & Weinberger, 2010). Lung cancer is then viewed more as a potentially preventable disease if one abstains from smoking, which is a behavior that is viewed as controllable. An illustration of the general public's initial response to individuals with lung cancer can be found in several qualitative articles on lung cancer stigma; lung cancer survivors often report that the first comment they receive after disclosing their diagnosis is, "Did you smoke?" (Chappel et al., 2004; Weiss et al., 2012), which can lead to avoidance strategies and social isolation. Lung cancer survivors also report perceived judgment from healthcare professionals because it is assumed that they caused their own deadly disease (Chappel et al., 2004); this perceived stigma can lead to delay in treatment-seeking.

Qualitative reports of stigma on account of lung cancer have documented lung cancer survivors' experiences with stigma (Chappel et al., 2004; Faller, Schilling, & Lang, 1995). These studies have suggested that the higher proportion of lung cancer cases diagnosed at later stages may be due, in part, to a delay in treatment-seeking or to a reluctance of smokers to disclose symptoms of cancer to healthcare professionals (Chappel et al., 2004). Other quantitative reports have demonstrated that lung cancer survivors report more stigma compared to individuals with head and neck cancers (Lebel et al., 2013), breast cancer (LoConte et al., 2008), and prostate cancer (LoConte et al., 2008).

Stigma in lung cancer survivors has been associated with psychological, medical, and behavioral factors. Specifically, higher levels of stigma have been associated with greater depressive symptoms (Gonzalez & Jacobsen, 2010), lower levels of quality of life (Cataldo et al., 2012), greater levels of shame and guilt (LoConte et al., 2008) and a smoking history (LoConte et al., 2008). In light of the associated negative psychosocial impact of lung cancer stigma, authors have called for interventions to ameliorate the impact of unnecessary blame and stigmatization (Chambers et al., 2012).

Models of Lung Cancer Stigma

Although most studies of lung cancer stigma are atheoretical (Chambers et al., 2012; Lebel et al., 2013), several models of lung cancer stigma have been utilized in conceptualizing the experience of stigma. These models include the health-related stigma model (Cataldo et al., 2011) and the illness-intrusiveness framework (Lebel et al., 2013). According to the health-related stigma model, an individual experiences stigma when one recognizes that the health condition one has (e.g., lung cancer) is associated with a controllable behavior (e.g., smoking) and thereby labeling one with an undesirable health condition. Fallout from this identification with such a health condition includes a) vigilance for situations and nonverbal communication that may suggest differential treatment and b) negative emotional (e.g., depression) and social consequences (e.g., isolation). According to the illness-intrusiveness model, disease and treatment can intrude upon one's major life domains (e.g., relationships and career). Disruptions in one's life can then contribute to negative psychosocial impact (e.g., greater depression and lower quality of life). Authors who utilized this model (i.e., Lebel et al., 2013) hypothesized that the impact of stigma on distress and subjective well-being would be mediated by illness intrusiveness of one's cancer on major life domains. Unlike findings that support the validity of the health-related stigma model (Cataldo et al., 2011; LoConte et al., 2008), the illness-intrusiveness model has not received as much support (i.e., illness intrusiveness was not found to mediate the relationship between stigma and distress and subjective wellbeing). Although authors are beginning to set investigations of lung cancer stigma within a theoretical framework, interventions to address the negative psychosocial impact of lung cancer stigma have yet to be designed and implemented, despite calls by authors for said interventions (Chambers et al., 2012).

Summary

Lung cancer is a deadly disease associated with high physical symptom burden and high risk for psychosocial problems. The most recognized risk factor for developing lung cancer, cigarette smoking, has gained the attention of the public and the media, likely contributing and/or causing the stigma that lung cancer survivors currently experience. The study of lung cancer stigma is a currently burgeoning area in the literature with increasing recognition of the need for interventions to address its associated negative effects (e.g., depression and low quality of life). Although lung cancer stigma is increasingly studied, how lung cancer survivors cope with stigma is still poorly understood.

Aims of the Current Dissertation

The specific aims of this dissertation are to a) quantitatively analyze associations between stigma and health status and psychological well-being, b) qualitatively analyze lung cancer survivors' experiences with coping with lung cancer stigma (felt and experienced), and c) utilize the results of the quantitative and qualitative analyses to inform the development of a brief pilot intervention to ameliorate the negative effects of lung cancer stigma.

CHAPTER TWO

PERSONAL RESPONSIBILITY, REGRET, AND MEDICAL STIGMA AMONG INDIVIDUALS LIVING WITH LUNG CANCER

Introduction

The psychosocial needs and experiences of adults living with lung cancer have received relatively little attention compared with other cancer types, yet the available data suggest that those with lung cancer suffer disproportionately from depression, anxiety, and other symptoms (Else-Quest et al., 2009; Lebel et al., 2013; LoConte et al., 2008; Zabora et al., 2001). Additionally, lung cancer is considered a stigmatizing disease (Cataldo et al., 2011; Chapple et al., 2004; Gonzalez & Jacobsen, 2010), in part because 90% of cases of lung cancer are attributable to cigarette smoking, a personally controllable health behavior (Alberg et al., 2007). Understanding the degree to which adults with lung cancer experience regret, take personal responsibility for their disease, and experience stigmatization from others is important, because these experiences may be linked with treatment nonadherence, feelings of isolation, avoidance of healthcare providers (Chapple et al., 2004), and poor quality of life (Gonzalez & Jacobsen, 2010). The goals of the current study are to characterize how levels of regret, personal responsibility, and perceived stigma from medical staff vary across current, former, and never smokers and are associated with psychosocial outcomes.

Cancer in general has long been stigmatized (Abrams & Finesinger, 1953), and only in the recent past have societal attitudes begun to shift (Holland, 2002). However, attitudes may not have changed as much for lung cancer as for other cancers. Smoking is considered by most people to be a controllable behavior, and people often associate lung cancer with previous smoking behavior, regardless of whether the person with lung cancer was a smoker, exposed to secondhand smoke from a family member, or had no smoking history.

In qualitative studies, perceived stigma, assumption of personal responsibility, and regret are common themes that emerge from the experiences of those living with lung cancer (Chapple et al., 2004; Tod et al., 2011). Although these constructs are related conceptually, it is important to distinguish between them. Stigma occurs when others consider one to be undesirable due to possessing a certain attribute (Goffman, 1963). Perceived responsibility refers to a sense of acceptance that one is responsible for causing something to happen (e.g., a lung cancer diagnosis). Finally, regret involves the presence of ruminative thoughts regarding past behavior and negative emotions (Wrosch, 2007). Many patients are reluctant to disclose their diagnosis, in part because the most common response from others is, “Did you smoke?” implying that the patient is responsible for his or her disease (Chapple et al., 2004). Many patients view such questions about their smoking history as inherently judgmental and stigmatizing, in part because they ignore nuances in behavioral risk factors for lung cancer, such as exposure to primary or secondhand smoke, length of smoking history, quantity of smoking, exposure to other carcinogens, engagement in other cancer prevention behaviors, and individual susceptibility to environmental exposures. The stigma associated with lung cancer may manifest in a number of ways, including being blamed for causing one’s illness (Chambers et al., 2012), being treated differently by healthcare providers (Wassenaar et al., 2007), or being given less scientific attention compared to other cancer types (Chapple et al., 2004; Parker-Pope, 2008).

Feelings of regret and personal responsibility may derive from internalized feelings or exposure to stigma in the environment (Earnshaw & Chaudoir, 2009). At least one cross-sectional study revealed associations between stigma, self-esteem, anxiety, and personal responsibility in lung cancer survivors (Else-Quest et al., 2009). An important question is whether current, former, and never smokers experience such feelings in different ways. Because lung cancer and smoking behaviors are so tightly linked in the public imagination, it is possible that even never smokers experience stigma, personal responsibility, and regret. Smoking behaviors are linked with caregivers' attitudes and feelings about their loved one with lung cancer (Lobchuk et al., 2008), but no studies to date have evaluated the effect of smoking history on personal experiences of perceived stigma, personal responsibility, and regret in lung cancer survivors.

Similarly, little is known about how feelings of personal responsibility, regret, and perceived stigma might influence psychological outcomes differently for those with distinct smoking histories. Understanding the nature of the relationships that exist between these constructs and psychological outcomes is important given that adults living with lung cancer are at high risk for experiencing depressive symptoms (Gonzalez & Jacobsen, 2010), anxiety (Myrdal et al., 2003), and considerable distress (Graves et al., 2007). How personal responsibility and regret might influence psychological outcomes in those with lung cancer has not previously been addressed in the literature, and only a handful of studies have evaluated links between stigma and psychological outcomes. Specifically, the experience of stigma is linked with higher depression (Gonzalez & Jacobsen, 2010), worse quality of life (Cataldo et al., 2012), and greater feelings of personal responsibility and regret (LoConte et al., 2008). In at least one study, having a smoking history was not associated with levels of stigma (Cataldo et al., 2012), whereas smoking was linked with greater perceived stigma in another study (LoConte et al., 2008).

The first aim of the present study was to characterize differences in the rates and intensity of personal responsibility, regret, and medical stigma in current, former, and never smokers with lung cancer. Given results of previous studies (e.g., Cataldo et al., 2012) and the strength of the association between smoking behaviors and risk for lung cancer, it was hypothesized that lung cancer survivors with a smoking history would report higher levels of personal responsibility, regret, and medical stigma compared to those without a smoking history. The second aim of the study was to evaluate the impact of personal responsibility, regret, and medical stigma on psychosocial and health-related outcomes. Hamann et al. (2014) used qualitative methods to identify a number of potentially significant consequences of perceived stigma (e.g., medical stigma) and internalized stigma (e.g., regret), such as increasing psychological distress and avoidance. In this study, we were able to test these hypotheses that higher levels of personal responsibility, regret, and medical stigma would be associated with worse psychological adjustment, poorer physical health-related outcomes, more use of avoidance-oriented coping, and more supportive care needs and to evaluate whether these associations differed for those with different smoking histories.

Method

Participants

Participants were at least 18 years of age, English-speaking, diagnosed with nonsmall cell or small cell lung cancer, and recruited from Loma Linda University Medical Center (LLUMC) and City of Hope Medical Center (COH). Exclusion criteria included mesothelioma diagnosis, feeling too sick or physically incapable to take part, and not being fluent in reading and writing in English. All participants recruited from COH had received their lung cancer diagnosis no more than 6 months prior to joining the study, whereas participants recruited from LLUMC were not excluded on the basis of time since diagnosis.

Procedures

All procedures were approved by institutional review boards of each of the institutions involved. At LLUMC, participants were recruited from the cancer registry. All those diagnosed with lung cancer in the past 12 months were mailed information about the study, and a research assistant attempted to contact each potential participant by telephone. Questionnaire packets were mailed to those who were interested in participating. Approximately 40% of those who were mailed information about the study were successfully contacted, and of these, 63% consented to participate in the study. At COH, participants were identified by the project coordinator (PC) along with clinic staff and the attending physician before the patient's scheduled appointment. The study was explained to the participants by the PC during their visit to the cancer center, and informed consent was obtained. Questionnaires, a copy of the IRB-approved consent form, and a return envelope to the COH Department of Psychology were given to patients who consented. Study personnel successfully contacted 62% of all eligible patients, and

98.4% of these consented to participate. All participants who completed the questionnaire were provided with a gift cards ($20 at CoH, $10 at LLUMC).

Measures

Psychological Adjustment

Intrusion Symptoms

Intrusion symptoms were measured using the Impact of Event Scale-Revised (Horowitz et al., 1979), which assesses the frequency and severity of cancer-related thoughts and feelings associated with one's cancer experience. The scale is reliable and sensitive to psychological intervention (Edgar et al., 1992; Horowitz et al., 1979). The Intrusion scale showed good internal consistency in the current study (Cronbach's α = .88).

Depressive Symptoms

Depressive symptoms were measured using the 20-item Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977). The scale is valid for use in cancer populations (Baker et al., 2002; Hann et al., 1999) and was internally consistent in the current study, α = .90.

Distress

Distress was measured with the Distress Thermometer (DT; Roth et al., 1998). Respondents circle a number on a 0-10 Likert scale (visually represented as a thermometer) to indicate the severity of distress experienced over the previous week. The

DT is sensitive and specific in identifying clinically significant distress in cancer survivors (Jacobsen et al., 2005).

Physical Health-Related Adjustment

Physical Functioning

The Medical Outcomes Study Short Form (SF-36) 10-item Physical Functioning subscale (Ware & Sherbourne, 1992) assesses the effect of personal health on physical activity and engagement in instrumental activities of daily living (ADLs; Ware & Sherbourne, 1992). Participants indicate how much their physical activity and ADLs are limited by their health (does not limit the activity, limits the activity a little, limits the activity a lot). Reliability of this subscale in the current study was good ($\alpha = .93$). Each participant also provided self-reported medical and cancer-related history (e.g., cancer type and stage of disease).

Symptom Bother

Physical symptom bother was assessed using the Memorial Symptom Assessment Scale-short form (MSAS-SF). Twelve symptoms from the MSAS-SF (Chang et al., 2000; Portenoy et al., 1994) were scored on a 5-point Likert scale to indicate the severity of bother for each symptom within the past week: pain, lack of energy, cough, dry mouth, nausea, shortness of breath, lack of appetite, difficulty swallowing, weight loss, distorted taste, constipation, and insomnia. Those who did not experience a particular symptom in the past week were considered to have zero bother associated with that symptom. The MSAS-SF has good convergent validity in cancer populations (Chang et al., 2000). A total Symptom Bother scale was created by summing the item ratings and was internally consistent ($\alpha = .84$).

Satisfaction with Healthcare

Satisfaction with Healthcare was measured using a 10-item author-constructed scale. On a 6-point Likert scale, patients rated their level of agreement to items, which included ‘I have complete trust in my doctors and nurses’ and ‘I feel that my doctors and nurses listen to what I have to say.’ Internal consistency was adequate ($\alpha = .73$).

Supportive Care Needs

Supportive Care Needs were measured using the Supportive Care Needs Survey, Short Form (SCNS). The SCNS (Bonevski et al., 2000) is a 31-item scale, which measures the participant’s level of need in four domains: psychological needs (e.g. fears about cancer returning), health system and information needs (e.g. opportunity to talk to someone who understands and has been through a similar experience), physical and daily living needs (e.g. feeling unwell), and patient care and support needs (e.g. hospital staff attending promptly to physical needs) (McElduff et al., 2004). Participants indicate ‘no need’ (1 ‘not applicable’, 2 ‘satisfied’) or some need (3‘low need’, 4‘moderate need’, 5 ‘high need’). Scores for the four subscales were generated by averaging the completed items. Construct validity and internal reliability for the SCNS have been established (McElduff et al., 2004). The four scales were internally consistent in the current study, Cronbach’s $\alpha > .84$.

Coping Strategies

Coping strategies were measured using items from the COPE (Carver et al., 1989; Thornton et al., 2012), which assesses how often individuals use specific strategies to manage stress. Each item was measured using Likert scales (1 = 'I don't do this at all'; 4 = 'I do this a lot') specific to the cancer experience. Problem-focused coping was derived from two COPE subscales: coping through planning and active coping efforts (4 items, α = 0.81). Avoidant coping was a composite derived from the mental disengagement, behavioral disengagement, and denial subscales (12 items; α = 0.75).

Personal Responsibility, Regret, and Medical Stigma

Personal Responsibility, Regret, and Medical Stigma were measured with the author-constructed Cancer Responsibility and Regret Scale (CRRS). When data collection occurred, no Personal Responsibility, Regret, or Medical Stigma scales for use in cancer survivors had appeared in the literature. Twenty-three items, based on clinical interactions with members of a lung cancer support group and existing items from relevant non-cancer-specific measures, were developed to measure four proposed dimensions of guilt and blame: 1) personal responsibility, 2) regret, 3) social or medical stigma, and 4) blaming others. Participants rated their agreement with each of the items using a 7-point Likert scale (1 = strongly disagree, 7 =strongly agree). The 23 items were factor analyzed, and factor extraction was conducted using parallel analysis (Horn, 1965). Parallel analysis involves the random generation of a data set with the same number of cases and variables; eigenvalues are averaged from multiple principal components analyses. Upon comparing the randomly-generated and observed eigenvalues, only observed eigenvalues greater than the averaged random eigenvalues were retained. This process led to the extraction of 3 factors, using Varimax rotation. Items were removed if they a) did not load above .40 on any factor or b) there was substantial cross-loading on a second factor (i.e., the difference between primary factor loading and secondary factor loading < .15). As items were removed, the underlying factor structure did not change. The final three factors demonstrated simple structure (Thurstone, 1947), with each of the 11 final items loading strongly on only one factor (see Table 1).

Factor 1 was labeled Personal Responsibility and accounted for 21.2% of the variance prior to rotation. The four items that comprise this factor reflect feelings of personal responsibility for being diagnosed with lung cancer. Internal consistency for the factor was high (Cronbach's $\alpha = .84$). Factor 2 was labeled Regret and accounted for 14.5% of the variance. The three items reflect a general sense of regret about one's life decisions and cancer-related shame. Internal consistency was acceptable, Cronbach's $\alpha = .71$. Factor 3 was labeled Medical Stigma and accounted for 12.5% of the variance. The four items comprising the factor reflect perceptions of being blamed by medical care providers, as well as the feeling of having received less than adequate care. Internal consistency was Cronbach's $\alpha = .64$, slightly lower than optimal for research purposes. Average item responses above 4 were considered as "high" levels of each of the factors.

Table 1. *Factor Solution for the Cancer Responsibility and Regret Scale.*

Item	Factor Loadings			$\bar{x}$ (*SD*)
	Personal Responsibility	Regret	Medical Stigma	
When it comes to my cancer I am to blame.	**.84**	.13	.09	4.6 (2.2)
I accept personal responsibility for getting cancer.	**.81**	.01	.04	4.7 (2.2)
If I had done things differently, I probably would not have developed lung cancer.	**.66**	.32	.04	4.6 (2.1)
There is nothing I could have done to keep myself from getting cancer.*	**.63**	.27	-.05	4.7 (2.2)
I have no regrets when it comes to choices I've made in life.*	.13	**.78**	.02	3.5 (2.1)
I have no regrets about the way I've lived my life.*	.18	**.76**	.06	3.2 (2.1)
When it comes to my cancer, I have nothing to be ashamed of.*	.11	**.44**	.12	2.4 (2.0)
Nurses who have cared for me seem to blame me for my cancer.	.12	.16	**.74**	1.9 (1.6)
I feel that I have gotten worse medical care than other patients with cancer.	-.02	.02	**.58**	1.6 (1.3)
Doctors have taken steps that have made my cancer worse than it would have been otherwise.	-.15	.01	**.51**	1.6 (1.4)
My doctor acts as if I am to blame for my cancer.	.24	.07	**.50**	2.3 (1.9)

Note. * Item is reverse coded.

Data Analysis

Descriptive statistics were computed for demographic and medical characteristics as a function of participants' smoking status (former smoker, current smoker, never smoker). Tests of significant differences by smoking status groups on demographic and medical characteristics were one-way ANOVAs for continuous variables and chi-square goodness-of-fit tests for categorical variables. One-way ANOVAs were conducted to test for significant smoking group differences on personal responsibility, regret, and medical stigma scores. Significance was set at $\alpha = .05$, two-tailed, and Bonferroni corrections were applied for *t*-tests of *post hoc* pairwise differences between smoking groups. Demographic and medical characteristics that differed significantly between smoking groups were included as covariates in all subsequent tests of the effect of smoking group. Covariates were added in step 1 of a stepwise multiple regression model, followed by smoking group in step 2. Given a lack of differences between former and current smokers, these groups were collapsed into "ever smokers" for comparison with "never smokers." Univariate correlations were performed within ever and never smokers between factor scores and psychosocial adjustment variables. Significant differences between univariate correlations for ever and never smokers on psychological adjustment variables were tested via *z*-scores.

Results

Demographic characteristics ($N = 213$) are shown in Table 2. Smoking groups differed significantly on ethnicity, $\chi^2\ (2) = 8.2$, $p = .02$, years of education, $F\ (2, 208) = 6.11$, $p = .003$, age, $F\ (2, 210) = 3.63$, $p = .03$, and type of lung cancer, $\chi^2\ (4) = 9.5$, $p = .05$. There was a higher proportion of Caucasians among current (73.7%) and former (83.0%) smokers than among never smokers (61.8%). *Post hoc* pairwise comparisons showed that never smokers completed significantly more years of education than current, $t(69) = -3.28$, $p = .002$, and former smokers, $t(171) = -3.06$, $p = .003$, who did not

Table 2. *Demographic and Medical Characteristics of the Sample*

	Current Smokers (*n* = 38)		Former Smokers (*n* = 141)		Never Smokers (*n* = 34)		*p*
	N	%	*N*	%	*N*	%	
Gender							> .05
Male	17	44.7	68	48.2	9	26.5	
Female	21	55.3	73	51.8	25	73.5	
Ethnicity							**.02**
Caucasian	28	73.7	117	83.0	21	61.8	
Other	7	18.4	20	14.2	12	35.3	
Unreported	3	7.9	4	2.8	1	2.9	
Cancer Stage							> .05
I	6	15.8	21	14.9	2	5.9	
II	2	5.3	15	10.6	3	8.8	
III	5	13.2	24	17.0	5	14.7	
IV	9	23.7	38	27.0	17	50.0	
Not sure	16	42.1	43	30.5	7	20.6	
Type of Lung Cancer							**.05**
Small Cell	14	36.8	35	24.8	4	11.8	
Nonsmall Cell	12	31.6	74	52.5	18	52.9	
Other/Don't Know	12	31.6	32	22.7	12	35.3	
	$\bar{x}$	(*SD*)	$\bar{x}$	(*SD*)	$\bar{x}$	(*SD*)	
Education (Years)	12.8	2.5	13.3	2.6	14.9	2.7	**.003**
Age (Years)	64.4	9.8	68.2	10.2	63.9	12.2	**.03**
Weeks since diagnosis	65.3	95.9	48.7	66.5	50.0	74.1	> .05

significantly differ, $p = .32$. Former smokers were significantly older than current smokers, $t(177) = 2.10$, $p = .04$, or never smokers, $t(173) = 2.12$, $p = .04$. A lower proportion of never smokers (11.8%) reported having small cell lung cancer than either former smokers (24.8%) or current smokers (36.8%). Smoking groups did not differ significantly on gender, cancer stage, and weeks since diagnosis. Age, ethnicity, years of education, and cancer type were treated as covariates in subsequent covariate-adjusted analyses. Although symptom bother, $F\ (2,210) = 3.20$, $p < .05$, and problem-focused coping, $F\ (2,202) = 3.84$, $p < .03$, were significantly different across smoking groups in unadjusted one-way ANOVAs, there were no covariate-adjusted differences between smoking groups on any of the psychological adjustment, physical health-related adjustment, supportive care needs, and coping strategies variables.

Differences in Personal Responsibility, Regret, and Medical Stigma across Smoking Groups

High levels of Personal Responsibility (i.e., average item response above 4) were reported by 74% of current smokers, 80% of former smokers, and 27% of never smokers, $F\ (2, 207) = 43.50$, $p < .001$. After Bonferroni adjustment for Type I error, two of the three pairwise comparisons were significant. Never smokers reported lower Personal Responsibility than either current smokers, $t\ (70) = 6.80$, $p < .001$, Cohen's $d = 1.61$, or former smokers, $t\ (170) = 9.40$, $p < .001$, $d = 1.80$, who did not differ from one another (see Figure 1). In the full model, $F\ (7, 192) = 12.47$, $R^2 = .31$, $p < .001$. In the full model, education ($p = .41$), ethnicity ($p = .88$), and lung cancer type ($p = .064$) were not associated significantly with Personal Responsibility, but older age was related to lower

Personal Responsibility, $t = -2.22$, $\beta = -.14$, $p = .03$. After adjustment for those covariates, the main effect of smoking status on Personal Responsibility remained significant, ΔF (2, 192) = 33.16, $\Delta R^2 = .24$, $p < .001$.

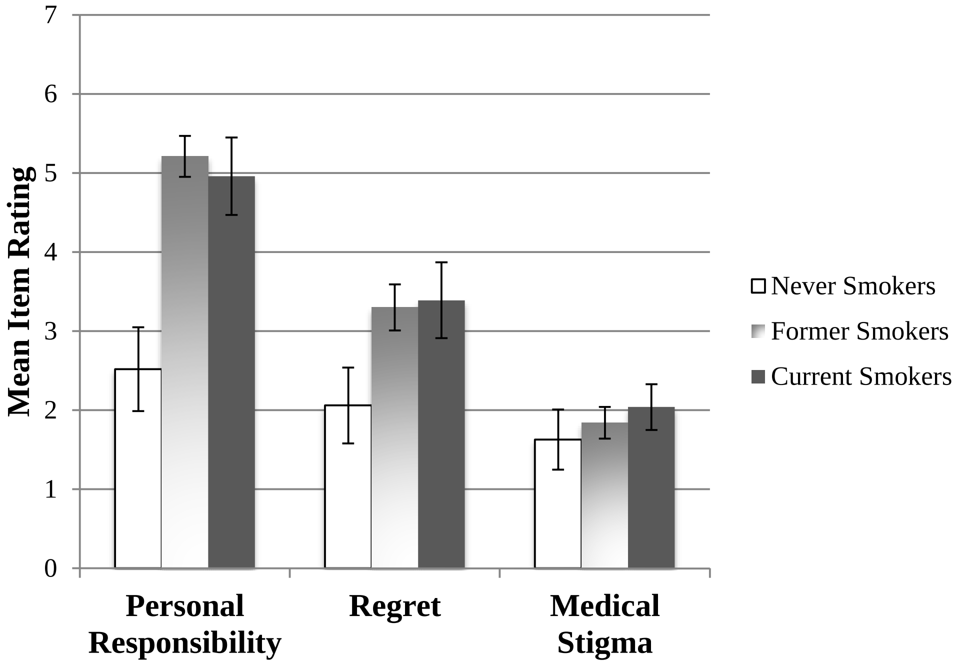

Figure 1. Unadjusted mean differences in Personal Responsibility, Regret, and Medical Stigma levels between current, former, and never smokers. Error bars represent 95% CIs.

High Regret (i.e., average item response above 4) was reported by 32% of current smokers, 35% of former smokers, and 9% of never smokers, F (2, 208) = 8.52, $p < .001$. Never smokers reported lower feelings of Regret than either current smokers, t (170) = 3.94, $p < .001$, $d = 0.93$, or former smokers, t (171) = 3.88, $p < .001$, $d = 0.74$, who did not differ significantly from each other (see Figure 1). In the full model (F (7, 193) = 3.14, $R^2 = .10$, $p < .004$), education ($p = .82$), ethnicity ($p = .65$), lung cancer type ($p = .34$), and age ($p = .14$) were not associated with Regret. After adjustment for those factors, the main effect of smoking group on Regret remained significant, ΔF (2, 193) = 8.22, $\Delta R^2 = .08$, $p < .001$.

High levels of Medical Stigma (i.e., average item response above 4) were reported by 5% of current smokers, 10% of former smokers, and 9% of never smokers. In the full model (F (7, 192) = 1.35, $R^2 = .05$, $p = .23$), education ($p = .37$), ethnicity ($p = .067$), lung cancer type ($p = .47$), and age ($p = .57$) were not associated with Medical Stigma. Levels of Medical Stigma did not differ across smoking groups in either unadjusted, F (2, 206) = 1.27, $p = .28$, or adjusted, ΔF (2, 192) = 1.77, $\Delta R^2 = .02$, $p = .17$, analyses.

Associations of Personal Responsibility, Regret, and Medical Stigma with Psychosocial Adjustment by Smoking Group

Associations between Personal Responsibility, Regret, and Medical Stigma and psychosocial outcomes were explored in all lung cancer patients and those who had ever ($n = 179$) and never ($n = 34$) smoked (see Table 3, Table 4, and Table 5). For ever smokers, no significant relationships were found between Personal Responsibility and psychosocial outcomes. However, for never smokers, Personal Responsibility demonstrated moderate associations with depressive symptoms ($r = .49$), satisfaction with healthcare ($r = -.57$), psychological needs ($r = .41$), and use of avoidance coping strategies ($r = .37$; p's $< .032$). The associations between Personal Responsibility and depressive symptoms ($z = -2.39$, $p = .01$), satisfaction with healthcare ($z = 4.05$, $p = .001$), and psychological needs ($z = -2.13$, $p = .02$) for never smokers were significantly higher than those in ever smokers.

Table 3. *Univariate Correlations between Personal Responsibility and Psychosocial Outcomes in Ever Smokers and Never Smokers.*

Variables	All	Ever Smoke	Never Smoke	*z*(*p*)	*M*(*SD*)	Range
Factors						
Personal Responsibility	-	-	-	-		1-7
Regret	**.33**	**.18**	**.41**	-1.30(.19)		1-7
Medical Stigma	.11	.04	**.42**	**-2.09(.04)**		1-7
Psychological Adjustment						
Intrusion symptoms	.07	.02	.25	-1.21(.11)	8.7(8.3)	0-35
Depressive symptoms	**.15**	.07	**.49**	**-2.39(.01)**	14.4(10.6)	0-53
Distress	.07	.01	.27	-1.37(.08)	3.3(2.9)	0-10
Physical Health-Related Adjustment						
Physical functioning	-.07	-.05	.09	-.72(.23)	43.7(28.2)	0-100
Symptom bother	.07	-.01	.27	-1.47(.07)	1.3(.8)	0-3.25
Satisfaction with healthcare	.001	.14	**-.57**	**-4.05(.00)**	52.5(10.3)	18-60
Supportive care needs						
Psychological needs	**.14**	.02	**.41**	**-2.13(.02)**	2.7(1.0)	1-5
Health system and information needs	-.05	-.06	.08	-.72(.24)	2.3(.8)	1-5
Physical and daily living needs	.08	-.03	.10	-.67(.25)	3.3(1.1)	1-5
Patient care and support needs	.05	.03	.17	-.73(.23)	2.1(.6)	1-5
Total supportive care needs	.08	-.01	.24	-1.31(.10)	2.6(.7)	1-5
Coping strategies						
Problem-focused coping	-.01	.10	.08	.10(.46)	2.7(.8)	1-4
Avoidance coping	.10	.11	**.37**	-1.43(.08)	1.6(.4)	1-3.08

Note. *z*(*p*) = significance test of difference between Ever and Never Smoker correlations. $p < 0.05$ = bold.

Table 4. *Univariate Correlations between Regret and Psychosocial Outcomes in Ever Smokers and Never Smokers.*

Variables	All	Ever Smoke	Never Smoke	*z*(*p*)	*M*(*SD*)	Range
Factors						
Personal Responsibility	-	-	-	-		1-7
Regret	-	-	-	-		1-7
Medical Stigma	**.17**	.12	**.36**	-1.32(.19)		1-7
Psychological Adjustment						
Intrusion symptoms	**.24**	**.22**	.29	-.38(.35)	8.7(8.3)	0-35
Depressive symptoms	.24	**.16**	**.67**	**-3.33(.00)**	14.4(10.6)	0-53
Distress	.13	.06	**.53**	**-2.72(.00)**	3.3(2.9)	0-10
Physical Health-Related Adjustment						
Physical functioning	-.13	-.09	-.18	.47(.32)	43.7(28.2)	0-100
Symptom bother	.09	-.01	**.47**	**-2.67(.00)**	1.3(.8)	0-3.25
Satisfaction with healthcare	**-.18**	-.15	-.31	.87(.19)	52.5(10.3)	18-60
Supportive care needs						
Psychological needs	**.22**	**.15**	**.50**	**-2.13(.02)**	2.7(1.0)	1-5
Health system and information needs	.06	.07	.10	-.16(.44)	2.3(.8)	1-5
Physical and daily living needs	**.20**	.13	**.36**	-1.26(.10)	3.3(1.1)	1-5
Patient care and support needs	.10	.07	.27	-1.06(.14)	2.1(.6)	1-5
Total supportive care needs	**.20**	.14	**.39**	-1.39(.08)	2.6(.7)	1-5
Coping strategies						
Problem-focused coping	-.06	.03	-.21	1.25(.11)	2.7(.8)	1-4
Avoidance coping	**.15**	**.16**	**.36**	-1.11(.13)	1.6(.4)	1-3.08

Note. $z(p)$ = significance test of difference between Ever and Never Smoker correlations. $p < 0.05$ = bold.

Table 5. *Univariate Correlations between Medical Stigma and Psychosocial Outcomes in Ever Smokers and Never Smokers.*

Variables	All	Ever Smoke	Never Smoke	*z*(*p*)	*M*(*SD*)	Range
Factors						
Personal Responsibility	-	-	**-**	-		1-7
Regret	**-**	-	-	-		1-7
Medical Stigma	-	-	-	-		1-7
Psychological Adjustment						
Intrusion symptoms	**.15**	**.19**	.17	.11(.46)	8.7(8.3)	0-35
Depressive symptoms	**.28**	**.20**	**.67**	**-3.12(.00)**	14.4(10.6)	0-53
Distress	**.17**	.11	**.52**	**-2.39(.01)**	3.3(2.9)	0-10
Physical Health-Related Adjustment						
Physical functioning	-.11	-.13	-.10	-.16(.44)	43.7(28.2)	0-100
Symptom bother	**.26**	**.24**	**.46**	-1.30(.10)	1.3(.8)	0-3.25
Satisfaction with healthcare	**-.44**	**-.42**	**-.68**	**1.96(.03)**	52.5(10.3)	18-60
Supportive care needs						
Psychological needs	**.26**	**.23**	**.44**	-1.22(.11)	2.7(1.0)	1-5
Health system and information needs	**.31**	**.32**	.32	.00(.50)	2.3(.8)	1-5
Physical and daily living needs	**.17**	**.16**	.24	-.43(.33)	3.3(1.1)	1-5
Patient care and support needs	**.30**	**.29**	**.41**	-.70(.24)	2.1(.6)	1-5
Total supportive care needs	**.31**	**.30**	**.41**	-.65(.26)	2.6(.7)	1-5
Coping strategies						
Problem-focused coping	.04	.09	-.09	.93(.18)	2.7(.8)	1-4
Avoidance coping	**.24**	**.19**	**.59**	**-2.49(.01)**	1.6(.4)	1-3.08

Note. *z*(*p*) = significance test of difference between Ever and Never Smoker correlations. $p < 0.05$ = bold.

Regret demonstrated small but significant associations (*r* = .15 - .22) with higher intrusion symptoms, depressive symptoms, avoidance coping, and psychological needs in ever smokers. However, for never smokers, Regret demonstrated moderate to strong associations with depressive symptoms (*r* = .67), distress (*r* = .47), symptom bother (*r* = .47), psychological needs (*r* = .50), physical and daily living needs (*r* = .36), total supportive care needs (*r* = .39), and avoidance coping strategies (*r* = .36; *p*'s < .038). The associations between Regret and depressive symptoms (*z* = -3.33, *p* = .001), distress (*z* = -2.72, *p* = .001), symptom bother (*z* = 2.67, *p* = .001), and psychological needs (*z* = -2.13, *p* = .02) for never smokers were significantly greater than said associations in ever smokers.

For ever smokers, Medical Stigma showed significant small to moderate associations (*r* = .16 - .42) with intrusion symptoms, depressive symptoms, symptom bother, psychological needs, health system and information needs, physical and daily living needs, patient care and support needs, total supportive care needs, and avoidance coping. Medical Stigma also was negatively associated with satisfaction with healthcare (*r* = -.42). For never smokers, Medical Stigma showed moderate to strong associations with depressive symptoms (*r* = .67), distress (*r* = .52), symptom bother (*r* = .46), satisfaction with healthcare (*r* = -.68), psychological needs (*r* = .44), patient care support needs (*r* = .41), total supportive care needs (*r* = .41), and avoidance coping (*r* = .59; *p*'s < .017). As before, the associations between Medical Stigma and depressive symptoms (*z* = -3.12, *p* = .001), distress (*z* = -2.39, *p* = .001), satisfaction with healthcare (*z* = 1.96, *p* = .03), and avoidance coping (*z* = -2.49, *p* = .01) were significantly greater in never smokers than ever smokers.

Discussion

Our findings suggest that feelings of personal responsibility are common in lung cancer survivors, particularly those with a history of smoking (74-80%). Even 27% of never smokers report strong feelings of personal responsibility, perhaps due to past exposures to second-hand smoke (e.g., from a parent or spouse), other environmental risk factors for lung cancer (e.g., asbestos, radon; Salander, 2007; Faller et al., 1995), or psychosocial factors (e.g., stress). Hypothesis 1, that personal responsibility would be higher in those with a smoking history, was supported. Additionally, being younger was associated with a greater sense of responsibility. Given increases in awareness about the health consequences of smoking and erosion in social acceptance of smoking, it is not surprising that younger lung cancer survivors feel a stronger sense of personal responsibility than do older survivors. The second hypothesis that personal responsibility would be associated with psychosocial and health-related outcomes was only partially supported. For those with a smoking history, feelings of personal responsibility appear to be benign and have little association with overall psychological functioning. In endorsing the Personal Responsibility items, it is likely that ever smokers were acknowledging the reality of their smoking's contribution to lung cancer without experiencing the negative affective consequences that can accompany self-blame (Shaver & Drown, 1986). Although endorsement of Personal Responsibility was relatively low in never smokers, when it was endorsed, Personal Responsibility was associated with poorer adjustment. Perhaps those never smokers attribute cancer causation to some other internal (e.g., negative character traits) or external (e.g., partner smoking) factors, which in turn are linked to poor adjustment, or perhaps depressed never smokers are likely to assume personal responsibility for bad outcomes.

Consistent with the first hypothesis, Regret was more prevalent in lung cancer survivors with a smoking history than those who never smoked. Endorsement of Regret was much less prevalent than Personal Responsibility (32-35% of ever smokers; 9% of never smokers). The second hypothesis was also partially supported. Regret was associated with greater intrusive thoughts/feelings, unmet psychological needs, and use of avoidance-oriented coping strategies. Perhaps regret represents an internalized experience of intrusive thoughts regarding past decisions that led to one's cancer, and those who experience significant levels of regret may spend more time dwelling on past decisions than in actively confronting current stressors. Fortunately, regret may be modifiable. Wrosch et al. (2007), in a study of older adults not specific to those with lung cancer, found that a regret-focused writing intervention significantly reduced feelings of regret intensity. In those with cancer, studies have suggested that simply audio taping clinical encounters can reduce regret associated with cancer-related treatment decisions (Good et al., *in press*). Accordingly, it may be possible to intervene with those lung cancer survivors who experience intense feelings of regret to decrease intensity of regret and concomitant negative symptoms (e.g., intrusive thoughts/feelings).

Although an uncommon experience across smoking groups, greater Medical Stigma was associated with worse psychosocial functioning and specifically with worse satisfaction with healthcare, greater health system and information needs, and greater total supportive care needs, providing additional support to our second hypothesis. However, contrary to our first hypothesis, Medical Stigma was reported as often for never smokers as those with a smoking history, which corroborates Chapple et al.'s (2004) qualitative findings suggesting lung cancer survivors felt blamed for their disease by hospital staff, regardless of whether they had ever smoked. It is possible that the stigma experience (i.e., feeling blamed by medical staff) hinders meeting health system and information needs because it contributes to avoidance of healthcare providers and treatment noncompliance (Chapple et al., 2004).

Ever and never smokers significantly differed in several of their associations between Cancer Responsibility and Regret Scale factors and adjustment variables. More specifically, never smokers demonstrated stronger associations between factors and adjustment variables. Of note, never smokers demonstrated stronger associations between every factor score and depressive symptoms when compared to ever smokers. These findings suggest that the presence of perceived personal responsibility, regret, and perceived stigma may have particularly adverse effects on the psychological adjustment of never smokers relative to current and former smokers, although reciprocal causation cannot be ruled out.

Our findings are consistent with theory and evidence regarding stereotype threat (Aronson et al., 2013; Steele & Aronson, 1995), which may be present in interactions between lung cancer survivors and medical staff as well as the larger social network. As lung cancer patients seek to make causal attributions for their disease (Faller et al., 1995), they may be simultaneously vigilant of others' verbal and nonverbal cues to confirm any negative stereotypes associated with being a lung cancer survivor. It is possible that smokers who assume personal responsibility for their lung cancer are less vigilant to stereotype cues and experience less impact with respect to negative psychosocial outcomes. Regret, however, may be accompanied by rumination regarding past decisions (e.g., "How could I have smoked?…that was the worst decision I could have made"), which could intensify identification with the negative stereotype, increase use of avoidant coping strategies, and increase depressive symptoms. Our results also overlap strongly with the model of lung cancer stigma proposed by Hamann et al. (2014), which identifies two main factors associated with stigma: perceived/felt stigma (which includes medical stigma) and internalized/self stigma (which includes regret and self-blame/guilt).

Several limitations of the current study should be noted. Because the present results are cross-sectional, we are unable to estimate the extent to which personal responsibility, regret, and medical stigma might causally influence psychological adjustment. Longitudinal and experimental research is needed to evaluate contributors to and consequences of personal responsibility, regret, and medical stigma, as well as their malleability through intervention. Second, this study was conducted among lung cancer survivors who were sufficiently healthy to complete questionnaires, and those with worse disease or functional status may be under-represented in the current sample relative to the general population of those with lung cancer. Given the high mortality rate in this population, obtaining large, representative samples is challenging, and the present study provides one of the largest samples to date to yield high-quality psychosocial data. Third, subsample sizes were low for current and never smokers compared to former smokers, but the distribution is comparable to other samples of lung cancer survivors who reported smoking history (Gonzalez & Jacobsen, 2010; LoConte et al., 2008). Additionally, internal consistency of the Medical Stigma factor could be improved in future studies by adding additional items. Finally, none of the items retained for use in the CRRS provided a measure of non-medical social stigma or blame (e.g., from friends, family members, and others). Although the original item pool included several lung-cancer specific social stigma items, none were retained in the final measure due to lack of internal consistency. There are current efforts underway to develop comprehensive measures of stigma that will likely include items specific to social stigma, medical stigma, self-blame, guilt/shame, anger, regret, and consequences of stigma (Hamann et al., 2014).

Given the associations between medical stigma and psychological adjustment, satisfaction with healthcare, and avoidance coping, there is a need to better understand how and when feelings of personal responsibility, regret, and medical stigma arise and how they might predict psychosocial and health-related outcomes. As those with lung cancer present for treatment, they may feel vulnerable and vigilant to unfair treatment, and even well-intentioned interactions can activate socially-shared beliefs, such as the belief that smokers can be refused treatment (Chapple et al., 2004). It may then be possible to develop brief tools that providers could use for communicating with patients about stigma. For example, medical professionals may need to pay particular attention to how they discuss questions related to current smoking, smoking history and patients' health behaviors that contribute to cancer or well-being, while minimizing negative or blaming verbal and nonverbal communication. Such training may improve interactions with lung cancer survivors, even for those with no significant smoking history, and minimize the potential for later internalized regret for these patients. Finally, many unanswered questions remain, such as the extent to which regret, blame, and stigma are associated with other key aspects of treatment for lung cancer, such as physician-patient communication patterns, adherence to difficult treatments, adoption of recovery-oriented health behaviors, and appropriate healthcare utilization.

CHAPTER THREE

COPING WITH LUNG CANCER STIGMA: A QUALITATIVE STUDY

Introduction

Lung cancer is a deadly and psychosocially detrimental disease, accounting for more deaths than any other cancer type (ACS, 2013) and higher levels of distress compared to other cancer types (Zabora et al., 2001). During 2013 in the United States, lung cancer accounted for 159,480 deaths and 228,190 new cancer cases (ACS, 2013). In other words, lung cancer was attributed to more than a quarter (27%) of all deaths attributable to cancer (ACS, 2013). Poor survival rates in lung cancer are attributable to late diagnosis of the disease. Lung cancer is most often diagnosed at later stages of the disease; 85% of lung cancer cases are diagnosed at advanced stages whereas only 15% are diagnosed at localized stages (ACS, 2013).

Although lung cancer can be attributable to numerous environmental, genetic, and behavioral risk factors, the best known of these factors is cigarette smoking. Since the 1964 US Surgeon General's report of the causal link between cigarette smoking and lung cancer (1964), anti-smoking campaigns have warned against the use of cigarettes and often included alarming images and messages that imply lung cancer and death as consequences of not heading their warnings (Holland, Kelly, & Weinberger, 2010; Weiss et al., 2012). As one of the results of these warnings, lung cancer survivors have felt blamed by the general public, reporting that the first question they are often asked after disclosing their cancer diagnosis is, "Did you smoke?" (Chappel et al., 2004; Weiss et al., 2012).

In the research of stigma, it is important to clearly define key terms, specifically, “perceived (felt) stigma” and “internalized (self) stigma” (Hamann et al., 2014). Perceived stigma involves a “negative appraisal” and “devaluation from others” due to having an undesirable condition (e.g., lung cancer; see Figure 1 on p. 84, Hamann et al. 2014). Self-stigma involves the “internalization of perceived stigma,” characterized by self-blame, guilt/shame, anger, and regret (see Figure 1 on p. 84, Hamann et al., 2014). The construct of self-stigma is further characterized by Corrigan, Larson, and Ruesch (2009), describing self-stigma in the context of a “Why Try” model of stigma towards individuals with mental illness. Corrigan, Larson, and Ruesch (2009) described self-stigma “as a hierarchical relationship; a person with mental illness must first be aware of corresponding stereotypes before agreeing with them and applying self-stigma to one’s self” (p. 75-76). In this way, lung cancer survivors must be aware of what the stereotypes of having lung cancer are (e.g., “You must have smoked.” “You are responsible for your own illness.”) before they experience “self-stigma.”

Qualitative studies have reported that lung cancer survivors have felt blamed, shamed, and stigmatized (Chappel et al., 2004). These investigations have documented that some lung cancer survivors delay disclosure of their diagnosis to others, including healthcare professionals, due to fear that they will not be treated for their disease and be blamed for their disease (Chappel et al., 2004). This is concerning given that the majority of lung cancer cases are diagnosed at Stage III or Stage IV (ACS, 2013). While ambiguous symptoms may contribute to delayed diagnoses (e.g., a “funny cough”), it is unclear how great of an impact on said delay is made by the experience of lung cancer stigma. Thus far, the only statistic regarding how stigma might affect lung cancer treatment is from Hamann et al. (2014), who report that 48% of their sample provided qualitative data that could be coded as having “less engagement with care,” presumably as a maladaptive consequence to experiencing lung cancer stigma. Quantitative studies have been carried out so as to better characterize how lung cancer stigma adversely impacts psychosocial outcomes as well as how the experience of stigma might differ across different cancer populations.

Investigations have utilized scales of stigma to assess differences in levels of experienced or felt stigma between lung cancer survivors and individuals with other cancers as well as possible associations between lung cancer stigma and other psychosocial variables. Lung cancer survivors have reported greater perceived stigma compared to individuals with prostate (LoConte et al., 2008), breast (LoConte et al., 2008), and head and neck cancers (Lebel et al., 2013). High levels of lung cancer stigma have been associated with higher levels of depressive symptoms (Gonzalez & Jacobsen, 2010), lower levels of quality of life (Cataldo et al., 2012), and higher levels of personal responsibility and regret (LoConte et al., 2008). However, to the best of the author’s knowledge, no studies have characterized what coping strategies lung cancer survivors utilize most often when dealing with lung cancer stigma.

The APA Presidential Task Force on Evidence-Based Practice (Anderson, 2006) included qualitative research as one of the methods of research that can help build evidence-based practices. In a qualitative study of lung cancer stigma, Hamann et al. (2014) reported that their sample of lung cancer survivors indicated having maladaptive and adaptive consequences as a result of their experience with perceived (i.e., stigma from others) and internalized (i.e., self) stigma. The maladaptive consequences included emotional resignation about lung cancer, distress/depression, decreased disclosure to others, and less engagement in care. Adaptive responses included interest in advocacy, helping others, and increased involvement in treatment. However, it is unclear as to how lung cancer survivors would describe how they cope with lung cancer stigma.

Intervention development may be informed by incorporating and facilitating methods of coping that lung cancer survivors already utilize into research-based interventions (Green & Kreuter, 1999). Given the apparent need for interventions to address the negative effects of lung cancer stigma (Chambers et al., 2012; Hamann et al., 2014), it is important to understand the subjective experiences of lung cancer survivors with regards to how they already cope with stigma before an intervention is delivered. Therefore, the aim of the current study is to extract themes of coping strategies that lung cancer survivors utilize in response to perceived and internalized stigma so as to inform future efforts for intervention development.

Method

Participants

Individuals who were at least 18 years of age and have been diagnosed with lung cancer were eligible for participation in the current study. Participants were sampled from volunteers of the Phone Buddy program via the LCA. The purpose of the Phone Buddy program is to connect lung cancer survivors with each other so as to function as a source of social support. Representatives from the LCA provided participants' responses to a questionnaire regarding their experience with stigma to the author. Data were not provided to the author that would have revealed participants' identities (e.g., names, addresses).

Procedure

Lung cancer survivors who participated as volunteers for the LCA's Phone Buddy program were invited by the LCA to complete online and mailed surveys that asked them closed- and open-ended questions about their experiences with and responses to lung cancer stigma (see Appendix A for the full survey). Completion of the survey was voluntary.

Survey

The survey was composed of 10 questions: one question requesting the participant's name, 6 close-ended questions with optional open-ended follow-up responses (asking the participant to explain their endorsements), and three open-ended questions (see Appendix A). Although the first question requests the participant's name, the author was not provided with participant names; subject identification numbers were utilized to match responses to their respective participants in a manner that protected their identities. The second question asked participants to answer whether they have ever experienced lung cancer stigma in the past ("yes" or "no"); all participants who answered "no" to the second question did not complete the remaining eight survey questions. The third survey question asked participants whether they would be interested in being "matched" to others so as to talk further about their stigma experiences ("yes" or "no"). The fifth question asked that participants endorse as many of three types of stigma experiences (“self,” “family/friends,” or “strangers/medical team”) that they have experienced. The fifth question asked that participants endorse as many types of responses to stigma as they have experienced (“reluctance to share the diagnosis;” “social isolation;” increased feelings of guilt, shame, anger, depression;” “considered not entering treatment, delayed treatment;” “stress in relationships with family and friends;” “loss of hope;” “other”). The sixth question asked participants to indicate as many types of coping strategies that they utilized (see Table 6). Question seven asked participants to select how they dealt with lung cancer stigma at the time they completed the survey (“really good…,” “okay…,” “I still struggle…,” “I no longer experience stigma,” “other”). Participants were asked to write open-ended explanations to their endorsements of questions four through seven.

Table 6. *Coping strategy categories listed in Question 6.*

I take/took the opportunity to educate about lung cancer (cited statistics, told my story, shared in some other way).
I tell/told them how I felt, that I didn’t appreciate the comments.
I got a second opinion/switched centers or doctors because I wasn’t offered treatment and/or given any hope.
I got a Phone Buddy, joined a support group or found other ways to connect with people who understood, whether other lung cancer survivors or professionals.
I get/got angry.
I shut down. I just can’t handle those situations.
Other.

Note. *n* = 49 participants answered this question.

Questions eight through ten asked participants to answer via open-ended responses. Question eight asked participants to describe the most helpful ways that they and/or others have coped with lung cancer stigma. Question nine asked participants to report what they would say to others who are not coping well with lung cancer stigma. Finally, question ten asked participants to describe anything else about their experience with lung cancer stigma that they would like to enter into the survey.

Data Analysis

Data were obtained from participants' demographic data. Specifically, demographic and medical characteristics regarding participants were included in chi-square goodness-of-fit tests (for categorical variables: type of cancer, stage of cancer, recurrence, smoking history, sex) and *t*-tests (for continuous variables: age at diagnosis and years since diagnosis) to check for systematic differences between participants who indicated that they experienced stigma and those who indicated that they did not experience stigma. Proportions of the study sample that indicated a response for each survey question were obtained (see Appendix A). Tests of significance were set at $\alpha = .05$, two-tailed.

Open-ended responses to survey questions were qualitatively analyzed, focusing on sections of text that described how lung cancer survivors coped with stigma. The method of qualitative analysis that was utilized can be described as "conventional content analysis" (Hsieh & Shannon, 2005). Prior to analysis, the investigators did not utilize other research findings to prematurely form categories/themes; rather, three investigators independently scanned the open-ended responses to survey questions for themes that answered the question, “How do lung cancer survivors cope with stigma?” When scanning the responses, investigators highlighted sections of text that they believed to reflect a specific theme of coping with stigma. After independently forming themes and highlighting sections of text, the investigators met to compare themes and highlights. Once a final set of themes and highlighted text was determined, two graduate research assistants were trained on the themes and example (not actual) sections of text that reflected those themes. After training, the assistants assigned themes to sections of highlighted text so as to determine inter-rater reliability (i.e., the reliability between each of the two research assistants and the investigators). Inter-rater reliability was reported as kappa statistics, wherein kappa’s greater than 0.60 indicate at least “substantial agreement” (Landis & Koch, 1977).

Results

Characteristics of Participants

See Table 7 for demographic and medical characteristics of the study sample. Out of N = 91 lung cancer survivors who provided close-ended or open-ended responses to the survey, n = 61 participants indicated that they have experienced stigma. Lung cancer survivors who reported experiencing stigma (M = 53.03, SD = 10.26) were significantly younger than those who reported not experiencing stigma (M = 59.27, SD = 7.89), $t(88)$ = -2.92, $p < .004$. All other demographic and medical characteristics were similarly distributed across lung cancer survivors who did and did not experience stigma, p’s > .05. A *post hoc* chi-square goodness-of-fit test between smoking history and stigma experience was run without individuals who had an unknown smoking history, which

Table 7. *Demographic and Medical Characteristics of the Study Sample*

Variable	Stigma (*n* = 61)	No stigma (*n* = 30)
	N(%)	*N*(%)
Lung cancer type		
NSCLC	53(86.9)	28(93.3)
SCLC	7(11.5)	2(6.7)
Mixed type	1(1.6)	0(0.0)
Stage of cancer		
I	20(32.8)	10(33.3)
II	6(9.8)	3(10.0)
III	17(27.9)	11(36.7)
IV	7(11.5)	4(13.3)
Limited	7(11.5)	2(6.7)
Unknown	4(6.5)	0(0.0)
Cancer recurrence		
No	37(60.7)	24(80.0)
Yes	23(37.7)	6(20.0)
Unknown	1(1.6)	0(0.0)
Sex		
Female	45(73.8)	27(90.0)
Male	16(26.2)	3(10.0)
Smoking history		
No	12(19.7)	5(16.7)
Yes	45(73.8)	18(60.0)
Unknown	4(6.5)	7(23.3)
	M(*SD*)	*M*(*SD*)
Age at diagnosis*	53.03(10.26)	59.27(7.89)
Years since diagnosis	9.22(4.07)	8.17(4.92)

Note. * $p < .05$, two-tailed. NSCLC = non-small cell lung cancer. SCLC = small cell lung cancer.

demonstrated that the proportion of participants with a smoking history did not significantly differ whether the experience of stigma was endorsed, $p > .05$.

Responses to Survey Questions

Participants who indicated that they did not experience stigma ($n = 30$) provided no closed- or open-ended responses to survey questions regarding experiences of, responses to, or coping strategies for lung cancer stigma. See Appendix A for proportions of responses to each question. Most participants reported experiencing stigma from strangers and/or a medical team (*n* = 46, 88.5%). The most common responses to stigma were increased feelings of guilt, shame, anger, and/or depression (*n* = 22, 47.8%); reluctance to share the diagnosis (*n* = 18, 39.1%); and stress in relationships with family and friends (*n* = 16, 34.8%). The most common coping strategies utilized to cope with stigma were taking the opportunity to educate others about lung cancer (*n* = 43, 87.8%), joining or connecting with others (*n* = 24, 49.0%), and telling others how they felt and/or that they did not appreciate their comments (*n* = 14, 28.6%). Almost half of the participants who indicated how they are currently dealing with stigma reported that they are doing really well (*n* = 24, 49.0%) and only one lung cancer survivor indicated that he/she still struggles with stigma (2.0%).

Qualitative Identification of Strategies Used to Cope with Stigma

Out of the participants who indicated that they experienced stigma (*n* = 61), *n* = 49 participants provided open-ended responses to survey questions that included highlighted sections of text, indicative of one of the final themes agreed upon by the investigators (see Table 8), which addressed the aim of the current study: What strategies do lung cancer survivors find helpful when coping with lung cancer stigma? Frequencies of lung cancer survivors who provided open-ended responses that corresponded to themes are shown in Figure 2.

Table 8. *Coping Strategies Utilized by Lung Cancer Survivors in Response to Stigma*

Category	Description	Example as expressed by lung cancer survivors
Education	Educating others as a response to their apparent ignorance, lack of understanding, and/or uninformed concern; teaching oneself can prepare and facilitate coping by learning general information about lung cancer.	"I also point out that there are many nonsmokers who are diagnosed with lung cancer;" "…instead of losing hope, I decided to read everything about my condition."
Avoidance strategies	Disregard or ignorance towards others' stigmatizing acts and/or avoiding others altogether.	"I try not [to] tell people who don't know me very well what kind of cancer I have had;" "I refuse to answer moronic, leading questions like, 'Have you ever smoked?'"
Support	Active or passive receipt of support from others (e.g., support groups, Phone Buddy, professional help).	"[I] joined a support group to help myself in the beginning;" "I did get a Phone Buddy."
Helping Others	Sharing one's personal experience with lung cancer with others and/or helping others by giving hope, listening, and supporting others/survivors.	"I share my story now to give hope to others;" "hopefully [I] am able to encourage others."
Acceptance	Validation of one's emotions and/or accepting circumstances that led to one's cancer.	"I accepted my responsibility the fact that I had smoked;" "smoking is an addiction I got caught up in, but that doesn't mean that I deserve cancer."
Assertive Expression	Expression of personal thoughts/feelings to others.	"I have over 10 years recovery that makes me stronger and quick to respond to negative comments;" "I told them

Table 8 (continued)

		they wouldn’t understand how my outlook on life changed…”
Positive Attitude	Keeping a “fighting spirit” and/or taking an overtly positive outlook on one’s cancer experience/prognosis.	“Through it all I am still very positive;” “it’s important to do what I can in the face of what treatment lies ahead.”
Cognitive Reappraisal	Reframing and adjusting how one reacts to stigma over the course of one’s lung cancer experience.	“I am slowly learning to accept others’ opinions but it is a process.”
Advocacy	Some level of involvement in efforts to influence public policy and/or opinion.	“I also tell them to advocate wherever they can which will relieve much of their anxiety over the stigma…”
Spirituality	Using personal faith to cope and/or finding meaning through the cancer journey.	“Never lost hope that I would survive, always kept the faith;” “…how grateful I am that I have stopped smoking!”
Anger	Feeling anger and/or responding to others with anger.	“I then allowed myself to get angry.”
Humor	Using jokes and laughter to cope.	“I make jokes like telling little kids I live on the moon and can’t breathe earth air.”

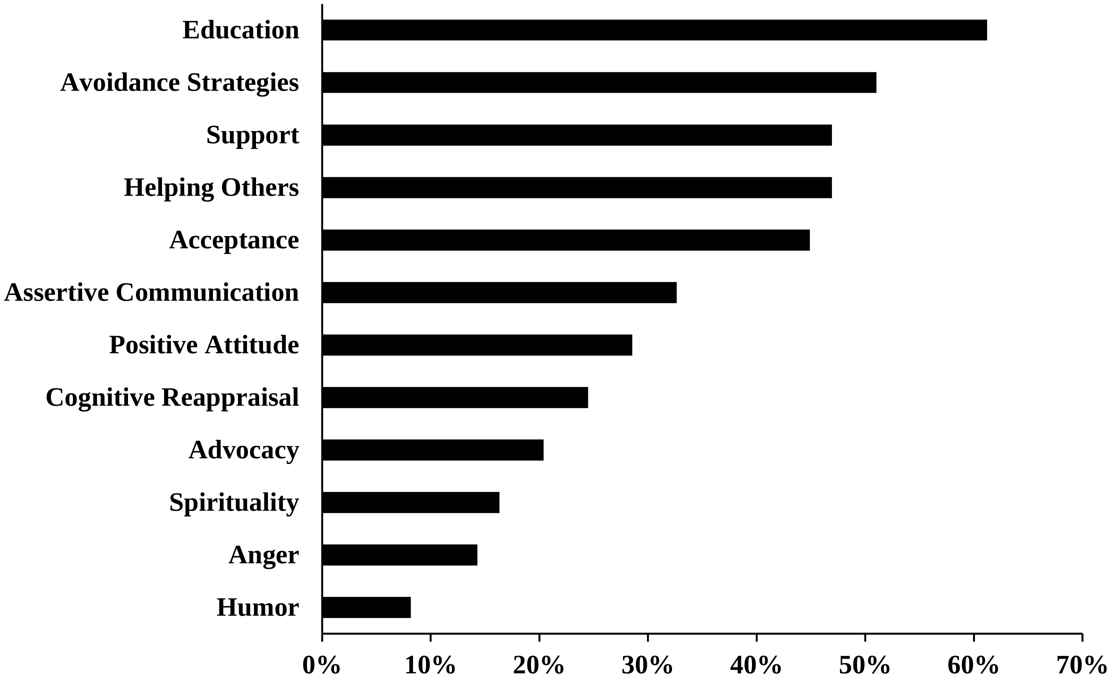

Figure 2. Frequencies of lung cancer survivors who responded to open-ended questions to the study survey (*n* = 49) with themes of coping strategies in response to lung cancer stigma.

Education

Most participants (*n* = 30, 61.22%) indicated that they utilized strategies that fit with the education theme. More specifically, most participants (*n* = 30, 61.22%) indicated that they would educate others regarding the lung cancer experience and correct errant assumptions; some participants (*n* = 7, 14.29%) indicated that they would prepare for the lung cancer experience by learning general information about their cancer (e.g., statistics).

Avoidance Strategies

Approximately half of the participants (*n* = 25, 51.02%) indicated that they utilized strategies that fit with the theme of utilizing avoidance strategies. More specifically, almost one-quarter of participants (*n* = 11, 22.45%) indicated that they avoided certain topics (e.g., lung cancer, stigma) and/or their emotional reactions regarding said topics; several participants (*n* = 9, 18.37%) indicated that they were dismissive of others' questions/comments (may also have indicated having a contemptuous quality to their dismissals); some participants (*n* = 8, 16.33%) indicated that they selectively talk with certain individuals (e.g., family) and not with others (e.g., acquaintances, strangers); and some participants (*n* = 4, 8.16%) avoided answering common questions (e.g., "Did you smoke?") with questions (e.g., "Would you ask a diabetic if they ever ate sugar?").

Helping Others

Almost half (*n* = 23, 46.94%) of the participants indicated that they utilized strategies that fit with the theme of helping others. More specifically, approximately one-quarter of participants (*n* = 14, 28.57%) indicated that they shared their personal experience with lung cancer to help other lung cancer survivors; approximately one-quarter of participants (*n* = 13, 26.53%) indicated that they gave hope, listened, and supported other lung cancer survivors in various ways.

Support

Almost half of the participants (*n* = 23, 46.94%) indicated that they utilized strategies that fit with the support theme. More specifically, some of the participants (*n* = 9, 18.37%) indicated that they took part in a support group; a few participants (*n* = 4, 8.16%) indicated that they received support from the Phone Buddies program; almost one-third of the participants (*n* = 16, 32.65%) indicated that they received support through talking with others (e.g., therapist, counselor, other cancer survivors); and a few participants (*n* = 4, 8.16%) indicated that they passively accepted support from others who offered help.

Acceptance

Almost half of the participants (*n* = 22, 44.90%) indicated that they utilized strategies that fit with the acceptance theme. More specifically, few participants (*n* = 5, 10.20%) indicated that they have come to accept their emotions (e.g., anger and sadness); almost one-quarter of the participants (*n* = 12, 24.49%) indicated that they accepted responsibility for past decisions (e.g., smoking) that may have contributed to their cancer; and a few participants (*n* = 8, 16.33%) indicated that they learned that they do not deserve cancer despite past actions.

Assertive Communication

Approximately one-third of the participants (*n* = 16, 32.65%) indicated that they utilized strategies that fit with the theme of assertive communication. More specifically, approximately one-quarter of the participants (*n* = 14, 28.57%) indicated that they confronted others by expressing their thoughts and emotions; a few participants (*n* = 4, 8.16%) indicated that they considered the motives of others' questions/comments before assertively responding.

Positive Attitude

Approximately one-quarter of the participants (*n* = 14, 28.57%) indicated that they utilized strategies that fit with the positive attitude theme. More specifically, a few participants (*n* = 8, 16.33%) indicated that they focused on maintaining a positive attitude regardless of their circumstances; approximately one-fifth of the participants (*n* = 10, 20.41%) indicated that they focused on maintaining a fighting spirit regardless of upcoming treatments or circumstances.

Cognitive Reappraisal

Approximately one-quarter of the participants (*n* = 12, 24.49%) indicated that they utilized strategies that fit with the cognitive reappraisal theme. These participants indicated that they adjusted their method of coping over time (e.g., learned to adjust one's thoughts and emotional reactions to others' comments or behaviors).

Advocacy

Approximately one-fifth of the participants (*n* = 10, 20.41%) indicated that they utilized strategies that fit with the advocacy theme. These participants indicated that they took part in organizational or public advocacy efforts so as to raise awareness of issues pertinent to lung cancer survivors (e.g., stigma).

Spirituality

A few participants (*n* = 8, 16.33%) indicated that they utilized strategies that fit with the theme of spirituality. More specifically, some participants (*n* = 5, 10.20%)

indicated that they used their spiritual beliefs to cope; some participants (*n* = 5, 10.20%) indicated that they coped by finding meaning through their cancer "journey" (e.g., They express gratitude for their experiences and their lives).

Anger

Several participants (*n* = 7, 14.29%) indicated that they utilized strategies that fit with the theme of anger. These participants indicated that they experienced or expressed their feelings of anger.

Humor

Several participants (*n* = 4, 8.16%) indicated that they utilized strategies that fit with the theme of humor. These participants indicated that they used laughter, jokes, or other ways to express/show humor to cope.

Discussion

Closed-ended responses to survey questions provided data regarding percentages of participants who experienced different types of stigma, responses to stigma, coping strategies, and how well participants were coping with stigma at the time of the current study. Approximately half of the participants reported experiencing self (internalized) stigma, and most participants endorsed experiencing stigma from strangers and/or their medical team (perceived stigma). Interestingly, this differs from the proportion of the sample of lung cancer survivors who reported high levels of Medical Stigma in Chapter 2 (5-10%). This difference may be due at least in part to the lack of delineation between perceived stigma from strangers and stigma from the medical team. Also, this sample differs from Hamann et al.'s (2014) sample of lung cancer survivors in that the proportions reporting stigma from family and friends (62%) and self stigma (60%) are different from the current study (38.5% for family and friends; 48.1% for self-stigma). Indeed, this sample may be unique from other study samples as it was obtained via a lung cancer advocacy group and sampled from volunteers who participate in a social support program.

The most common responses to lung cancer stigma were increased feelings of shame, anger, depression; reluctance to share the diagnosis; others (presumably described in open-ended responses); and stress in relationships with family and friends. Also, a very low percentage of participants in the current study reported that they delayed or considered not entering treatment as a result of experiencing stigma. Interestingly, this sample also differs from Hamann et al.'s (2014) sample in that only 6.5% of the current study sample responded to lung cancer stigma by considering not entering treatment or delaying treatment. Again, differences in where lung cancer survivors were sampled (primary care settings vs. volunteers via an advocacy group) may help explain the contrast in characteristics of responses to stigma.

The most commonly endorsed coping strategies used by participants in the current study include taking the opportunity to educate about lung cancer; getting a Phone Buddy, joining a support group, or finding other ways to connect with people who understand; and telling others how they felt. Although "shutting down" was an option on the survey, no participants endorsed that choice. Again, this is in contrast to the sample from Hamann et al.'s study (2014) in that they found that 69% of their sample reported having an emotional resignation about lung cancer and 48% reported decreased disclosure to others.

Most lung cancer survivors in the current study who provided open-ended responses to survey questions indicated that they coped with lung cancer stigma by educating themselves and others and by avoiding certain topics (e.g., avoiding common questions, such as, “Did you smoke?”) or certain people. Other common coping strategies involved helping others (e.g., giving hope to other lung cancer survivors), acceptance (e.g., accepting that one’s past actions contributed to cancer), receiving and seeking support (e.g., engaging in a support group or seeking professional help), and assertively expressing one’s thoughts and emotions to others. These data inform the literature by providing novel information regarding how lung cancer survivors tend to cope with lung cancer stigma, which is novel information to the best of this author’s knowledge.

Sanders et al. (2010) reported that lung cancer survivors tended to utilize avoidance coping (*M* = 1.7, *SD* = 0.4) some of the time (1-4 Range). Also, it was observed that lung cancer survivors with a smoking history who utilized avoidance coping strategies tended to experience higher levels of stigma from healthcare professionals and higher levels of regret (see the “Results” in Chapter 2). The current study demonstrated that approximately half of the lung cancer survivors in the sample utilized avoidance coping in response to experiencing stigma. Hamann et al. (2014) characterized emotional resignation and decreased disclosure to others (aspects of the avoidance theme in this study) as maladaptive consequences of lung cancer stigma. It should be noted that avoidance coping is a strategy that has been shown to be associated with worse psychosocial functioning in other cancer populations as well as with higher levels of Medical Stigma (see Chapter 2).

Hamann et al. (2014) also observed that there were adaptive consequences to experiencing lung cancer stigma. These adaptive consequences included an interest in advocacy and helping others. Both of these themes emerged from the qualitative data of the current study. The proportion of participants who reported that they coped by helping others in the current study (approximately 47%) is similar to the percentage reported in Hamann et al.'s study (2014; 48% reported having an interest in advocacy/helping others). In addition to these two coping strategy themes, education, support, and acceptance themes were endorsed by approximately half of the participants in the current study. However, it is unclear how helpful these coping strategies are due to the paucity of literature on how these coping strategies relate to lung cancer stigma and psychosocial outcomes.

Limitations

Several limitations regarding the current study should be noted. Categories regarding types of stigma experienced by lung cancer survivors were not well delineated; more specifically, stigma from family and friends and especially stigma from medical professionals and strangers should be separated into two categories to determine from whom the stigma was experienced. Also, the close-ended response data regarding types of experienced lung cancer stigma, responses to stigma, and coping strategies utilized by participants were not mutually exclusive, thereby inhibiting the use of significance tests of group mean differences (e.g., ANOVA). For example, the author was unable to run an

ANOVA to test for significant differences between groups who endorsed different types of stigma experiences (Question 3) and how they currently “deal with lung cancer stigma today” (Question 7).

It should also be noted that the generalizability of this study may be adversely impacted by characteristics of this sample. Only one individual indicated that he/she still struggled with stigma, which may limit generalizability of these data to lung cancer survivors who report that stigma is still difficult to cope with. However, in light of most study participants reporting that they did not struggle with stigma at the time of data collection, these data may suggest coping strategies that help lung cancer survivors to successfully mitigate the detrimental effects of lung cancer stigma. Also, a convenience sample of lung cancer survivors who were volunteers for a social support program (Phone Buddy) was used for data collection. Indeed, no responses were collected from lung cancer survivors who were not involved in the above-mentioned program; but the qualitative data may be useful in identifying helpful coping strategies to test in future pilot intervention studies that address lung cancer stigma.

Clinical Implications

Healthcare professionals who work with lung cancer survivors can encourage the use of coping strategies that they already use, and they can recommend alternative coping strategies, such as those reported in the current study (e.g., assertive communication training), for survivors whose past coping strategies were not helping them to address internalized and experienced stigma. Careful assessment of available resources can help to guide treatment recommendations for stigma-related issues (e.g., support groups, advocacy opportunities). Given the paucity of available research on which coping strategies may be most helpful in mitigating the negative psychosocial impact of lung cancer stigma, it is difficult to provide specific clinical recommendations for the application such coping strategies.

Recommendations for Future Research

The results of the current study suggest that lung cancer survivors most often utilize coping strategies that fit under the themes of education, avoidance, helping others, receiving support, and assertively expressing feelings. However, it is unclear as to how helpful these strategies are with addressing stigma and its negative impact on psychosocial outcomes. Future research should investigate how the use of specific coping strategies in response to lung cancer stigma (e.g., avoidance coping, educating others) affect psychosocial outcomes (e.g., quality of life, depression, anxiety) so as to better understand which coping strategies contribute to improved psychosocial outcomes in lung cancer survivors who experience stigma.

Also, the findings in the current study suggest that lung cancer survivors experience perceived stigma from strangers and their medical teams more than internalized stigma, corroborating Hamann et al.'s (2014) findings. However, it is unclear as to whether individuals who endorse different types of stigma (e.g., internalized vs. perceived stigma) may tend to utilize different coping strategies. Further research is needed to understand how lung cancer survivors who experience different stigma types (e.g., self-stigma, stigma from healthcare professionals, stigma from family and/or friends) differ with regards to psychosocial outcomes and with regards to which coping strategies are used.

CHAPTER FOUR

PROPOSED INTERVENTION TO ADDRESS LUNG CANCER STIGMA

Introduction

Given the apparent need for interventions to address lung cancer stigma (Chambers et al., 2012; Hamann et al., 2014), the proposed pilot intervention will be designed to fill this need by utilizing the available literature on lung cancer stigma and a qualitative analysis of lung cancer survivors' responses to what helpful strategies they use to cope with stigma (see Chapter 3). It is expected that this proposed pilot intervention will be helpful in alleviating the negative psychosocial impact of lung cancer stigma (e.g., greater depressive symptoms and lower quality of life) because it will be designed to facilitate coping strategies that lung cancer survivors have utilized and to incorporate aspects of a pilot intervention targeting health-related stigma in another population (HIV/AIDS) that has been shown to be effective in decreasing levels of internalized stigma (Rao et al., 2012). The feasibility study by Rao et al. (2012) was selected for review on how to develop an intervention to address internalized stigma in lung cancer survivors because a) no literature currently demonstrates that interventions have been tested and documented for lung cancer survivors who experience internalized stigma and b) Rao et al.'s (2012) pilot intervention is the only study that has been documented to show effectiveness in reducing internalized stigma in a population experiencing health-related stigma, to the best of the author's knowledge.

Rao et al. (2012) utilized an adapted version of the HIV Stigma Toolkit (Kidd, Clay, & Chiiya, 2007) to address internalized stigma in their sample of African-American women living with HIV. The modules included in the toolkit that overlap with coping strategies that lung cancer survivors were shown to most often utilize in Chapter 3 will be adapted for use with lung cancer survivors who experience internalized stigma. Essentially, the intervention will be a feasibility study so as to test whether Rao et al.'s (2012) promising findings can be replicated by using an adapted and brief intervention in lung cancer survivors.

In Chapter 3, it was found that the coping strategies most often utilized by lung cancer survivors who experience stigma fit the themes of education, avoidance, seeking support, helping others, acceptance, and assertive communication. Fostering avoidance strategies will not be included in the design of the current proposed pilot intervention due to multiple studies that theorized (Hamann et al., 2014) and demonstrated that greater use of avoidance coping strategies are related to poorer psychosocial outcomes (Hack & Degner, 2004) and higher levels of Regret (Chapter 2). However, the other coping strategies (education, seeking support, helping others, acceptance, assertive communication) show strong overlaps with the intervention described by Rao et al. (2012).

Seeking support and acceptance are themes that are central to the intervention described by Rao et al. (2012). The intervention is structured in a group format so as to foster a supportive atmosphere while participants assist each other in the completion of module exercises. Exercises more specific to helping others and fostering assertive communication were a) sharing coping strategies from other group members, b) discussing how to handle potentially stigmatizing situations with family, in the workplace, and in other settings, and c) role playing ways to navigate these difficult situations. Indeed, the modules will very likely be informative for group members and foster education by learning the use of helpful self-care and relaxation techniques; it is likely that group members will be learning directly from the materials presented via the toolkit modules in addition to information shared by other group members.

Although conducting this pilot intervention may be best carried out through an in-person group format, this may not be feasible for a group of lung cancer survivors. Lung cancer survivors have documented difficulties with high symptom burden (Sanders et al., 2010) and fatigue (Hung et al., 2011; Okuyama et al., 2001; Stone et al., 2000). It may be due to those difficulties that recruitment is difficult for this population and should be considered when planning a study. Therefore, to help ease the burden of travel and still preserve the group format, it is proposed that the pilot intervention be carried out over telephone on conference calls.

Target Population and Sampling Strategy

The target population of the proposed pilot intervention will be lung cancer survivors who experience lung cancer stigma. Given that the Lung Cancer Alliance is currently concerned with the issue of lung cancer stigma and has partnered with the investigators (see Chapter 3 under "Method"), it is expected that the investigators can recruit lung cancer survivors who have experienced lung cancer stigma via the Lung Cancer Alliance. Just as study participants in Chapter 3 were contacted for the survey via email and/or mail, potential participants can be contacted about potential participation in the intervention through the same communication channels. As this is a pilot intervention, a small number of lung cancer survivors (*N* = 20) will be sampled for the intervention.

Specific inclusion and exclusion criteria will help ensure that intervention participants are appropriate for studying the feasibility of the proposed pilot intervention. More specifically, the inclusion criteria are that participants a) have a documented diagnosis of lung cancer, b) can speak and understand English their primary language outside of home, c) are 18 years or older, d) endorse having a history of smoking at least 100 cigarettes, e) endorse having the experience of internalized stigma ("Would you say that believe that you are the cause of your cancer because of something you did in the past, such as smoking?") and regret (i.e., endorsing a high level of regret via the Regret scale utilized in Chapter 2), and f) have access to a telephone. Exclusion criteria include participants that a) are younger than 18 years of age, b) are unable to provide informed consent, c) are unable to see, read, and communicate in written and verbal English, d) cannot provide documentation of their lung cancer diagnosis, e) deny having a history of smoking at least 100 cigarettes, f) deny the experience of internalized stigma or regret, and g) do not have access to a telephone.

Outline of the Pilot Intervention

The pilot intervention will be a brief two-week intervention delivered via telephone to lung cancer survivors who endorse experiencing internalized stigma and regret. All participants will be mailed copies of outlines of the exercises to be completed as part of the pilot intervention. The intervention will take place in groups of five participants on weekends for one hour each on Saturday and Sunday so as to accommodate weekday schedules. Groups are separated into groups of five so as to control the number of participants in each group (i.e., groups of 10 or more would likely be unwieldy to facilitate). Just as a peer advocate carried out facilitation of the module exercises (Rao et al., 2012), a volunteer selected through the Lung Cancer Alliance can be recruited and trained to deliver the exercises. One week after engagement in the intervention, the participants will be reassessed so as to determine pre-post intervention changes in levels of psychosocial outcome measures of internalized stigma and regret.

Module Exercises

Module exercises will include practicing relaxation and self-care; sharing coping strategies from other group members; discussing how to handle potentially stigmatizing situations with family, in the workplace, and in other settings; and role-playing ways to navigate these difficult situations. These modules can be adapted from the HIV Toolkit, which was utilized by Rao et al. (2012). An example of how a module from the HIV Toolkit could be adapted from addressing HIV stigma to addressing lung cancer stigma can be found in Appendix B (adapted from module E, Exercise 6, p. 93-95).

Planned Measures

Quantitative measures of constructs pertinent to studies of lung cancer stigma will be included in the proposed pilot intervention. Constructs to be included for measurement were selected based on the purpose of the proposed intervention (to reduce levels of internalized stigma). Based on previous studies, in addition to a measure of internalized stigma, levels of regret will also be assessed due to its theorized relationship with internalized stigma (Hamann et al., 2014). The time period between the pre- and post-intervention assessments will be three weeks.

Internalized Lung Cancer Stigma

Levels of perceived stigma will be assessed via the Stigma Scale for Chronic Illness Short Form (SSCI; Molina et al., in press; Rao et al., 2009). The SSCI has been shown to be sensitive to differences in internalized stigma over time in individuals with a chronic and stigmatizing illness (Rao et al., 2012). The full scale has eight items: six items load onto an enacted stigma factor and two items load onto an internalized stigma factor. The two items pertaining to internalized stigma will be utilized due to the purpose of this proposed intervention being the reduction of internalized stigma. The internalized stigma items are “I felt embarrassed about my illness” and “I felt embarrassed because of my physical limitations.” The scores are rated on a five-point Likert scale regarding the frequency of which the statements depicted in the items are true within the past 24 hours (1 = “never” to 5 = “always”). The internal consistency of the SSCI has been shown to be excellent (alpha = .93; Rao et al., 2012).

Regret

Levels of regret will be assessed by utilizing the three Regret factor items presented in Chapter 2 (see Table 1). The items are “I have no regrets when it comes to choices I’ve made in life,” “I have no regrets about the way I’ve lived my life,” and “When it comes to my cancer, I have nothing to be ashamed of.” All items are reverse-coded so as to ease the interpretation of data (i.e., higher scores will translate to higher Regret levels if items are reverse-coded). Items are rated on a seven-point Likert scale, indicating agreement with each of the items (1 = “strongly disagree” to 7 = “strongly agree”). Internal consistency of the items has been shown to be acceptable in the sample of lung cancer survivors portrayed in Chapter 2, alpha = .71.

CHAPTER FIVE

SUMMARY

Although the study of lung cancer stigma is in its early stages, meaningful work has been done to characterize stigma in the context of a theoretical framework, to better understand how lung cancer stigma is detrimental to psychosocial outcomes, and to report that lung cancer stigma may be linked to delayed diagnosis and treatment of lung cancer. Lung cancer stigma has been placed in the context of two theoretical models: the health-related stigma model (Cataldo et al., 2011) and the illness-intrusiveness framework (Lebel et al., 2013), which are described in Chapter 1 under the "Models of Lung Cancer Stigma" section. Another conceptual model of lung cancer stigma has been presented in the literature (Hamann et al., 2014) since this dissertation had begun.

The conceptual model of lung cancer stigma described by Hamann et al. (2014) splits stigma into two categories: perceived/felt stigma (stigma from others) and internalized/self stigma (highlighted by self-blame, guilt/shame, anger, and regret; see Figure 1 on p. 84). It is assumed that a lung cancer survivor will first experience perceived stigma, which will lead to the establishment of internalized stigma. Once this relationship is established, internalized and perceived stigma can influence each other in a bi-directional relationship. This directional relationship from perceived to self stigma appears to be supported by the "Why Try" model of stigma in mental illness (Corrigan, Larson, & Ruesch, 2009). As Corrigan et al. (2009) stated, "This perspective represents self-stigma as a hierarchical relationship; a person with mental illness must first be aware of corresponding stereotypes before agreeing with them and applying self-stigma to one's self" (p. 75-76). Interestingly, this model posits that internalized and perceived stigma both lead to maladaptive as well as adaptive consequences. Maladaptive consequences can include less engagement in care, emotional resignation about lung cancer, distress/depression, and decreased disclosure to others. Adaptive consequences include interest in advocacy, helping others, and increased involvement in treatment. According to this model, experiencing internalized and/or perceived stigma does not "doom" the lung cancer survivor to a negative psychosocial impact; adaptive coping strategies are also possible (and may even be seen as a consequence of the experience of stigma). However, what is not clear from this model is by what mechanisms do some lung cancer survivors utilize maladaptive coping strategies while others utilize adaptive ones. Existing cross-sectional data regarding associations between lung cancer stigma and psychosocial outcomes generally show that higher levels of stigma are related to worse psychosocial outcomes.

It has been demonstrated that higher levels of perceived stigma in lung cancer survivors are associated with higher levels of depression (Gonzalez & Jacobsen, 2010), lower levels of quality of life (Cataldo et al., 2012; Gonzalez & Jacobsen), and personal responsibility and regret (LoConte et al., 2008). The study presented in Chapter 2 also suggests that higher levels of internalized stigma (e.g., regret) and perceived stigma (i.e., from medical staff) contribute to higher levels of depression, intrusion symptoms, psychological needs, and use of avoidance coping strategies. Although there is a paucity of quantitative studies on how lung cancer stigma affects psychosocial outcomes, qualitative studies have described another issue that requires attention: Lung cancer stigma may have a role to play in the delay of the diagnosis and treatment of lung cancer.

As mentioned by Hamann et al. (2014) under the category of “maladaptive consequences” of perceived and internalized stigma, it has been documented that lung cancer stigma may be, at least in part, to blame for delayed treatment and diagnosis of lung cancer as well as poor treatment adherence over time (Chappel et al., 2004). More specifically, it was reported that lung cancer survivors feared that they would be treated somehow differently if they disclosed their diagnoses to healthcare providers. Indeed, the proportional impact of lung cancer stigma on delays in treatment and lower engagement levels for treatment need to be characterized in future research so as to better understand how lung cancer stigma might impede the treatment process. The studies described in this dissertation are intended to help the lung cancer stigma literature expand upon its understanding of how lung cancer stigma is characterized across individuals with different smoking histories, how lung cancer stigma is related to psychosocial outcomes, and what coping strategies lung cancer survivors who experience stigma utilize.

The two studies presented in this dissertation help propel lung cancer stigma research towards intervention development for said stigma in several ways. First, the investigation presented in Chapter 2 helped characterize levels of Personal Responsibility, Regret, and Medical Stigma across lung cancer survivors with different smoking histories. The results suggested that current and former smokers experience similar levels of Personal Responsibility and Regret, which are significantly higher than lung cancer survivors who never smoked. However, Medical Stigma was endorsed at a similar level regardless of smoking history, suggesting that individuals who never smoked feel just as stigmatized from medical providers as other lung cancer survivors with a smoking history. This is certainly troubling as it was stated by Hamann et al.

(2014), “Patients’ mistrust of their treatment team can adversely affect clinical communication, treatment decision making, and satisfaction with care” (p. 88), and it appears that even lung cancer survivors who have not smoked perceive stigma from medical providers. Although high levels of Medical Stigma were endorsed to a low degree across study participants (5-10%), it was the Medical Stigma factor that showed the strongest associations with worse psychosocial outcomes compared to the other two factors.

Second, the investigation described in Chapter 2 also helped support how the constructs of Regret and Medical Stigma show adverse impact on psychosocial outcomes, as predicted by the relationships between perceived stigma (e.g., stigma from medical providers), internalized stigma (e.g., highlighted by regret), and maladaptive consequences (e.g., distress/depression) in the conceptual model of lung cancer stigma (Hamann et al., 2014). What is interesting is how Personal Responsibility did not associate with any of the psychosocial outcome variables for lung cancer survivors with a smoking history; however, Personal Responsibility was associated with worse psychosocial outcomes in the subsample of lung cancer survivors without a smoking history. Corrigan et al.’s (2009) conceptualization of self-stigma may be helpful in understanding how Personal Responsibility may not be associated with negative psychosocial outcomes in ever smokers; there are “three A’s” required to experience “self-stigma:” awareness, agreement, and application. Akin to Personal Responsibility, Corrigan et al. (2009) indicated that having an awareness (e.g., People who smoke are blamed for having lung cancer) and an agreement (e.g., Yes, my smoking probably caused my cancer) are not sufficient for self-stigma. It is with the third “A,” application (e.g., I have smoked so I must be to blame for my cancer), that self-stigma is realized. It is interesting that lung cancer survivors without a smoking history differ from those with a smoking history in this regard.

It should also be noted again that levels of Medical Stigma did not significantly differ across smoking groups (i.e., current, former, and never smokers). The findings from the study in Chapter 2 suggest two important things that will be briefly mentioned here: 1) Lung cancer survivors without a smoking history experience similar levels of perceived stigma to lung cancer survivors with a smoking history, and 2) those lung cancer survivors without a smoking history who endorse high levels of Personal Responsibility for their lung cancer are inappropriately taking said responsibility for their illness, resulting in poorer psychosocial outcomes. Although Hamann et al. (2014) state that "never smokers may rationalize that stigma is not self-relevant…and deflect the impact through preemptive disclosures about nonsmoking histories and other self-defensive actions" (p. 88), data from the study in Chapter 2 suggest that some lung cancer survivors without a smoking history may not be able to mitigate the negative psychosocial impact of misattributing Personal Responsibility to their disease, internalizing stigma (e.g., Regret), and perceiving stigma from healthcare providers.

The study presented in Chapter 3 helped to characterize the coping strategies used most often by lung cancer survivors who experience stigma. The coping strategies most often utilized by lung cancer survivors fit under the themes of education, avoidance, helping others, support, and acceptance. It should be noted that this sample had two characteristics: 1) The lung cancer survivors who participated in the study were sampled from volunteers of a social support program (i.e., Phone Buddy program), and 2) only one participant (2.0%) indicated that he/she still struggled with stigma at the time of the study. Although the first above-mentioned characteristic of the study sample may threaten its generalizability to other samples of lung cancer survivors, it should also be noted that the very low proportion of participants who still struggle with lung cancer stigma may suggest that the coping strategies reported by the sample have been helpful in dealing with lung cancer stigma.

The proposed pilot intervention in Chapter 4 of this dissertation is a way to translate the previous research on health-related stigma in lung cancer and other populations (e.g., HIV/AIDS survivors who experience stigma) and the results from the two studies in this dissertation into a research-based intervention. This intervention would be the first that would specifically address coping strategies for individuals who experience lung cancer stigma, to the best of the author's knowledge. Indeed, the outlined pilot intervention described in Chapter 4 is an important step towards addressing self- and perceived stigma, after it has had its impact upon an individual with lung cancer.

In the backdrop of a high detrimental impact to psychosocial outcomes seen in the lung cancer population, stigma, thus far, appears to be positively related to negative psychosocial outcomes (Cataldo et al., 2012; Gonzalez & Jacobsen, 2010). However, exactly how stigma relates to psychosocial outcomes is unclear and will require further testing of proposed models in the existing literature (Cataldo et al., 2011; Hamann et al., 2014; Lebel et al., 2013). Further complicating the conceptual picture of stigma, studies have suggested that the experience of stigma may lead to adaptive consequences (Hamann et al., 2014), such as advocacy efforts and helping others (see Chapter 3). As future interventions geared towards lung cancer stigma are developed and tested, it will be important to a) measure lung cancer stigma and its associated constructs (e.g., regret, guilt/shame, personal responsibility) with instruments that are firmly rooted in testable theoretical frameworks (e.g., Cataldo et al., 2011; Hamann et al., 2014), b) track psychosocial outcome variables and their changes as a result of the treatment response via the intervention, c) and observe any differences in how stigma variables (e.g., perceived stigma and internalized stigma) might be associated differently with outcome variables and change over time differently depending on smoking history (e.g., comparing outcomes between ever vs. never smokers). As future interventions are tested, it may be helpful to include follow-up interviews of participants for the review of the effectiveness/efficacy of said interventions; qualitative analysis of participants' experiences with the interventions can be helpful in improving interventions to better meet the needs of the target population (i.e., lung cancer survivors who experience stigma; Green & Kreuter, 1999).

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APPENDIX A

QUESTIONS INCLUDED IN THE LUNG CANCER ALLIANCE SURVEY

1[a]. Please provide your name so that we can add the information we collect into your Phone Buddy Volunteer Record.

2. We know not everyone experiences lung cancer stigma. Do/did you? (N = 91 answered this question)

Yes (n = 61, 67.0%)
No (n = 30, 33.0%)

3. Are you willing to be matched with others specifically to talk about the stigma experience? (n = 62 answered this question)

Yes (n = 55, 88.7%)
No, I'd rather not (n = 7, 11.3%)

4. Please check the types of lung cancer stigma you experienced. Please explain those you checked. Specific quotes are helpful. (n = 52 answered this question)

Self (n = 25, 48.1%)
Family/Friends (n = 20, 38.5%)
Strangers/Medical Team (n = 46, 88.5%)

5. People respond to stigma in different ways. Here are some common ones, please check any you experienced. Please explain those you checked. (n = 46 answered this question)

Reluctance to share the diagnosis (n = 18, 39.1%)
Social isolation (n = 13, 28.2%)
Increased feelings of guilt, shame, anger, depression (n = 22, 47.8%)
Considered not entering treatment, delayed treatment (n = 3, 6.5%)
Stress in relationships with family and friends (n = 16, 34.8%)
Loss of hope (n = 12, 26.1%)
Other (n = 15, 32.6%)

6. People also cope with stigma in different ways. Here are some common ones, please indicate any you have used. Please explain those you checked. (n = 49 answered this question)

I take/took the opportunity to educate about lung cancer (cited statistics, told my story, shared in some other way). (n = 43, 87.8%)
I tell/told them how I felt, that I didn't appreciate the comments. (n = 14, 28.6%)

I got a second opinion/switched centers or doctors because I wasn’t offered treatment and/or given any hope. (*n* = 12, 24.5%)

I got a Phone Buddy, joined a support group or found other ways to connect with people who understood, whether other lung cancer survivors or professionals. (*n* = 24, 49.0%)

I get/got angry. (*n* = 8, 16.3%)

I shut down. I just can’t handle those situations. (*n* = 0, 0%)

Other. (*n* = 9, 18.4%)

7. Regardless of how you dealt with it in the past, please select the answer that most closely describes how you deal with lung cancer stigma today. Please explain. (*n* = 49 answered this question)

Really good. I know what to say to people who say things that make me uncomfortable or I just don't let it get to me. (*n* = 24, 49.0%)

Okay. Sometimes it still surprises me when people ask about smoking or treat me differently because of the lung cancer. (*n* = 11, 22.4%)

I still struggle. I just don't know what to do or say. (*n* = 1, 2.0%)

I no longer experience stigma. (*n* = 9, 18.4%)

Other (*n* = 4, 4.4%)

8. What have been the most helpful ways you have coped with stigma (and/or have heard how others cope)? (*n* = 49 answered this question)

9. What would you say to a person who is not coping well with lung cancer stigma? (*n* = 49 answered this question)

10. Is there anything else you would like to tell us about your experience with lung cancer stigma? (*n* = 49 answered this question)

Note. [a] These data were replaced with subject identification numbers.
Participants who indicated that they did not experience stigma from Question 2 (*n* = 30) did not answer questions 4-10. All responses to questions were not mutually exclusive with the exception of responses to Questions 2, 3, and 7.

APPENDIX B

EXAMPLE OF AN EXERCISE THAT WAS ADAPTED FROM THE HIV TOOLKIT

Discussion

“What is Assertiveness?”

Facilitator reads the following statement:

“One reason why people with lung cancer are treated as victims is that they allow themselves to be treated as victims. They remain passive, allow others to think and decide for them and keep their own feelings hidden. People with lung cancer need to be more assertive if they are to gain more control over their lives and defend their rights.”

Open the following points up for discussion:

- What do you think about this view?
- What does it mean to be assertive?
- Why does being assertive help?

Facilitator will describe the definition and potential benefits of assertiveness:

“Assertiveness is saying what you think, feel, and want in a clear and honest way that is good for yourself and others. It is not being aggressive or showing anger. It is simply telling people in a clear and honest way what you a) think, b) feel, and c) want.”

“There are some reasons to be more assertive. Practicing assertiveness can increase your confidence, help you stand up for your rights, gain more respect from others, improve your relationships, and gain more control over your life.”

Facilitator will now ask for two volunteers from the group to take part in a role-playing exercise and ask that the group refer to their vignettes that were prepared for this exercise. On volunteer will take the role of the lung cancer survivor and the other volunteer will take the role of a family member.

Family Member: “What are you doing?”

Lung Cancer Survivor: “I am sweeping the floor.”

Family Member: “But this work is probably too much for you!”

Lung Cancer Survivor: “”No, this is good for me-I am taking rests from time to time.”

Family Member: “No, you should rest.”

Lung Cancer Survivor: “No, I want to continue sweeping. I want to be useful around the house.”

Family Member: “But this work will probably make you get out of breath!”

Lung Cancer Survivor: “No, it is lifting my spirits and making me feel involved and helping out. I promise that if I start to feel sick, I will stop.”

Facilitator no asks a series of questions and allows the group to discuss their responses with each other after each question: “What happened?” “How did you feel?” “How can you assert your rights to contribute in different settings and keep control over your life?”

If group members discuss alternative responses to the scenario, ask the volunteers to replay the scenario by using that alternative approach to assertiveness. The facilitator can ask the following followup questions: “How was this different?” “Did you notice any differences in how you felt compared to the first time?”

Finally, the facilitator can summarize assertiveness techniques that group members can review on their own with their exercise handouts:

- Tell people what you think, feel, and want clearly and forcefully
- Say “I feel…” or “I think…” or “I would like…”
- Don’t apologize for saying what you think or put yourself down
- Stand or sit straight in a relaxed way
- Hold your head up and look the other person in the eye
- Speak so that people can hear you clearly
- Stick with your own ideas and stand up for yourself
- Don’t be afraid to disagree with people
- Accept other people’s right to say “No” and learn how to say “No” for yourself