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Explore the Relationship Among Lung Cancer Stigma, Social Support, and Psychosocial Distress

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EXPLORE THE RELATIONSHIP AMONG LUNG CANCER STIGMA, SOCIAL SUPPORT, AND PSYCHOSOCIAL DISTRESS

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Nursing
at the University of Kentucky

By
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ABSTRACT OF DISSERTATION

EXPLORE THE RELATIONSHIP AMONG LUNG CANCER STIGMA, SOCIAL SUPPORT, AND PSYCHOSOCIAL DISTRESS

There is longstanding causal relationship between cigarette smoking and lung cancer. Smoke-free policies and anti-smoking campaigns have been linked to the decline in smoking acceptance and contribute to the unintended consequence of stigmatizing smokers. Lung cancer is viewed as a self-inflicted disease and patients' feel judged in a manner different from other cancers affecting social interactions between family, friends, and healthcare professionals. Lung cancer stigma contributes to depression, anxiety, poor self-esteem, guilt, shame, blame, threatens a person's social identity, and limits social support that deeply affects patients and their support persons.

This dissertation contains a review of the literature related to smoking and stigma, an evaluation of the psychometric properties of an investigator-developed instrument, "Lung Cancer Stigma Scale" (LuCaSS) and the main findings from a cross-sectional observational study of 104 lung cancer patients assessing factors associated with lung cancer stigma. The *Model of Stigma Induced Identity Threat* provides the framework to examine stigma and the relationship between social constraints, self-esteem, and smoking and to test whether social support mediates the relationship between stigma, and depression/anxiety.

The LuCaSS was a reliable and valid instrument measuring lung cancer stigma (alpha = 0.89). The principle components analysis determined three subscales measuring internalized stigma: social rejections/judgment, blame/guilt, and shame. Social constraints, self-esteem, smoking each significantly contributed to the prediction of stigma controlling for SES. Lung cancer patients with greater social constraints and lower self-esteem and who were smokers scored higher on stigma. Social support was a mediator for the relationship between stigma and depression but not for anxiety. The findings are consistent with Stigma Induced Identity Threat Model. A stigmatized identity can lead to stress-related health outcomes such as depression.

A lung cancer diagnosis has numerous negative psychosocial effects on patients. Integrating stigma tools (i.e. LuCaSS) in practice settings may assist with determining potential stigma related distress among lung cancer patients. Emphasizing the need for social support and implementing more advocacy efforts may also help minimize the

effects of stigma and depression. Future studies are necessary to further examine the role of social support in minimizing stigma and psychosocial distress.

KEYWORDS: Stigma, smoking, lung cancer, social constraints, self-esteem, social support.

Lisa Maggio

Student's Signature

August 31, 2015

Date

EXPLORE THE RELATIONSHIP AMONG LUNG CANCER STIGMA, SOCIAL SUPPORT, AND PSYCHOSOCIAL DISTRESS

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This dissertation is dedicated to my father, Ignace Fenlon "Bud" Winterberg and all those inflicted with lung cancer

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CHAPTER ONE

Introduction

The causal relationship between cigarette smoking and lung cancer has been known for more than 50 years (USDHEW, 1964; US Department of Health & Human Services, 2014). Lung cancer is the leading cause of cancer death in men and women in the United States (American Cancer Society, 2012). More people die from lung cancer than from breast, colorectal, prostate and pancreatic cancer combined and more women die from lung cancer than breast cancer. In excess of 160,000 deaths were attributed to lung cancer in 2012, with approximately 90% related to cigarette smoking in men and almost 80% in women (American Cancer Society, 2012).

To address the tobacco related disease epidemic, public health initiatives have focused on restricting tobacco use through public policy (e.g., smoke-free policies) and anti-smoking campaigns for more than 30 years (Fichtenberg & Glantz, 2002). These initiatives have been designed to protect non-smokers from the hazards of secondhand smoke and de-normalize smoking behavior (Poutvaara & Siemers, 2008). As a result, these initiatives have reshaped societal thinking about tobacco use and unintentionally placed blame on smokers for the diseases it causes.

In most areas of the United States, smoking is viewed as an unacceptable behavior (Bayer, 2008; Gilpin, Lee, & Pierce, 2004; Alamar & Glantz, 2006; Stuber, et al., 2008). The unintended consequences of effective antismoking campaigns and smoke-free policies have led to the stigmatization, ostracism, and discrimination of smokers (Falomir-Pichastor, et al., 2009). Smokers are often stigmatized and set apart from non-smoking society members leading to stereotyping, judgment and discrimination. Lung cancer is viewed as a self-inflicted disease regardless of person's smoking status, perpetuating the belief that those with the disease do not deserve empathy or support (Struber, Galea, & Link, 2008; Chapple et al., 2004). The repercussions may be membership in a devalued social group increasing a person's exposure to stressful identity threatening situations (Major and O'Brien, 2005). Identity threat endangers the aspect of one's self or self-esteem, producing physical and psychosocial challenges that compromise a person's quality of life and promote social constraints that may lead to

depression and anxiety (Else-Quest, et al., 2009; Carlson et al., 2005; Chapple et al., 2004).

The Model of Stigma Induced Identity Threat (Major and O'Brien, 2005) provides the framework for this dissertation. Key concepts of the model are tested including personal characteristics (socioeconomic status, self-esteem, social constraints smoking) and the effects of lung cancer stigma on psychosocial distress (i.e., anxiety and depression) and the role of social support as a mediator of those relationships. The model posits that being stigmatized produces a threat to the aspect of the self that is derived from membership in a devalued social group or category (lung cancer patient) and assumes that possessing a devalued social identity increases one's exposure to potentially stressful (identity threatening) situations. A threat to one's identity can result in discrimination and lead to a number of psychosocial distress and negative health outcomes such as depression/anxiety and limited social support (Chapple, et al., 2004; Major and O'Brien, 2005; Cataldo, et al., 2011; Brown-Johnson, et al., 2014;). Stigma-induced identity threat results when an individual appraises demands as potentially harmful to their social identity and the demand exceeds the resources to cope (Major and O'Brien, 2005).

This dissertation consists of five chapters. Chapter 2 is an integrative review of the literature related to smoking stigma and how it pertains to lung cancer and mental health outcomes. Stigma is an attribute or behavior that conveys a devalued social identity separate from an accepted normal one (Goffman, 1963). Public health initiatives aimed at protecting non-smokers and de-normalizing smoking behavior have had unintended consequences contributing to the stigma that smokers experience (Struber, Galea, & Link, 2008; Chapple et al., 2004). Stigma in healthcare is considered a powerful force in the lives of individuals from marginalized groups such as those with HIV/AIDS, mental health, cancer, and sexually transmitted infections (Phelan, et al., 2002).

Stigma affects the psychological wellbeing of those who experience it. Having a stigmatized social identity contributes to anxiety, depression, guilt, shame, blame, and poor quality of life (Chapple, et al., 2004; Cataldo, et al., 2012; Carlson, et al., 2005; Brown-Johnson, et al., 2014; Morse, et al., 2008). Stigma functions by signaling disgust in those perceived to be "normal" and shame in those who are stigmatized. Experiencing

stigma triggers fear of rejection, limits seeking help and social support, (Corner, et al., 2005) and is associated with poor health outcomes and decreased survival (Struber, Galea, & Link, 2008; Chapple et al., 2004; Cataldo, et al., 2011).

Chapter 3 describes the development and psychometric testing of the investigator-developed Lung Cancer Stigma Scale (LuCaSS). Items from validated HIV stigma measures were modified for the LuCaSS and framed in the context of lung cancer (Berger, et al., 2001; Fife & Wright, 2000; and Elmet, 2005; Sowell, et al., 1997). The primary aims of Chapter 3 are to describe the internal consistency of the LuCaSS and evaluate the construct validity of the instrument through principle components analysis. Testing instruments designed to assess a patient's perceived stigma and its effects may enhance knowledge, empathy and understanding to improve comprehensive, nonjudgmental care and develop future prevention strategies.

Chapter 4 describes the results of a cross-sectional observational study of 104 lung cancer patients to assess factors (i.e., social support, social constraints and self-esteem) associated with stigma and how these variables are related to anxiety and depression. Testing constructs of the *Model of Stigma-Induced Identity Threat,* the study has three main objectives: 1) explore the relationships among social constraints, self-esteem, smoking, and stigma; 2) determine the relationships between stigma and anxiety and depression, controlling for smoking and socioeconomic status (SES); and 3) determine if social support mediates the relationships between stigma and depression and stigma and anxiety. It was hypothesized that there would be a relationship between self-esteem, social constraints, smoking, and lung cancer stigma. Hypothesis 2 was that social support would mediate the relationships between stigma, depression, and anxiety.

Chapter 5 provides a summary of the findings from the dissertation. In addition, implications for practice and suggestions for future research, prevention, and advocacy are discussed. Also, the ethical considerations associated with deploying stigma as a justified means of social control to discourage unhealthy behaviors are discussed. Smoke-free policies, anti-smoking campaigns and associated media messages are beneficial to curbing smoking prevalence and de-normalizing smoking behavior. However, more research is needed to understand how stigma impacts initiation and help seeking behaviors as well as how social movements may demand action to reduce stigma (Brown,

1995). Social movements led and championed by professional associations and advocacy organizations may provide effective population-based social support to minimize stigma experienced by lung cancer patients, caregivers, and providers.

CHAPTER TWO

Stigma, Smoking, and Lung Cancer: A Systematic Review of the Literature

Abstract

Aims: This systematic literature review explored the: a) concepts of health-related stigma; b) effects of stigma on the lack of lung cancer research funding and advocacy; c) relationship between smoking stigma and lung cancer; and d) overview of the Model of Stigma-Induced Identity Threat and the psychosocial effects of being stigmatized.

Background: Stigma is an attribute that conveys a devalued "social identity" outside of an accepted "normal" one. The unintended consequences of smoke-free policies and anti-smoking campaigns have contributed to the view that smoking is an unacceptable behavior and that lung cancer is a "self-inflicted" disease as a result of smoking.

Data Source: Literature search included the following key words: stigma, smoking, and lung cancer. Lung cancer funding and advocacy were also reviewed with regard to their relationship with smoking and lung cancer stigma.

Review Methods: Inclusion criteria included peer-reviewed research manuscripts and systematic reviews of research published between January 1998 and December 2014. Nineteen manuscripts met the inclusion criteria for smoking, stigma and/or lung cancer. Determining eligibility for manuscript selection was achieved through skimming the abstracts and titles.

Results: Stigma is most likely to exist among people with diseases linked to controllable causes (smoking) prompting less empathy and more blame. As a result, lung cancer patients are seen as responsible or "deserving" of their disease regardless of their smoking status. Prevention and cessation efforts, provided through smoke-free policies, are essential for lung cancer prevention and treatment. However, the stigma experienced by lung cancer patients negatively impacts psychological adjustments and interpersonal communication. The *Model of Stigma-Induced Identity Threat* explains how lung cancer stigma "threatens a person's identity" and is associated with greater distress, poorer psychological adjustment and limited use of support services.

Lung cancer stigma as “identity threat” has influenced the lag in appropriate research funding and advocacy affecting any advances toward better prevention, treatment and survival.

Conclusion: Stigma is a social process resulting in discrediting or devaluation of a person or group and exists as a means of social control and regulating behavior. Smoking represents the primary risk factor for lung cancer and is the connection to the growing negative public perceptions that unintentionally result in stigma against lung cancer patients. As a result, lung cancer patients experience higher levels of cancer-related stigma than patients with other cancers.

Key words: smoking, stigma, and lung cancer.

Introduction

As one of the most common smoking-related malignancies, lung cancer is the leading cause of cancer death in men and women in the United States (American Cancer Society, 2012). More people die from lung cancer than from breast, colorectal, prostate and pancreatic cancer combined and more women die from lung cancer than breast cancer. In excess of 160,000 deaths were attributed to lung cancer in 2012, with approximately 90% related to cigarette smoking in men and almost 80% in women (American Cancer Society, 2012). Lung cancer is among the most preventable diseases (CDC, 2010).

The hazards of smoking have been well established for more than 50 years (US Department of Health & Human Services, 2014) and are known to contribute to an epidemic of smoking-related diseases and millions of deaths worldwide. Although active smoking is responsible for the majority of new lung cancer cases and deaths, secondhand smoke (SHS) exposure is also a cause of lung cancer. More than 7,300 nonsmokers die from lung cancer acquired from exposure to SHS each year (U.S. Department of Health and Human Services, 2014). Tobacco use presents just one of the known causes of lung cancer. There are other carcinogens present in the workplace and home that may increase the risk of developing lung cancer such as radon and asbestos exposure. It is estimated more than 20,000 radon-induced lung cancers occur each year in the U.S. (United States

Environmental Protection Agency, 2012). Radon, an odorless, colorless gas that comes from rocks and soil, can get trapped in buildings and, if undetected, increases the risk of developing lung disease and cancer (EPA, 2012). In addition, high levels of radon combined with smoking produces a synergistic effect adding to the increased risk of developing lung cancer. Examples of other substances that may be found in some workplaces and increase lung cancer risk include arsenic, some forms of silica, and chromium (USDHHS, 2004).

Other variables known to increase the chances of developing lung cancer include gender differences and molecular alterations between never smokers and smokers, indicating other potential causes of the disease (Sun, Schiller, & Gazdar, 2007). Studies have shown that the "Y" chromosome, thought to contribute to tumor containment, is deleted in the blood of men who smoke making men more susceptible to lung cancer. Smoking and age were associated with a loss of "Y" chromosome in the blood, increasing the risk for lung cancer in men (Dumanski, Rasi, Lonn, et al., 2014). In women, estrogen or its metabolites may be a factor that increases lung cancer risk. Smoking alters estrogen receptors expressed on lung cancer cells, increasing cell proliferation of mutated cells and estrogen's role in both premalignant and malignant disease progression (Sun et al. 2007; Couraud, et al. 2012; Taioli &Wynder, 1994; Pesatori, Carungno, et al. 2013). EGFR (epidermal growth factor receptor) and EML4-ALK (echinoderm microtubule-associated protein-like 4-anaplastic lymphoma kinase) are specific mutations found mostly in non-smokers with lung cancer (Rudin, et al. 2009; Wing-SzeWong, D., et al. 2009).

Lung cancer has one of the lowest survival outcomes of any cancer (Howlander, et al., 2014). The overall five-year survival rate for lung cancer has not changed in more than 40 years (13% in 1970 vs. 17.4% in 2014). The five-year survival rate for lung cancer when confined to a primary site, diagnosed and treated, is approximately 53% but declines significantly to 3.9% when the cancer has metastasized. Unfortunately, only approximately 16% of lung cancer cases are diagnosed in an early-localized stage (Howlander, et al., 2014). One factor that contributes to the dismal survival rates is late diagnosis of the disease when the tumor is inoperable or has metastasized. Early diagnosis greatly improves the chances of long-term survival (ACS, 2012).

The purpose of this systematic review was to explore the: a) concepts of health-related stigma; b) effects of stigma on the lack of lung cancer research funding and advocacy; c) relationship between smoking stigma and lung cancer; and d) constructs of the Model of Stigma-Induced Identity Threat and the psychosocial effects of being stigmatized.

Methods

A systematic literature search was conducted via numerous library databases (PsycINFO, WebSPIRS, OVIDSP, PubMed, CINAHL) using the key words of *stigma, smoking, and lung cancer (neoplasms). Lung cancer funding* and *advocacy* were also reviewed with regard to their relationship to stigma. Inclusion criteria included conceptual definitions of stigma associated with lung cancer and smoking. To be included, research studies and systematic reviews were published in peer-reviewed journals between January 1998 and December 2014 and limited to the English language. Studies that were not specific to health-related stigma were excluded from the search, as were those pertaining to treatment, diagnostic, or prevention studies.

The initial search method produced 111 publications and abstracts. Forty-seven studies were regarded as "supportive literature" related to the concept of stigma. Nineteen publications met the inclusion criteria for smoking, stigma and/or lung cancer (see Table 2.1). Determining eligibility of studies was achieved through skimming the abstracts and titles.

Concepts of Health-related Stigma

Stigma is defined as an attribute, behavior, or reputation that is socially discrediting in a specific way that may cause an individual to be mentally classified by others in an undesirable, rejected stereotype, rather than in an accepted, normal one (Goffman, 1963). Since the original stigma work (Goffman, 1963), the definition of stigma has varied considerably to include a characteristic of an individual contrary to the norm of the social unit. The meaning of "norm" includes a common belief that a person ought to behave in a certain way at a certain time (Stafford & Scott, 1986).

More recently, the words "stigma" and "stigmatization" refer to an "invisible sign" of disapproval permitting "insiders" to draw a line around the "outsiders" in order

to distinguish group inclusion limits. The distinction permits "insiders to know who is 'in' and who is 'out' and allows the group to maintain its commonality by demonstrating what happens to those who deviate from the accepted norm of conduct (Falk, 2001). Stigma and the act of stigmatization are an issue of disempowerment and social injustice (Scheyett, 2005).

Link and Phelan (2001) described stigma as "when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" (p.377). Stigma exists when the following interrelated components converge. The first component is that people distinguish and label human differences. Second, dominate cultural beliefs associate labeled persons to undesirable characteristics and negative stereotypes. Third, distinct categories label persons in order to achieve separation of "us" from "them." The fourth component occurs when labeled persons experience a loss in status and discrimination leading to unequal outcomes. Lastly, stigmatization is solely dependent on access to social, economic, and political power permitting the identification of differentness, creation of stereotypes, division, loss of status, and discrimination (Link & Phelan, 2001).

According to these five components of stigma, the nature of labeling a person provides the impetus to separate us from them. The person is thought to be the thing that they are labeled. For example, because smoking causes lung cancer, these patients may be labeled as "smokers" regardless of their actual smoking status. Another example, people who have seizures may be labeled as epileptics instead of a person with epilepsy. Labeling helps us understand the social processes involved in how society allows one group's views to dominate what becomes a real and important consequence for another group.

Stigma is further described by sociologist Gerhard Falk (2001) and is categorized into two types: 1) existential stigma, and 2) achieved stigma. Existential stigma is derived from a condition that occurs without a known cause or from which there was little control. Achieved stigma is earned based on a person's conduct and/or because they contributed heavily to the condition or behavior (Falk, 2001). Existential stigma often accompanies a cancer diagnosis, because there is a lack of understanding of the cause and it is often viewed as a death sentence (Lapore & Revenson, 2007; Chapple et. al., 2004).

Patients often experience vulnerability, lack of control over their health, and a need to protect others from embarrassment (Rosman, 2004; Frank, 1991). Although the patient often asks, "what did I do to cause this?" the reality is that some malignancies are genetic occurrences or the cause is unknown and not controllable. Cigarette smoking is a known cause of lung cancer, as noted in the 1964 United States Surgeon General's Report on Smoking and Lung Cancer –a clear indication of the causal relationship between cigarette smoking and lung cancer (U.S. Department of Health, Education, and Welfare, 1964). A lung cancer diagnosis can result in achieved stigma because the disease is considered to be "self-inflicted" (Chappel et.al. 2004; Spader, 2008; Gylyn & Youssef, 2010).

Diseases associated with the highest degree of stigma share common attributes: (1) a person with the disease is seen as responsible for having the illness; (2) the disease is progressive and incurable; (3) the disease is not well understood among the public; and (4) the symptoms cannot be concealed (Goffman, 1963, Falk, 2001). People often try to conceal stigmatized health conditions or avoid situations that may reveal these conditions, which often lead to delays in seeking health care and information (Link et. al. 1992, Tod, Craven, Allmark, 2007), unnecessary suffering, lost productivity, and sub-optimal use of health care resources (Berger, Wagner, & Baker, 2005). Researchers conclude that the process of stigmatizing someone is not possible unless they lack social, economic or political power in comparison to the person being stigmatized (Link & Phelan, 2001). The powerful have greater access to resources and influence. Stigma exists when labeling, negatively stereotyping, discriminating against, exclusion, and low status co-occur in power situations that allow them to occur (Link & Phelan, 2001). Stigma differs from prejudice, stereotype, and discrimination, although they are part of the stigma experience. Prejudice is an attitude or negative judgment toward a group and its members. Stereotype is a belief about a group, and discrimination is an unjustified negative or harmful behavior toward members of a group (Heatherton, et al., 2003).

In summary**,** stigma is the expression of negative attitudes about someone or something thought to be socially unacceptable. Stigma can be a result of misinformation leading to fear and misunderstanding. As the dangers of smoking became more apparent, well-intentioned efforts to restrict smoking and exposure to secondhand smoke may have caused a negative reaction to smokers. Because smoking represents the primary risk for

lung cancer, the disease is still seen by many as self-inflicted. Stigma ascribed to controllable factors (achieved stigma) such as smoking elicits a greater negative reaction than stigma ascribed to uncontrollable factors (existential stigma) such as breast cancer (Weiner, Perry, & Magnusson, 1988). Stigma may also threaten a person's identity, social life, and economic opportunities and deeply affect families and support persons (Fife et al. 2000). Stigma associated with disease is dependent on the perception of patient responsibility for the disease and whether the disease leads to a serious disability, disfigurement, lack of control, or disruption of social interactions (Goffman, 1963; Falk, 2001; Link, Cullen, Mirotznik, & Struening, 1992; Berger, Wagner, & Baker, 2005).

Stigma and Lung Cancer Research Funding and Advocacy

Although lung cancer contributes to one of the highest cancer mortality rates, it receives the least amount of federal government research funding compared to breast, colon and prostate cancer. Total research spending dollars per death in fiscal year 2010 was $28,660 for breast cancer; $13,697 for prostate cancer; $6,872 for colon cancer, and $1,386 for lung cancer (National Cancer Institute, 2012; Centers for Disease Control & Prevention, 2010). The limited research funding for lung cancer may result from the public view that lung cancer is a punishment for smoking resulting in stigmatization of lung cancer patients (Chapple, et at. 2004; Knapp-Oliver, 2012; Oliver and Moyer 2012). The inequity in research funding contributes to the lack of progress and improvement in early detection, screening, treatment, advocacy and awareness (Gulyn and Youssef, 2010). The history of stigma research provides the context for understanding the processes related to the disparities noted in lung cancer and the expected outcomes of being stigmatized.

Relationship between Smoking Stigma and Lung Cancer Stigma

Because of the longstanding causal relationship between cigarette smoking (USDHEW, 1964) and lung cancer, smoke-free policies were introduced not only to protect non-smokers from exposure to secondhand smoke but also to aid public health strategies aimed at de-normalizing smoking and encourage society to view tobacco use as undesirable antisocial behavior (Bayer, 2008; Gilpin, Lee, & Pierce, 2004; Americans for Non-Smokers' Rights, 2003; Alamar & Glantz, 2006). Although smoke-free policies

have contributed to the decline in tobacco use in the U.S. (Almar & Glantz, 2006), they also have added to the stigmatization and prejudice toward smokers (Stuber, Meyer, & Link, 2008; Chapple et al., 2004).

Denormalizing tobacco use by changing the social norms became the basis for the tobacco control movement (Bell et al., 2010) including strategies to limit where smoking is permitted, how tobacco products are sold, the dangers of first and secondhand smoke through media campaigns and exposing the tobacco industry's manipulative tactics to promote their products (Bell et al., 2010).

The role of social norms, defined as rules or standards that are understood by members of a group, are in place to guide and/or constrain social behaviors with or without law enforcement. Goffman (1963) argued that stigma is a common feature of any society because nonconformity of social norms is unavoidable and persistent. Therefore, stigma is a consequence for failing to comply with social norms for the purpose of making the nonconformist less deviant so they can rejoin the group (Stuber and Galea, 2009). For example, when family and friends express disapproval of smoking, these social norms contribute to smoker-related stigma (Stuber, et al., 2008).

The rise of smoke-free policies in the United States not only reminds us of the health consequences of secondhand smoke exposure but also that the societal attitude has changed and public smoking is no longer considered acceptable (Stuber et al. 2009). The unintended consequences of effective antismoking campaigns and smoke-free policies have led to stigmatization, ostracism, and discrimination endured by smokers (Falomir-Pichastor, et al., 2009). In addition, healthcare providers and epidemiologists may describe smokers as defiant, weak, making poor choices, or lacking willpower (Street, 2004). In reality, many smokers attempt to quit numerous times only to relapse due to challenges of nicotine addiction and withdrawal (Fiore et.al. 2008). A person who smokes may have the desire and willingness to address their smoking addiction and comply with the new social norms. However, the addictive nature of nicotine and the lack of support for or access to nicotine dependence treatment create a dilemma for the smoker.

Smoke-free policies contribute to stigma in two ways: 1) social policy contributes via structural forms of discrimination (private and governmental policies); and 2)

symbolic messages or moral condemnation (Schneider & Ingram, 1993). Structural policies perpetuate discrimination that restricts opportunities of "marginalized" groups, whether intentional or not, and range from companies refusing to hire smokers to employers having to pay more for the health insurance of their employees who smoke. By way of structural policies, the process to separate or lower placement or status may potentiate smoking-related stigma (Pample, 2006; Stuber, and Galea, 2009). Symbolic messages or moral condemnation are designed to punish or segregate a particular group from another, thereby increasing stigmatization. Smoke-free laws, designed to protect non-smokers, arguably were imposed on the act of smoking and not on the smoker. However, these policies that force smokers to huddle outside or segregate them to designated smoking rooms at airports, may create the perception of an undesirable person. Many smokers view the media as promoters of stigma because television advertisement aimed at the young to deter smoking illustrate a dreadful and terrifying death, exacerbating fear and anxiety (Chapple et al., 2004). The awareness of smoke-free policies by smokers and former smokers contribute to the likelihood of experiencing smoker-related stigma (Stuber et al., 2008).

In summary, as the dangers of tobacco use have become known, well-intentioned efforts to restrict it have often led to negative reactions to smokers. Because a history of smoking is the primary cause of lung cancer, the disease is seen as self-inflicted, leading to a higher incidence of stigma for this type of cancer. Stigma exists among people who develop lung cancer, regardless of their smoking status (current, former, or never smokers) (Chapple, et. al., 2004; Sun, Schiller, & Gazdar, (2007).

Model of Stigma-Induced Identity Threat

Overview. The Model of Stigma-Induced Identity Threat (Major, O'Brien, 2005) integrates identity threat models of stigma (Crocker, Major, Steele, 1998) with transactional models of stress and coping (Lazarus, Folkman, Smith 1984). An identity threat is a threat to the aspect of self that is derived from membership in a devalued social group or category (Tajelf and Turner, 1986). The model assumes that possessing a consensually devalued social identity (stigma) increases one's exposure to potentially stressful (identity threatening) situations. The model posits that situational cues, collective representations of one's stigma status, personal beliefs and motives shape

people's appraisals of the significance of those situations for wellbeing (Major, O'Brien, 2005). Identity threat appraisals result when an individual appraises the demands imposed by being stigmatized as potentially harmful to their social identity and those stressors exceed the individual's coping mechanisms. Events are appraised for significance of wellbeing and outcomes of this appraisal process directs affective, cognitive, behavioral and physiological responses to that event. The response is then involuntary (non-volitional responses) and/or voluntary (volitional responses) leading to specific outcomes (See Figure 1.1).

Mechanisms of Stigmatization. There are four mechanisms that directly affect the psychological wellbeing of those who are socially stigmatized: (1) Negative treatment or direct discrimination; (2) expectancy confirmation or self-fulfilling prophecy; (3) automatic stereotype activation behavior; and (4) stigma induced identity threat.

Negative treatment or direct discrimination limits access to certain life domains that affect a person's social status, psychological wellbeing and physical health. For example, healthcare systems establish tobacco-free campus policies that clearly designate the boundaries where smokers are not permitted to smoke. Those who violate the policy face corrective action or reprimands. Also, in accordance with hospital credentialing, healthcare providers assess the smoking status of every patient upon admission. Smoke-free policies and smoking assessment policies signal that the smoking behavior is unacceptable and can create a separation between "us" and "them" (Stuber, et al., 2008). The accumulation of institutional policies and practices may work to further disadvantage those who are stigmatized even when individual prejudice or discrimination are absent.

Expectancy confirmation or self-fulfilling prophecy occurs when individuals perceive negative stereotypes that influence certain behaviors toward a stigmatized person in ways that directly affect their thoughts, feelings, and behaviors (Darley and Fazio, 1980). The stigmatized person may then confirm the initial inaccurate expectations, stereotypes, or prejudicial attitudes. For example, patients with symptoms of lung cancer may delay seeking treatment as a coping mechanism to avoid being judged (Corner, et al. 2006). Contributing to this mechanism of stigmatization, when healthcare providers perceive lung cancer to be self-inflicted and hopeless, they are less likely to offer aggressive treatment options than they would to other cancer patients, especially if

the patient continues to smoke (Levealahti, et al. 2007). Important to note is that perceptions of situations do not always correspond to objective events. Some individuals who are targets of objective discrimination fail to realize it and others believe they are victims of discrimination even when they are not (Major et al, 2002b).

Automatic stereotype activation behavior creates an involuntary reaction in the absence of discriminatory behavior on the part of others. These automatic responses are referred to as "the power of an idea (over the body)" associated with linkages in memory between stereotypes and the behaviors they imply. These memory linkages lead to initiation of the stereotype and assimilate the stereotype behavior. Lung cancer patients who are aware of the stereotype (blame and guilt) may "automatically" behave differently (withdrawn, avoidance) regardless of whether there are observable discriminatory actions (Major and O'Brien, 2005). For example, a never smoking female lung cancer patient about to receive chemotherapy may tell people who ask when she loses her hair, that she has breast cancer because she doesn't want to be judged.

Stigma as Identity Threat

Stigma-induced identity threat is the model that explains how experiencing a stigmatized identity can lead to stress and stress-related health outcomes through the coping process (Major and O'Brien, 2005). A person's identity may be derived from their race, age, ethnicity, occupation, heritage etc. Social identity provides a sense of membership or connection with other people (Tajfel and Turner, 2004), and is a valuable key contributor to self-esteem and self-concept. People are motivated to protect their identities from anything that may threaten or harm their self-esteem by demeaning or devaluing their identity (Steel et al., 2002). Possessing a consensually devalued social identity (stigma) increases the potential exposure to stressful or identity threatening situations. *Stigma-induced identity* threat can occur as a result of discrimination or other identity related threatening situations leading to psychological, physiological, and social outcomes such as depression/anxiety, considerable stress, and limited social support (Major and O'Brien, 2005; Steele, Spencer, & Aronson, 2002). Stigma related identity threat occurs as a result of three processes that shape a persons' evaluation of being stigmatized and the significance of situations: collective stereotypes/representations, situational cues, and individual personal characteristics (Major & O'Brien, 2005) .

Collective Stereotypes/Representations are based on prior experiences and exposure to the dominant culture (i.e., non-smokers, health care providers, anti-tobacco messages). Stigmatized members develop shared understandings of the dominant view of their stigmatized status in society (Crocker 1999, 1998; Steele, 1997). Collective representations include awareness that individuals are devalued in the eyes of others, knowledge of the dominant cultural stereotypes of their stigmatized identity, and recognition that they are victims of discrimination (Crocker et al. 1998).

Collective representations influence how the stigmatized perceive and appraise stigma-relevant situations. They can affect the behavior of the stigmatized in the absence of obvious forms of discriminatory behavior on the part of others, and even when no other person is immediately present. For example, anti-smoking media messages don't directly tell a smoker their behavior is unacceptable. However, they create images that may induce harm to the person or others (Crocker et al. 1998*).*

Situational cues differ in their social identity threat potential or the extent to which they signal one is at risk of being devalued, negatively stereotyped, or discriminated against because of ones' social identity (Steele, et al., 2002). For example, when a stigmatized lung cancer patient experiences a threatening situation, such as being asked if smoking was the cause of their disease, they may immediately feel blame regardless of their smoking history or they may feel incorrectly judged because they never smoked. There could also have been exposure to situational cues such as certain media messages or images that reinforce negative stereotypes of one's group (Davies et al, 2002).

Personal Characteristics influence how situations are perceived and appraised. There are a number of personal characteristics that contribute to the appraisals such as socioeconomic factors, self-esteem, experiencing social constraints, and smoking history. The personal characteristic appraisals are explained through *sensitivity to stigma, group identification, and goals and motives.*

Stigma sensitivity involves expecting to be treated on the basis of their group membership (i.e., smoker) rather than their personal identity. Because a person belongs to a certain group they become more sensitive to rejection and they often expect to be treated differently. For example, smoking is no longer viewed by society as an acceptable

behavior. People with lung cancer who continue to smoke may "expect to be treated" with less respect or feel disdain based solely on their group membership of being a smoker. The disdain experienced by smokers may directly affect their self-esteem, self-concept and lead to greater social constraints from family and friends. People who score higher on a measure of stigma consciousness or sensitivity are more likely to perceive themselves as targets of discrimination at both a personal and group level; they also tend to lean more toward words that threaten their social identity (Pinel, 1999).

Group identification refers to individuals who view their stigmatized social identity as an essential part of their self-identity. These individuals are more likely to see themselves as objects of personal and group discrimination, especially when the prejudice cues they experience are ambiguous. For example, smoke-free workplace policies require workers who smoke to go outside. Smokers are expected to "huddle" outside in the cold and are singled out by their co-workers as less motivated, unfairly using the smoke break as a means to avoid work, and lacking will-power or discipline for continuing to smoke (Stuber, et al., 2008).

Goals and motives also shape how individuals perceive and appraise situations. There are two motives that are emphasized in the stigma literature: 1) the motive to protect or enhance self-esteem; and 2) belief that the system is just and they are fairly treated (Crocker, et al. 1998). For example, not every lung cancer patient believes they are to blame for their disease and will reject any notion that they had control over the cause or any attempt to stigmatize them. This belief has been reported mostly in former or never smokers and those with higher self-esteem, social support and social influence (Major, et al., 2002b).

Identity Threat Appraisal is assessment of the demands, the relevance of the situation, and resources to cope with those demands. Threat is the perception that a person is at risk for a negative or possibly harmful event (Major and O'Brien, 2005). For example, being stigmatized may lead to feelings of rejection, judgment, and limited resources or social support (Chapple et al., 2004; Cataldo et al., 2010). Stigma-induced identity threat results when a person appraises the demands imposed by a 'stigma-relevant' stressor as potentially harmful to the persons' social identity and the resources to cope are surpassed (Major and O'Brien, 2005).

The appraisal process can occur through automatic, nonverbal, instantaneous and the unconscious. Appraisals can also result from feelings that are processed from shared observations of dominant views (situational cues). The coping mechanisms for identity threatening situations are through involuntary and voluntary responses (Major and O'Brien, 2005).

Involuntary responses are coping mechanisms to address identity threat and include non-verbal anxiety and physiological/emotional and cognitive responses such as elevated blood pressure, increased vigilance and working memory load; and behavioral responses that may affect academic achievement and health. These responses do no serve to regulate or modify stressful experiences (Major and O'Brien, 2005). *Voluntary responses* also influence our ability to cope by way of conscious "volitional" efforts to control emotion, cognition, behavior, physiology and environmental responses to events or circumstances viewed as stressful. Seeking and receiving social support is a voluntary response and a coping mechanism (Major and O'Brien, 2005).

Individuals cope with stigma-induced identity threat in several ways: engaging or blaming the discrimination they feel on others versus blaming themselves; disengaging or withdrawing their efforts from the situations where they are negatively stereotyped or fear being the target of discrimination. Stigmatized groups may also cope with identity threat by aligning more closely with their group (Allport, 1954). The advantage of belonging to a group is that they can provide those who are stigmatized with emotional, informational and influential support, and social validation for their perceptions and a sense of belonging. Branscombe et al. (1999) found a positive correlation between group identification and self-esteem, resulting in favorable outcomes.

Outcomes of stigmatization involve coping strategies and trade-offs. Strategies necessary to achieve specific outcomes (e.g., preserving self-esteem, limiting anxiety and depression) may interfere with achieving other outcomes, such as minimizing prejudice and discrimination. (Major & O'Brien, 2005). In order to improve the predicament of the stigmatized, we need to seek a better understanding of the factors that contribute to an individual's vulnerability as well as their resilience to stigma so that effective coping strategies are identified for dealing with identity-threatening situations.

In summary, the Model of Stigma-Induced Identity Threat examines how mechanisms of stigma can directly affect the psychological wellbeing of those who are socially stigmatized. Identity threat poses a risk to a person's self that is derived from membership in a devalued social group. This can increase a person's exposure to potentially stressful or identity threatening situations. Experiencing a stigmatized identity can lead to stress-related health outcomes such as depression/anxiety. Individuals who experience stigma may appraise threatening situations through collective representations, situational cues, and personal characteristics. Coping mechanisms for identity-threatening situations may occur through involuntary or voluntary responses and the outcomes may vary based on one's coping abilities, their vulnerability and resilience to being stigmatized.

Lung Cancer Stigma and the Effects on Psychological Well-being

Stigma contributes to depression, anxiety, guilt, shame, and blame (Chapple et al., 2004; Cataldo et al., 2012; Brown-Johnson, et al. 2014; Morse, et al. 2008). In a prospective study, researchers evaluated guilt, shame, and depression among non-small cell lung cancer (NSCLC) patients compared to patients' with breast and prostate cancer. Women with NSCLC were found to have increased levels of guilt, shame, and depression compared to breast cancer patients. They were also more likely to experience depression than their male counterparts. Guilt, shame, and depression may hamper patients' ability to advocate for themselves and may affect treatment outcomes. (Schmidt, Else-Quest, Hammes, Eickhoff, Hyde, & Schiller, 2006). In addition, psychological stress responses can lead to impaired social responses and interactions between the stigmatized and their health care providers (Stuber, et al., 2008). Further, depression, anxiety, (Gonzales and Jacobsen, 2010) and feelings of blame can negatively affect the physician-patient relationship (Chapple et al., 2004; Street, 2004). Prejudice and discrimination contribute to health disparities jeopardizing prevention and treatment efforts (USDHHS, 2002). To avoid judgment, lung cancer patients may avoid discussions that draw attention to their unhealthy behaviors. Stigma can produce individuals who are feared, avoided, regarded as deviant, and even blamed for their choices that caused their affliction (Guttman & Salmon, 2004). Lung cancer patients often feel judged in a manner that is different from

any other cancer with a less apparent cause, affecting social interactions among family, friends, and medical professionals (Chapple, et al. 2004, Sun, Schiller, & Gazdar, 2007).

Stigma associated with lung cancer also contributes to concealment of illness after diagnosis and threatens necessary coping mechanisms that lead to decreased adherence to treatment, greater disability and reduced quality of life (Carter-Harris, Herman, et al. 2014; Conlon et al. 2010). For example, researchers found that healthcare system mistrust, stigma and smoking status influenced delay in seeking medical treatment. Delaying and concealing illness was related to the expected blame they would receive for their illness regardless of their smoking status. Without psychosocial supports, lung cancer patients feel shunned by society, their families, and abandoned by the oncology community (Corner et al. 2005; Sun, Schiller, & Gazdar, 2007).

Stigma has been shown to threaten a person's identity, social life, and economic opportunities and deeply effect families and support persons (Fife, et al. 2000). Lung cancer stigma and prejudice have been linked to serious health consequences including constricting social networks and compromised quality of life (Chapple, et al. 2004; Zoe & Raleigh, 2010).

A cancer survivor's ability to cope with their diagnosis involves the "mutual influence" of their social network (significant others, family, friends) as a means of cognitively and behaviorally addressing the stressors of the disease (Lepore & Revenson, 2007). Individuals who experience stigma may feel constrained and avoid discussing their cancer in an attempt to buffer against intrusive thoughts that are upsetting in order to limit the amount of negative social interactions. Avoidance may hinder the necessary coping processes by limiting contemplation of the experience. The negative effect of a person's intrusive thoughts on mental health is also exaggerated by social constraints. In contrast to social constraints, social support can strengthen mental health through environments essential for cognitive processing of the traumatic events and by utilizing verbal disclosure of thoughts and feelings (Lepore and Helgeson, 1998).

Social constraints can affect how patients communicate with and confide in their health care providers, loved ones, and advocacy organizations. Levelalhti et al. (2007) conducted a descriptive study exploring the views of patients with inoperable lung cancer, who have survived the first year post diagnosis, in regard to how they frame and

conceptualize the onset of their illness (Levelalhti, Tishelman, & Ohlen, 2007). Patients experienced a wide array of bodily experiences that may not immediately lead to a diagnosis. Some reported symptoms related to other disorders such as heart disease or systemic complaints thought to be symptoms or indicators of a serious problem (malaise & poor condition). Other symptoms were less frequent but triggered an immediate reaction such as debilitating cough and vomiting (Levelalhti, Tishelman, & Ohlen, 2007). A lack of a strong communal voice between lung cancer patients and advocacy organizations was also reported. The lack of patient advocacy for lung cancer patients differs drastically from other cancer groups, such as breast cancer patients, who have actively influenced public and professional awareness (Else-Quest et al., 2009; Zoe and Raleigh, 2010; Siminoff, et al., 2010). Media coverage for lung cancer is focused on the connection with smoking, which study participants emphasized as connections to their past rather than their current situation. Media coverage associating stigma and blame portrayed the smoker as lax in responsibility to practice self-care and quit smoking (Levelalhti, Tishelman, & Ohlen, 2007; Street, 2004).

Summary

Researchers have studied the effects of stigma on mental health and relationship lifestyles (HIV/AIDS, smoking) for more than 20 years and conclude that the prejudice against members of stigmatized or oppressed groups causes undue emotional, social, and physical stressors (Bayer, 2008; Bell, et. al., 2010; Struber, Meyer, Link, 2008). Researchers have also identified the importance of understanding the linkages between stigma, prejudice, discrimination and health, essential in the development of effective public health initiatives (Struber, Meyer, Link, 2008). The public attitude and perceptions toward lung cancer patients show a lack of concern, caring and sensitivity needed by not only health care professionals, but also community members, especially when communicating with patients about their illness that many consider “self-inflicted” (Chapple et al., 2004).

Discussion

There are a number of indicators that determine the social discovery of a disease. According to Brown (1995), the following four indicators need to be present: 1) lung

cancer patients and their loved ones need to initiate seeking help; 2) there needs to be a social movement demanding action for lung cancer patients'; 3) health care professionals dealing with the disease must be champions for lung cancer; and 4) having strong advocacy organizations is imperative (Brown, 1995). To date, lung cancer has missed these key indicators and only recently has stigma been addressed in the media, among healthcare providers, and patient advocacy groups.

Additional studies are needed to further assess attitudes and perceptions of lung cancer patients, their families, community members, media, and policymakers. Assessing the level of stigma related to smoking and lung cancer among the general public is important to better understand barriers to funding research, advocacy, prevention and treatment efforts. There may be benefits in examining smoke-free policy and anti-tobacco messaging so that they don't alienate tobacco users from non-tobacco users. The message from "Free to Breathe," a lung cancer advocacy organization is "if you have lungs you can get lung cancer" (Freetobreathe.org). The benefits of assessing this population may lead to development and testing of population-based interventions to reduce societal stigma and enhance advocacy, awareness, and social support. Perhaps we have neglected the true source of suffering? If the aim is to minimize "the stress," psychological harm, and increase the self-esteem of the victim, we may have overlooked that the perpetrator (society) is the problem and not the victim. We seem to have chosen to focus on the problems of the oppressed rather than on the problem of the oppressor (Meyer, 2003).

Conclusion

For more than 160,000 Americans, a lung cancer diagnosis can mean a death sentence. Assessment of the effects of stigma associated with smoking and lung cancer may provide insight into the threat to social support, advocacy efforts and adequate research funding. Addressing the stigma felt by so many lung cancer patients may also pave the way toward the development of population-based interventions that limit the effects of stigma and judgment threatening the psychological wellbeing of lung cancer patients and their families.

Table 2.1 Stigma, Smoking and Lung Cancer Summary of the Literature

Author(s) Citation	Purpose/Design	Sample/Methods	Findings/Conclusion
1. Alamar, B., & Glantz, S. (2006). Effect of increased social unacceptability of cigarette smoking on reduction in cigarette consumption. *American Journal of Public Health,* 96,1359-1363.	Cigarette consumption affected by taxes and social factors. Impact measured with social unacceptability index regarding permissible locations for smoking.	Data on cigarette prices and consumption from tax burden on tobacco, survey data on individual attitudes toward smoking policy.	Policies that increase the social unacceptability of smoking and taxes that increase cigarette prices have similar effects in terms of reducing cigarette consumption. Social unacceptability index and price effects are independent.
2. Bayer, R. (2008). Stigma and the ethics of public health: not can we but should we. *Social Science & Medicine*, 67, 463-472.	Provides a systematic review of stigma, the targets, and the effects on public health, the moral concerns.	Systematic review of stigma and public health literature. HIV/AID and smoking stigma, ethics	It is the responsibility of public health officials to counteract stigma if they are to fulfill their mission to protect community health. Mobilization of stigma may effectively reduce the prevalence of behaviors linked to disease and death and human rights issues.
3. Brown-Johnson, C., Brodsky, J., Cataldo, J. (2014). Lung cancer stigma, anxiety, depression, & quality of life. *Journal of Psychosocial Oncology*, 32, 59-73.	Investigated lung cancer stigma, anxiety, depression and QOL & validated variable similarities between ever and never smokers. Descriptive cross-sectional study, correlational design.	Evaluating relationships among anxiety, depression, LCS, & QOL. Online questionnaire N=149.	LCS is positively associated with anxiety and depression and negatively associated with QOL. Regardless of smoking status, lung cancer patients experience LCS.

Table 1.1 (Continued)

4. Carter-Harris, L., Hermann, C., Schreiber, J., Weaver, M., Rawl, S. (2014). Lung cancer stigma predicts timing of medical-help-seeking behavior. *Oncology Nursing Forum*, 41, 3, E203-E208.	Examines relationships among demographic variables, healthcare system distrust, lung cancer stigma, smoking status, & timing of medical health-seeking behavior in individuals with symptoms suggestive of lung cancer.	Descriptive cross-sectional, correlational study, self-report survey controlling for SES and social desirability.	Lung cancer stigma was independently associated with timing of medical help-seeking behavior in patients with lung cancer serving as barrier to prompt medical help seeking behavior. Findings suggest that stigma influences medical-help seeking behavior and is a barrier to prompt medical care.
5. Cataldo, J., Jahan, T., Pongquan, V. (2012) Lung cancer stigma, depression, and quality of life among ever and never smokers. *European Journal of Oncology Nursing*, 16(3): 264-9.	Compare levels of lung cancer stigma & relationship between lung cancer stigma, depression, & QOL among ever & never smokers.	Exploratory descriptive study of 192 patients diagnoses with lung cancer. Self-report online survey.	Positive relationship between stigma & depression. Strong inverse relationship with QOL. Controlling for age, gender, smoking & depression, lung cancer stigma contributes to variance in QOL. Perceived stigma can lead to negative outcomes including increased levels of depression and decreased QOL.
6. Chapple, A., Ziebland, S., & McPherson, A. (June, 2004). Stigma, Shame, and Blame experienced by patients with lung cancer: Qualitative study. *British* Medical *Journal, 10*(7C), 1-5. Retrieved April, 19, 2008,	Explores perceptions and experience of stigma among lung cancer patients.	Qualitative Study to draw on narrative interviews with patients with 45 lung cancer.	Patients with lung cancer report stigmatization with far reaching consequences. Efforts to help people to quit smoking are important, but clinical and educational interventions should be presented with care so as not to add to the stigma experienced by patients with lung cancer and other smoking related diseases.

Table 1.1 (Continued)

7. Conlon, A., Gilbert, D., Jones, B., Aldredge, P. (2010). Stacked stigma: oncology social workers' perceptions of the lung cancer experience. *Journal of Psychosocial Oncology*, 28 (1), 98-115.	Explores stigma in lung cancer experience.	Qualitative interviews with 19 oncology social workers who provide care to people diagnosed with lung cancer and their family members.	Content analysis of interviews: stacked stigma (multidimensional) exists with respect to cigarette smoking. Poor prognosis and disparity in advocacy efforts emerged as stigmatizing events linked to smoking stigma, particularly in arenas of support groups, patient matching programs & availability of resources.
8. Corner, J. Hopkinson, J. Roffe, L. (2006). Experience of health changes and reasons for delay in seeing care: a UK study of the months prior to the diagnosis of lung cancer. *Social Science & Medicine,* 62, 1381-1391.	Determining events leading to delay in diagnosing cancer. Data recalled from events prior to early & late stage lung cancer diagnosis are explored.	Descriptive study, quota sample, interview study *N*=22, recently dx early & late stage lung cancer.	Individuals, regardless of disease stage or social background failed to recognize symptoms (serious) experienced over many months prior to eventual diagnosis. Symptoms were attributed to everyday causes. Some were more reluctant to seek help because unclear in distinguishing normal from abnormal or feeling unworthy of medical care.
9. Else-Quest, N.,LoConte, N., Schiller, J, Hyde, J. (2009). Perceived stigma, self-blame, and adjustment among lung, breast, and prostate cancer patients. *Psychology & Health;* 24(8): 949-64.	Descriptive study examines the links among stigmatization, self-blame and adjustment in advanced stage lung, breast and prostate cancer patients.	172 participants, 96 stage IV lung cancer, 30 breast and 46 prostate cancer patients. Mailed questionnaire assessing stigma, self-blame, self-esteem, anxiety, anger, depressed affect and causal attributions for cancer.	Lung cancer patients attributing their disease to internal causes reported higher self-blame, poorer self-esteem, and higher depressed affect, anxiety and anger than patients with breast or prostate cancer. Lung cancer patients who felt guilt, shame, or blame for their disease had worse mental health outcomes.

Table 1.1 (Continued)

10. Gonzalez, B. and Jacobsen, P. (2010). Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology*. 10, 102-18.	Descriptive study Identifies the association between perceived stigma related to lung cancer diagnosis and depressive symptomatology.	N=95 stage 2-4 LC receiving RX in outpatient center. Modified labeling theory.	Positive association b/t perceived stigma & depressive symptomatology, $r=0.46$, $p<0.001$. Avoidant coping, poorer social support, dysfunctional attitude.
11. Gulyn, L. M., & Youssef, F. (2010). Attribution of blame for breast and lung cancers in women. *Journal of Psychosocial Oncology, 28*(3), 291-301.	Descriptive study reviewing social perception of blame involved in breast and lung cancer.	Research review of social perception of serious illness & causal explanation.	Causal explanation fall into 2 categories: 1) patients behavior; 2) factors outside the patient control. Additional questions concerning coping, stigma, & responses of health care providers and research communities suggested for future study.
12. Knapp-Oliver, S. (2012). Causal attributions predict willingness to support the allocation of funding to lung cancer treatment programs. *Journal of Applied Social Psychology*, Vol. 42 (10), pp. 2368-2385.	Descriptive study examines whether causal attributions for the contractions of lung cancer predict the stigmatization of individuals with the disease by investigating willingness to support the allocation of funds to hypothetical lung cancer treatment programs.	462 participants randomized to receive lung or breast questionnaire to determine preferences using hypothetical situations.	Participants who made causal attributions preferred to support allocations to fund programs that value the lives of breast cancer patients rather than lung cancer patients. Implications for understanding the influence of causal attributions on the stigmatization of lung cancer.
13. Morse, D., Edwardsen, E., & Gordon, H. (2008). Missed opportunities for interval empathy in lung cancer communication. *Archives of Internal Medicine, 168*(17), 1853-1858.	Descriptive study evaluates empathetic opportunities physician responses.	137 VA lung cancer patients interviewed. A qualitative analysis.	MD provided little emotional support of often shifting to biomedical questions& statements. When empathy was provided 50% occurred in last 1/3 of encounters. Empathy is important in patient/md communication.

Table 1.1 (Continued)

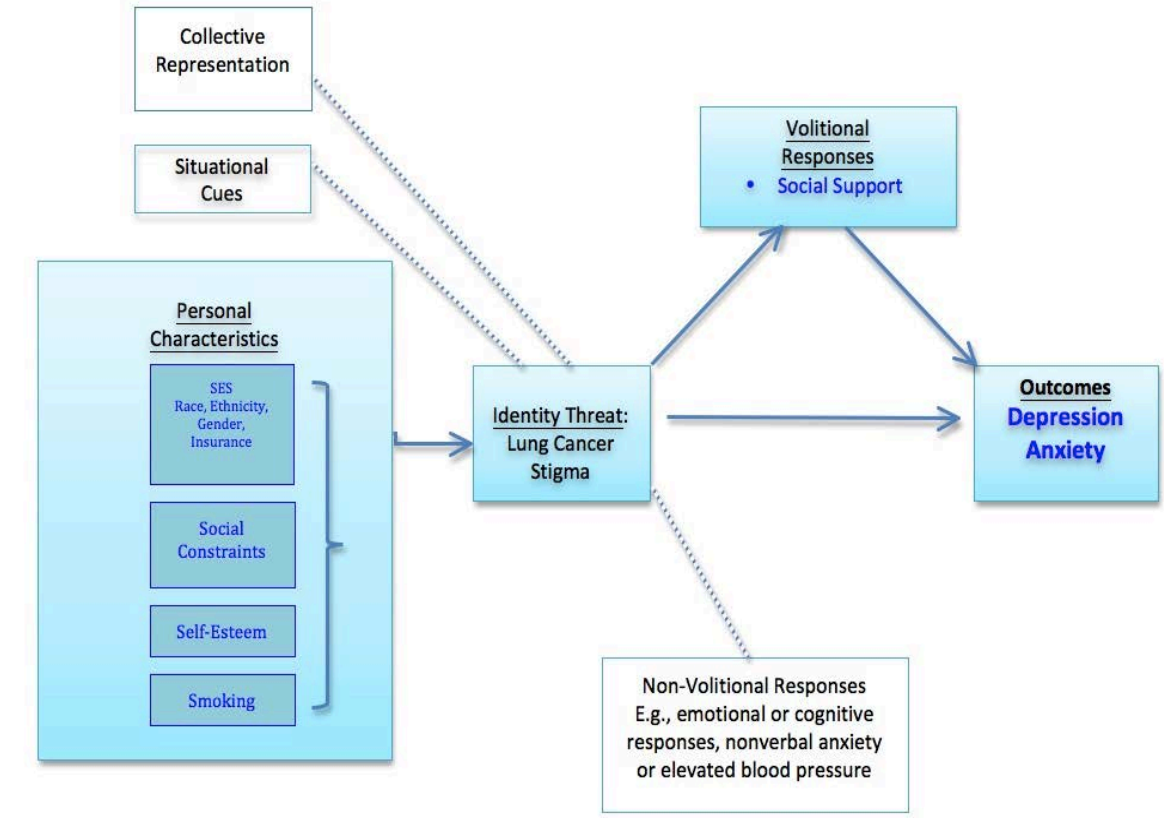
14. Schmidt, N., Else-Quest, N., Hammes, L., Eickhoff, J., Hyde, J., Schiller, J. (2006). Evauations of guilt, shame and depression in non-small cell lung cancer (NSCLC) relative to breast and prostate cancer. *Journal of Clinical Oncology*, 2006 ASCO Annual Meeting Proceedings Part 1, Vol. 24, No.185 (June 20 Supplement) 7158.	Prospective quantitative study evaluating guilt, shame and depression in NSCLC relative to breast and prostate cancer.	Completion of 3 surveys over 6 months. Standardized tests of shame, guilt and depression.	NSCLC is associated with increased levels of guilt and shame leading to depression, relative to breast and prostate cancer. This disparity is particularly striking among women with NSCLC. Guilt, shame, and depression may hamper a patients' ability to advocate for themselves and may affect treatment outcomes.
15. Siminoff, L., Wilson-Genderson, M., Baker, S. (2010). Depressive symptoms in lung cancer patients and their family caregivers and the influence of family environment. *Psycho-Oncology*, 19; 1285-1293.	Investigates depressive symptomatology in lung cancer patients and their identified caregivers.	Semi-structured interviews and measures of family environment, depressive symptomatology, and the extent to which the caregiver blamed the cancer on the patient.	The family environment and blaming the patient during times of illness can affect both patient and caregiver depression. Younger caregivers, spouse caregivers, and caregivers who blamed the patient for the cancer had higher depressive symptom scores.
16. Stuber, J., Meyer, I., Link, B. (2008). Stigma, prejudice, discrimination and health. Social Science & Medicine, 67, 351-357.	Descriptive study examines stigma formation in the context of the tobacco epidemic & examined the role of attribution, fear, tobacco control policies, power and social norms in the formation of smoker-related stigma.	Population –based sample of 816 current and former smokers in NYC. Telephone questionnaire items measuring stigma-related to being a smoker. 12-item scale to assess devaluation & discrimination.	Perceptions of individual's attributions for smoking behaviors and fear about the health consequences of secondhand smoke are important influences on smoker-related stigma. White, more educated respondents perceive more smoker-related stigma than less education. Black & Latino perceive less smoker-related stigma than white persons. Social norms & family/friends expressed disapproval of smoking contributing to smoking-related stigma.

Table 1.1 (Continued)

17. Tod, A. M., Craven, J., & Allmark, P. (2007). Diagnostic delay in lung cancer: a qualitative study. *Journal of Advanced Nursing, 61*(3), 336-343.	Identifies factors influencing delay in reporting symptoms of lung cancer.	Qualitative study, *N*=18 conducted from July 2005 to May 2006. Purposive sample of people diagnosed with lung cancer in community & hospital settings.	Barriers to symptoms reporting included experience, lack of knowledge fear, blame stigma related to smoking. Cultural factors, nonstandard healthcare utilization & underlying stoical attitudes. Family support positive influence in overcoming delay.
18. Tod, A. M., & Joanne, R. (2010). Overcoming delay in the diagnosis of lung cancer: a qualitative study. *Nursing Standard, 24*(31), 35-43.	Explores factors influencing the delay in reporting symptoms of lung cancer; develops early reporting tool to prompt report of symptoms.	Qualitative, *N*=16 healthcare professional (HCP), survivors, community members to discuss content. 6 focus groups with 39 HCP & members of the public to assist with development of screening tool.	Poor knowledge of lung cancer symptoms. Tendency to attribute other meanings to the symptoms, self-management of cough & fear of HCP attitudes, i.e., blame and stigma associated with smoking.
19. Raleigh, Z. (2010). A biopsychosocial perspective on the experience of lung cancer. Journal of Psychosocial Oncology, 28 (1), 166-125.	Examines the effects of an individual's smoking status (current, former, never) on the biological, social, and psychological aspects of lung cancer.	A review of literature related to biopsychological perspective including social aspects and psychological aspects.	Social stigma of lung cancer affects all patients with lung cancer irrespective of smoking status; the psychological and biological consequences of the disease vary with smoking status.

Figure 1.1 An Identity-Threat Model of Stigma in Lung Cancer

Figure 1. An Identity-Threat Model of Stigma in Lung Cancer*



Blue/Solid Line = represent model constructs tested in the proposed study.
* Adapted from A Model of Stigma-Induced Identity Threat (Major, B., O'Brien, L. 2005.)

CHAPTER THREE

Lung Cancer Stigma Scale (LuCaSS):

Measuring Perceived Stigma in People with Lung Cancer

Abstract

Purpose/Objectives: Describe the development of an investigator-developed instrument, "Lung Cancer Stigma Scale" (LuCaSS) and evaluate its psychometric properties by: 1) describing the internal consistency of the LuCaSS; and 2) assessing the construct validity of the instrument through principle components analysis (PCA).

Design: Psychometric analysis of cross-sectional descriptive data set.

Sample: 104 patients diagnosed with lung cancer.

Methods: Cronbach's alpha coefficients to assess internal consistency and Principle Components Analysis (PCA) and to assess dimensionality and construct validity of the 15-item LuCaSS.

Findings: The LuCaSS was a reliable and valid instrument measuring lung cancer stigma (alpha = 0.89). The principle components analysis determined three subscales measuring internalized stigma: social rejections/judgment, blame/guilt, and shame.

Conclusions: Lung cancer patients are at high risk for psychological distress. Feelings of rejection/judgment, blame/guilt and shame can manifest as a result of feeling stigmatized. Testing instruments that assess stigma assist in understanding the salient constructs associated with stigma and research tools needed to further the study of and test interventions to minimize stigma experienced by lung cancer patients.

Introduction

Lung cancer is the most common smoking-related malignancy and the leading cause of cancer death in both men and women (United States Cancer Statistics, 2015). Lung cancer poses many challenges to those afflicted because of high mortality rates, (Howlander et al., 2014), psychological stressors (Gonzalez and Jacobsen, 2010; Cataldo et al., 2010; Carlson, et al. 2005), and societal stigma (Chapple, et al. 2004; Cataldo et al. 2011). These challenges can weaken a person's essential beliefs and expectations about themselves and their illness, their relationships, and their future (Lepore & Revenson, 2007).

The public often holds misperceptions about lung cancer and smoking. Some believe lung cancer is justified as they think only smokers get lung cancer; the disease is self-inflicted; and they deserve it. As a result, lung cancer patients may suffer from societal stigma and its consequences (Couranud, et al., 2012; LoConte, et al., 2008; Chappel, et al., 2004).

Stigma is considered a powerful force in the lives of individuals believed to be marginalized such as HIV/AIDS, mental health, cancer, and sexually transmitted infections (Link and Phelan, 2001). Testing instruments designed to assess a patient's perceived stigma and the effects on their psychological well being may be advantageous to enhancing our knowledge, empathy and understanding so we can improve our ability to provide comprehensive, nonjudgmental care. It may also provide opportunities for health care providers to advocate for these stigmatized populations, promote earlier diagnosis, and minimize the adverse effects of feeling stigmatized.

The purpose of this study was to describe the development of an investigator-developed instrument, "Lung Cancer Stigma Scale" (LuCaSS) and evaluate its psychometric properties by: 1) describing the internal consistency of the LuCaSS; and 2) assessing the construct validity of the instrument through principle components analysis (PCA).

Background

Smoking, Lung Cancer and Stigma

There has been a longstanding causal relationship between cigarette smoking and lung cancer (USDHEW, 1964). In recent years, there has been an increase in the social unacceptability of smoking in the United States linked to smoke-free policies and changes in social norms (Bayer, 2008; Gilpin, Lee, & Pierce, 2004; Alamar & Glantz, 2006; Stuber 2008; Fichtenberg & Glantz, 2002). These policies were introduced not only to protect non-smokers from exposure to secondhand smoke but also to aid public health strategies designed to de-normalize smoking and encourage society to view tobacco use as an undesirable and antisocial behavior (Bayer, 2008; Gilpin, Lee, & Pierce, 2004; Americans for Non-Smokers' Rights, 2003; Alamar & Glantz, 2006). De-normalizing tobacco use became the basis for the tobacco control movement (Bell et al., 2010) including strategies to limit where smoking is permitted, how tobacco products are sold, the dangers of first- and secondhand smoke through media campaigns, and exposing the tobacco industry's manipulative tactics used to promote their products (Bell et al., 2010). The meaning of "norm" implies the common belief that a person ought to behave in a certain way at a certain time (Stafford & Scott, 1986).

Although smoke-free policies have contributed to the decline in tobacco use in the U.S. (Almar & Glantz, 2006), they also have contributed to the stigmatization and prejudice toward smokers (Struber, Galea, & Link, 2008; Chapple et al., 2004). The stigmatization of smokers and the strong relationship between smoking and lung cancer may promote the stigma felt by both smokers and those diagnosed with lung cancer (Bayer, 2008).

A lung cancer diagnosis creates additional challenges for patients and families due to the societal perception that lung cancer is a smoker's disease (Chapple, et al., 2004; LoConte, et al., 2008) and that people who smoke willfully bring the disease on themselves (Struber, et al., 2008). This perception can lead to a number of emotions including a sense of guilt, shame, anger, blame and remorse (Chapple, et al., 2004; Carmack, et al., 2008). As a result, people with lung cancer may experience greater fears, lower self-esteem, emotional distress, and feelings of isolation, anxiety, and depression (Gonzalez and Jacobsen, 2010; Cataldo, et al., 2011; Johnson, et al., 2014;

Siminoff, et al., 2010). People diagnosed with lung cancer often experience negative reactions from others such as criticism from family and societal blame. They often endure feelings of guilt, and the emotions may become so stressful that they often delay or decide not to seek appropriate screening and treatment (Tod, et al., 2010; Corner, et al., 2005).

Stigma Research and Repercussions of Stigma

Stigma is defined as an attribute, behavior, or reputation that is socially discrediting in a specific way that may cause an individual to be mentally classified or labeled by others in an undesirable, rejected stereotype, rather than in an accepted, normal one (Goffman, 1963). The person who experiences stigma is thought to be the thing they are labeled. For example, lung cancer is associated with smoking, so people diagnosed with lung cancer are often considered by society as "smokers", regardless of their smoking status.

Stigmatization is an issue of disempowerment and social injustice (Scheyett, 2005). Stigma associated with disease may be linked to the perception that the patient is responsible for the disease and whether it leads to serious disability, disfigurement, lack of control, or disruption of social interactions (Goffman, 1963; Falk, 2001; Link, Struening, et.al. 2001; Berger, Wagner, Baker, 2005).

Lung cancer carries with it greater social stressors and societal stigma than other cancers or other chronic diseases (Chapple, 2004; Conlon, 2010, Cataldo, 2011). The public perception is that the disease is mostly preventable or associated with controllable factors. Controllable factors create strong negative reactions (Weiner, Perry, Magnusson, 1988) affecting social interactions among all lung cancer patients regardless of their smoking status (Raleigh, 2010).

Perceived stigma contributes to greater depressive symptomatology (Gonzales, 2010), feelings of shame for having caused the disease or guilt for not having prevented it (Chapple, Ziebland, & McPherson, 2004), and feelings of blame that can negatively affect psychosocial support between patient and physician and/or patient and family (Chapple, et al., 2004). Limited psychosocial supports leave patients feeling ostracized by the public, abandoned by the oncology community (Sun, Schiller, Gazdar, 2007), and contribute to a lack of empathy for the patient (Morse, Edwardsen, Gordon, 2008). Lung

cancer patients often feel judged in a manner that is different than other cancers with a less apparent cause. This feeling of being judged can affect social interactions among family, friends, and medical professionals (Chapple, et al. 2004, Sun, Schiller, Gazdar, 2007).

Stigma associated with lung cancer also contributes to concealment of illness after diagnosis and threatens necessary coping mechanisms that may lead to decreased adherence to treatment, greater disability and reduced quality of life (Chapple et al., 2004; Morse, et al. 2008; Lobchuk, et al. 2008). Judgment, feeling ostracized, blame, and guilt contribute to lack of treatment by more than half of all people with advanced lung cancer, far more than for any other type of cancer (Small, et al., 2012; Earle, et al., 2002; Ramsey, et al., 2004).

Methods

Development of the Lung Cancer Stigma Scale (LuCaSS)

When the Lung Cancer Stigma Scale (LuCaSS) was initially developed, there were no other measures of lung cancer stigma. Much of the groundwork for measuring stigma originated from HIV research: *The HIV Stigma Scale* (Berger, et. al. 2001; *Social Impact Scale* (Fife & Wright, 2000), and *HIV Stigma Scale* (Emlet, 2005; Sowell et al., 1997). These instruments have been consistently used and are considered to be the most reliable and valid instruments for measuring HIV related stigma (Bunn, Solomon, Miller, Forehand, 2007). Each of the three instruments was chosen because they evaluated a diverse population (i.e., elderly, gender-specific, ethnic and cultural differences) and one evaluated stigma in HIV patients compared to cancer patients (Fife & Wright, 2000). Although the main focus of the survey questions has been to examine perceptions of stigma related to HIV/AIDS, they have been adapted to examine the perception of stigma in other health conditions (Else-Quest, et al., 2009). Table 3.1 provides a summary of the three instruments used to develop the LuCaSS. Below is a brief summary of each of the three existing instruments that were adapted to form items for the LuCaSS.

Berger's HIV Stigma Scale. Berger and colleagues (2001) developed an instrument to measure perceived stigma experienced by people with HIV based on the stigma literature and psychological aspects of having HIV. The *Model of Perceived*

Stigma in people with HIV was developed and the final instrument yielded 40-items on a 4-point Likert scale (strongly disagree, disagree, agree, and strongly agree). A high score indicated stronger agreement with the item. The reading level was below sixth grade (Berger, et. al., 2001). Examples include: "I work hard to keep my HIV a secret; I feel guilty because I have HIV." The Cronbach's alpha for this scale was .96. Five of the 40 items representing rejection, judgment, and guilt dimensions were adapted for the LuCaSS based on feedback from an expert panel (see below). Examples of the items adapted from the Berger instrument and the dimension it reflects: "I have been hurt by how people reacted to learning I have lung cancer (rejection);" "I feel guilty because I have lung cancer (guilt)."

Social Impact Scale. Fife & Wright (2000) developed the "Social Impact Scale," grounded in the Modified Labeling Theory (Link et al., 1989) to assess the effects of stigma associated with HIV/AIDS and cancer on self-esteem. Based on information from previous studies and focus groups, the final instrument yielded 24 items measuring four dimensions of perceived stigma: social rejection, internalized shame, social isolation, and financial insecurity (Fife & Wright, 2001). Examples of instrument items are: "I have been treated with less respect than usual by others (judgment)"; I feel others avoid me because of my illness (rejection)"; and "I feel others think I am to blame for my illness (blame)." The Cronbach's alphas ranged from .85 to .90 (Fife & Wright, 2000). Seven of the 24 items representing rejection, judgment, blame and shame dimensions were adapted for the LuCaSS.

HIV Stigma Scale. The HIV Stigma Scale was originally developed by Sowell et al. (1997), measures how often individuals have thoughts and feelings of being stigmatized or feel threatened because of their illness. The greatest contribution of this scale is that it recognizes that stigma is not a one-dimensional occurrence (Emlet, 2005). The 13-item instrument utilizes a 4-point Likert type scale ranging from 1 to 4 (1-not at all, 2-rarely, 3-sometimes, and 4-often). Examples of survey items: "I felt ashamed of my illness (shame);" "I avoided getting treatment because someone might find out about my illness (shame);" and "People who know I am HIV (lung cancer) positive treat me with kid gloves (rejection)." Cronbach's alpha was .83. Three of the 13 items representing rejection and shame were adapted for the LuCaSS.

Modification of these items was necessary to frame them in the context of lung cancer. For example, “I avoided getting treatment because someone might find out about my HIV” was modified to, “I avoided getting treatment because someone might find out about my lung cancer.”

Evaluating the Psychometric Properties of the LuCaSS

Design and Procedure.

A convenience sample of lung cancer patients (N = 104) were invited to complete a cross-sectional 15-item questionnaire, the Lung Cancer Stigma Survey (LuCaSS), and they each received a $10 gift card. A total of 125 patients were approached to participate between July and August 2014 (participation rate = 83.2%). Of these participants, twenty-one (16.8%) declined due to fatigue or poor health. The university’s medical institutional review board approved the study materials and procedures. With approval from clinic physicians, patients were pre-screened by diagnosis before approached by research staff. There were two methods for administering the survey: 1) REDcap (Research Electronic Data Capture) electronic data capture tool; or 2) paper/pencil for participants who preferred this method. REDcap is a secure web-based application for building and managing online surveys and databases that is hosted by the university and facilitated by the researcher. All participants chose the REDcap electronic version as the preferred method of participation in this study. Confidentiality was maintained by conducting all interviews in the clinic patient rooms where each question was read aloud to the patient by the research staff.

Sample Recruitment.

The sample was recruited from a medical/surgical thoracic oncology clinic at an urban academic tertiary care medical center. The study aims were explained to the medical/surgical thoracic oncology physicians during tumor conference prior to recruitment. Permission to recruit participants was obtained and patients were pre-screened to determine study eligibility: confirmed non-small cell lung cancer (NSCLC) or small cell lung cancer (SCLC) diagnosis, 18 years and older, and able to read and understand English.

Instrument.

An eight-member panel of five lung cancer survivors and three healthcare professionals with degrees in sociology and psychology disciplines with stigma expertise agreed to serve as reviewers to determine content validity. Based on procedures recommended by Streiner and Norman (2008), content experts were asked to assess the degree to which each of the 65-items from the three pre-existing instruments related to the concept, clarity, and relevance of stigma in people diagnosed with lung cancer. Of the 65 items reviewed, 45 items were discarded based on a lack of relevance to lung cancer patients. Of the twenty remaining items, five were discarded due to redundancy. The final lung cancer stigma survey (LuCaSS) included 15 items (see Table 3.1), each scored on a 4-point Likert scale ranging from "1" (strongly disagree) to "4" (strongly agree). The response options were arranged so that higher scores indicated greater perceived stigma.

Data Analysis.

To determine summary scores from responses, descriptive statistics (means and standard deviations or frequency distributions) were calculated for all variables. Internal consistency of the total scale and the subscales was determined by estimating Cronbach's alpha. Pearson's correlation coefficients were used to estimate the associations among the LuCaSS subscales. To assess the size and adequacy of partial correlations among variables, the Kaiser-Meyer-Olkin Measures of Sampling Adequacy (MSA) was applied to determine whether the associations were sufficient for factorability. MSA scores greater than 0.60 are deemed sufficient for factorability (Kaiser, 1981), and the MSA score for this study was 0.86 ($p < .001$). The sample was found to be favorable for factorability adequacy using both the Kaiser-Meyer-Olkin Measures of Sampling Adequacy (MSA) (Kaiser, 1981) and the Bartlett Sphericity Test (Dziuban & Shirkey, 1974).

Principle components analysis was done to assess the dimensionality and construct validity of the 15-item LuCaSS. The number of subscales was indicated by the relative size of eigenvalues, as displayed in the corresponding scree plot. A factor-loading cutoff of .5 was used to gauge which items loaded on which factors. The varimax rotation was specified for maximum subscale separation. All data analysis was done using SPSS 22.0 (SPSS Inc.)

Results

Sample Characteristics

The sample comprised 104 patients with lung cancer (all stages and types) between the ages of 18 and 85 (see Table 3.2). The average age was 61.9 years (*SD* =9.2). About half of the participants were male (52.0%) and the majority was Caucasian (85.6%). Almost sixty percent had graduated from high school and equal percentages were retired or unemployed/disabled (41.3%). More than three-fifths of participants were former smokers (63.0%) and 21.2% were current smokers.

Internal Consistency Reliability

The Cronbach's alpha for the total 15-item Lung Cancer Stigma Scale (LuCaSS) was 0.89. The Cronbach's alpha calculated for each of the three subscales also provided evidence of internal consistency reliability (See Table 3.3). The alphas for the three subscales ranged from 0.71 to 0.87. Table 3.4 displays the correlations among the LuCaSS subscales and Cronbach's alphas. There were eight items in the judgment/rejection subscale (Cronbach's alpha = 0.87); three items in the blame/guilt subscale (Cronbach's alpha = 0.74); and four items in the shame subscale, (Cronbach's alpha = 0.71). These subscales indicated a positive correlation with each other and with the total score. The strongest correlation was between the total score and the judgment/rejection subscale.

Construct Validity of the Lung Cancer Stigma Scale (LuCaSS)

Construct validity was evaluated using principle components analysis to determine the underlying structure of the LuCaSS (See Table 3.3). Principle components analysis with varimax rotation produced three components with eigenvalues greater than 1, explaining 40.8%, 8.9%, and 8.7% of the variance, respectively. The three components explained a total 58.5% of the variability among items in the LuCaSS. A 4-point Likert-type scale (strongly disagree, disagree, agree, strongly agree) was used with a score of four indicating the strongest sense of stigma; all of the items had the same polarity so no reverse coding was necessary.

Factor 1. Rejection and judgment subscale

The first subscale consisted of eight items with loadings ranging from 0.52 to 0.78. Seven items had loadings greater than 0.6 on this component. One of these seven loaded moderately (0.52) on another subscale (i.e., blame/guilt) but was included here due to higher (0.64) loading on this subscale. One other item loaded on this component] with a moderate loading of 0.53. These items took the form of rejection and judgment related to the patient's personal sense of stigma (Table 3.4).

Factor 2. Blame and guilt subscale

There were three items that loaded on the second component, with loadings ranging from 0.62 to .081. This factor captured the constructs of blame and guilt identified from the lung cancer stigma literature and consistent with the blame/guilt subscale adapted from the HIV/AIDS scale.

Factor 3. Shame subscale

Four items loaded on the third component, with loadings ranging from 0.57 to 0.77; these items captured the construct of shame associated with lung cancer.

Discussion

The final 15-item instrument is representative of a persons' internalized experience with feeling stigmatized, with three subscales including social rejections/judgments, blame/guilt, and shame. The overall Cronbach's alpha for the LuCaSS was 0.89, reflecting that the instrument has strong internal consistency reliability in measuring lung cancer stigma. The principle components analysis determined there was three subscales that together measured stigma among lung cancer patients. The three subscales that emerged in the analysis are consistent with constructs identified in studies of other stigma-associated diseases (Berger et al., 2001; Else-Quest, et al., 2009; Carlson, et al. 2005; Cataldo, et al., 2011). The 15-item LuCaSS instrument measures internalized stigma including constructs of social rejections/judgment, blame/guilt, and shame.

Lung cancer patients are at high risk for psychological distress. Feelings of rejection/judgment, blame/guilt and shame have been identified in lung cancer and they can create psychological distress that can manifest as a result of being stigmatized. In

addition, persons who are stigmatized experience depression, anxiety, lack of social support and a decrease in quality of life that contribute to low self esteem and social constraints (Else-Quest, et al., 2009; Carlson, et al. 2005; Chapple, et al., 2004; Carmack et al., 2008; Gonzalez and Jacobsen, 2010; Cataldo, et al., 2011; Johnson, et al., 2014; Greene and Banerjee, 2006). Hence, understanding the salient constructs that are associated with stigma among lung cancer patients can provide guidance in preventing or reducing stigma. For example, noting that a lung cancer patient scores high on feelings of judgment or rejection provides an opportunity to acknowledge, empathize and offer support to the patient.

Limitations of this study include convenience sampling reducing generalizability to the broader lung cancer population. The small sample size consisted of mostly Caucasian participants from one clinical setting and lacked ethnic and cultural diversity. Further studies would benefit from a larger, more diverse sample. Given the lack of stigma measures for lung cancer, it is important to further develop and test brief measures that could be used by both researchers and clinicians to appropriately assess the stigma experience. Based on the findings reported here, the LuCaSS is a reliable and valid measure of lung cancer stigma and may be useful in identifying individuals who feel stigmatized and could benefit from tailored interventions.

Stigma is an obstacle to prevention, treatment, and access to healthcare among patients with HIV/AIDS, mental health, and cancer in general (Fife & Wright, 2000; Chapple, et al., 2004; Sarna, et al., 2005; Schmidt, Else-Quest, et al., 2006; Else-Quest, et al., 2009; and Unger, 2006). Although there have been several measures of stigma developed and tested with HIV/AIDS patients as well as cancer in general, only two other measures have specifically focused on lung cancer stigma (Fortenberry, et al., 2002; Brown, et al., 2003; Kang, et al., 2006; Buseh, et al., 2006; Berger, et al., 2001; Emlet, 2005; Mak, Cheung, et. al. 2007). First, Hamann et al. (2014) used qualitative methods to identify stigma-related themes during semi-structured interviews with lung cancer patients. To date, however, there is not a published scale based on this work. Second, Cataldo's 31-item lung cancer stigma scale (CLCSS) was adapted from the Berger et al. (2001) HIV measure and was found to be a reliable (coefficient alpha .96) and valid measure of stigma. The CLCSS has four subscales: stigma and shame; social isolation,

discrimination, and smoking ranging from 0.75 to 0.96 (Catlado, et al., 2011). The CLCSS is based on only one HIV stigma scale. In contrast, the LuCaSS includes items from three different HIV stigma scales (see Table 3.1). Each of the three HIV scales was representative of the multi-dimensional aspects of perceived stigma, *The HIV Stigma Scale* (Berger, et. al. 2001); *Social Impact Scale* (Fife & Wright, 2000), and *HIV Stigma Scale* (Emlet, 2005; Sowell et al., 1997), provided additional insights into the three LuCaSS constructs of stigma. For example, the *Social Impact Scale* not only includes social isolation, but also social rejection and internalized shame (Fife & Wright, 2000). This instrument was unique in that it was tested among HIV and cancer patients. Incorporating constructs from three different measures may have further captured the LuCaSS' dimensionality of stigma while reducing the number of items necessary for patients to answer.

Future studies are needed to establish the criterion related validity of the LuCaSS. For example, the LuCaSS could be compared with other measures of stigma in lung cancer patients (i.e., Cataldo et al., [2011] lung cancer stigma scale). In addition, because lung cancer stigma is closely related to smoking stigma, future studies could use the LuCaSS to examine stigma experiences among patients living in areas with and without smoke-free policies.

The LuCaSS could be used in lung cancer diagnosis and treatment settings to identity potential patients who feel stigmatized to promote greater sensitivity from healthcare providers and family/support persons. Insensitive comments made by healthcare providers and loved ones may be a result of not knowing what to say, a reflection of their own fears about developing lung cancer, or lack of knowledge about the existence or impact of stigma. Comments may be made innocently without thinking about the impact on the patient feeling stigmatized. For example, healthcare providers and caregivers could be assessed for blame and anger toward lung cancer patients, particularly if the patient continues to smoke.. Sensitivity training with healthcare providers and caregivers may enhance the understanding of how negative and insensitive comments are linked to emotions and impact the ability to cope. Cancer treatment is challenging enough without adding hurt feelings or additional stress from insensitive comments. Healthcare providers and family members who recognize the potential for

stigma may have a greater ability to empathize with, advocate for, and provide unconditional support to the lung cancer patient.

Table 3.1. Description of measures used in the development of LuCaSS

Author (Year); Instrument (s)	Constructs measured	# of Items; Response Scale	LuCaSS items used from each scale	Reliability coefficient alpha	Model or theory
Berger et.al. (2001) HIV Stigma Scale	Personalized Stigma, Disclosure, Negative self image, Public Attitude	40 –item 4 pt Likert	5	.96	Model of Perceived Stigma in People with HIV (Berger, 2001)
Fife & Wright (2000). Social Impact Scale	Social Rejection & Financial insecurity, Internalized Shame & Social Isolation	12-items 12-items 4-pt Likert	7	.85-.90	Modified Labeling Theory (Link et al. 1989)
Emlet, (2005); Sowell, (1997) HIV Stigma Scale	Distancing Blaming Discrimination	13-item 4-pt Likert	3	.83	Goffman (1963) Stigma Theory

Table 3.2. Sample Characteristics

Characteristic	n	%
Sex		
Female	50	48.1
Male	54	51.9
Ethnicity		
White	89	85.6
Non-white	15	14.4
Education		
High school graduate or less	62	59.6
Some college or greater	42	40.4
Marital Status		
Married/Cohabitating	59	56.7
Widowed/ Divorced/ Separated	33	31.7
Never married	12	11.5
Employment		
Employed/Homemaker	18	17.3
Retired	43	41.3
Unemployed/disabled	43	41.3
Annual income		
$\leq$ $30,000	37	35.6
$31,000 to $59,999	16	15.4
$\geq$$60,000	22	21.2
Preferred not to answer	29	27.9
Insurance type		
Private	59	56.7
Medicare/Medicaid	45	43.3
Smoking Status		
Never	12	11.5
Former	70	67.3
Current	22	21.2

Table 3.3. Factor Loadings of the Lung Cancer Stigma Scale (LuCaSS) Items

Statement	Subscale	Component		
		1	2	3
I have been hurt by how people reacted to learning I have lung cancer [1]	Rejection	0.787	---	---
I feel others avoid me because of my lung cancer [2]	Rejection	0.773	---	---
People judge me for my type of cancer [1]	Judgment	0.666	---	---
People's attitude about lung cancer make me feel worse about myself [1]	Rejection	0.663	---	---
I worry that people will judge me when they learn I have lung cancer [1]	Judgment	0.641	0.538	---
I feel I have been treated with less respect than usual by others [2]	Judgment	0.618	---	---
I feel set apart from others who are well [2]	Rejection	0.611	---	---
People who know I have lung cancer treat me with "kid gloves" [3]	Rejection	0.527	---	---
I feel I am at least partially to blame for my lung cancer [2]	Blame	---	0.812	---
I feel others think I am to blame for my lung cancer [2]	Blame	---	0.764	---
I feel guilty because I have lung cancer [1]	Guilt	---	0.627	---
I do not think I can be open with others about my lung cancer [2]	Shame	---	---	0.774
I feel I need to keep my lung cancer a secret [2]	Shame	---	---	0.691
I feel/felt ashamed of my lung cancer [3]	Shame	---	---	0.679
I avoided getting treatment because someone might find out about my lung cancer [3]	Shame	---	---	0.571

Sources: [1]Berger, et. al. 2001; [2]Fife & Wright, 2000; [3]Emlet, 2005;Sowell et al., 1997.

Table 3.4. Correlations and Cronbach's Alphas for the Lung Cancer Stigma Scale (LuCaSS) and Subscales

Scale/Subscale	Number of items	Cronbach's alpha	Mean (SD)	Pearson's product moment correlations		
				Rejection/ Judgment	Blame/ Guilt	Shame
LuCaSS Total	15	0.89	26.4 (6.9)	0.92	0.78	0.74
Rejection/Judgment	8	0.87	14.0 (4.0)	1.00	0.57	0.54
Blame/Guilt	3	0.74	6.2 (2.1)		1.00	0.44
Shame	4	0.71	6.2 (1.9)			1.00

Note. All correlations p<. 001

CHAPTER FOUR

Lung Cancer Stigma, Social Support, and Psychosocial Distress

Abstract

Background: Lung cancer patients experience more psychosocial distress than those with any other type of cancer. Because lung cancer is closely associated with smoking, society often views the disease as self-inflicted contributing to the "blame the victim" mentality and the stigma and prejudice often experienced by lung cancer patients. Blaming patients who contract lung cancer may further influence our interactions with all lung cancer patients, regardless of their smoking status, denying them the social support routinely provided to those with other cancer diagnoses.

Purpose: The purpose of this study was to investigate lung cancer stigma, social support, and psychosocial distress using an adapted Model of Stigma-Induced Identity Threat. The specific aims were to: 1) explore the relationships among social constraints, self-esteem, smoking and stigma; 2) determine the relationships of stigma with anxiety and depression, using smoking and socioeconomic status (SES) as covariates; and 3) determine if social support mediates the relationships between stigma and psychosocial distress (as measured by depression and anxiety). It was hypothesized that there would be a relationship among social constraints, self-esteem, smoking, and lung cancer stigma, and that social support would mediate the relationships between stigma and psychosocial distress.

Methods: A cross-sectional study with a convenience sample of 104 patients between the ages of 18-85 diagnosed with lung cancer. Surveys were administered to lung cancer patients recruited from an NCI-designated lung cancer clinic using secure online data collection. Data collected included demographics (age, sex, education, employment, income, insurance), social constraints, self-esteem, smoking, lung cancer stigma, social support, depression and anxiety.

Results: Social constraints, self-esteem, and smoking status each significantly contributed to the prediction of stigma controlling for SES. Social constraints contributed 23%, self-esteem contributed 34%, and smoking status contributed 26% in the final

stigma model (adjusted R^2=. 25, F=4.20, p=<. 0001). In the model without covariates, stigma was associated with depression (*p*=. 004) and anxiety (*p*=. 039). When controlling for covariates (SES and smoking), however, there was no longer a significant association between stigma and depression (*p*=. 229) or stigma and anxiety (*p*=. 128). Social support was a strong mediator for the relationship between stigma and depression but was not a mediator for anxiety.

Discussion: There was a relationship among social constraints, self-esteem, smoking, and lung cancer stigma. Social support was a strong mediator for predicting the effects of stigma on depression but not anxiety.

Conclusion: A lung cancer diagnosis can be associated with increased psychological distress and stigma. Lung cancer patients with greater social constraints and lower self-esteem and who were smokers scored higher on stigma. It will be essential for healthcare providers to enhance social support for lung cancer patients to mitigate potential stigma and psychosocial distress. Integrating stigma tools (i.e. LuCaSS) in practice settings will assist with determining potential stigma related distress among lung cancer patients and future studies are required to further examine the role of social support in the experience of stigma and psychosocial distress in lung cancer patients. Such studies can contribute to minimizing stigma induced identity threat among lung cancer patients.

Introduction

A lung cancer diagnosis means poor survival rates (SEER, 2014), very few survivors or advocates (NCI, 2012), and limited research funding for awareness, prevention and treatment (Knapp-Oliver, et al., 2012, NCI, 2012). Because lung cancer is primarily caused by smoking, society often views the disease as self-inflicted. This view contributes to the “blame the victim” mentality (Alamar & Glantz, 2006; Gilpin, Lee, Pierce, 2004; Fichtenberg & Glantz, 2002) and the stigma and prejudice often experienced by lung cancer patients. Stigmatizing patients who contract lung cancer (Chappel et al., 2004; Stuber, et al., 2008) may deny them the social support routinely provided to those with other cancer diagnoses (Raleigh, 2008; Cataldo et al., 2011).

Background

Smoking Stigma.

Smoke-free policy initiatives and antismoking campaigns are essential to reducing the harm from exposure to first and secondhand smoke. However, they may have unintended consequences resulting in the undesirable reputation and stereotyping of smoking and smokers (Bell, McCullough, et al., 2010; Bell, Salmon, et al., 2010;Stuber, et al., 2008; McCool, 2013). As a result, smokers report feelings of shame, described as a dejected emotional state, placing their self-worth under attack and criticizing "the self" for failing to live up to the ideals of society (Stuber, et al., 2008; Ritchie, et al., 2010). Negative feelings about oneself can lead to poor self-esteem and self-concept, threatening a persons' social identity and leading to psychosocial distress (Major and O'Brien, 2005). The growing negative perception of smoking may inadvertently result in stigma against lung cancer patients (Chapple et al., 2004; Bayer, 2008; Stuber, et al., 2008; Burris, 2008).

Stigma and Social Identity

Stigma is defined as an attribute, behavior, or reputation which is socially discrediting in a particular way that may cause an individual to be perceived by others in an undesirable, rejected stereotype rather than in an accepted, normal one (Goffman, 1963). Stigma occurs because of the human need to belong to a group and belonging to a group is necessary in order to establish a social identity (Tajfel and Turner, 2004; Turner, 1979). Social identity is defined by social and physical characteristics that differentiate us such as race, ethnicity, religion, occupation, and behaviors (Turner, 1979). Social identity also affects our self-esteem and our connections or sense of membership with other people (Tajfel and Turner, 2004). We are motivated to protect our social identity from anything that causes harm or is devaluing in order to maintain our self-esteem and self-concept (Steele and Aronson, 1995). Threats to our social identity can lead to psychosocial distress.

Psychosocial effects of lung cancer stigma.

Lung cancer patients experience more stigma and psychosocial distress than those with any other type of cancer (Else-Quest, et al., 2009; Carlson et al., 2005; Chapple e al., 2004). Psychosocial distress factors such as blame, depression, anxiety and poor quality of life have been positively correlated with lung cancer stigma (LoConte, Murdoch, 2008; Gonzalez and Jacobsen, 2010; Johnson, et al., 2014) and reflect feelings of discrimination, shame, guilt, and social isolation (Alamar & Glantz, 2006; Gilpin, Lee, Pierce, 2004; Fichtenberg & Glantz, 2002). Lung cancer stigma has also been linked to lack of empathy in interactions with lung cancer patients (Morse, et al., 2008) and delay in seeking medical help (Carter-Harris et al., 2014: Tod and Joanne, 2010). This occurs even though many patients experience symptoms prior to diagnosis (Corner, et al., 2005) but fear judgment from family and healthcare providers (Carter-Harris, et al., 2014; Stuber and Galea, 2009).

Social Constraints and Psychosocial Distress.

In addition to experiencing blame and low self-esteem (Else-Quest et al., 2009), patients with lung cancer also report significant social constraints (Badr & Carmack, 2006; Bayer and Stuber, 2006). Social constraints are barriers that prevent an individual from expressing thoughts and feelings associated with a traumatic event due to negative reactions from others. Patients who experience a traumatic event, such as a cancer diagnosis, need to process the trauma to validate, appraise and find meaning necessary for successful psychological adjustments (Lepore & Helgeson, 1998; Cordova et al., 2001). Minimizing social constraints by supporting the expression of thoughts and feelings may improve psychological adjustment and coping with psychosocial distress.

Social Support.

A main coping strategy necessary for ameliorating psychosocial distress is social support (Berger, Wagner, Baker, 2005; Brown, 2001; Crocker, Major, & Steele, Whereas unaddressed psychosocial distress can threaten ones' self-esteem and social identity, social support can foster a person's self-concept and social identity (Major and O'Brien, 2005). A cancer survivor's ability to cope with the distress of the disease involves the "mutual influence" of their social network (significant others, family, friends) as a means

of cognitively and behaviorally addressing the stressors of the disease (Lepore & Revenson, 2007). Hence, understanding the role of social support in limiting the effects of psychosocial distress is essential in addressing lung cancer stigma.

Conceptual Framework

Based on the conceptual model of *Stigma Induced Identity Threat* (Major and O'Brien, 2005), having a "consensually devalued social identity (stigma)" increases the likelihood that an individual will experience potentially stressful (identity threatening) situations (Major and O'Brien, p. 398). Three factors influence identity threat and the significance of an individual's appraisal of those factors: collective representations, situational cues, and personal characteristics (see Figure 4.1).

Collective representations are based on previous experiences and awareness of cultural norms that enable stigmatized groups to incorporate shared understandings of the dominant view of their position in society (Crocker, 1999; Crocker et. al., 1998; Steel, 1997). *Situational cues* and *personal characteristics* build on collective representations by reinforcing a lack of value, discrimination or negative stereotype. For example, anti-smoking media messages may reinforce negative stereotypes of one's group behavior (smoking) and the awareness that an evaluator (i.e., society, healthcare provider, patient support) is prejudice against one's group (lung cancer patient). The Model of Stigma-induced Identity Threat has been adapted to guide the study reported here to focus solely on the personal characteristics of stigma. Personal characteristics for this study included demographic factors such as age, sex, education and employment; social constraints, self-esteem, and smoking (Major and O'Brien, 2005).

The Model of Stigma-induced Identity Threat defines how having a stigmatized identity can lead to stress and stress-related health outcomes (Major and O'Brien, 2005). Threat is a situation that communicates the possibility of harm and having a stigmatized identity increases the individual's exposure to identity –linked stressors. Stigma-induced identity threat results from discrimination or other identity-related threatening situations leading to psychological, social and physical outcomes such as stress, anxiety, and depression (Major and O'Brien, 2005; Steele and Aronson, 1995; Salvatore, and Shelton, 2007). Identity threat occurs when an individual appraises demands (i.e., collective responses, situational cues, personal characteristics) imposed by a stigma-relevant

stressor as potentially harmful to their social identity and exceeds resources available to cope with those demands (Major and O'Brien, 2005). According to the model, volitional responses, such as seeking social support, influence our ability to cope by way of conscious cognitive processes to control emotion, perception, physical and behavioral responses to stressful situations or events.

The purpose of this study was to determine the relationship among personal characteristics and lung cancer stigma, and the effects of stigma on psychosocial distress (i.e., anxiety and depression) guided by an adapted Model of Stigma-Induced Identity Threat. The specific aims were to: 1) explore the relationships among social constraints, self-esteem, smoking and stigma; 2) determine the relationships of stigma with anxiety and depression, controlling for smoking and socioeconomic status (SES); and 3) determine if social support mediates the relationships between stigma and psychosocial distress. It was hypothesized that there would be a relationship among social constraints, self-esteem, smoking, and lung cancer stigma. It was also hypothesized that social support would mediate the relationships between stigma and psychosocial distress (i.e., depression and anxiety).

Methods

Design and Sample

This cross-sectional, descriptive study involved survey administration with a convenience sample of patients with lung cancer at the University of Kentucky Multidisciplinary Lung Cancer Clinic (UKMLCC) through the NCI-designated Markey Cancer Center. The study population included patients between the ages of 18 to 85 years of age and diagnosed with any stage non-small cell lung cancer (NSCLC) or small cell lung cancer (SCLC) within the past five years. Participants were required to be able to read and speak English and provide written documentation of consent. Approval was obtained from the medical Institutional Review Board. A total of 125 lung cancer patients were invited to participate; twenty-one (16.8%) declined to participate due to fatigue or poor health. The final sample comprised 104 patients.

Procedures

Lung cancer patients visiting the UKMLCC clinic were pre-identified and screened according to the inclusion/exclusion criteria using Sunrise Clinical Manager, the electronic medical record. A total of 125 patients were approached to participate between July and August 2014. Of these participants, twenty-one (16.8%) declined due to fatigue or poor health. A total of 104 patients were consented to take part in the study (participation rate = 83.2%). The university's medical institutional review board approved the study materials and procedures. With approval from clinic physicians, patients were pre-screened by diagnosis before approached by research staff. The survey was administered using REDcap (Research Electronic Data Capture) electronic data capture (Paul et al., 2009), a secure web-based application for building and managing online surveys and databases that is hosted by the university and facilitated by the researcher. Confidentiality was maintained by conducting all interviews in the clinic patient rooms where each question was read aloud to the patient by the research staff. Participants received a $10 gift card and a lung cancer awareness pin after completing the survey.

Measures

Lung Cancer Stigma

The identity threat variable in the adapted Model of Stigma-induced Identity Threat (Major and O'Brien, 2005) was defined as lung cancer stigma and measured using the 15-item, self-report *Lung Cancer Stigma Scale (LuCaSS),* an investigator-developed survey that adapted items from three existing measures of HIV stigma (Fife & Wright, 2000; Berger, et al., 2001; Emlet, 2005; Sowell et al., 1997). Items are rated on a 4-point Likert scale ranging from (1) 'strongly disagree' to (4) 'strongly agree'. Items are summed to generate a total score ranging from 15 to 60 with higher total scores indicating greater perceived stigma. Subscales include judgment/rejection, blame/guilt, and shame. For example: "I avoided getting treatment because someone might find out about my lung cancer (judgment/rejection);" "I feel I need to keep my lung cancer a secret (shame);" "I have been hurt by how people reacted to learning I have lung cancer (blame/guilt)." The Cronbach's alpha for the total LuCaSS in this sample was 0.89.

Psychosocial Distress

Depression and anxiety were measured using the 15-item PROMIS Depression and Anxiety Scale (DeWalt, et al., 2007; Cella, et al., 2007). The PROMIS initiative, part of the National Institutes of Health, developed, validated, and standardized item banks to measure patient reported outcomes pertinent across common medical conditions (Fries et al., 2005; Kelly, et al., 2010). These instruments measure frequencies of symptoms reflecting negative affect (depression scale) and autonomic arousal and threat (anxiety scale) in the past month.

The depression scale consists of eight items and the anxiety scale consists of seven items with strong psychometric properties. Items are rated on a 5-point Likert scale ranging from 1 (never) to 5 (always) and summed to generate a total score ranging from 8-40 for depression and 7 to 35 for anxiety. Higher scores indicate greater depression and anxiety. The Cronbach's alpha for depression was 0.91 and the Cronbach's alpha for anxiety was 0.93. A sample item for depression is: "In the past month I felt worthless;" for anxiety "In the past month I felt worried."

Personal Characteristics

According to the *Model of Stigma-Induced Identity Threat (*Major and O'Brien, 2005*)*, personal characteristics influence how situations are perceived and appraised. Personal characteristics included in the model adapted for the study reported here were social constraints, self-esteem, smoking, and demographics (see Figure 4.1).

The Social Constraints Scale (SCS) (Lepore, 1997) measured the social conditions or environments that cause trauma by discouraging expression of emotions. Participants were asked to respond to the 15-item SCS to assess social constraints related to disclosure about cancer. Responses for each item were rated on a 4-point Likert scale ranging from (1) 'never' to (4) 'often'. Total scores range from 15 to 60 with higher scores indicating greater social constraints. Sample items are: How often in the past month did your (family/friends) "change the subject when you tried to discuss your experience with cancer," "avoid you," and "give you the idea they didn't want to hear about your experiences with cancer." Cronbach's alpha for the SCS for this sample was 0.83.

Rosenberg Self Esteem is a widely used self-report instrument for evaluating individual self-esteem and is a measure of global self-worth for both positive and negative feelings about the self (Rosenberg, 1979). The construct was measured using the 10-item uni-dimensional scale. Responses are rated on a 4-point Likert scale ranging from (1) 'strongly agree' to (4) 'strongly disagree.' A total score is calculated as the average of the 10-items with ranges from 10 to 40. Sample items are: "I take a positive attitude toward myself" and "I feel I do not have much to be proud of." Being stigmatized may contribute to a lower self-esteem score and identity threat. Cronbach's alpha was 0.84 for this sample.

Smoking items were adapted from the Global Adult Tobacco Survey Collaborative Group (GATS, 2011). This survey is considered standard for monitoring a variety of tobacco related questions to assess current, former and never tobacco use (GATS, 2011). A total of 8 questions measuring smoking history such as age of tobacco initiation, advice to quit, and quit attempts were included. Current smoking is defined as the percentage of respondents who had smoked tobacco in the past 30 days; former smoker is defined as the percentage of participants who had ever smoked but who were currently not smoking; never smokers are those who had never smoked and not currently smoking. For mediation analysis, smoking status was categorized into 'current' versus 'former/never' smoker categories.

Demographic variables. Sex (male/female), age of participants (in years), marital status (married/cohabitating vs. widowed/divorced/separated vs. never married), ethnicity [(white vs. non-white (African American, Asian, Hispanic)], educational level [(high school graduate or less, some college or greater (less than 1 year, college degree, Bachelors/Masters/Doctoral degree)], annual income level ($30,000 or less, $31,000-59,999, $60,000 or greater, prefer not to answer), health insurance (private vs. Medicare/Medicaid) were assessed.

Social Support

Social support was selected as the volitional response variable, measured by *the Duke—UNC Functional Social Support Questionnaire (DUKE SSQ),* an 8-item self-report scale designed to measure satisfaction with available social support (Broadhead et al., 1988). Items were rated on a 5-point Likert scale ranging from 1 (much less than I

would like) to 5 (as much as I would like). Items are summed to create a total score ranging from 8 to 40 with higher total scores indicating greater social support. Sample items include: 'People care what happens to me…' and 'chances to talk to someone I trust about my personal and family problems,' with responses ranging from 'as much as I would like' to 'much less than I would like.' Cronbach's alpha for the Duke SSQ in this sample was 0.83.

Data Analysis

The study variables were summarized using frequencies (for categorical) or means with standard deviations (for continuous variables). Personal characteristics including, social constraints, self-esteem, smoking, demographics and lung cancer stigma (i.e., identity threat), and social support (i.e., volitional responses); and depression and anxiety were tested for bivariate associations using chi-square analyses for categorical variables and t-tests for continuous variables. Relationships between the personal characteristics and outcome variables were determined using the two-sample t-test, analysis of variance (ANOVA), and the Kruskal-Wallis test. Pearson's correlations were used to assess associations between continuous demographic and personal variables and the main outcome variables. Post hoc analysis was performed when the ANOVA indicated a significant group effect overall.

To test whether social support mediated the relationship between stigma and depression/anxiety (see Figure 4.2), multiple regression analysis was used following the four-step method described by Baron and Kenny (1986). For this study, the four steps to be satisfied before mediation could take place included ensuring that: 1) the predictor variable (stigma) was a significant predictor of the mediator variable (social support); 2) the predictor variable (stigma) was a significant predictor of the outcome variable (depression); 3) the mediator (social support) was a significant predictor of the outcome (depression); and 4) when both the mediator (social support) and the predictor (stigma) were included in the same regression as potential predictors of the outcome (depression), the latter was no longer significant. The Sobel test was performed to assess the statistical significance of the indirect effect of the mediator in each of the mediation models (Sobel, 1982).

The multiple regression standardized beta weights were used to summarize the direct and indirect effects of the predictor or mediator on the outcome as the direct effect (i.e., the regressions with just one independent variable) and the indirect effect of stigma on the outcome when the mediator was included in the regression. Each regression model contained the following demographic and personal characteristics as control variables: age, sex, smoking status (current vs. former/never), and employment status (retired/disabled vs. other). These control variables were chosen because they are the known demographic and disease-specific indicators that may be most closely aligned with the outcomes. All analyses were performed using the SPSS Statistics 22.0. An alpha level of .05 was used throughout the analysis (SPSS, 2009).

Results

Demographic Characteristics

Table 4.1 summarizes the characteristics of the sample. The sex of participants was approximately equally distributed (48% women). Participants were primarily white (86%), former smokers (67%), and married (57%), with a mean age of 61.9 (*SD* = 9.2) years. Sixty percent had a high school degree or less education. Most participants were either retired (41%) or unemployed/disabled (41%) and more than half had private insurance (57%). More than half of participants made less than $60,000/year (51%); nearly one in three preferred not to disclose annual income (28%).

Scale scores

The average score on the LuCaSS scale was 26.4, (*SD*= 6.7). The depression subscale score was 16.3 (*SD*=6.8); anxiety subscale score was 17.3 (*SD*=7.0). The social constraints scale was 22.2 (*SD*= 6.6); self-esteem scale score was 22.5 (*SD*=4.9), and the social support scale was 35.4 (*SD*=5.7).

Associations of social constraints, self-esteem, and smoking with stigma

Aim 1 was to examine the associations of social constraints, self-esteem and smoking with stigma (see Table 4.2). Controlling for SES variables, social constraints, self-esteem, and smoking status each significantly contributed to stigma. Social

constraints contributed 23%, self-esteem contributed 34%, and smoking status contributed 26% to stigma in the final model.

Association of stigma with anxiety and depression controlling for SES and smoking

For Aim 2, the relationships of stigma with anxiety and depression were examined (see Table 4.3). In the model without covariates, stigma was associated with depression (p=. 004) and anxiety (p=. 039). When controlling for SES and smoking, there was no longer a significant association between stigma and depression (p=. 229) or stigma and anxiety (p=. 128).

Test of social support as a mediator of the relationships of stigma with depression and anxiety

For Aim 3, a mediation analysis was conducted to test whether social support mediated the relationship of stigma with depression and anxiety (see Table 4.5). Social support was a strong mediator of the relationship between stigma and depression (Figure 4.2). However, social support was not a mediator of the relationship between stigma and anxiety, because stigma did not significantly predict anxiety.

Discussion

The first hypothesis was that there would be a relationship among social constraints, self-esteem, smoking, and lung cancer stigma. Indeed, lung cancer patients who reported greater social constraints, lower self-esteem, and who were current smokers scored higher on the stigma measure. Consistent with the literature, lung cancer patients experiencing stigma may also encounter greater social constraints and lower self-esteem (Badr, and Taylor, 2006; Else-Quest, et al., 2010; Cataldo, et al., 2011). Further, smokers experience more stigma than non-smokers (Chapple, et al., 2004; Gulyn & Youssef; 2010; Cataldo, et al., 2011).

Individuals who experience social constraints may avoid talking about cancer in an attempt to buffer against upsetting “intrusions” such as being blamed for their smoking behavior. The findings indicated that social constraints were significantly associated with stigma even after controlling for SES, social constraints, self-esteem, and smoking. Experiencing social constraints may be associated with stigma by directly

exposing the stigmatized to environments that limit access to supportive relationships and resources (Link & Phelan, 2001). However, supportive social networks can provide a context for cognitive processing of traumatic events utilizing verbal disclosure of thoughts and feelings, which can improve mental health (Lepore and Helgeson, 1998).

Stigma contributes to low self-esteem, can threaten a person's identity and varies as a function of personal characteristics (Crocker, 1999). In one study for example, pessimistic women who were exposed to persistent sexism experienced more threat appraisals and lower self-esteem than optimistic women (Kaiser, et al., 2004). Longitudinal and cross-sectional studies of individuals experiencing stigmatized identities have shown that stigma precedes reduced self-esteem in people with mental illness (Verhaeghe, et al., 2008), individuals with HIV (Fife and Wright, 2000), and in those with lung cancer (Fife and Wright, 2000; Else-Quest, et al., 2010; Cataldo, et al., 2011).

Lung cancer patients who smoke experience more stigma than non-smokers (Stuber, et al., 2008). The level of responsibility that a person assigns to their illness (i.e., smoking as a cause of lung cancer) determines the degree of perceived stigma (Falk, 2001). Controllable factors such as smoking, elicit greater negative reaction than from uncontrollable factors (Falk, 2001). Smokers are viewed more negatively and experience more self-blame than non-smokers (LoConte, Else-Quest, et al., 2008; Gulyn, & Youssef, 2010) due, in part, to the unintended consequences of smoke-free policies and anti-smoking campaigns (Stuber, et al., 2008; Fichtenberg & Glantz, 2002).

For the second hypothesis, social support mediated the relationship of stigma with depression. Social support was a strong mediator for predicting the effects of stigma on depression; when included in the model, social support changed the relationship between stigma and depression, suggesting that strong social support may decrease the negative effect of stigma on depression. Therefore, it is possible that in understanding depression among lung cancer patients, social support may lessen the impact of depression as a result of their feelings or experiences of being stigmatized. These findings are preliminary and need to be replicated to better understand the nature of the relationships between stigma, social support and depression.

Social support was not a mediator for predicting the effects of stigma on anxiety. There was not an observed relationship between the independent variable (stigma) and the dependent variable (anxiety). In the mediation model, the effects of stigma on anxiety were not significant, and social support was not a mediator of stigma and anxiety. This finding could be related to the time parameters on the anxiety survey instrument "in the past month" that may have influenced responses. Also, the data are cross-sectional and finding a convincing association may be more likely in a longitudinal design. It is possible that anxiety (feeling fearful, anxious, worried, nervous, uneasy, tense) could precede or contribute to stigma or perhaps social support is not the best mediator or volitional response. There may be other positive mediators, such as meditation or specific complimentary therapies that may impact the effects of stigma on anxiety. Future studies are needed to further examine the association between stigma and anxiety using robust data sets and longitudinal design.

Limitations

There are several limitations to this study. First, the non-probability sample did not fully represent the general lung cancer population**.** The sample was homogenous with respect to race and ethnicity, which limits generalizability to the broader lung cancer population. The sample size was small (n =104), although adequately powered based on preliminary power analysis calculations (Cohen, 1988). The age of the sample was slightly younger than the national average (62 years vs. 72 years) (ACS, 2012). There may have been some bias in that almost all interview responses were given aloud with a caregiver/family/friend in the room and this may have influenced the truthfulness in answering questions related to anxiety, social constraints and social support. Finally, lung cancer awareness has been growing steadily for the last eight years (Norris, 2015), which may have affected how the population perceives stigma or other variables such as patient support organizations and advocacy events affecting some of the main outcomes.

Future Research

Future psychometric testing of the LuCaSS is needed with a larger more diverse population. While the LuCaSS assesses perceived stigma of an individual diagnosed with lung cancer, studies are needed to examine differences in perceived stigma between

patient and caregiver. Further, research is needed to evaluate the feasibility and usability of implementing the LuCaSS as part of the clinical assessment when patients are initially diagnosed with lung cancer. If stigma can be identified early in the lung cancer diagnosis, interventions including social support can be developed and tested to minimize identity threat and psychosocial distress.

Other research implications may include exploring if lung cancer patients from counties/cities with smoke-free policy experience more stigma than those without a smoke-free policy. Anti-smoking and dangers of secondhand smoke messages may be more prevalent in smoke-free areas contributing to the societal view of smokers and lung cancer stigma. There may be opportunities to explore if interventions aimed at providing social support through advocacy can impact stigma outcomes.

Experiencing stigma can lead to psychosocial distress. Recognizing distress is one of the quality measures recommended by the Commission on Cancer (CoC), a program of the American College of Surgeons (ACoS), that recognizes cancer care programs for their commitment to providing comprehensive, high quality, and multidisciplinary patient centered care. The CoC is dedicated to improving survival and quality of life for cancer patients through standard setting and the monitoring of comprehensive quality care. Psychosocial Distress Screening (Standard 3.2) is a 2012 Standard and must be phased-in for 2015 (Commission on Cancer, 2012). All cancer programs will need to demonstrate that they screen patients diagnosed with cancer for distress. Through the CoC standards, the LuCaSS may help identify stigma that leads to psychosocial distress and can negatively impact the wellbeing of the lung cancer patient.

Conclusion

A lung cancer diagnosis can be associated with stigma and increased psychosocial distress (Else-Quest, et al., 2006; Chapple, et al., 2004; Cataldo, et al., 2011). The findings of the study reported here are consistent with the Model of Stigma Induced Identity Threat (Major and O'Brien, 2005) which states that having a stigmatized identity can be affected by social constrains, lower self-esteem, smoking and can lead to stress and stress-related health outcomes such as depression and anxiety (Major and O'Brien, 2005). To date, no other studies have applied the Model of Stigma Induced Identity Threat to lung cancer stigma research or tested whether social support mediated the

relationship between stigma and depression/anxiety. These findings specifically emphasize the need for healthcare providers to enhance social support for lung cancer patients in order to mitigate potential stigma and psychosocial distress. In addition, it is important to find a way to integrate stigma tools (i.e. LuCaSS) in practice settings when encountering lung cancer patients to determine potential stigma related distress. Finally, future studies are required to further examine the role of social support in the experience of stigma and psychosocial distress in lung cancer patients. Such studies can contribute to minimizing stigma induced identity threat among lung cancer patients.

Table 4.1. Sample Characteristics (*N*=104)

Characteristic	*n*	%
Sex		
Female	50	48.1
Male	54	51.9
Ethnicity		
White	89	85.6
Non-white	15	14.4
Education		
High school or less	62	59.6
Some college or greater	42	40.4
Marital status		
Married/Cohabitating	59	56.7
Widowed/Divorced/Separated	33	31.7
Never married	12	11.5
Employment		
Employed/Homemaker	18	17.3
Retired	43	41.3
Unemployed/disabled	43	41.3
Annual income		
Less than $30,000	37	35.6
$31,000 to $59,000	16	15.4
$60,000 or more	22	21.2
Prefer not to answer	29	27.9
Insurance type		
Private	59	56.7
Medicare/Medicaid	45	43.3
Smoking Status		
Never	12	11.5
Former	70	67.3
Current	22	21.2

Table 4.2. Association of Stigma with Each of Social Constraints, Self-Esteem, and Smoking, Controlling for SES

Variables	Estimated Beta	t	(p-value)
Social Constraints	.23	2.3	(.021)
Self-esteem	-.34	-3.3	(.002)
Smoking status (former/current vs. never smoker	.26	2.8	(.006)

Note: Final model controlling for sex, age, marital status, education, employment status, race and type of insurance.

Adjusted R^2 =. 25, F=4.2, df=10, p=<. 0001

Table 4.3. Association of Stigma with Each of Depression and Anxiety, Unadjusted for Covariates and Adjusted for SES and Smoking

Variable	Beta	t	(p-value)
LuCaSS Scale Score (unadjusted)			
Depression	.28	2.94	(.004)
Anxiety	.20	2.09	(.039)
LuCaSS Scale Score (adjusted for covariates)			
Depression	.12	1.21	(.229)
Anxiety	.18	1.53	(.128)

Note: Model for depression and anxiety were adjusted for SES and smoking status.

Adjusted model for depression, adjusted R^2 =. 27, F=5.02, p<. 0001); Adjusted model for anxiety, adjusted R^2 =. 05, F=1.53, p=. 149.

Table 4.4. Means, Standard Deviations and Correlations Among Predictor, Mediator and Dependent Variables (*N* = 104)

Variable	Variable type	Correlation (p-value)		
		Stigma	Social support	Depression
Stigma	Predictor			
Social Support	Mediator	-.32 (.001)		
Depression	Outcome	.28 (.004)	-.37 (<. 001)	
Anxiety	Outcome	.20 (.039)	-.26 (.008)	.73 (<.001)

Table 4.5. Test of Mediation for the Relationships of Stigma and Social Support as They Predict Depression and Anxiety (*N* = 104)*

1. Social Support mediates the effect of Stigma on Depression.

Predictor	*Potential mediator*	*Outcome*	*Std b for predictor*	*p-value*	*Sobel test p-value*
Stigma		Social support	-0.31	.003	
Stigma		Depression	0.20	.029	
Support		Depression	-0.26	.004	
Stigma	Support	Depression	0.11	.23	.020

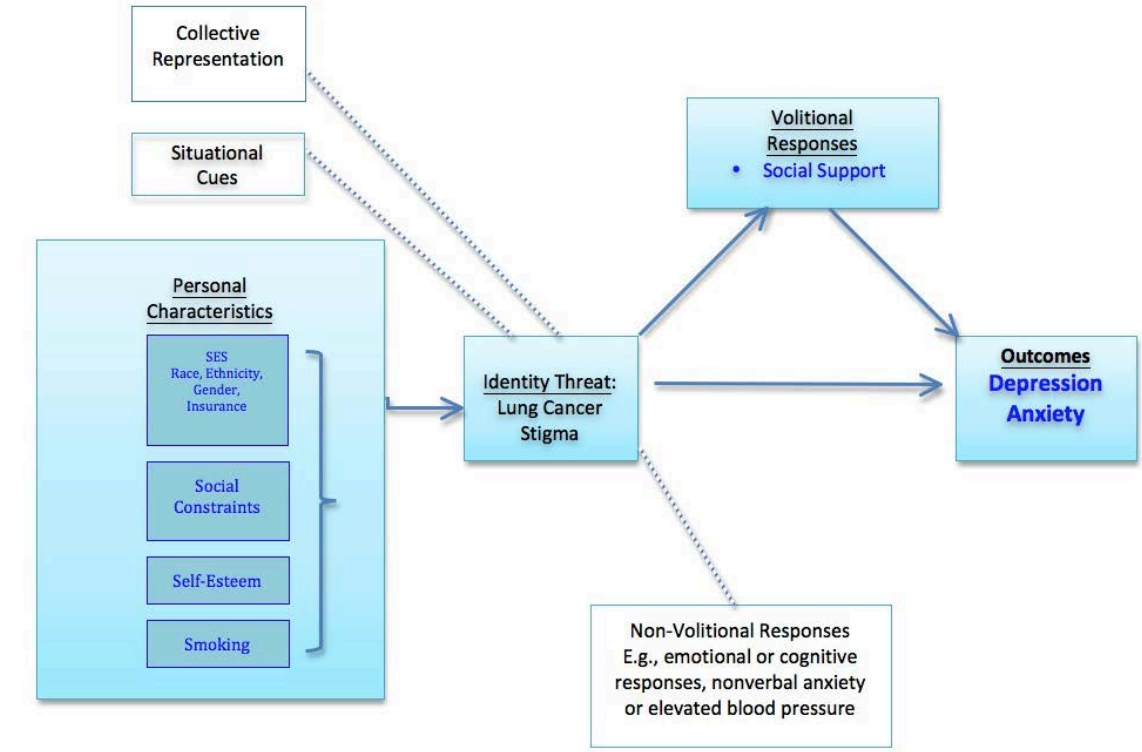
2. Social Support does not mediate the effect of Stigma on Anxiety.

Predictor	*Potential mediator*	*Outcome*	*Std b for predictor*	*p-value*	*Sobel test p-value*
Stigma		Social support	-0.31	.003	
Stigma		Anxiety	0.18	.086	
Support		Anxiety	-0.23	.025	
Stigma	Support	Anxiety	0.13	.25	.070

*Note – Covariates included in each model were: age, sex, employment status and current smoking status.

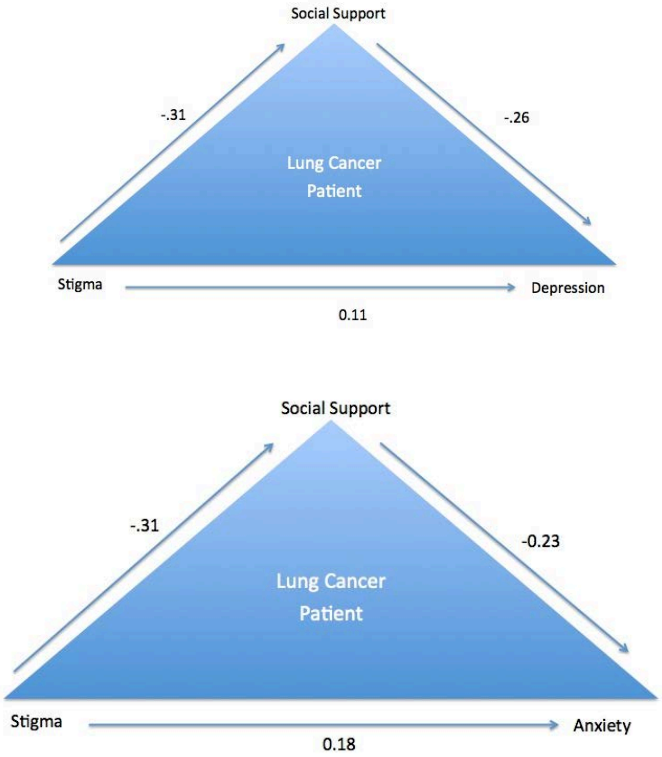
Figure 4.1 An Identity-Threat Model of Stigma in Lung Cancer

Figure 1. An Identity-Threat Model of Stigma in Lung Cancer*



Blue/Solid Line = represent model constructs tested in the proposed study.
* Adapted from A Model of Stigma-Induced Identity Threat (Major, B., O'Brien, L. 2005.)

Figure 4.2. Direct and Indirect Effects of Stigma on Depression and Anxiety.



CHAPTER FIVE

Conclusions

Three papers were presented in this dissertation: 1) "Stigma, Smoking and Lung Cancer: A Systematic Review of the Literature;" 2) "Lung Cancer Stigma Scale (LuCaSS): Measuring Perceived Stigma in People with Lung Cancer;" and 3) "Lung Cancer Stigma, Social Support, and Psychosocial Distress."

The first paper was a systematic review and the primary aims were to: a) explore the concepts of health-related stigma; b) describe the current status of lung cancer research funding and advocacy related to lung cancer stigma; c) explore the relationship between smoking stigma and lung cancer; and d) provide an overview of the Model of Stigma-Induced Identity Threat and the psychosocial effects of being stigmatized.

Stigma is a social process resulting in discrediting or devaluation of a person or group and exists as a means of social control and regulating behavior (Goffman, 1963). Stigma is most likely to exist among people with diseases linked to controllable causes such as smoking (Falk, 2001), prompting less empathy and more blame (Chapple, et al., 2004; Gulyn and Youssef, 2010) compared to other diseases with a less known cause. Smoking represents the primary cause of lung cancer and is related to growing negative public perceptions that unintentionally result in stigma against lung cancer patients (Fichtenberg and Glantz, 2002; Stuber, et al., 2008). As a result, lung cancer patients are often viewed as responsible for or deserving of their disease regardless of their smoking status and they may experience higher levels of cancer-related stigma than patients with other cancers (Stuber, et al., 2008)

The stigma experienced by many lung cancer patients negatively impacts psychological adjustments and interpersonal communication. The *Model of Stigma-Induced Identity Threat* explains how stigma "threatens a person's identity," or their self-concept and is associated with greater distress, poorer psychological adjustment (Major and O'Brien, 2005), and limited use of support services (Morse, et al., 2008; Carter-Harris et al., 2014). Lung cancer stigma as "identity threat" may have influenced the lag in appropriate research funding and advocacy related to lung cancer, limiting advances in better prevention, treatment, and survival (Knapp-Oliver and Moyer 2012). The *Model of*

Stigma-Induced Identity Threat was adapted to guide research described in the second and third papers.

The second paper was a psychometric analysis of the Lung Cancer Stigma Scale (LuCaSS), developed by the investigator to assess perceived stigma in lung cancer patients and address the void in brief measures currently available. The purpose of this study was to describe the development of an investigator-developed instrument, "Lung Cancer Stigma Scale" (LuCaSS) and evaluate its psychometric properties by: 1) describing the internal consistency of the LuCaSS; and 2) assessing the construct validity of the instrument through principle components analysis (PCA).

There is convincing scientific evidence that lung cancer patients experience stigma and are at high risk for psychosocial distress (Chapple, et al., 2004; Cataldo, et al., 2011; Else-Quest, et al., 2009). The development of this instrument was adapted from those known to measure HIV stigma (Berger, et. al. 2001; Fife & Wright, 2000; Emlet, 2005; and Sowell et al., 1997). The LuCaSS was found to be a reliable and valid instrument measuring lung cancer stigma. Three subscales measuring internalized stigma were identified: social rejection/judgment, blame/guilt, and shame. Testing instruments that assess stigma assist in understanding the salient constructs associated with stigma and are necessary to test interventions that may minimize stigma experienced by lung cancer patients.

The third paper investigated lung cancer stigma, social support, and psychosocial distress using the adapted Model of Stigma-Induced Identity Threat. Because lung cancer is closely associated with smoking, society often blames lung cancer patients (Gulyn and Youssef, 2010; Ritchie, et al., 2010; Chapple, et al., 2004). This may affect interactions with all lung cancer patients, regardless of their smoking status, creating psychosocial distress (Chapple, 2004; Gonzalex and Jacobsen, 2010; Cataldo, et al., 2011; Johnson, et al., 2014) and denying them the social support routinely provided to those with other cancer diagnoses (Badr, and Taylor, 2006; Else-Quest, et al., 2009; LoConte, et al., 2008).

The purpose of this study was to determine the relationship among personal characteristics and lung cancer stigma, and the effects of stigma on psychosocial distress (i.e., anxiety and depression) guided by an adapted Model of Stigma-Induced Identity

Threat. The specific aims were to: 1) explore the relationships among social constraints, self-esteem, smoking and stigma; 2) determine the relationships of stigma with anxiety and depression, controlling for smoking and socioeconomic status (SES); and 3) determine if social support mediates the relationships between stigma and psychosocial distress. It was hypothesized that there would be a relationship among social constraints, self-esteem, smoking, and lung cancer stigma. It was also hypothesized that social support would mediate the relationships between stigma and psychosocial distress (i.e., depression and anxiety).

A convenience sample of lung cancer patients (N = 104) were recruited from the University of Kentucky Multidisciplinary Lung Cancer Clinic (UKMLCC) through the NCI-designated Markey Cancer Center. Participants were surveyed in a cross-sectional study to explore the relationship among social constraints, self-esteem, smoking, and lung cancer stigma. Social support was also investigated as a mediator in the relationships between stigma and psychosocial distress (depression and anxiety). Lung cancer patients who reported greater social constraints, lower self-esteem, and who were current smokers scored higher on the stigma measure. Social support may be a meaningful coping strategy and was found to be a strong mediator for predicting the effects of stigma on depression but not anxiety. The findings are consistent with the Model of Stigma Induced Identity Threat, having a stigmatized identity can lead to stress and stress-related health outcomes such as depression.

Future Research and Practice Implications

Future studies are needed to advance understanding of lung cancer stigma and the effects on patients and their caregivers, as well as to develop and test interventions to minimize stigma in this high-risk population. Although the LuCaSS developed and tested in this dissertation was found to be a reliable and valid tool, future research is warranted to compare the LuCaSS with other newly designed measures of lung cancer stigma (i.e. Cataldo et al., 2011) to establish criterion related validity. Additional psychometric testing is also needed to test the LuCaSS with a larger more diverse population. The LuCaSS assesses an individual's perceived stigma when they are diagnosed with lung cancer. Differences in perceived stigma between healthcare providers, and caregivers could also be examined. The LuCaSS could also be evaluated for feasibility and usability

as part of the clinical assessment when patients are initially diagnosed with lung cancer. Implementing the LuCaSS to identify perceived stigma could, in part, satisfy the Commission on Cancer (CoC) psychosocial distress screening standard for quality measures.

Future research is also needed to explore if lung cancer patients from counties/cities with smoke-free policy experience more stigma than those without a smoke-free policy. If this is determined, clinical settings and public health organizations could partner to develop and test interventions to minimize stigma in these communities. The findings from this study specifically emphasize the need for healthcare providers to enhance social support for lung cancer patients to mitigate potential stigma and psychosocial distress. Further, the impact of advocacy events (e.g., lung cancer walks/runs) and/or other interventions designed to provide social support could be tested to examine whether participation in these events might diminish the effects of stigma on depression in lung cancer patients. In addition, future studies are required to further examine the role of social support in the experience of stigma and psychosocial distress in lung cancer patients. Such studies can contribute to minimizing stigma induced identity threat among lung cancer patients.

Finally, stigma in lung cancer occurs, in part, as an unintended consequence of smoke-free policies and antismoking campaigns. Some may question if it is ethical to stigmatize smokers in order to change behavior and social norms associated with smoking? Although the ethical considerations have been argued (Bayer, 2008; Burris, 2008), the more appropriate question is what can be done to minimize stigma? If the goal is to decrease the effects of smoking related stigma on lung cancer patients, strategies learned from other stigmatized health conditions could be developed and tested to reduce lung cancer stigma (Berger et al., 2005). For example, to lessen the stigma associated with lung cancer stigma, it is important to cast the disease as treatable. When there is fear associated with the disease due to limited treatment and survival, there is greater stigma (Goffman, 1963; Falk, 2001).

Some advances in lung cancer prevention, early detection and treatment are being made. Early detection and prevention continue to be addressed through tobacco treatment (Fiore, 2008), smoke- and tobacco-free policy (Callinan, et al. 2014), and early detection

through low dose CT screening (Wood, et al., 2012). Early detection and screening for lung cancer may provide the “hope” necessary to identify “at risk” patients and lead to improved survival rates for lung cancer patients. Other advances in treating lung cancer that are making a small impact on survival include the identification of actionable mutations and discoveries of newer targeted therapies (Johnson and Schiller, 2014).

Although there have been some advances in prevention and treatment, the challenges for lung cancer patients are still enormous. Lung cancer is severely underfunded in both the public and private sectors. The two main factors contributing to underfunding lung cancer research are stigma and the dismal 5-year survival rate (Knapp-Oliver and Moyer, 2012), which hasn’t changed in 40 years (13% in the 1970’s versus 17% in 2013) (SEER, 2013). The poor survival rate affects the number of survivors available to advocate for awareness and adequate funding for better treatments. Unless these factors are addressed, efforts to improve the lives of lung cancer patients and impact survival may not be attainable.

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2007- 2010	Genentech Bio Oncology HER Family Herceptin/Tarceva	Sr. Oncology Clinical Coordinator, II
2004- 2007	University of Kentucky College of Nursing, Lexington, KY	Faculty, Public Health Course Coordinator & Tobacco Policy Research
1999-2007	University of Kentucky College of Nursing, Lexington, KY	Research Assistant/ Project Coordinator, Tobacco Policy Research Program
1992-1998	Caretenders of the Bluegrass Lexington, Kentucky	Patient Care Liaison Marketing & Sales
1990- 1993	Central Baptist Hospital Lexington, Kentucky	Staff Nurse Surgical Intensive Care
1990- 1993	Healthcare and Nursing Consultants, Lexington, Kentucky	Health Education

Scholastic and professional honors

Year	Honors
2013	OCC North East Essence Award, Genentech BioOncology
2013	Choosing Growth Award, Bio-oncology poster submission
2012	Jenny McDevitt Award, Community Service
1998	Leadership Bluegrass, Leadership Development Program
1993	Nominated "Outstanding Nursing Commonwealth of Kentucky" Award, KNA
1990	Clinical Excellence Award in Nursing, Eastern Kentucky University

Professional Publications

Butler, K., Rayens, MK., Zhang, M., **Greathouse Maggio, L**., Riker, C., Hahn, E. (2009). Tobacco dependence treatment education for Baccalaureate nursing students. Journal of Nursing Education, 48 (5), 249-254.

Hahn, J., Riker, C., Butler, K., Cavendish, S., Lewis, P., **Greathouse-Maggio, L**., Nunley, V. (2007). Enforcement of tobacco purchase, use, and possession laws in four Kentucky communities. Policy, Politics, and Nursing Practice, 8 (2), May 2007, 140-147.

Rayens, M.K., Hahn, E.J., Langley, R., Hedgecock, S., Butler, K., & **Greathouse-Maggio, L.** (2007). Public opinion and smoke-free laws. Policy, Politics & Nursing Practice, 8(4), 262-270.

Greathouse, L.W., Hahn, E.J., Okoli, T.C., Warnick, T.A., Riker, C.A. (2005) Passing a smoke-free law in a pro-tobacco culture: A multiple streams approach. Policy, Politics, and Nursing Practice, 6 (3), 211-219.

Hahn, EJ, Rayens, MK, **Greathouse-Maggio, L**, Robertson, H, Peiper, N, Pasley, G, Okoli, C, Hedgecock, S, Cavendish, S, Lee, S, McGee, J, (2006) Secondhand Smoke and Smoke-free Policy. http://www.mc.uky.edu/tobaccopolicy.

Lisa Maggio

Signature