HEALTH-RELATED STIGMA IN ADVANCED LUNG CANCER

By

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Dedicated to my Mom and Bob

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CHAPTER 1

INTRODUCTION

With the advent of new therapies for lung cancer, patients with advanced disease have seen an improvement in survival after a diagnosis (Ramalingam, 2011). In 2015, however, nearly 158,040 people will still die from lung cancer (American Cancer Society, 2015) because approximately 50% of patients are diagnosed at an advanced stage of the disease (Ramalingam, 2011). Because of improvements in survival time of patients with advanced lung cancer, it is imperative to investigate potential problems and issues specific to this population.

Health related stigma (HRS) is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem (Weiss & Ramakrishna, 2006). HRS can be classified as internal or external HRS. A patient with internal HRS will blame herself or identify herself as the cause of the disease. For example, a patient with lung cancer may believe she caused her diagnosis by smoking. External HRS is directed at the patient from an outside source such as a healthcare provider, family caregiver, or someone from the general public. In external HRS, the outside source identifies the patient as the cause of his disease. Although almost all patients with cancer were once highly stigmatized due to their diagnosis, patients with certain types of cancers no

longer face the stigmas they once did. Patients who have cancers associated with certain lifestyle choices, such as lung or cervical cancer, however, continue to draw perceptions of blame and stigma. In these cases the disease is more prone to be seen as a reflection of personal responsibility (Marlow, Waller, & Wardle, 2010). Little is known about how internal or external HRS influences patients with advanced lung cancer. We do know, however, in an HIV/AIDS population HRS influences a patient's overall quality of life (QOL) (Buseh, Kebler, Stevens, & Park, 2008). HRS related to HIV/AIDS negatively influences psychological outcomes of patients and this influence is independent of health status or disease related symptoms (Clark, Linder, Armistead, & Austin, 2003; Kang, Rapkin, Remien, Mellins, & Oh, 2005; Lee, Kochman, & Sikkema, 2002). In an HIV population, HRS in family and healthcare settings caused more psychological damage than HRS from other social support settings (Slutterheim et al., 2009). As the number of intense and graphic anti-smoking campaigns increase, stigma associated with smoking as well as diseases linked to smoking may also increase and may have a negative impact on patients who suffer from these diseases (Marlow, et al., 2010).

Statement of Problem

The problem of interest is internal and external HRS in patients with advanced lung cancer. We know that HRS has a negative influence on multiple outcomes of patients with HIV/AIDS including psychological outcomes and QOL (Buseh, et al., 2008; Clark, et al., 2003; Kang, et al., 2005; Lee, et al., 2002; Slutterheim, et al., 2009). Internal and external HRS may also have negative effects on patients with advanced

lung cancer. It has been shown that 30% of lung cancer patients blame themselves for their diagnosis (internal HRS) (LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). It remains unclear how lung cancer patients perceive external HRS related to their disease. For this reason, there is a need to further investigate the role of HRS in patients with advanced lung cancer to determine if it influences physical symptoms, psychological symptoms, social support, QOL. Because limited research studies exist regarding HRS in advanced lung cancer there is a need to (1) examine the significance of internal and external HRS within the population, (2) examine the relationship of HRS to psychological and physical outcomes, and (3) examine the relationship of HRS to perceived social support and QOL.

Purpose of the Study

The purpose of this dissertation study is to examine the relationship of internal and external HRS to physical symptoms, psychological symptoms, social support, and QOL in patients with advanced lung cancer. The specific aims for the proposed study include:

1. To examine the relationship between internal and external HRS, physical symptoms, psychological symptoms, social support, and QOL in patients with advanced lung cancer.
2. To examine the associations between physical symptoms and social support, and QOL in patients with advanced lung cancer.
3. To examine the associations between psychological symptoms and social support and QOL in patients with advanced lung cancer.

Research Question

1. What are the associations between internal and external HRS and (a) symptoms, (b) social support, and (c) QOL in patients with advanced lung cancer?
2. What are the associations between physical symptoms and (a) social support and (b) QOL in patients with advanced lung cancer?
3. What are the associations between physical symptoms and (a) social support and (b) QOL in patients with advanced lung cancer?

Significance of the Issue to Society

Significance to Society

Incidence of Lung Cancer in the United States

Cancer is the second leading cause of death in the United States, (American Cancer Society, 2015; Xu, Kochanek, Murphy, & Tejada-Vera, 2010) and the chronicity of terminal cancer care is a significant stressor for the entire family unit (Sydney, Compas, Epping-Jordan, & Worsham, 1999). In 2015, approximately 1,668,370 new cases of cancer will be diagnosed in the United States and approximately 589,430 Americans will die from their disease (American Cancer Society, 2015). Cancer now accounts for nearly 1 out of every 4 adult deaths in the United States (American Cancer Society, 2015).

Lung cancer is the second most common cancer and the leading cause of cancer-related deaths in the United States (American Cancer Society, 2015). In the United States approximately 224,210 new cases of lung cancer will be diagnosed in 2015 and

approximately 159,260 patients will die (American Cancer Society, 2015). The 5-year relative survival rate of patients with lung cancer is 3.7% (American Cancer Society, 2015). In 2015, lung cancer will be the leading cancer diagnosis in Tennessee (American Cancer Society, 2015). Of the 6,200 people diagnosed with lung cancer in Tennessee, 4,600 will die from their disease (American Cancer Society, 2015).

Lung Cancer and Health Related Stigma

HRS associated with a diagnosis lung cancer has been established (Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Chapple, Ziebland, & McPherson, 2004), and when compared to other types of cancer, one study showed that lung cancer patients have more externally perceived HRS than those with other types of cancer (LoConte, et al., 2008). People who engage in behaviors that may contribute to their cancer diagnosis experience an increase in negative attitudes and more severe consequences of external HRS (Lebel & Devins, 2008). Because smoking is viewed as a contributing yet controllable factor of lung cancer, these patients may face more external HRS than patients with other types of cancer or diseases (Lebel & Devins, 2008). Self-blame attributions (internal HRS) have been found to be similar for a diagnosis of lung cancer or HIV (Greene & Banerjee, 2006).

Both smokers and non-smokers feel stigmatized after of a diagnosis of lung cancer (Cataldo, et al., 2011; Chapple, et al., 2004) which can lead to a fear of rejection, limited social support, increased depression, difficulty adhering to treatment plans, and general poor health (Chambers, 2012). Lung cancer patients have reported their diagnosis has negatively affected their relationship with their family and friends as well as interactions with the medical community (Chapple, et al., 2004). Patients who stopped smoking and

those who never smoked felt unjustly blamed for having the disease and some patients conceal a diagnosis from loved ones, negatively affecting potential support from family and friends (Chapple, et al., 2004).

Regardless of smoking status, stigma associated with a lung cancer diagnosis is related to an increase in depressive symptomology. As perceived stigma increased, the levels of depressive symptomology increased (Gonzalez & Jacobsen, 2010). Stigma has also shown a unique statistical contribution to depressive symptoms (Gonzalez & Jacobsen, 2010). Cataldo, Jahan, and Pongquan (2011) had similar results. The perception of stigma also had a negative impact on overall QOL of lung cancer patients.

Patients and caregivers attribute the cause of lung cancer to the patient with a history of smoking (Lobchuk, 2008), and caregivers feel more anger and attribute more blame when a patient continues to smoke after a diagnosis (Lobchuk, 2012). Negative emotions and blaming behaviors may cause caregivers to feel less empathy for their loved one and engage in fewer care activities (Lobchuk, 2012). Lack of appropriate caregiving at home is problematic for patients with advanced lung cancer due to the high number of physical and psychological symptoms experienced in this population. Because the majority of care for these patients is provided at home by a lay caregiver, it is imperative to investigate if patients perceive a stigma from their primary caregiver so that clinical interventions can be designed to intervene when there is a problem.

Summary

Regardless of smoking status, patients with lung cancer feel stigmatized because of their disease. At this time, relatively little information is available on how HRS may influence the overall experience of patients with lung cancer. Although we know stigma

increases depressive symptoms in lung cancer, we do not know if internal or external HRS is the most influential type of stigma or if HRS has other negative or preventable effects in patients with lung cancer. We know that some caregivers blame the patient for their diagnosis and this may impact care provided at home. For this reason, we need to clarify how patients perceive stigma from their primary caregiver.

Physical Symptoms

Multiple factors influence cancer patient symptoms. Patients with lung cancer typically present with the same physical symptoms regardless of histology (Hopwood & Stephens, 1995). Higher symptom distress is associated with both late stage as well as recurrent disease (Degner & Sloan, 1995; Sarna, 1993). and treatment modality has the greatest impact on the symptom experience (Nuamah, Cooley, Fawcett, & McCorkle, 1999; Tishman, Taube, & Sachs, 1991). In lung cancer patients, chemotherapy and comorbidities, especially respiratory conditions, have been shown to increase physical symptom burden and symptom distress (Sarna, 1993). Several demographic factors appear to be associated with symptom presentation in the lung cancer population including age(Degner & Sloan, 1995), female gender (Degner & Sloan, 1995), and African American race(O'Hare, Malone, Lusk, & McCorkle, 1993).

One study suggests that lung cancer patients experience more symptoms and have a higher symptom distress than patients with other types of cancer (Degner & Sloan, 1995). Symptom severity typically increases as the disease progresses (M. Cooley, 2000) and symptom distress has been shown to predict survival in lung cancer patients (Degner & Sloan, 1995). The most commonly reported lung cancer symptoms are: fatigue, dyspnea, cough, weight loss, anorexia, pain, insomnia, mental status changes,

and psychological distress (M. Cooley, 2000; Yount et al., 2011). The most distressing symptoms for lung cancer patients are difficulty breathing, pain, and fatigue, with difficulty breathing identified as the most distressing symptom over time. Fatigue, however, is the most intense symptom experienced by lung cancer patients (Tishman et al., 2005). At this time it is unknown if HRS influences the experience of symptoms in patients with lung cancer.

Symptom burden within this population is high (M. E. Cooley, Short, & Moriarty, 2003). Because symptoms progress as the disease progresses, it is of particular importance to appropriately and adequately manage symptoms in lung cancer patients (M. Cooley, 2000). In a comparison study, all subgroups of lung cancer patients had a high prevalence of reported symptoms, but the subgroup closest to death reported a higher intensity of symptoms than other groups (Tishman, Petersson, Degner, & Sprangers, 2007). The increase in symptom intensity as the disease progresses indicates the goal of treatment is proactive management of symptom burden and improved QOL for this population (Yount, et al., 2011).

Summary

Patients with lung cancer experience an extremely high number of symptoms. Most patients are diagnosed with late stage disease, which has been associated with a higher symptom burden. Patients with lung cancer may also experience more symptom distress than patients with other types of cancer.

Psychological Distress and Psychological Symptoms

Psychological distress, depression, and anxiety have been studied in oncology populations. Psychological distress is a discomforting and emotional state that has the

potential to temporarily or permanently harm an individual (Ridner, 2004). Anxiety and depression are the most commonly studied psychological symptomology and are thought to be the most prevalent disorders diagnosed within the oncology population (Maguire, Julier, Hawton, & Bancroft, 1974). In patients with advanced cancer these disorders are often under diagnosed leading to decreased QOL for patients and their family caregivers (Delgado-Guay, Parsons, Li, & al., 2009).

Patients with lung cancer have been shown to have the highest rates of psychological distress when compared to other cancer sites (Tagay et al., 2006; Wilgen, Dijkstra, Stewart, Ranchor, & Roodenburg, 2006; Zabora, Brintzehofeszoc, Curbow, Hooker, & Piantadosi, 2001). Regardless of age, over or under 65, lung cancer patients report similar levels of psychological distress (Turner, Muers, Haward, & Mulley, 2007).

Prevalence in advanced cancer populations may be as high as 29% for depression (Hotopf, Chidgey, & Addington-Hall, 2002) and 44% for anxiety (Delgado-Guay, et al., 2009). The prevalence of combined depression and anxiety in a lung cancer population has been estimated at 21% (Hopwood & Stephens, 2000). The presence of anxiety and depression has been shown to significantly impair QOL in patients with lung cancer (Montazeri, Milroy, Hole, McEwen, & Gillis, 1998) but healthcare providers routinely address physical illness symptoms more frequently than psychosocial symptoms.

Anxiety is frequently identified in newly diagnosed cancer patients although prevalence varies widely within the literature (Stark & House, 2000). Prevalence rates in a lung cancer population have been reported to be as high as 34%, with 17% of those having a severe anxiety (Hopwood & Stephens, 2000).

Severe depressive symptomology has been associated with a diagnosis of lung cancer (Montazeri, et al., 1998). Prevalence rates in a lung cancer population have been estimated at 33% (Hopwood & Stephens, 2000).

Several factors, including social functioning, symptom severity, and radiation treatment, have been shown to predict depressive symptomology in lung cancer patients (Kurtz, Kurtz, Stommel, Given, & Given, 2002). Patients with more restricted social interaction and a high level of symptoms had the highest rates of depressive symptoms and those who did not receive radiation had more depressive symptoms (Kurtz, et al., 2002). Statistically significant relationships have also been found between depression and the following physical symptoms: tiredness, breathlessness, cough, general pain, and chest pain (Hopwood & Stephens, 2000). Factors found to independently influence depression in a lung cancer population are 1) functional impairment and 2) physical symptom burden (Hopwood & Stephens, 2000).

Summary

Patients with lung cancer often experience high rates of depressive and anxiety symptoms and psychological distress may be more common in lung cancer than in any other type of cancer. HRS has been shown to increase the probability of depressive symptoms in lung cancer patients but no link between stigma and anxiety or psychological distress has been shown at this time. Furthermore, it is still unclear if internal or external stigma is the influencing factor in depressive symptomology.

Lung Cancer Patient Quality of Life

Initiating care to maintain or improve QOL is an important part of managing advanced lung cancer. Survival is limited by the disease process and patients have an extremely high physical and psychological symptom burden (Buccheri, 1998).

In general, patients with lung cancer have low QOL scores (Akin, 2010). QOL scores have shown improvement in advanced lung cancer patients who receive chemotherapy (Bozcuk, 2006). Age and QOL prior to chemotherapy have been shown to be predictors of QOL in patients with advanced lung cancer who receive chemotherapy (Bozcuk, 2006). Additionally, QOL is influenced by how manageable patients perceive their disease to be (Downe-Wambolt, 2006).

Summary

Patients diagnosed with late stage lung cancer continue to face difficulty maintaining a good QOL, especially during the last few months of life. Because treatments are now able to extend the life of more patients with advanced disease, it is important to find ways to maintain or improve QOL in patients who are non-curable.

Social Support

Three main types of social support interactions are: emotional support, informational support, and instrumental support (House, 1981; House & Kahn, 1985; Kahn & Antonucci, 1980). The perception of emotional support from family is associated with better social and emotional adjustment (Zemore & Shepel, 1989) and one study identified emotional support as the most helpful type of social support if present and the most damaging if absent (Dakof & Taylor 1990). For women with advanced breast cancer, the perception of emotional support from family was linked to a more favorable

outlook (Bloom & Spiegel, 1984). Informational support was most helpful from a physician and harmful if lacking in the clinical setting (Dakof & Taylor, 1990). Instrumental support was important for patients with a poor prognosis (Dakof & Taylor, 1990).

The lay public has misconceptions about the social support needs of cancer patients (Peters-Golden, 1982). Healthy controls wanted to “cheer up” the patients while patients said the “unrelenting optimism” of others was disturbing. When friends avoid the patient, however, this is particularly harmful to perceptions of support (Dakof & Shelley, 1990). Emotional support is positively correlated with reduced distress during the initial diagnosis of cancer and predicted survival in female breast cancer patients with local disease (Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992).

The psychosocial needs of patients with lung cancer remain relatively unknown (Carlsen, Jensen, Jacobsen, Krasnik, & Johansen, 2005) We do know they have many unmet supportive care needs (Hill, Amir, Muers, Connolly, & Round, 2003; Li & Girgis, 2006; Sanders, Bantum, Owen, Thorton, & Stanton, 2010) including social support and emotional and physical support needs. Among patients with lung cancer, those with the highest amount of unmet social support needs have the highest physical symptom burden and psychological distress (Sanders, et al., 2010). For patients with lung cancer, this means that those who suffer the most and who need the most help are not receiving adequate support. Limited studies show social support in the lung cancer population has been associated with a relief from depressive symptomology and non-directive instrumental support has been linked with better adaptation to a lung cancer diagnosis (Walker, Zona, & Fisher, 2006). The impact of social support on QOL in a

lung cancer population is unclear (Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007).

Summary

Little is known about the social support needs of patients with lung cancer. Benefits of social support have been seen in other cancer populations, and social support may also be beneficial to patients with lung cancer. Stigma, however, may strongly influence the amount and types of social support these patients receive. It is unclear if stigma has a negative influence on social support within this population.

Cost to Patients, Caregivers, and Society

Financial costs. Among all cancers, lung cancer carries one of the largest national expenditures. Approximately $10.32 billion dollars are spent on lung cancer treatments annually (National Cancer Institute, 2010). The majority of this cost occurs during the initial care phase and last year of life (National Cancer Institute, 2010). A relatively small portion of the total cost of lung cancer care occurs during the continuing care phase because of the short life expectancy for the majority of lung cancer patients.

The number of patients with lung cancer who are diagnosed at stage IIIB or stage IV and who receive chemotherapy has increased regardless of age (Surveillance Epidemiology and End Results (SEER) Program, 2011). The greatest percentages of expenditures for the care of lung cancer occurs in the first year after diagnosis and includes hospitalizations (33.6%) and other services (26.1%) not related to cancer treatment (Warren et al., 2008) which can be attributed to the high incidence of symptoms these patients experience compared to other types of cancer.

Other costs. Cost of treatment is not the only expense to patients and their caregivers facing a lung cancer diagnosis. The burden of cancer, or caring for a loved one with cancer, has a high psychological, emotional, and physical toll. Lung cancer has the greatest loss of revenue for loss in time and economic productivity when compared to all other cancer sites (Bradley et al., 2008). The loss of productivity for lung cancer patients has been estimated at $36.13 billion dollars each year. The next highest loss of productivity is for breast cancer, and is estimated at $12.10 billion dollars annually (Bradley, et al., 2008).

Despite the obvious high economic burden of lung cancer in the United States and the fact that more Americans die from lung cancer every year than any other type of cancer, research on the disease from the NIH lags behind other types of cancer. In 2010, $281.9 million dollars was awarded from NIH for lung cancer research compared to $631.2 million for breast cancer and $300.5 million for prostate cancer (National Cancer Institute, 2010).

Significance to Healthcare

Decrease Cost of Medical Care

The majority of expenditures for lung cancer are hospitalizations and services rather than treatment related cost (Warren, et al., 2008). Compared to other types of cancer, more money is spent within the healthcare system for other necessary hospitalizations in lung cancer than in any other type of cancer (Warren, et al., 2008). Hospitalizations take an enormous amount of resources including physical space, medical staff, use of medical equipment, and supplies. Improved care options for lung

cancer patients may decrease the cost to the health care community by decreasing the amount of resources required per patient.

Improved Palliative Care

Both private and public health arenas have a vested interest in improving care for patients with advanced disease and their caregivers because of the high caregiver burden, the effect on personal and national financial resources, and the impact on the healthcare system. In order for patients and their families to achieve optimal outcomes there is a need for access to alternative supportive care programs that offer physical and emotional support for advanced cancer populations (Mazanec et al., 2009) Recommendations have been set forth by both the World Health Organization (World Health Organization, 2007) and the National Consensus Project for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2009) to integrate palliative care with oncology care services from the time of a terminal diagnosis through death. A recent study published in the *New England Journal of Medicine* (Temel et al., 2010), demonstrated that patients receiving early palliative care as an integral component of their oncologic care had improved QOL, fewer depressive symptoms, and increased survival. Of note, patients receiving palliative care services used less "inappropriately aggressive" end-of-life care as defined by American Society of Clinical Oncology (ASCO) quality parameters.

Significance to Nursing

The American Nurses Association (ANA) defines nursing as "the protection, promotion, and optimization of health and abilities, prevention of illness and injury,

alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations" (American Nurses Association, 2011). For patients with lung cancer, nurses promote interventions that prevent or treat symptoms and act as advocates to connect patients with important resources in the community such as support groups, nutrition support, or social work.

Nurses frequently collaborate with other healthcare professionals. They assess for problems and coordinate care as well during the administration of chemotherapy. Nurse practitioners also serve as an important role by diagnosing and managing symptoms associated with disease and treatment.

The Oncology Nursing Society (ONS) identifies the unique and significant involvement that nurses provide to oncology (Oncology Nursing Society, 2009). In addition to patient care, nurses also contribute substantially to the advancement of research. The 2009 – 2013 ONS research agenda identifies several areas as priorities for oncology nursing research including an in-depth understanding for cancer related symptoms. End of Life (EOL) is also a priority research area for ONS and is particularly relevant within a lung cancer population due to the high mortality associated with the disease. The primary EOL research focus includes expanding the understanding of symptoms and symptom management for EOL patients and promoting and improving QOL for both patients and their families facing EOL. Finally, ONS recognizes the importance of research in the area of psychosocial and family issues. Research in this area is to include reducing negative outcomes, such as depression or symptom burden, and improving positive outcomes, such as QOL, in both patients and family caregivers.

As educators, nurses can reduce the stigma after diagnosis of lung cancer and provide information about optimal care for symptoms at home. Nurses can also educate patients and their families about connections within the community to bolster social support which is especially important in rural clinics where other types of healthcare workers, such as social workers, are not readily available.

Summary and Gaps

Significant gaps exist in the lung cancer literature regarding stigma. Some evidence suggest the depression and stigma may be linked in a lung cancer population; we do not know, however, how perceived stigma may influence anxiety or psychological distress. HRS may lead to fewer available social supports for patients with lung cancer. Unlike patients with other cancers with large and widely visible support campaigns, like breast cancer, lung cancer patients may feel shunned, and supports may not exist because of the stigma associated with the disease. If patients' perceived stigma influences how they interact with nurses and other healthcare workers, they may not ask for needed social supports

It is important to study stigma in a lung cancer population because of the large number of people, both smokers and non-smokers, who are diagnosed with and die from the disease every year. Care for lung cancer is costly it is currently unclear what factors contribute to positive and negative symptom management experiences within this population. Because stigma has been shown to contribute to poor outcomes in other patient populations, such as HIV/AIDS, it is possible that it also contributes negatively to the lung cancer experience.

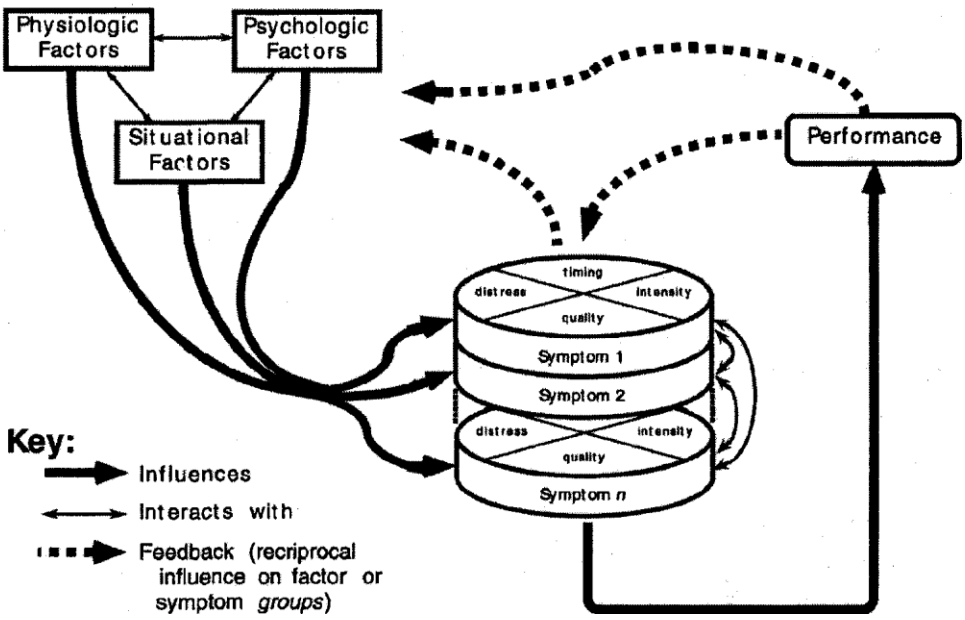
CHAPTER II

This section reviews the problem as it relates to the theoretical framework and the key concepts of the theoretical framework are discussed. Current literature is reviewed extensively, critically analyzed, and synthesized.

Theoretical Framework

Introduced as a "work-in-progress" in 1995, the Theory of Unpleasant Symptoms was updated in 1997 to its current form and includes three main components: influencing factors, symptoms, and performance (consequences of the symptom experience) (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). The original model depiction was updated to include multiple symptoms rather than one symptom because symptoms rarely occur in isolation. The following figure is the current picture model of the Theory of Unpleasant Symptoms (see Figure 1).

Figure 1. The Theory of Unpleasant Symptoms (Lenz, et al., 1997).



Influencing factors (stigma, social support, psychological distress, depression, anxiety)

The Theory of Unpleasant Symptoms assumes that there are three influencing factors that affect a patient's symptoms: physiologic factors, psychologic factors, and situational factors. Each of these three factors interacts with one other to exert influence over symptoms. The psychologic factors are a person's mood or mental state. Psychologic factors also include an individual's affective response to illness and the degree of knowledge and uncertainty about symptoms and their meaning. Situational factors refer to aspects of a person's social and physical environment that may affect the way a patient experiences or reports symptoms. Physiologic factors refer to normally functioning body systems, abnormal pathology, and the energy level of an individual.

In the proposed study, psychological factors, such as psychological distress, and situational factors, such as internal or external stigma or social support, may directly influence the patient's symptoms and symptom burden. Rapid changes in physiological function, such as pulmonary function, due to decline of lung cancer patients, may also contribute to the symptom experience.

Stigma (internal and external), the primary concept of interest in this proposal, is a situational factor that has been modified in other diseases, such as breast cancer and HIV/AIDS, through clinical psychoeducational interventions. Influencing the patient perception of lung cancer related internal and external stigma may directly impact the patient symptom burden and indirectly QOL. Modifying perceptions of lung cancer related stigma may also be a way to decrease depressive symptoms or anxiety caused by feelings of guilt associated with causing the disease.

Symptoms (Dyspnea, pain, fatigue, etc.)

Symptoms are the main focus of the Theory of Unpleasant Symptoms. The updated theory addresses both symptom clusters as well as single symptoms because symptoms are thought to be a multidimensional experience. There are four domains to each symptom that, although separate, are still related to one another. The domains are: 1) intensity (strength or severity), 2) timing (duration and frequency of occurrence), 3) level of distress perceived (degree of discomfort or bothersomeness), and 4) quality.

Physical symptoms of lung cancer patients will be assessed according to intensity and level of distress perceived within the proposed study. At present there are no known measures that address all four domains of symptoms in a lung cancer population. Lung cancer symptom research provides little description of symptoms that patients experience in clusters and which domains of the experienced symptoms are most important to the patient's subjective symptom experience. Psychological symptoms will be measured with the Hospital Anxiety and Depression Scale.

Performance

The outcome of the Theory of Unpleasant Symptoms is performance. Conceptually defined, performance includes both functional activities, such as physical activity, ADLs, social interactions and role performance, and cognitive activities, such as concentrating, thinking, and problem solving. In the Theory of Unpleasant Symptoms, performance can influence both the symptom experience and the three influencing factors. In the proposed study, quality of life and social dependency will be examined as the effects of lung cancer related symptoms.

Definition of Terms

The key concepts related to the phenomenon include health related stigma, symptoms, symptom burden, quality of life, psychological distress, and social supports. Definitions of key concepts are defined as follows (see Table 1).

Table 1 *Key Concepts Related to the Phenomenon*

Key Concepts	Definition	Related to the Phenomenon
Health Related Stigma	Health related stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem (Weiss & Ramakrishna, 2006).	External stigma relates to the perceptions of rejection or blame patients may feel from others related to a lung cancer diagnosis. Internal stigma relates to the perceptions of rejection or blame a patient feels from himself related to a lung cancer diagnosis.
Symptoms	A symptom is subjective evidence of disease or physical disturbance. It indicates a bodily disorder (Mirriam-Webster's Medical Dictionary, 2011).	Symptoms related to the phenomenon include physical symptoms (pain, fatigue, etc.) and psychological symptoms (depression, anxiety) as

	Symptoms are a subjective experience linked to personal appraisal (Liehr, 2005) and are often defined as either physical or psychological (Kroenke, 2003).	subjectively felt and reported by the patient.
Quality of Life (QOL)	Quality of life is an overall sense of well-being that an individual perceives within the context of their personal cultural and value system. Quality of life is a multidimensional concept based on patient self-assessment, on the interaction between a person's physical health, psychological state, personal beliefs, social relationships and the environment. Self-report questionnaires are typically used in medical studies to measure an individual's quality of life	Quality of life, as related to the phenomenon, is the overall quality of life from the perspective of patients.

	(Murphy, Herrman, Hawthorne, PInzone, & Evert, 2000).	
Psychological Distress	Psychological distress is the unique discomforting and emotional state caused by an individual's response to a specific stressor that has the potential to temporarily or permanently harm the individual (Ridner, 2004).	Psychological distress is related to the phenomenon as the emotional response of patients to a lung cancer diagnosis and stigma related to a lung cancer diagnosis.
Social Supports	Social support can have many meanings. Here, social support is defined as either the perceived or actual physical, material, psychological, or symbolic resources that have health related benefits (Cohen, Underwood, & Bottlieb, 2000). Social supports can be derived from personal, medical, or community resources.	The social supports related to the phenomenon are the perceived or actual supports that patients are able to identify and gain access to after a lung cancer diagnosis.

Critical Analysis of the Literature

Stigma in Lung Cancer

Although research on stigma has been extensive in other areas of healthcare such as HIV/AIDS (Buseh, et al., 2008; Clark, et al., 2003; Kang, et al., 2005; Lee, et al., 2002; Slutterheim, et al., 2009), it is limited in the lung cancer literature. Over the last several years researchers have begun to understand that HRS may play a role in the experience of the patient with lung cancer and an increasing number of studies have been published in this area. Table 2 reviews published literature that examine HRS in lung cancer and studies are then summarized.

Table 2 Analysis of Methods Used to Study *Stigma in Lung Cancer*

Study	Design	Sample	Methods	Analysis	Findings
Brown-Johnson, Brodsky & Cataldo (2015)	Cross sectional, descriptive design	n=149 Mean age=56.8 years 93% Caucasian 80% former smokers 75.2% Female	Cataldo Lung Cancer Stigma Scale Spielberger State Anxiety Scale CES-D Quality of Life Inventory	Univariate Analysis Correlations Hierarchical regression	Relationship between QOL and anxiety ($p<0.01$) and depression ($p<0.01$) Stigma plays a unique role in QOL ($p=0.015$) No relationship between depression and QOL and smoking status
Brown & Cataldo (2013)	Qualitative	n=8 Former and never smokers 100% Female	One-on-one interviews and focus groups Open ended interview format	Discourse analysis	Unvoiced precursors—tobacco industry and addiction influence Perception of lung cancer stigma—diagnosis and interaction with healthcare providers Perception of stigma—shifting identities Response to stigma—information control, advocacy

Carter-Harris (2015)	Cross-sectional, descriptive design	n=93 Convenience Sample 62.4% Female 82.8% Caucasian 46.2% Stage IV 32.3% Never smoker	Cataldo Lung Cancer Stigma Scale Self-report dates	Pearson correlations One-way ANOVA	Mean days from first symptom to doctor visit 41 days No significant difference between smoking status and perceived stigma Positive correlations between number of days to seeking treatment and stigma and blame ($p<0.05$), social isolation ($p<0.05$), and smoking ($p<0.05$)
Cataldo & Brodsky (2013)	Cross-sectional, descriptive design	n=144 Mean age=57 years 93% Caucasian 79% Current or former smoker 74% Female	Cataldo Lung Cancer Stigma Scale Speilberger State Anxiety Questionnaire CES-D Lung Cancer Symptom Scale	Univariate analysis Correlations Hierarchical multiple regression	Significant relationship between stigma and anxiety ($r=0.413$, $p<0.001$), depression ($r=0.559$, $p<0.001$), and symptom severity ($r=0.483$, $p<0.001$) Stigma played a unique role in the stigma experience ($p<0.05$)

Cataldo, Jahan & Pongquan (2012)	Cross-sectional, descriptive design	n=190 Mean age=55.05 years 85.2% Caucasian 67.9% Married 79.5% Ever smokers	Cataldo Lung Cancer Scale CES-D Quality of Life Inventory	Correlations Multiple regression	Significant correlations were found between stigma and depression (r=0.68, p<0.001) and QOL (r=-0.65, p<0.001) LCS provides a unique and significant explanation of the variance of QOL over and above that of depression, age, gender, and smoking status, by 2.1% (p < 0.001)
Chambers et al. (2015)	Pre/Post Test, Phase I trial Cognitive behavioral intervention	n=14 Mean age=62.15 years 88% Female 52% Not currently smoking	HADS Impact of Events Scale CES-D Cataldo Lung Cancer Stigma Scale Functional Assessment of Cancer Therapy—Lung (FACT-L)	Interpretive phenomenonologcal analysis Independent sample t-tests Mann-Whitney tests Chi-squared tests Partial Eta squared	Identified themes: the Therapeutic Relationship; Self-management of Distress; Family Relationships improvements were observed in psychological (η_p^2=0.182) and cancer-specific distress (η_p^2=0.056); depression (η_p^2=0.621); health-related stigma (η_p2=0.139) Quality of life declined (η_p^2=0.023)

Chapel, Zeibland & McPherson (2004)	Cross-sectional	n=45 Age range=50-61 Purposeful sampling 99% Caucasian	Qualitative Face-to-face unstructured interviews	NUD*IST software was use to code interviews	Both smothers and non-smokers felt a stigma due to lung cancer Feelings of internal and external stigma associated with a lung cancer diagnosis affected the way lung cancer patients interacted with family, friends, and their physician
Gonzalez & Jacobsen (2010)	Cross-sectional, descriptive design	n=95 Mean age=64 years Stage IV 66.3% 92.6% Caucasian 71.6% Former smoker	Social Impact Scale Coping Responses Inventory—Cognitive Avoidance Subscale ENRICHD Social Support Instrument Dysfunctional Attitudes Scale	Correlations Hierarchical regressions	Positive correlation between the perception of stigma and depressive symptoms ($p<.001$) Stigma was a unique contributor to depressive symptomology beyond what was accounted for by demographic, clinical, and psychosocial factors (3%, $p=0.043$) Two SIS subscales accounted for significant variability in depressive symptomology, the Financial Insecurity subscale (3%, $p<0.036$)

			CES-D		and the Social Isolation subscale (7%, p<0.001).
Gonzalez & Jacobsen (2012)	Cross-sectional, descriptive design	n=95 Mean age=64.04 Stage IV 66.3% 92.6% Caucasian 71.6% Former smoker	Social Impact Scale Coping Responses Inventory—Cognitive Avoidance Subscale ENRICHD Social Support Instrument Dysfunctional Attitudes Scale CES-D	Independent sample t-tests ANOVAs Chi-squared	Positive association between stigma and depression (r=0.46, p<0.001) Stigma accounted for a unique variance in depression symptoms (β50.19, p<0.05)
Hamann et al. (2014)	Cross-sectional	n=42 (individual interviews) n=23 (focus groups)	Qualitative Semistructured indiividual interviews Focus groups	Iterative coding	Two main themes identified: perceived (felt) stigma and internalized (self) stigma Widespread knowledge of perceived stigma Varying degrees of internalized stigma

Lebel et al. (2013)	Cross-sectional, descriptive design	n=107 (lung cancer) n=99 (head and neck cancer) Mean age=63 years Canadian-born More head and neck participants had recurrent disease (p<0.01)	Affect Balance Scale CES-D Explanatory Model Interview Catalogue—a subscale (not defined) Illness Intrusiveness Ratings Scale Post-Traumatic Growth Inventory Disfigurement Scale 1-item Self-Blame Likert Scale Marlowe-Crown Social Desirability Scale	Multiple regression analysis Pearson correlations Chi-squared t-tests	Patients with lung cancer reported higher levels of self-blame (t(199) = -5.06, p<0.001) Stigma was correlated with disfigurement (r=0.43, p<0.01), illness intrusiveness (r=0.46, p<0.01), depressive symptoms (r=0.44, p<0.01), affect scale (r= -0.27, p<0.01) stressful life events (r=0.36, p<0.01), and social desirability (r= -0.16, p<0.05) Stigma correlated significantly with distress (β=0.25, p<0.001) Lung cancer patients reported higher levels of stigma than head and neck cancer patients (p<0.001)

Lehto (2014)	Cross-sectional, descriptive	n=11 Mean age=69.8 years Non-small cell lung cancer 55% Female	Focus groups	Qualitative Focus group analysis	Six themes emerged: 1) societal attitudes; 2) institutional practices and experiences; 3) negative thoughts and emotions such as guilt, self-blame and self-deprecation, regret, and anger; 4) actual stigmatization experiences; 5) smoking cessation: personal choices versus addiction; and 6) causal attributions
LoConte et al. (2008)	Longitudinal, descriptive study	n=96 (lung cancer) n=30 (breast cancer) n=46 (prostate cancer) Mean age=65.6 (lung cancer) All had Stage IV disease Lung cancer specific:	Data collected at baseline, 2 months and 6 months Stigma scale developed for this study (6 questions) Interviews	Between subjects MANCOVA Two-sample t-tests	Feelings of embarrassment related to cancer diagnosis was higher in patients with lung cancer compared to breast and prostate cancer patients ($p<0.01$) Generalized guilt and shame was not different between groups ($p>0.05$) History of smoking was positively correlated with guilt and shame for all tumor types ($p<0.05$) Lung cancer patients with a history of smoking had

		93.8% Caucasian 66.7% Married 80.2% Former smoker			higher levels of guilt and shame than never-smoker lung cancer patients (p=0.024) Patients who perceived past lifestyle choices as a contributing factors to their current diagnosis had higher levels of guilt, shame, anxiety and depression (p<0.01).

Summary/Synthesis of Findings

Findings from these studies show that current, former, and never-smokers experience both internal and external stigma and embarrassment related to a diagnosis of lung cancer. Samples in the previously reviewed studies are primarily white and lack information on racially diverse populations. Stigma in lung cancer may be one important factor that contributes to depression though we do not know how lung cancer related stigma, internal or external, relates to other psychological, physiological, or psychosocial outcomes. Lung cancer patients may feel more embarrassment about their diagnosis than patients with others types of cancer because of the public perception of smoking as a bad life-style choice and risk factor for the disease.

Stigma in Lung Cancer: Measurement Tools

Three scales have been used to assess stigma in a lung cancer population (see Table 3). Two of the scales, the SIS and the CLCSS, have been previously validated in the literature, while the third scale, which I call the PCRS, was created by the authors specifically for their study and has not been validated or used in any other study. There were no validation parameters published within the study that used the scale (See Table 3).

Table 3 *Measures and Scales to Study Stigma in Lung Cancer*

Instrument	Concept	Validity	Reliability
Perceived Cancer-Related Stigma Scale (PCRS) **-LoConte, Else-Quest, Eickhoff, Hyde, & Schiller (2008)**	Stigma	Non-validated	0.75
Social Impact Scale (SIS)	Stigma	Construct	0.95
Cataldo Lung Cancer Stigma Scale (CLCSS)	Stigma	Construct	0.96

The PCRS was developed from a focus group of lung cancer support group participants. It is a 6-item Likert scale intended to measure self-blame as well as feelings associated with guilt, shame, or embarrassment as related to cancer. Possible answer choices range from 1 (strongly disagree) to 5 (strongly agree). The following questions comprise the scale: 1) I am ashamed I got my type of cancer, 2) I deserve my type of cancer, 3) People judge me for my type of cancer, 4) I am embarrassed to tell people my type of cancer, 5) My behavior contributed to my cancer, and 6) My family feels ashamed of my cancer (LoConte, et al., 2008). Scores are averaged to determine perceived stigma. A higher score indicates a higher perceived stigma.

The SIS was developed as a tool to measure stigma in those with a primary physical illness. It was initially tested and validated in an HIV/AIDS and heterogeneous cancer population. The scale consists of 24-items with four subscales. The subscales

of *social rejection* and *financial insecurity* are meant to measure the external experience of stigma and the subscales of *shame* and *social isolation* are meant to measure the personal internal experience of stigma. In the original study, the Cronbach alpha coefficient for the subscales ranges from 0.85 to 0.90 (Fife & Wright, 2000). The Cronbach alpha coefficient for all subscales in the lung cancer population was greater than or equal to 0.81 (Gonzalez & Jacobsen, 2010).

The CLCSS is the first and only scale to measure stigma specifically in a lung cancer population (Cataldo, et al., 2011). It was validated in a sample of 186 self-report lung cancer patients/survivors who were recruited online and who completed the scale as well as other measure via a secure and encrypted website, SurveyMonkey. Active links to the survey were placed on websites that would attract participants with lung cancer, including LUNGevity, the American Lung Association, Lung Cancer Alliance, and The American cancer Society's Cancer Survivor Network. The final version of the scale contains 31 Likert items. The Cronbach alpha coefficient for the entire scale is 0.96. The CLCSS has four subscales: 1) stigma and shame, 2) social isolation, 3) discrimination, and 4) smoking. The Cronbach alpha coefficient for the four subscales ranges from 0.75 to 0.96.

Summary

The use of scales to measure stigma in a lung cancer population is very limited. The Social Impact Scale, however, has been used in other populations to measure disease-related stigma and has been shown to be both valid and reliable. Although the Cataldo Lung Cancer Stigma Scale was developed specifically for use in a lung cancer

population, the scale was validated online in a sample self-reported to have lung cancer. The scale has not been used in a clinical setting in a face-to-face format.

Summary of Stigma in Lung Cancer

Although few studies examine lung cancer related stigma, those that have been published offer a strong argument that stigma is a problem within this population. Both qualitative and quantitative methods have been used. Samples are limited to primarily white populations and because of the low number of studies, measurement instruments are not consistent across studies. These findings suggest there is a need to further investigate stigma in a lung cancer population to determine the most appropriate measurement tools.

Physical Symptoms in Lung Cancer

Many studies have investigated physical symptoms of lung cancer patients and either focus on individual symptoms or on symptom clusters. Symptom clusters are two or more interrelated symptoms that present together , independent of other symptom clusters, and may or may not suggest a common etiology or underlying mechanism (Dodd, Miakowski, & Paul, 2001; Kim, McGuire, Tulman, & Barsevick, 2005). Recent research has begun to examine symptom clusters rather than isolated symptoms (Chan, Richardson, & Richardson, 2010; Jiminez, et al., 2001). Exemplar articles are presented in Table 4 and then immediately synthesized.

Table 4 *Analysis of Methods Used to Study Symptom in Lung Cancer*

Study	Design	Sample	Method	Analysis	Findings
Iyer, Taylor-Stokes & Roughley (2013)	Record-based, cross-sectional	n=1213 Mean age=63 years Male=67% White=93% Stage IIIB/IV Current smoker=45.1% Quit smoking=39.8% Never smoker=15.1% Non-small cell lung cancer France and Germany	Lung Cancer Symptom Scale Functional Assessment of Cancer Therapy-Lung (FACT-L) EuroQol (EQ-5D)	Descriptive statistics Multivariate regression analysis	Loss of appetite, fatigue, cough, pain, and shortness of breath were reported in ≥90% of patients The following were predictors of QOL: Fatigue (β= −0.122; p<0.001), loss of appetite (β= −0.170; p<0.001), pain (β= −0.145; p<0.001), shortness of breath (β= −0.118; p<0.001)
Iyer, Roughley, Rider & Taylor-Stokes (2014)	Cross-sectional, descriptive design	n=450 Mean age=64.7%	Patients and physicians	Descriptive statistics Kappa-statistic	Patients reported the following symptoms: Fatigue (100%), loss of appetite (97%),

		White=70.9% Current smoker=34.8% Quit smoking=43.4% Never smoker=21.9% Stage IIIB/IV Non-small cell lung cancer USA	completed questionnaires Lung Cancer Symptom Scale (LCSS) Functional Assessment of Cancer therapy-Lung (FACT-L)	Regression analysis	shortness of breath (95%), cough (93%0, pain (92%), blood in sputum (63%) Concordance was greatest for hemoptysis (kappa 0.4586) Concordance was lowest for loss of appetite (kappa 0.1701) The following were significant predictors of QOL: Loss of appetite (β=−0.204; p<0.001), cough (β=−0.145; p<0.01), pain (β=−0.265; p<0.001), and shortness of breath (β=−0.145; p<0.01)
Ma et al., (2014)	Cross-sectional, descriptive design	n=376 Mean age=57.4 years	Functional Assessment of Cancer Therapy-Lung (FACT-L)	Descriptive statistics Independent t-tests Mann-Whitney U-test	Patients reported symptoms as follows: loss of appetite (84.3%), breathing difficulty (79.0%) and

		Male=63.8% Never smoker=38.8% Former smoker=10.6% Recently quit=50.6% China Stage IIIB/IV	Cloud QOL System	Pearson correlations Multivariate regression analysis	Cough (75.5%), pain (53.5%) QOL and symptoms showed a significant correlations (p<0.001) All symptoms except shortness of breath was a negative indicator of QOL (p value not given)
Degner & Sloan (1995)	Cross-sectional descriptive design	n = 82 Consecutive recruitment from outpatient clinic Mean age=64.2 Male=61% Advanced disease=72% Location: Manitoba Ambulatory cancer patients	Medical chart review and face-to-face patient interview Symptom Distress Scale	Descriptive statistics Independent t-tests Pearson correlations Survival analysis/Wilcoxon likelihood ratio tests	Most problematic symptoms are fatigue and insomnia. 38.9% and 30.9% of patients reported moderate to high levels of distress with these symptoms. Patients with advanced disease reported higher distress than those with early stage disease (t=-5.44, p=0.0001).

					Women reported more distress than men (t=-2.05, p=0.041). Symptom distress was a predictor of lung cancer survival (p=0.0001).
Tishelman, Petersson, Degner, & Sprangers (2007)	Longitudinal repeated measures descriptive design	n = 400 Consecutive recruitment Data points: prior to treatment, 2 weeks, 1, 3, & 6 months, & 1 year Mean age=66.2 years NSCLC=85% Advanced disease=61% Male=52% Location: Sweden	Cancer registry review Fact-to-face data collection Thurston Scale of Symptom Distress—Lung Cancer EORTC-LC13	Relative ranking Kendall's coefficient of agreement	Over 50% of patients had problems with: physical role, emotional functioning, fatigue, dyspnea, and cough. In subgroups close to death reported symptoms were higher and function was lower (Physical function, p<0.001; Role function, p<0.001; Emotional function, p<0.001, Cognitive function, p<0.001; Social function, p<0.001; Fatigue, p<0.001; Nausea & vomiting,

					p=0.009; Pain, p=0.001; Dyspnea, p=0.001; Insomnia, p<0.001). Relative ranking shows symptoms with the most distress across subgroups were breathing, pain, and fatigue.
Cooley, Short, & Moriarty (2003)	Longitudinal repeated measure descriptive design -Secondary analysis	n = 117 Data points: baseline, 3 & 6 months recently diagnosed Mean age=64.7 years White=91% NSCLC=86% Male=54% Early diagnosis=37% &	Symptom Distress scale	Descriptive statistics ANOVA then Fisher's least significant differences multiple comparisons Logistic regression	Most distressing symptoms at all time points were fatigue (64% at baseline, 49% at 3 months, 43% at 6 months) and pain (56% at baseline, 32% at 3 months, 27% at 6 months). Surgery patients reported pain, fatigue, and insomnia as the most distressing symptoms. (Pain: 69% at baseline, 31% at 3 months, 40% at 6 months; Fatigue: 57%

		regional diagnosis=49%			at baseline, 39% at 3 months, 34% at 6 months; Insomnia: 57% at baseline, 30% at 3 months, 19% at 6 months). CCR patients reported fatigue and pain as the most distressing symptoms. (Fatigue: 65% at baseline, 60% at 3 months, 43% at 6 months; Pain: 50% at baseline, 35% at 3 months, 42% at 6 months) Four patterns of change in symptom patterns: homogenous linear, heterogeneous linear, homogenous curvature, and heterogeneous curvature. Demographic variables did not predict patterns of

					reported symptom distress over time.
Tishelman et al. (2005)	Longitudinal repeated measures descriptive design Qualitative analysis	n = 400 Consecutive recruitment Data points: prior to treatment, 2 weeks, 1, 3, & 6 months, & 1 year Mean age=66.2 years NSCLC=85% Advanced disease=61% Location: Sweden	Cancer registry review Fact-to-face data collection Field notes Thurston Scale of Symptom Distress—Lung Cancer Symptom Distress Scale (SDS)	Descriptive statistics Relative ranking Review of field notes	Relative ranking shows breathing, pain, and fatigue are associated with the most distress across time points. Fatigue on the SDS was rated as the most intense symptom across time points and was significantly higher than the next rated symptom ($p<0.05$). Patient comments from field notes show that breathing and pain are the most distressing symptoms.
Jiminez et al. (2011)	Cross-sectional descriptive design	n = 437 Consecutive recruitment	Edmonton Symptom Assessment System	Descriptive statistics Linear transformation	Several symptom clusters were identified: confusion (31%), neuropsychological

		Mean age=66 Male=61% Multiple types of cancer Location: Hospital Universitario La Paz	Author developed supplemental questions	Principal component analysis	(59%), anorexia-cachexia 96%), and gastrointestinal (23%). A unique symptom cluster was identified in lung cancer patients: dyspnea and diaphoresis. The confusion cluster was more common in patients ≥70 ($p<0.001$), and those with an ECOG status of 3 or 4 ($p<0.001$). The gastrointestinal cluster was more common in women ($p<0.05$) and in those with an ECOG status of 3 or 4 ($p<0.05$). There was no relationship between the number or location of metastasis and symptom clusters.

					The number of symptom clusters (SC) was related to median survival: 52 days for patients with no SC, 38 days with 1 SC, 23 days with 2 SCs, and 19 days with 3 SCs (p<0.0001).
Cooley, Short, & Moriarty (2002)	Longitudinal repeated measures Secondary analysis	n = 117 Selected from three previously completed studies Mean age=64.7 years White=91% Early stage=37% & regional stage=49% NSCLC=86% Male=54%	Symptom Distress Scale Medical record review	Descriptive statistics ANOVA Multiple regression models with backward elimination	There were no significant differences in total symptom distress across treatment groups at baseline or 6 months. At 3 months there were significant differences in distress between treatment groups (p=0.020). The surgery group had less distress than the radiation therapy group and the combined therapy group.

					At baseline, histology (p=0.023) and gender (p=0.009) were significant predictors of symptom distress. SCLC patients had less distress than NSCLC patients and men had less symptom distress than women. At three months, treatment modality (p=0.015) and nursing care (p=0.042) were significant predictors of symptom distress. Those who had surgery experienced less distress than those who received CCR or radiation therapy. Those with nursing care had less distress than those without nursing care.

Findings are consistent across studies. Symptom distress is high in lung cancer patients (Degner & Sloan, 1995; Tishman, et al., 2007). In general, pain and fatigue are the most distressing symptoms both at the time of diagnosis and at time points further from diagnosis (M. E. Cooley, et al., 2003; Degner & Sloan, 1995; Tishman, et al., 2005; Tishman, et al., 2007). Another consistent symptom problem in lung cancer patients is dyspnea/breathing (Jiminez, et al., 2001). Patients with advanced lung cancer have more symptoms than those diagnosed with earlier stages of the disease (Degner & Sloan, 1995; Tishman, et al., 2007).

The studies presented here are all quantitative and are a mix of cross-sectional and longitudinal, repeated measures designs. All studies are descriptive in nature. Within these studies, all samples were consecutive recruited from convenient populations. Furthermore, the majority of these studies focused on symptoms in lung cancer patients with NSCLC and those who had advanced and non-curable disease. Study samples consist primarily of those aged 65 or older, male, and white. A number of studies have been conducted in countries other than the United States.

There were no identified qualitative studies addressing symptoms in a lung cancer population.

Physical Symptoms in Lung Cancer: Measurement Tools

Several different tools have been used to assess physical symptoms in a lung cancer population. The tools are presented in the following table (Table 5) and then discussed.

Table 5 *Measures and Scales to Study Symptoms in Lung Cancer*

Instrument	Concept	Validity	Reliability
Symptom Distress Scale (SDS)	Symptom Distress	Construct	0.70 – 0.92
Thurston Scale of Symptom Distress—Lung Cancer (TSSD-LC)	Symptom Distress	See discussion below	See discussion below
EORTC—LC13	QOL-Symptoms	Construct/Clinical	0.70
Edmonton Symptom Assessment System (ESAS)	Symptoms	Construct	0.68 to 0.80

The most commonly used scale in the reviewed studies was the Symptom Distress Scale (SDS). The SDS was developed in an outpatient oncology population and has been validated in the literature. This scale assesses 13 different symptoms and the distress associated with that symptom on a five-point Likert type scale that ranges from one to five (R. McCorkle & Y. Young, 1978). The symptoms assessed on this scale include: nausea, appetite, pain, fatigue, insomnia, bowel pattern, concentration, appearance, outlook, breathing, and cough. The score for the scale is a sum of the 13 items with 13 (lowest possible score) indicating no distress and 65 (highest possible score) indicating severe distress. In the initial testing of this scale, reliability coefficient alpha for this scale was 0.82142 and the standardized coefficient alpha was 0.82557.

The Thurston Symptom Distress Scale—Lung Cancer uses pairwise comparison of nine symptoms that were identified as distressing for patients. These symptoms are insomnia, couch, bowel function, breathing, fatigue, pain, outlook, appetite, and appearance. Each of these symptoms is paired with each other for a total of 36 pairs.

Patients are asked to select the symptom that causes the most distress whether the patient is currently experiencing the symptom or not (Broberger, Tishman, & Essen, 2005; Tishman, et al., 2005). Internal consistency was tested by calculating the number of circular triads or inconsistencies in participant responses. In one study, all patients, family caregivers, and nurses were found to be consistent in responses. The Tukey's index of scalability, which accounts for response variability, was 0.94 for nurses and family caregivers and ranged from 0.95 to 0.98 for patient responses. The degree of consistency among patients, nurses, and family caregivers ranking was measured using Kendall's coefficient. It was 0.29 for patients, 0.28 for nurses, and 0.21 for family caregivers. This indicates low to moderate levels of agreement (Broberger, et al., 2005). In another study, between 96.7% and 98.7% of all patients were consistent when using the circular triads to calculate internal consistency. The Tukey and Gulliksen index of scalability was between 0.95 and 0.98. The Kendall coefficient ranged from 0.24 to 0.31, indicating low to moderate agreement between subjects (Tishman, et al., 2005).

Part of the EORTC, the LC13 includes specific disease and treatment related questions. In addition to measuring overall health-related QOL, this scale measures disease symptoms and treatment related side effects. The scale was developed in a large sample of non-curable lung cancer patients recruited from 17 different countries. The scale has been validated within the literature for use in a lung cancer population. Clinical validity was assessed via known-groups comparison. The Cronbach alpha coefficient was >0.70 (Bergman, Aaronson, Ahmedzai, Kaasa, & Sullivan, 1994).

The Edmonton Symptom Assessment System (ESAS) is a patient self-report measure that evaluates the patient's perception of symptoms at the current time. It was

developed and validated in a palliative care setting. Symptoms are assessed via nine questions that are rated on a visual analogue scale that ranges from zero to 100, with 100 as the most severe rating. Validation testing of this scale has shown the Cronbach alpha coefficient for this scale to be 0.79 (Chang, Hwang, & Feuerman, 2000). Despite the practicality of the scale in the clinical setting, it has been inconsistently used in the literature and modified many times (Richardson & Jones, 2009).

Summary

A variety of scales have been used from Likert type scales to visual analog scales like the ESAS. Although the visual analog type scale may be easier for patients to use (less patient burden) the efficacy of the scale is difficult to determine due to the fact that many researchers modify the scale from study to study. The SDS is the most popular symptom measurement tool in a lung cancer population. It is an effective scale because it measures the frequency of the symptom as well as the distress the symptom causes, both important clinical factors.

Psychological Symptoms in Lung Cancer

Compared to 14 other types of cancer, lung cancer patients report the highest amount of psychological distress (43%) (Zabora, et al., 2001). Depression and anxiety are the two most common types of psychological symptoms diagnosed in a cancer population (Maguire, et al., 1974) and the two variables are commonly studied together in an advanced cancer population (Delgado-Guay, et al., 2009; Vignaroli et al., 2006). Some studies suggest that depression and anxiety are underdiagnosed in an advanced cancer setting and that this cause a significant amount of stress for both patients and caregivers (Delgado-Guay, et al., 2009). The prevalence of depression and anxiety has

been estimated at 25% of the advanced cancer population (Salvo et al., 2011). However, inconsistency in the literature as well as clinician debate on how to best measure mental health problems in an advanced cancer population remains a problem (Hotopf, et al., 2002; Pasquini & Biondi, 2007). A wide variation in assessment methods, diagnosis criteria, and time of measurement has been attributed to the wide range of prevalence of depression and anxiety in an advanced cancer population (Delgado-Guay, et al., 2009; Vignaroli, et al., 2006). There are two studies that investigate depression as it relates to stigma in a lung cancer population. The methodological analysis of these articles, Cataldo et al. (2011) and Gonzalez & Jacobsen (2010) can be found under stigma. The articles examined in the following table (Table 6) are those that address general psychological distress, depression, and anxiety within the lung cancer population.

Table 6 *Analysis of Methods Used to Study Psychological Symptoms in Lung Cancer*

Study	Design	Sample	Methods	Analysis	Findings
Arrieta et al., (2013)	Prospective, longitudinal study	n=82 Mean age=58.9 years old Female=58.5% Smokers=50% Stage IIIB/IV NSCLC Mexico	HADS International Neuropsychiatric Interview EORTC QLQ-C30 QLQ-LC13 Medical chart review Baseline, 3 and 6 months	Descriptive statistics Independent t-tests Mann-Whitney U Chi-squared Spearman correlations	Depression was associated with female gender (p=0.034), poor performance status (p=0.048) 58% of patients had depressive symptoms Patients with depressive symptoms had poorer adherence to treatment (p=0.0004)
Haun et al. (2014)	Cross-sectional survey	n=54 dyads (patient and caregiver) matched community dyads n=162) <u>Patients</u>: Mean age=62.3 years old	Medical chart review Functional Assessment of Cancer Therapy-Lung (FACT-L)	Two-tailed student t-tests Cohen's D Spearman's correlations Independent t-test	32.1% of patients and 31.4% of partners met criteria for depression 28.9% of patients and 36.0% of partners met criteria for anxiety

		Female=35% <u>Partners</u>: Mean age=60.8 years old Female=67% Germany	ECOG performance status Patient Health Questionnaire-4 Generalized Anxiety Disorder Scale-2 Questionnaire on Distress in Cancer Patients-Short Form Supportive Care Needs Survey	ANOVA	No difference in depression or anxiety between patients and partners
Lekka et al. (2014)	Cross-sectional, descriptive study	n=101 Mean age=65.49 years old Male=82.2% Greece	Spielberger's State-Trait Anxiety Inventory Brief Pain Inventory Family Support Scale	Descriptive statistics Independent sample t-tests ANOVA Pearson correlations	Females scored significantly higher on anxiety scale ($p<0.01$) 53% of males presented with state anxiety symptoms compared to 73.3% of females

					56.43% of all participants presented with state anxiety symptoms 33.7% of males presented with trait anxiety symptoms compared to 61.1% of females 38.1% of all patients presented with trait anxiety symptoms
Lie et al. (2015)	Cross-sectional, descriptive study	n=969 Advanced cancer, all types Mean age=62.18 years old 85% with metastatic disease Convenience sample Multi-country	Chart review PHQ-9 Biomarkers Brief Pain Inventory	Cohen's Kappa Chi-square Mann-Whitney U Bivariate logistical regression	45.3% of patients identified as depressed n=197 scored in moderate depression range n=75 scored in moderate-severe depression range n=31 scored in severe depression range

					Depression was associated with receiving opioid-based medications (p<0.001), pain (p<0.001), poor physical performance (p<0.001) and shorter survival time (91-270 days, p<0.001; 271+ days p=0.01)
Shi, Gu, Hou & Hu (2015)	Cross-sectional, descriptive study	n=104 Inpatient NSCLC Age range=31-76 years old Male=76.9% China	Self-rating Depression Scale Social Support Revalued Scale Visual Analog Scale	T-tests F-tests Multivariate analysis	46.1% of patients were diagnosed with depression Multiple factors were predictors of depression including: sex (p=0.000), disease duration (p=0.006), self-care ability (p=0.004), and p=0.003)

Kurtz, Kurtz, Stommel, Given, & Given (2002)	Longitudinal repeated measures descriptive design	n = 228 Convenience sample Mean age=72 years Male=60.1% Advanced disease=54%	Medical chart review and face-to-face interviews Data points: baseline (soon after treatment), 12-16 weeks, 26-30 weeks, 1 year CES-D	Descriptive statistics ANOVA Repeated measures ANOVA Bonferroni corrections	The following factors were important predictors of depressive symptoms: social functioning ($p<0.0001$), symptom severity ($p<0.0001$), and radiation treatment ($p=0.017$). High symptom burden ($p<0.0001$) and restricted social functioning ($p<0.0001$) were associated with an increase in depressive symptoms.
Buccheri (1998)	Cross-sectional descriptive design	n = 133 Consecutive recruitment Mean age=65 years Male (n=122)	Medical chart review All new patients received questionnaire Self-rating Depression Scale	Descriptive statistics Students t-test Wilcoxon test	Depressed patients survived significantly less than non-depressed patients ($p=0.048$).

		Majority at advanced stage	A. Carle Hospital of Chest Diseases		
Hulbert-Williams, Neal, Morrison, Hood, Wilkinson (2011)	Longitudinal cohort design	n=160 Convenience sample Breast, colorectal, lung, & prostate cancer	Data points: diagnosis, 3, & 6 months Hospital Anxiety Depression Scale	Paired and independent-sample t-tests ANOVA Mann-Whitney U Kruskal-Wallis Chi-squared Regression models	67.5% of variance in psychosocial outcomes (QOL) at 6 months can be explained by baseline clinical factors, demographic variables, and earlier levels of depression and anxiety ($p<0.01$).
Hopwood & Stephens (2000)	Longitudinal RCT Descriptive Secondary analysis	n=987 Data from three RCTs drug trials	Data collected during drug study visits Hospital Anxiety Depression Scale	Descriptive statistics Univariate Analysis Wilcoxon-signed ranks test Stepwise logistic regression	Depression identified pre-treatment persisted in over 50% of patients after initiation of treatment. An increased symptom burden was associated with an increase in depressive symptoms ($p<0.0001$)

					Depressive symptoms were associated with severity of tiredness ($p<0.0001$), breathlessness ($p<0.0001$), cough ($p<0.0002$), general pain ($p<0.0001$), and chest pain ($p<0.0006$). The following factors were significantly associated with depression at presentation for treatment ($p<0.0001$ for all): cell type, performance status, functional status, physical symptom burden, tiredness, and breathlessness.
Liao, Liao, Shun, Yu, Yang, & Lai (2010)	Cross-sectional descriptive design	n=152 Convenience sample	Face-to-face Self-report	Descriptive statistics ANOVA with post hoc comparison	Lung cancer patients report a high number of supportive care

		In active treatment of follow up Mean age=60.2 years NSCLC=87.5% Location: Taiwan	Hospital Anxiety Depression Scale	Chi-square with Fisher's exact test Logistic regression	needs (M=43.7, SD=20.0). The top three need domains for patients were: health system and information (M=67.9, SD=27.5)), psychological (M=41.9, SD=24.4), and patient care and support (M=41.1, SD=23.1). Significant relationships existed between overall symptom levels and depression (r=0.55, p<0.001) and anxiety (r=0.42, p<0.001). There was no significant difference in depression and anxiety among treatment subgroups.

Salvo et al. (2011)	Retrospective analysis	n=1439 Convenience sample Mean age = 69 years Multiple cancer sites: Lung, breast, prostate, other Location: Odette Cancer Center	Completed on touch screen kiosk or manually Edmonton Symptom Assessment System (modified) Hospital Anxiety Depression Scale	Univariate ordinal logistic regression Odds ratio Pearson Chi-squared Multivariate ordinal logistic regression Wald Chi-square	55% of patients reported depressive symptoms, 65% reported anxiety symptoms. The following demographic variables were predictors of depression severity: KPS ($p<0.0001$), gender ($p=0.049$), primary cancer site (specifically lung cancer $p=0.008$), and referral to radiotherapy rapid response for spinal cord compression ($p=0.007$). Women were more likely to report depression than men. Patients with primary lung cancer were more depressed than

					other types of cancer (p=0.0008).
Nakaya et al. (2006)	Longitudinal repeated measures design	n=229 NSCLC only Post resection with curable intent Majority over age 60 Majority male Majority married Majority past or quit smokers Location: Japan	Structured clinical interviews to diagnose depression -Profile of Mood States	Cox proportional hazard regression Hazard ratio	Subjects with depression were more likely to have a poor performance status 3 months post-surgery (p=0.30). Depression was not a predictor of survival in lung cancer patients after curative intent resection.
Turner, Muers, Haward, & Mulley (2007)	Prospective observational cohort study	two groups, over 75 (n=49) and under 65 (n=83) Convenience sample	Self-report Data points: before and after treatment Hospital Anxiety Depression Scale	Wilcoxon matched-pairs signed-ranks Mann-Whitney U test Chi-squared test	There were no significant differences in psychological distress between the two groups.

		Advanced disease (82%/54%) NSCLC (86%/84%) Location: radiotherapy planning clinic			There was a trend towards higher depressive and anxiety symptoms post treatment (not statistically significant). There were no significant differences in the number of concerns in either group before and after treatment.
Montazzeri, Milroy, Hole, McEwen, & Gillis (1998)	Longitudinal descriptive study	n=129 Convenience sample Outpatient Mean age=67.5 Male=60% Early stage disease=78% Location: Scotland	Data points: baseline & 3 months Hospital Anxiety Depression Scale	Descriptive statistics Wilcoxon matched-pairs signed-ranked tests Mann-Whitney U test Kruskal-Wallis one way ANOVA	At baseline, most patients had normal depression (84%) and anxiety (77%) scores. Patients with borderline depression/anxiety scores at baseline were double at follow up (depression: 11% to 22%; anxiety: 6% to 11%).

					There was a statistically significant difference between baseline and follow up depression scores (p=0.0002) but not anxiety scores (p=0.64).

The literature suggests that depression and anxiety are ongoing problems in the lung cancer population. There is, however, conflicting published evidence on whether depression or depression symptoms predicts survival in lung cancer patients. Buccheri (1998) found that depression was correlated with shorter survival while Nakaya et al. (2006) found that depression was not correlated with shorter survival times. A variety of factors, including clinical and demographic factors, have been investigated to determine what may contribute to depression in lung cancer (Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2011; Kurtz, et al., 2002; Salvo, et al., 2011). Studies that examine anxiety in this population are more limited. Psychosocial factors, such as social support, have not been adequately addressed. The relationship between stigma and depression in lung cancer has been investigated and was presented in a previous section of this paper.

Studies identified in the literature review are descriptive in nature. There are a wide variety of designs used to gather data, including descriptive data gathered during a randomized control trial. Most of the studies sought to identify what types of patient factors contributed to depressive symptomology or psychological distress in lung cancer patients. Although the majority of studies only recruited lung cancer patients, there are a few comparison studies with other cancer sites (breast, prostate, colorectal). Sample sizes for these studies are large although the majority of participants have NSCLC, are near or over age 65, and have advanced disease. Descriptive statistics reveal that most studies have an equal number of male and female participants.

There are currently no known qualitative studies that examine psychological distress in a lung cancer population.

Summary

Based on this literature review, the role of stigma and other psychosocial factors that may be related to depression and anxiety in lung cancer patients warrants further investigation. The impact of psychological symptoms on physical symptoms in patients with lung cancer should also be explored.

Psychological Symptoms in Lung Cancer: Measurement Tools

Tools that have been used to study depression and anxiety symptomology in the lung cancer patient population are presented in the following table (Table 7).

Table 7 *Measures and Scales to Study Psychological Symptoms in Lung Cancer*

Instrument	**Concept**	**Validity**	**Reliability**
CES-D	Depression	Construct/concurrent	0.85 – 0.92
Self-Rating Depression Scale	Depression	Construct	0.79 – 0.81
Hospital Anxiety Depression Scale (HADS)	Depression and Anxiety	Construct	0.85 – 0.89

Depressive symptomology can be measured with the Center for Epidemiological Studies Depression Scale (CES-D). There are 20 items on this survey with each question rated on a Likert type scale from zero to three (0 = rarely/none of the time to 3 = almost all the time). Items are added for a summed scale score. In general, a cut-off score of 16 is used to indicate a depressed mood in a patient, however, this can vary by population (Penninx et al., 1998). The CES-D has been previously validated in the literature (Radloff, 1977; R. Roberts & Verson, 1983). In the original validation study, the Cronbach alpha was 0.85 in the general population sample and 0.90 in the patient

population sample. Content validity was based on the clinical relevance of symptoms assessed on the scale (Radloff, 1977).

The Self-Rating Depression Scale was originally developed with an inpatient population and subsequently validated in an outpatient population as well. The scale consists of 20 categorical items that cover pervasive effect, psychological equivalents, and physiological concomitants. Half of the items are worded symptomatically positive and half symptomatically negative. The survey is scored by assigning a number, one through four (1 = a little of the time, 2 = some of the time, 3 = a good part of the time, or 4 = most of the time), to each item. The highest possible score for this scale is 80 and a higher score indicate a more depressed patient (Zung, 1965). In an outpatient population consisting of 1,173 patients, the Cronbach alpha was 0.79 (Knight, Waal-Maaning, & Spears, 1983).

The most commonly used scale to measure depression and anxiety symptomology in a lung cancer population is the Hospital Anxiety Depression Scale (HADS). The survey was originally developed in patients with a concurrent physical illness. The scale contains 14 items with two subscales, one for depressive symptoms and one for anxiety symptoms. Questions are rated on a four-point Likert scale. The instrument is summed with a higher score equating higher depressive or anxiety symptoms. The maximum score for this scale is 21. A score of 11 or greater represents a significant case of psychological morbidity (Zigmond, 1983). Both depression ($r=0.60$ to 0.30, $p<0.02$) and anxiety ($r=0.76$ to 0.41) subscale questions were correlated. In the original sample, there were 1% false positives and 1% false negatives for the depression subscale and 1% false negatives and 5% false positive for the anxiety

subscale (Zigmond, 1983). In a large cancer population, the Cronbach alpha for the anxiety subscale was 0.83 and it was 0.79 for the depression subscale (Smith et al., 2002).

Summary

The most commonly used tool to study depression and anxiety in this population is the HADS. Because it measures both anxiety and depression within one measurement tool, it may be a good choice in a lung cancer population to minimize subject burden. The CES-D, however, has been used widely outside of the lung cancer literature. Selecting this scale may make it easier to compare results from a lung cancer population to other cancer populations. Unfortunately this measurement tool does not address anxiety. The HADS may be the more appropriate choice at this time due to the fact that anxiety has not been as widely studied as depression in lung cancer.

Social Support in Lung Cancer

Social support can come in various forms. Emotional social support is the verbal and non-verbal communication of caring or concern offered by others to an ill individual. Emotional support has the ability to help provide some purpose or meaning to the illness experience through the expression of feelings (Helgeson & Cohen, 1996). This type of support often takes the form of empathy and reassurance (Helgeson & Cohen, 1996). Informational social support provides patients a way to manage their illness through information that can be used to guide decisions. It can give patients a sense of control over their illness. Informational support helps patients to understand their diagnosis, the possible risk factors that contributed to the disease, as well as treatment and symptom management (Helgeson & Cohen, 1996). Instrumental social supports are

concrete goods or services. This can include money/finances, transportation, or help with commonplace activities like ADLs or running errands. Instrumental supports are tangible (Helgeson & Cohen, 1996).

Although the research has identified the importance of social support after a cancer diagnosis, there is little empirical evidence that investigates social support in a lung cancer population. The literature review identified five papers that address social support in relation to some aspect of lung cancer. There is currently no literature published on stigma and social support in a lung cancer population. The published literature regarding social support in lung cancer is summarized in Table 8.

Table 8: Analysis of Methods Used to Study Social Support in Lung Cancer

Study	Design	Sample	Methods	Analysis	Findings
Lekka et al. (2014)	Cross-sectional, descriptive study	n=84 Mean age=65.49 years old Male=82.2% Greece	Spielberger's State-Trait Anxiety Inventory Brief Pain Inventory Family Support Scale	Descriptive statistics Independent sample t-tests ANOVA Pearson correlations	Females had lower scores than males in family support ($p<0.01$) Family support was negatively correlated with pain severity ($p<0.05$), pain interference ($p=0.022$), state anxiety ($p<0.001$) and trait anxiety ($p<0.001$) Family support explained 16.1% of variance in anxiety (R square change: 0.161, F: 15.72, B:0.129, $P<0.01$)
Luszcynska, Pawlowska, Cieslak, Knoll & Scholz (2013)	Systematic review	n=2759 patients n=14 studies	Range: 1990-2011 Databases used: PsychINFO, PsychArticles, Health Source: Nursing/Academic Addition, Medline, ScienceDirect	QOL was coded into 4 categories: physical, emotional, social, functional	Three types of support identified: support from family and friends, from healthcare personnel, any available source 53% of studies showed significant correlations between QOL and support from family and friends

			Key terms: lung cancer, social support, QOL Initially retrieved: 721 studies		67% of studies shows significant correlations between QOL and support from healthcare personnel 25% showed significant correlations between QOL and social support from other sources
Shi, Gu, Hou & Hu (2014)	Cross-sectional, descriptive study	n=104 Inpatient NSCLC Age range=31-76 years old Male=76.9% China	Self-rating Depression Scale Social Support Revalued Scale Visual Analog Scale	T-tests F-tests Multivariate analysis	30.8% reported higher levels of social support Social support was a predictor of self-reported depression in patients with lung cancer (p=0.002)
Henoch, Bergman, Gustafsson, Gaston-Johansson & Danielson (2007)	Descriptive, longitudinal study	n=105 Median age=69 years old NSCLC=72%	MOS SSS QOL	Spearman rank correlations Univariate stepwise regression	Social support was positively correlated with overall QOL at several time points (baseline: 0.31, p<0.05; six months: 0.41, p<0.05; nine months: 0.36, p<0.05)

		Metastatic disease=50% All terminally ill, pursuing no treatment			Social support predicted overall QOL at six months (p=0.036) and nine months (p=0.021)
Walker, Zona & Fisher (2005)	Cross-sectional, descriptive study	n=119 Mean age=59.1 years old Post-surgical lung cancer patients Stage I or II White=84% Female=59%	Social Support Inventory	Zero order correlations First-order partial correlations Structural Equation Modeling	Less adaptive coping methods (r=0.351, p<0.01) and directive instrumental social support (r=0.332, p<0.01) were positively correlated with more depressive symptoms There was no relationship between non directive social support and depressive symptoms
Ell, Nishmoto, Mediansky, Mantell & Hamovitch (1991)	Prospective, descriptive cohort study	n=294 Consecutive recruitment Mean age=61 year old White=83%	Record review Cancer registries Structured interviews	Univariate analysis	Non-survivors had less social integrations than survivors (t=2.21, p<0.01) Non-survivors reported more emotional support than survivors (t=2.54, p<0.01) In both survivors and non-survivors psychological

		Female=78% Lung cancer=17%			distress was negatively correlated with emotional support and social integration (range from -0.18 to 0.37, no p value given) In lung cancer patents, social support was not a statistically significant factor for survival

Summary

Research that examines social support in a lung cancer population is limited. To date, there are no studies that examine the affect that lung cancer related stigma may have on patient perceptions of social support. It is also unclear at this time if lung cancer patients feel their social support needs are met. At this time, all published studies only address social support in lung cancer from a quantitative perspective.

Social Support in Lung Cancer: Measurement Tools

Several quantitative measurement tools have been used to assess social support within a lung cancer population as depicted below (Table 9). Pertinent validation information on these measures is presented in the following table.

Table 9 *Measures and Scales to Study Social Support in Lung Cancer*

Instrument	**Concept**	**Validity**	**Reliability**
Social Support Inventory (SSI)	Social Support	Construct	0.76 – 0.88
Social Support Survey (MOS SSS)	Social Support	Construct	0.97
Supportive Care Needs Survey (SCNS)	Support Care Needs	Construct	0.87

The SSI is a tool used to measure reported social support. Possible responses for each item range from one to five and a composite score reflects the mean of the individual items. This 27-item scale has been used in several other populations including HIV, diabetes, systemic lupus erythematosus, and cancer (Fisher, LaGreca, Greco, Arfken, & Schneiderman, 1997; Scott, Fisher, & Hong, 1998; Walker, Larsen,

Zona, Govindan, & Fisher, 2004). Within the scale are four subscales that assess both directive and nondirective support. The four subscales are: 1) directive emotional, 2) directive instrumental, 3) nondirective emotional, and 4) nondirective instrumental. In the study by Walker, Zona, & Fisher (2005), the Cronbach alpha coefficient for the subscales ranged from 0.76 to 0.88.

The MOS SSS is a multidimensional self-report questionnaire that measure social support validated in a sample of 2987 adults as part of a larger study. The final product was a 19-item survey that measures functional support. After factor analysis, four subscales emerged. The subscales are tangible support, affectionate support, positive social interaction, and emotional/informational support. The Cronbach alpha for each subscale was 0.92, 0.91, 0.94, and 0.96 respectively. The Cronbach alpha for the total scale was 0.97 (Sherbourne & Stewart, 1991).

The SCNS is a 34-item survey that has previously been validated in the literature (Boyes, Girgis, & Lecathelinais, 2009). Questions are answered on a divided Likert scale. There is the option to choose no need for a particular item (1=not applicable or 2=satisfied) or some need for a particular item (3=low need, 4=moderate need, and 5=high need). The SCNS measure four domains related to supportive care needs, which are health system and information needs, such as talking with someone who have been through a similar experience, physical and daily living needs, such as not feeling well, patient care and support needs, such as a member of the healthcare team caring for the patients needs, and psychological needs, such as fear of recurrent disease. The Cronbach alpha coefficient for all four scales for the sample of lung cancer patients was 0.87 (Sanders, et al., 2010).

Summary

Both the SSS and the SCNS measure support in a multi-dimensional way. The SCNS, however, is more focused on supportive care needs rather than social support. The SSI has been extensively used in other populations.

Advantages and Disadvantages of Methods Used in the Literature

The following section will address the advantages and disadvantages of the methodological approaches found in the literature. Additionally, the strengths and weaknesses of each type of methodology will be discussed. The following areas will be addressed: 1) design, 2) sample, and 3) instrument options.

Many designs have been used to study the following key variables in lung cancer: 1) stigma, 2) social support, 3) psychological distress, and 4) symptoms/symptom burden. Designs include cross-sectional, longitudinal, as well as data collected randomized controlled trials. Both prospective and retrospective designs are found within the literature. Furthermore, both quantitative and qualitative methodological approaches have been used to study these variables of interest.

Cross-sectional designs have been used to investigate stigma, symptoms, and social support associated with lung cancer. Some of the main advantages to using cross-sectional studies are that they are time-saving, economical, and practical (Polit & Beck, 2004). Oftentimes, cross-sectional studies have a low attrition rate due to how data is collected. A major strength of this type of design is all data can be collected within one visit. A cross-sectional design may be preferable in a lung cancer population because of the often quick decline and short life expectancy of lung cancer patients. This is true even for newly diagnosed lung cancer patients. High mortality within this

population can contribute to higher attrition rates if there are several time points for data collection. Furthermore, cross-sectional studies are less of a time burden on patients who may prefer to spend their time focused on other things, like preferred activities or time spent with family.

A cross-sectional design is an appropriate way to collect descriptive data when the research question does not involve change over time. This type of design eliminates the pre/posttest effect and test/rest test subject bias. One weakness, however, is that a cross-sectional designs does not allow for questions that involve time-related causation (Polit & Beck, 2004).

Longitudinal data have been used to identify patterns in physical and psychological symptoms and severity of these symptoms in lung cancer patients. In an advanced lung cancer population, longitudinal data are difficult to collect because of attrition due to death or the time commitment from patients who are so ill. Pretest/posttest and test-retest bias is introduced in longitudinal study designs as well as an increased subject burden. Because most lung cancer patients are diagnosed at advanced stage, it can be assumed that many of these patients will have high disease burdens and therefore research burden should be minimized.

Within the reviewed studies, the majority of data were self-reported. Only one study diagnosed depression through structured clinician led interviews. Self-reported symptoms, though important, are subjective measures. This is especially problematic for symptom reporting: physical symptom reporting may be highly influenced by emotional and social distress (Koller et al., 1996). Although clinician rating of symptoms may be preferable, the limited data within the lung cancer population has shown that

nurse's assessment of patient symptoms may not be accurate (Broberger, et al., 2005).Self-report of variables is practical because it is low-cost and practical to implement in a clinical setting. It can be completed with a regularly scheduled clinic visit or taken home to be completed at the convenience of the patient. Quality self-report data can be collected through careful selection of study instruments that have been previously tested and validated in the literature and used within a lung cancer patient and caregiver population. Furthermore, patient perception of their physiological or psychological distress is important because that perception represents the "reality" of what the patient experiences.

Several measures have been used in the literature to measure symptoms, social support, and psychological variables in lung cancer patients with some used more extensively than others. Although there is consistency with measures for depression/anxiety and physiological symptoms, social support has been measured in many ways, some with open-ended questions/self-report. Because of this there is no consistency across studies as to the best or even an accurate way to measure this variable. Qualitative data on lung cancer patients experience with physical symptoms, psychological symptoms, social support and QOL is noticeably absent from the current literature. The degree to which patients find these key concepts to be problematic are important pieces of knowledge to determine the extent to which these variables are clinically relevant.

Summary and Synthesis of Methodological Knowledge

Although there are more deaths due to lung cancer than any other type of cancer in the United States per year, the literature remains scant on factors that may influence

the lung cancer experience and health outcomes for patients within this population. As the public perception of smoking continues to become more stigmatized, the effect of this stigma on lung cancer patients, both smokers and non-smokers, becomes an important factor for clinicians to understand. Participation in previous health behaviors such as smoking is not a valid reason for anyone to have suboptimal care.

At this time research to examine the effects of HRS on patients with lung cancer remains limited. Evidence about the perception of and access to social support in patients with lung cancer is scant. This is especially true when lung cancer is compared to other highly stigmatized diseases, such as HIV/AIDS, where disease-related stigma has been shown to have a negative effect on social support and patient outcomes.

Though a considerable amount of research on physical and psychological symptoms in a lung cancer population has been published, studies are limited by cross-sectional designs and use of quantitative methods (i.e. surveys) which fail to provide a complete picture of the patient experience. Samples have been limited due to the majority of participants being age 65 and being primarily Caucasian samples. No studies utilize purposeful sampling to maximize participation by non-smokers or minority populations to detect differences between groups.

Through the methodological approaches reviewed, the following implications are proposed:

(1) There is a need to systematically research the phenomenon of internal and external HRS as they relate to the experience and care of patients with lung cancer.

(2) There is a need to conduct descriptive studies to clearly describe the effect of internal and external HRS on physical symptoms, psychological symptoms, social support, and QOL for lung cancer patients.

(3) There is a need to develop an evidence base to guide future intervention studies regarding stigma in the lung cancer population.

(4) There is a need to develop intervention studies to reduce the perception of stigma in lung cancer.

In summary, lung cancer HRS is an important concept and needs to be investigated from a theoretical and evidence-based clinical viewpoint.

III. Methodology

The purpose of this section is to describe the methodology used in the dissertation study. This section will include research design, research setting, sample and sampling plan, data collection methods, and data analysis procedures.

Research Design

A cross-sectional design was used in this study. Stage and chemotherapy status was established through oral medical history or medical chart review. Internal and external stigma was measured with the Internal and External Stigma Scale (Phelan, Griffin, Jackson, et al., 2011). Physical symptoms were measured with the MD Anderson Symptom Inventory—Lung Cancer (MDASI-LC) (Mendoza et al., 2011). Psychological symptoms, depression and anxiety, was identified via the Hospital Anxiety and Depression Scale (HADS) (Smith, et al., 2002; Zigmond, 1983). Psychological distress (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004) was measured using a one item scale. Social support was examined with the Medical Outcomes Survey—Social Support Survey (MOS SSS) (Sherbourne & Stewart, 1991) and the Social Constraints Scale (Lepore, 2001; Lepore & Ituarte, 1999). QOL was measured using the Linear Analog Self-Assessment Scale (LASA) (Locke et al., 2007).

Research Setting

The study was conducted in the outpatient clinics at the Vanderbilt Ingram Cancer Center located in Nashville, TN. The number of new NSCLC patients seen at the Vanderbilt Ingram Cancer Center in a year is 314 with 131 of those having Stage IV disease. Of the 32 new cases of SCLC seen, 15 have stage IV disease (J. Roberts, 2012) and these numbers do not include patients who come to Vanderbilt after

completing some type of therapy elsewhere. Or those who have progression of disease while at Vanderbilt (J. Roberts, 2012). Patients were also identified with the assistance of LUNGevity and the Lung Cancer Alliance. PI contact information was provided via website and mail to members.

Sample and Sampling Plan

Size of Sample

Stigma in patients with lung cancer remains a relatively understudied phenomenon. LaConte et al. (2008) found that approximately 30% of patients with lung cancer experienced feelings of stigma. For this study a convenience sample of 62 participants was recruited from a combination of patients at the Vanderbilt Ingram Cancer Center and from LUNGevity and the Lung Cancer Alliance.

Criteria of Sample Selection

The targeted population was adult patients with lung cancer. Inclusion criteria included: (1) 18 years old; (2) received chemotherapy for lung cancer; (3) speaks English. Exclusion criteria include the following; (1) have not received chemotherapy for lung cancer; (2) documentation of cognitive impairment that would preclude the ability to provide informed consent; (3) have any other active cancer, (4) enrolled in hospice.

The underlying principles for the proposed exclusion criteria were as follows: (1) Patients who receive chemotherapy have an advanced stage of lung cancer and therefore have a higher degree of symptom burden than those with early stage disease (Degner & Sloan, 1995). Patients with curable disease may experience different treatment strategies from those with non-curable disease and therefore have different physical and emotional responses. These varying responses may be potential

confounding variables in the proposed research study. (2) Patients with documented cognitive impairments may not be able to fully understand informed consent and excluding these patients will help avoid any confounding effects on the self-reported subjective measures in the proposed research study. (3) Patients with other active cancers may experience different treatment regimens than those who only have lung cancer. Patients with other active diseases may therefore experience different physical or emotional responses to treatment and the varying responses may be potential confounding variables in the proposed research study. (4) Patients enrolled in hospice have different goals of care and receive different treatment interventions that may change the number or perception of physical or psychological symptoms.

Methods for Subject Recruitment

Patients were identified by the PI or physician by screening patients at the Vanderbilt-Ingram Cancer Center (VICC). Patients were recruited via the following steps: (1) The PI visited with medical oncologist at VICC and told them about the purpose and procedures of the study. (2) The medical oncologist told potential participants about the study. (3) The PI screened and recruited participants who expressed interest in the study using the eligibility criteria form.

Additional patient subjects were recruited via the internet through LUNGevity, and the Lung Cancer Alliance. Study measures were loaded onto Red Cap, an online program, and contact information to the PI was placed on relevant websites.

Strategies to Ensure Human Subject Protection

Approval from the Institutional Review Board (IRB) at Vanderbilt University and the Scientific Review Committee (SRC) at the VICC were obtained prior to recruitment. Participation was open to all patients who had received chemotherapy to treat lung cancer and there was no exclusions based on gender, race, or ethnicity. No risks were anticipated for participants other than time inconvenience. Participants could withdraw for any reason by informing the PI of their desire to do so.

Compliance to study protocol was maintained by the PI through meetings with the PI's advisor, Dr. Sheila Ridner. Random selections of participant data were examined and the PI reported any study related issues to the advisor which included difficulty with recruitment, retention, data collection, or data entry or any other problem.

Local Participants

The PI obtained informed consent of all participants prior to data collection. The following steps were used: (1) The PI explained the study to potential participants. (2) Potential participants were provided with a hard copy of the consent to read and review. (3) The PI provided all potential participants with the opportunity to ask questions during and after their review of the informed consent. (4) The PI answered all questions about the study. (5) Potential participants agreed to be in the study and signed the informed consent with the PI serving as witness. To ensure confidentiality, informed consent was obtained in a private location.

Distance Participants

Participants who do not receive care at VICC contacted the PI via a toll-free study number or by email. (1) The PI explained the study to potential participants. (2)

The patient was given the opportunity to answer questions and the PI answered all questions. (3) Eligible patients who participated were sent a link to a REDCap survey via a designated email address. (4) Informed consent was on the REDCap survey so no hard copy of the consent will be maintained by the PI.

To maintain participant confidentiality, the PI contacted, screened, obtained informed consent, and conducted data collection in a private area. All data files were saved in hard copy format and password protected electronic format. Hard copies of data are stored in a locked file cabinet. All data collected was coded and given a participant number so that the participant's name and other identifiable information was not associated with the data. The PI, the PI's advisor, and the statistician (member of dissertation committee) had access to the electronic data files. Only the PI and the PI's advisor had access to the hard copy data. The hard copies of the data will be stored in a locked cabinet and the PI and the PI's advisor will maintain the electronic data in the password-protected database.

Data Collection Methods

Procedures

Local Participants

The researcher contacted subjects using a script and possible participants were screened using an eligibility form. Once an exclusion criterion was met, no other information was gathered. Eligible subjects were given the Short Portable Mental Status Questionnaire. If the patient was eligible he or she was provided an informed consent

and interested participants signed the consent. Patients then answered the study measures. All data collected from participants will be locked and stored in a safe place.

Distance Participants

Distance participants were screened verbally over the phone to determine eligibility. The PI administered the Short Portable Mental Status Questionnaire over the phone to eligible patients. If the patient passed the screening, an email with a REDCap link was sent to the participant. One week later a reminder email was sent if he or she has not completed the study measures.

Instruments

The instruments used to measure stigma, physical symptoms, psychological symptoms, social support, and QOL are listed below. The content, reliability, and validity of the selected instruments are discussed.

Stigma This scale consisted of 6 questions and was adapted from previously used stigma and blame scales to measure general cancer stigma, self-blame (internal stigma) and perceived blame (external stigma) in veteran male colorectal cancer patients. Two general cancer stigma items frequently endorsed by cancer patients were adapted from the Experiences of Rejection and Stigma Measure (Fife & Wright, 2000). Two additional general cancer stigma items were selected from other stigma literature (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Phelan, Griffin, Hellerstedt, et al., 2011; Szmukler et al., 1996). One item was selected to measure self-blame (internal stigma) and one item was selected to measure the perception of blame from others

(external stigma). Both items were adapted from the Experiences of Rejection and Stigma Measure (Fife & Wright, 2000).

In this dissertation study, items on this scale were individually scored and individually correlated with other study measures. Because the scale was not summed no Cronbach's alpha was generated for this study measure.

M.D. Anderson Symptom Inventory—Lung Cancer. The MDASI-LC consisted of the 13 core symptom items found on the original MDASI measurement instrument as well as six core MDASI symptom interference items and three lung cancer specific questions (coughing, constipation, and sore throat) (Mendoza, et al., 2011). Scores for both symptom severity and symptom interference were calculated although symptom interference was not part of this dissertation study. The Cronbach's alpha for the symptom severity portion of the MDASI-LC in this study was 0.92 and for the symptom interference was 0.93.

Psychological Distress. Psychological distress was measured with the one item Distress Thermometer (DT) developed by the National Comprehensive Cancer Network (NCCN). Patients were asked to rate their distress on a scale from 0 to 10.

Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale (HADS) is a self-report instrument that was developed to measure symptoms of depression and anxiety in the non-psychiatric hospitalized population (Zigmond, 1983). In this study depression and anxiety subscales were used as separate variables in the statistical analysis and the total scale score for the HADS was not used in any statistical analysis. The Cronbach's alpha for the depression subscale was 0.83 and for the anxiety subscale was 0.86.

Quality of Life Scale (Linear Analog Self-Assessment LASA). The LASA is a 5-item, psychometrically validated, linear analog scale. In this study individual items on this instrument were correlated with other study measures.

Social Support

Social support was measured by two instruments.

Medical Outcomes Survey—Social Support Scale. The MOS SSS is a multidimensional self-report questionnaire that measure social support validated in a sample of 2987 adults as part of a larger study (Sherbourne & Stewart, 1991). The summed score from this scale was used in statistical analysis. The Cronbach's alpha for this measure in this dissertation study was 0.95.

Social Constraints Scale. The Social Constraints Scale consists of 15 items that measures social constraints due to disclosure of a cancer diagnosis (Lepore, 2001; Lepore & Ituarte, 1999). This scale specifically measures behaviors that the spouse or partner of a patient may participate in after a cancer diagnosis, such as willingness to discuss the diagnosis, and how often the spouse engages in these behaviors. In this study, the summed score was used in statistical analysis. The Cronbach's alpha for this instrument in this study was 0.94.

Demographic and Background Information Form. This form included age, gender, race, level of education, marital status, employment status, current medications, smoking history, and other pertinent risk factor exposure information. Information for this form was collected via patient or nurse interview.

Lung Cancer Disease and Treatment Information Form. This form included date of diagnosis and type of lung cancer, TNM stage, and tumor type. It also included types and dates of treatments and treatment toxicity information.

Table 10 *Data Resources and Data Collection Methods*

Concepts Measured	Measurement Variables	Measurement Instruments	Data Collection Methods
Stigma	Stigma	Stigma and Self-Blame Scale	Subject Self-report
Symptoms	Physical Symptoms	MD Anderson Symptom Inventory-Lung Cancer (MDASI-LC)	Subject Self-report
	Psychological Symptoms	Hospital Anxiety and Depression Scale (HADS)	Subject Self-report
Psychological Distress	Psychological Distress	NCCN Distress Thermometer	Subject Self-report
Social Support	Social Support	Medical Outcomes Survey Social Support Survey (MOS SSS)	Subject Self-report
		Social Constraints Scale	Subject Self-report
Quality of Life	Quality of Life	Linear Analog Self-Assessment Scale (LASA)	Subject Self-report
	Demographic Data	Demographic and Background Information Form	Researcher Interview
	Cancer Treatment Data	Lung Cancer Disease & Treatment Information Form	Researcher Medical Chart Review

Data Analysis

The PI entered the data into SPSS version 23. Data validation and data cleaning was used to check for outliers, wild codes, and internal data consistency (Polit & Beck, 2004). To address missing data, the PI determined the distribution and pattern of the missing data and a decision was made based on the extent and patterns of the missing values. Cases which contained no or minimal data were eliminated and one variable (function) was eliminated due to paucity of collected data and interpretation difficulties

(Polit & Beck, 2004). Decisions regarding missing data were made after discussions with the statistician.

Descriptive statistics were used to describe the sample and to check the distribution of continuous variables, such as demographic information and self-report measure scores. Mean and standard deviation were used to describe participant age. All other continuous variables were skewed and median and interquartile range were used to describe these variables. Categorical and ordinal data were summarized using frequency distributions. In addition, ordinal scale data summaries included median and inter-quartile range when appropriate. Data were then analyzed according to the proposed aims of the study.

1. What are the associations between internal and external HRS and (a) symptoms, (b) social support, and (c) QOL in patients with advanced lung cancer?

Data Analysis Methods: Spearman rho correlations were used to determine relationships between stigma and subsequent variables.

2. What are the associations between physical symptoms and (a) social support and (b) QOL in patients with advanced lung cancer?

Data Analysis Methods: Spearman correlations were used to determine relationships between physical symptoms and subsequent variables.

3. What are the associations between psychological symptoms and (a) social support and (b) QOL in patients with advanced lung cancer?

Data Analysis Methods: Spearman rho correlations was then used to determine relationships between psychological symptoms and subsequent variables.

CHAPTER IV

FINDINGS

Findings of the study based on statistical analysis are found in this chapter. In the first section, the study participants and study measure scores are described. In the second section the results of the study aims are presented.

Sample Characteristics

In this section the demographic characteristics, health behaviors characteristics, and sample scores will be described.

A convenience sample of 67 adult patients with lung cancer were recruited from the Vanderbilt-Ingram Cancer Center as well as via nation-wide e-mail and paper mail announcements through the Lung Cancer Alliance and the LUNGevity Foundation. Data were collected from November 2012 through August 2014. All participants received some type of chemotherapy as treatment for their disease.

Demographic Characteristics

Demographic data were collected (see Table 11). Patients ranged in age from 42-83 years with a mean age of 64.45 (8.69) years. The majority were female (59.7%), white (87.1%), and married (77.4%). Most participants in this study were highly educated with 21.0% completing some college and 43.5% completing college or a higher degree. Approximately 40% of patients lived in a rural setting (38.7%).

Table 11 Demographics of Study Sample (n=62)

Characteristic	Mean	Standard Deviation
Age (years)	64.45	8.69
Characteristic		Frequency (%)
Gender	Male	24 (38.7)
	Female	37 (59.7)
Race	American Indian/Alaskan Native	2 (3.2)
	Asian	1 (1.6)
	Black or African American	4 (6.5)
	White	54 (87.1)
Education	Some high school	4 (6.5)
	High school graduate	18 (29.0)
	Some college	13 (21.0)
	College degree or higher	27 (43.5)
Marital Status	Single	5 (8.1)
	Single, living with partner	1 (1.6)
	Married	48 (77.4)
	Widowed	7 (11.3)
Employment	Full time	14 (22.6)
	Part time	5 (8.1)
	Homemaker	1 (1.6)
	Retired	30 (48.4)
	Unemployed	3 (4.8)
	Other	8 (12.9)
Residence	Urban	34 (54.8)
	Rural	24 (38.7)

Health Behavior Characteristics

In this study, smoking was defined as smoking more than 100 cigarettes in a lifetime. Smoking data are presented in Table 12.

The majority of patients reported a smoking history (66.1%). Of those patients who report a history of smoking, however, 90.2% reported they had stopped smoking prior to the study assessment. Within those who report a smoking history, 59.7% reported smoking cigarettes and 6.5% reported smoking marijuana.

Of those who reported a history of smoking, the number of years smoked ranged from 2-52 years. Patients reported a history of using 1-60 cigarettes per day with a mean of 27.1 (14.5) cigarettes per day. The mean number of years ago that patients in this study stopped smoking ranged from 1-47 years. Only seven patients in this study reported they were currently smoking.

Table 12 *Health Behavior Characteristics (n=62)*

Characteristics	Yes		No	
	Frequency (%)		**Frequency (%)**	
Have you ever smoked?	41 (66.1)		19 (30.6)	
Have you quit smoking	37 (59.7)		7 (11.3)	
Do you drink alcohol?	20 (32.3)		41 (66.1)	
Have you quit using alcohol?	3 (4.8)		12 (19.4)	
Characteristic	**IQR**	**Median**	**Min**	**Max**
Smoking History (years)	15-40	27.50	2	52
Quit Smoking (years ago)	4-29	15.50	1	47
Number of Cigarettes (per day—past)*	20-40	22.00	1	60
Number of Cigarettes (per day—current)*	n/a	10.00	3	12

*n=3

Descriptive Summaries of Scores from the Study Instruments

Scores on study instruments are summarized in Table 14. Stigma only data are in Table 13.

STIGMA. Higher scores indicate a higher degree of perceived stigma. In this study, 69.4% of patients reported they did not feel that other people avoided them because of a diagnosis of lung cancer. When patients were asked if they felt others were awkward or tense around them because of lung cancer, 46.8% reported this was not at all true and 29.0% reported this was a little true. Patients were asked if they felt that there is a stigma associated with lung cancer and 46.8% of patients said this was not at all true while 33.9% of patients said this was completely true. Patients were asked if they felt that people thought less of someone with lung cancer and 56.5% reported this was not at all true. In this study sample only 11.3% of patients reported it was completely true that they were to blame for their disease compared to 58.1% feel that is not at all true. Only 14.5% of patients reported they feel it is completely true that others blame them for their diagnosis of lung cancer while 40.3% feel this is not at all true.

Table 13 *Sample Scores on Stigma Scale*

	Not at all True N (%)	A Little True N (%)	Somewhat True N (%)	Completely True N (%)
External Stigma				
I feel that some people avoid me because I have lung cancer.	43 (69.4)	8 (12.9)	7 (11.3)	4 (6.5)
I feel that some people feel awkward and tense around me because I have lung cancer.	29 (46.8)	18 (29.0)	9 (14.5)	6 (9.7)
I feel there is a stigma that goes with my condition.	29 (46.8)	6 (9.7)	6 (9.7)	21 (33.9)
I feel that most people think less of a person who has lung cancer.	35 (56.5)	10 (16.1)	10 (16.1)	7 (11.3)
Internal Stigma				
I feel I am to blame for my disease.	36 (58.1)	8 (12.9)	11 (17.7)	7 (11.3)
I feel other people think I am to blame for my disease.	25 (40.3)	16 (25.8)	11 (17.7)	9 (14.5)

MOS SSS. In this study, scores ranged from 2.2 to 5.0 (scale range 0 – 5). Higher scores indicate a patient perceives high access to social support. The patients in this sample displayed a median of 4.7 (IQR = 2.2-4.9). The high median score on the MOS SSS indicates that within this sample the majority of patients felt they had access to social supports. (see Table 14)

SCS. Lower scores on the SCS indicates a patient perceives their main caregiver to be more supportive (scale range 0-150). Patients in this sample displayed a median score of 12.0 (IQR = 4.0-39.0). The low median score on this scale show that most patients in this study felt their main caregiver was supportive after their diagnosis of lung cancer. (see Table 14)

MDASI-LC. Higher scores indicate a higher symptom burden severity or a higher interference of symptoms on the patient's feelings and function. In this sample, the

median score for the symptom severity scale was 1.4 (IQR = 0.5-2.7) and the median score for the symptom interference scale was 1.7 (IQR = 0.2-3.5), indicating the majority of patient's experienced extremely mild symptom burden severity and symptom interference. (see Table 14)

HADS. Higher scores on the HADS indicate more symptoms of depression or anxiety. On the depression subscale, scores ranged from 0 to 14.0 (median=3.0; IQR = 2.0-7.0) and on the anxiety subscale, scores ranged from 0 to 20.0 (median=6.0; IQR = 3.0-8.0). Data indicate most patients in this study had relatively few symptoms of depression or anxiety. (see Table 14)

DISTRESS THERMOMETER. Patients were asked to rate their level of distress. On this scale, lower scores indicate a lower level of overall distress. The median level of distress was 3.0 indicating that most participants were experiencing mild to moderate levels of distress. (see Table 14)

LASA. LASA was used to examine QOL for patients in several specific domains and general QOL. A higher scores indicates a higher level of QOL (Physical domain, M=6.6; Emotional domain, median = 8.0, IQR = 5.8-10.0; Spiritual domain, median = 9.0; IQR = 7.6-10.0; Intellectual domain, median = 8.0, IQR = 7.0-10.0; Overall domain, median = 8.0, IQR = 7.0-9.0). Within this sample, most participants reported a moderate to high degree of QOL in both specific domains and overall QOL. (see Table 14)

Table 14 *Internal Consistency and Sample Scores on the Instruments*

Instrument (# items)	N	Median	IQR (25, 75)		Min	Max	Cronbach's Alpha
MOS SSS	62	4.7	2.2	4.9	2.2	5.0	.95
Social Constraints Scale	60	12.0	4.0	39.0	0.0	106.0	.94
MDASI-LC							
Severity (16)	63	1.4	0.5	2.7	0.0	7.4	.92
Interference (6)	62	1.2	0.2	3.5	0.0	7.5	.93
HADS							
Depression (7)	58	3.0	2.0	7.0	0.0	14.0	.83
Anxiety (7)	56	6.0	3.0	8.0	0.0	20.0	.86
Distress Thermometer	61	2.0	0.0	5.0	0.0	9.0	--
LASA (5)							
Physical item (1)	62	7.0	5.0	8.0	2.0	10.0	--
Emotional item (1)	62	8.0	5.8	10.0	1.0	10.0	--
Spiritual item (1)	62	9.0	7.8	10.0	2.0	10.0	--
Intellectual item (1)	62	8.0	7.0	10.0	2.0	10.0	--
Overall item (1)	62	8.0	7.0	9.0	1.0	10.0	--

Findings Related to Study Aims

Aim 1: To examine the relationship between patient perceived internal and external HRS, physical symptoms, psychological symptoms, social support, and QOL.

Correlations of external HRS with patient scores on the MDASI-LC (symptom severity only), HADS, distress thermometer, MOS SSS, and SCS are shown in Table 16. None of the correlations with questions related to external HRS and the MDASI-LC or the HADS were statistically significant ($p > 0.05$). (see Table 15)

Three of the four scale items related to external stigma showed statistically significant positive correlations with patient distress. Those questions include: 1) patient perception that others feel awkward or tense around them ($r_s(63) = .30$, $p = .018$), 2) patient perception that there is a stigma with lung cancer ($r_s(63) = .26$, $p = .047$), and 3) patient perception that others think less of a person with lung cancer ($r_s(63) = .30$, $p =$

.020). As the patient perception of external stigma increased, patient distress also increased. (see Table 15)

Responses to the individual external stigma questions showed negative correlations with the MOS SSS. As patient perception of external stigma increased patient reported access to social supports decreased. The strongest correlation was found between perceiving there is a stigma associated with lung cancer and access to social support ($r_s(62) = -.44$, $p < .001$). (see Table 15)

Statistically significant positive correlations were found between three individual questions related to external stigma and scores on the SCS. This indicates that as patient perception of external stigma increases the perception that the main caregiver is less supportive also increases or that as the perception of support from the main caregiver decreases the perception of external HRS increases. (see Table 15)

Table 15 *Correlations of External HRS with Physical Symptoms, Psychological Symptoms and Social Support*

	Physical Symptoms	Depression	Anxiety	Distress	Social Support	
					MOS SSS	SCS
I feel that some people avoid me because I have lung cancer.	-.17 (.200)	-.01 (.950)	-.05 (.713)	.19 (.147)	-.26 (.044)	.25 (.055)
I feel that some people feel awkward and tense around me because I have lung cancer.	-.03 (.831)	.03 (.848)	.02 (.883)	.30 (.018)	-.35 (.006)	.39 (.002)
I feel there is a stigma that goes with my condition.	-.04 (.791)	-.001 (.979)	.02 (.918)	.26 (.047)	-.43 (.001)	.33 (.011)
I feel that most people think less of a person who has lung cancer.	.01 (.915)	-.004 (.979)	.06 (.689)	.30 (.020)	-.44 (<.001)	.36 (.005)

* Note: Values in cells are r_s (p-value)

Correlations of external HRS with QOL are shown in Table 16. Almost all domains of QOL showed statistically significant negative correlations with patient's perceptions of external stigma. The strongest association was observed for the patient's perception that some people feel awkward and tense due to a diagnosis of lung cancer with overall QOL ($r_s(63) = -.47$, $p < .001$). As patient perception of external stigma increased, in general, the patient's perception of QOL decreases, or conversely, as the

patient's perception of most domains of QOL decreases, the perception of external HRS increased.

Table 16 *Correlations of External HRS with Domains of QOL*

	Physical Domain	Emotional Domain	Spiritual Domain	Intellectual Domain	Overall QOL
I feel that some people avoid me because I have lung cancer.	-.26 (.041)	-.21 (.108)	-.16 (.210)	-.30 (.018)	-.38 (.002)
I feel that some people feel awkward and tense around me because I have lung cancer.	-.36 (.004)	-.40 (.001)	-.36 (.003)	-.46 (<.001)	-.47 (<.001)
I feel there is a stigma that goes with my condition.	-.36 (.004)	-.29 (.024)	-.27 (.033)	-.30 (.019)	-.38 (.002)
I feel that most people think less of a person who has lung cancer.	-.40 (.001)	-.34 (.006)	-.33 (.008)	-.39 (.001)	-.36 (.004)

* Note: Values in cells are r_s (p-value)

Table 17 shows the correlations of patient perception of internal stigma related to a lung cancer diagnosis with physical symptoms, psychological symptoms, and social support. No statistically significant associations of the two internal stigma items with physical or psychological symptoms nor with the perception of support by the main caregiver as measured by the SCS measurement tool were found. There was a single statistically significant inverse correlation between the perception that others blame the patient for their disease with the scores on the MOS SSS ($r_s(62) = -.29$, $p = .025$) indicating that when a patient feels others think he or she is to blame for their disease they perceives less access to social supports or that when a patient perceives less access to social supports the perception that one is to blame for lung cancer increases.

Table 17 *Correlations of Internal HRS with Physical Symptoms, Psychological Symptoms and Social Support*

	Physical Symptoms	Depression	Anxiety	Distress	Social Support	
					MOS SSS	SCS
I feel I am to blame for my disease.	-.007 (.956)	-.04 (.800)	-.26 (.067)	-.05 (.732)	.02 (.858)	-.15 (.272)
I feel other people think I am to blame for my disease.	-.14 (.287)	-.12 (.401)	-.20 (.164)	.24 (.064)	-.29 (.025)	.23 (.083)

* Note: Values in cells are r_s (p-value)

The correlations of internal HRS with QOL are shown in Table 18. Blaming oneself for the disease showed an inverse association with scores for physical QOL ($r_s(63) = -.41$, $p = .001$) and emotional QOL ($r_s(63) = -.27$, $p = .031$). Feeling like others blamed the patient for lung cancer showed an inverse association with physical QOL (r_s $(63) = -.30$, $p = .021$), intellectual QOL ($r_s(63) = -.26$, $p = .046$), and overall QOL (r_s $(63) = -.31$, $p = .016$). QOL decreased for patients as the perception of internal stigma related to a diagnosis of lung cancer increased or as the perception of internal stigma increased for patients, QOL decreased.

Table 18 *Correlations of Internal HRS with Domains of QOL*

	Physical Domain	Emotional Domain	Spiritual Domain	Intellectual Domain	Overall QOL
I feel I am to blame for my disease.	-.41 (.001)	-.27 (.031)	-.14 (.269)	-.10 (.462)	-.23 (.067)
I feel other people think I am to blame for my disease.	-.30 (.021)	-.20 (.118)	-.21 (.101)	-.26 (.046)	-.31 (.016)

* Note: Values in cells are r_s (p-value)

Aim 2: To examine the associations between physical symptoms and social support, and QOL in patients with advanced lung cancer.

Associations of scores on the measure of social support and QOL with reports of physical symptoms are shown in Table 20. No statistically significant correlations were found. (See Table 19)

Table 19 *Correlations of Physical Symptoms with Social Support and QOL*

	Physical Symptoms
MOS SSS	-.18 .188
SCS	-.09 .502
QOL	
Physical Domain	-.13 .334
Emotional Domain	-.05 .685
Spiritual Domain	-.20 .123
Intellectual Domain	-.04 .739
Overall QOL	-.04 .745

* Note: Values in cells are r_s (p-value)

Aim 3: To examine the associations between psychological symptoms and social support, QOL, and function in patients with advanced lung cancer.

Associations of scores on the measures of social support and QOL with HADS depression scores are shown in Table 20. No statistically significant correlations were found. (See Table 20)

Table 20 *Correlations of Social Support and QOL with HADS Depression Scores*

	HADS Depression Score
MOS SSS	-.26 (.062)
SCS	.05 (.707)
QOL	
Physical Domain	-.04 (.788)
Emotional Domain	.09 (.502)
Spiritual Domain	-.12 (.400)
Intellectual Domain	.02 (.886)
Overall QOL	.02 (.903)

* Note: Values in cells are r_s (p-value)

Associations of score on the measures of social support and QOL with HADS anxiety scores are shown in Table 22. No statistically significant correlations were found. (See Table 21).

Table 21 *Correlations of Social Support and QOL with HADS Anxiety Scores*

	HADS Anxiety Scores
MOS SSS	-.14 (.324)
SCS	-.12 (.420)
QOL	
Physical Domain	.14 (.319)
Emotional Domain	.10 (.465)
Spiritual Domain	-.14 (.318)
Intellectual Domain	.06 (.697)
Overall QOL	.06 (.689)

* Note: Values in cells are r_s (p-value)

Associations of scores on the measure of distress and social support and QOL with distress are shown in Table 23. No statistically significant associations were found of scores on the MOS SSS and SCS with the distress thermometer score. Statistically significant inverse associations of the QOL scores with the distress score were observed ($r_s(63) = -.32$, $p = .013$), emotional QOL ($r_s(63) = -.63$, $p < .001$), spiritual QOL ($r_s(63) = -.50$, $p < .001$), intellectual QOL ($r_s(63) = -.61$, $p < .001$), and overall QOL ($r_s(63) = -.60$, $p < .001$). As distress increased, patient QOL decreased in all four domains of QOL as well as overall QOL or as QOL decreased patient distress increased. (See Table 22)

Table 22 *Correlations of Distress and Social Support with QOL*

	Distress Thermometer Scores
MOS SSS	-.13 (.321)
SCS	.16 (.239)
QOL	
Physical Domain	-.32 (.013)
Emotional Domain	-.63 (<.001)
Spiritual Domain	-.50 (<.001)
Intellectual Domain	-.61 (<.001)
Overall QOL	-.59 (<.001)

* Note: Values in cells are r_s (p-value)

CHAPTER V

DISCUSSION

A discussion of study findings is presented in this chapter and outlined as follows: (a) critique of study design, (b) sample (c) aims, (d) study limitations and alternative explanations, (e) implications, and (f) recommendations for future research.

Critique of Study Design and Methods

The following section will address the credibility, rigor and validity of the research design and methods used in this dissertation study. Additionally, strategies for minimizing weakness are identified and discussed.

A cross-sectional design was selected for this dissertation study. One reason this design was chosen was to minimize attrition by collecting all data during a single patient visit. Despite advances in treatment, advanced lung cancer patients continue to have a high mortality rate and therefore attrition can be problematic in longitudinal studies in this population. Additionally, a cross-sectional design limits the time burden patients with advanced lung cancer spend completing study instruments. This allows patients to spend more time with family or friends or engaged in activities they find enjoyable. By selecting a cross-sectional design, pre/posttest effect and test/retest subject bias was avoided. Finally, this study did not attempt to address changes in perception of stigma or other variables over time making a cross-sectional design an appropriate choice. However, the inability to address time-related causation is a weakness in the design

choice. The patients who enrolled in this study were all at various points in their treatment continuum. Some were just beginning chemotherapy and some had exhausted all traditional treatments and were enrolled in experimental drug trials. Stigma, physiological and psychological variables, as well as distress and social support may be different at different points in the treatment trajectory and study was not able to detect these differences. To minimize this weakness, appropriate statistical analysis was used and results were interpreted to represent the data as collected.

Self-report measures were chosen to collect data for this dissertation study. The limited data available in patients with lung cancer indicate that nurse assessment of patient symptoms may not be accurate (Broberger, et al., 2005). To ensure the quality of self-report data and to minimize any weakness from collecting only subjective, self-report data in this dissertation study, instruments were carefully selected through a thorough review of all available instruments for all concepts measured. The PI, in conjunction with the dissertation chair, then selected the best available instruments taking into account the reliability and validity of each instrument and its previous use in patient with lung cancer. The patient perception of physiological and psychological symptoms is extremely important. Like pain, which can only be defined by the patient, physiological and psychological symptoms are also a patient-centered experience and are best measured through the perception of the individual patient. Only the individual patient experiences the “reality” of their own symptoms.

Social support is an understudied concept in patients with lung cancer. Because of this, there is little prior data on which to base the selection of instruments. A lack of previously tested social support measures is a weakness in the methods of this study.

Two measures of social support were chosen for this study in order to minimize this weakness.

Summary and Synthesis of Study Design and Methods

Although there are more deaths due to lung cancer than any other type of cancer in the United States per year, the literature remains scant on factors that may influence the lung cancer experience and health outcomes for patients within this population. As the public perception of smoking continues to become more stigmatized, the effect of this stigma on lung cancer patients, smoking and non-smoking, becomes an important factor for clinicians to understand. Participation in previous health behaviors such as smoking is not a valid reason for anyone to have suboptimal care.

At this time there is a paucity of research to examine the effects of stigma on lung cancer patients. Evidence about the perception and actual social support needs of lung cancer patients is also lacking, especially when compared to other stigmatized diseases, such as HIV/AIDS, where disease-related stigma has been shown to have a negative effect on social support and patient/caregiver outcomes

A cross-sectional design was the most appropriate choice for this study to minimize attrition and time burden on patients with advanced lung cancer. Unfortunately this limits the scope of the study to a single time point and it was unable to detect changes in the concepts measured over the treatment trajectory. Self-report measures were selected to reflect the “reality” of the experience of patients with advanced lung cancer. All measures chosen were subjective in nature but study instruments were carefully selected to minimize the lack of objective data collected in the study.

Sample Characteristics

This study recruited patients with lung cancer who had received chemotherapy as part of their treatment. The demographic characteristics of this sample were similar to other samples reported in the literature when stigma was a primary variable. The mean age in this study was 64.45 years which is similar to the mean age of 62.15 reported by Chambers et al.'s (2015), 64 years reported by Gonzalez & Jacobsen (2010, 2012), 63 years reported in Lebel et al.'s (2013) study, and 65.6 years reported in LoConte et al.'s (2008) study. In this study, 59.7% of patients identified as female. Although most studies that investigated stigma reported higher participation by women, the percentage varied within the literature. The percent of females in this study is lower than Brown-Johnson, Brodsky, & Cataldo (2015) (75.2%), Brown & Cataldo (2013) (100%), Cataldo & Brodsky (2013) (74%), Chambers et al. (2015) (88%), and similar to Carter-Harris (2014) (62.4%) and Lehto (2014) (55%). The most recent data from the American Cancer Society (2015) indicates the incidence and mortality rates for lung cancer remain higher for men than for women.

The majority of patients in the present study reported a smoking history (66.1%) which was lower than the majority of currently published studies investigating stigma in lung cancer. Other published studies reported higher rates of smoking history including Brown-Johnson, Brodsky & Cataldo (2015) (80% former smokers), Cataldo & Brodsky (2013) (79% current or former smokers), Cataldo, Jahan & Pongquan (2012) (79.5% ever smokers), and LoConte et al. (2013) (80.2% with a smoking history). Only two studies reported similar percentages of smoking history including Carter-Harris (2014)

(67.7% with a smoking history) and Gonzalez & Jacobsen (2010, 2012) (71.6% with a smoking history).

Of the 62 patients included in the analysis for this study, the majority identified as white (87.1%) with a minority identifying as black (6.5%). This is consistent with all other reviewed studies investigating HRS. The percentage of patients who identified as white in previously published studies ranges from 82.8% (Carter-Harris, 2013) to 99% (Chapel, Zeibland, & McPherson, 2004). According to the U.S. Census Bureau (2014), 72.4% of the American population is white, 12.6% is black, and 4.8% identify as Asian. The race demographics of this study sample indicate that minorities are underrepresented. This is of concern as both black men and women continue to have a higher incidence of lung cancer compared to white men and women as well as a higher mortality rate from lung cancer when compared to white men and women (American Cancer Society, 2015). The experience of stigma associated with a lung cancer diagnosis may be different for black Americans for cultural or other reasons. Efforts to improve minority participation in stigma studies is crucial in the future to develop a greater understanding of how stigma may play a role after a diagnosis of lung cancer in minority patients.

Aims

1. To examine the relationship between internal and external HRS, physical symptoms, psychological symptoms, social support, and QOL in patients with advanced lung cancer.

Associations between Stigma and Symptoms

This study builds on the current body of knowledge that contributes to the understanding of HRS as it relates to the experience of symptoms that accompany a lung cancer diagnosis. Unlike previously published studies, this dissertation study attempted to explain the association of HRS to symptoms by specifically examining two different types of HRS: internal stigma (self-blame) and external stigma (perception of blame from others).

Physical Symptoms. Results of this study showed no statistically significant correlations between internal or external HRS and physical symptoms experienced by patients with lung cancer. Multiple studies that specifically examine symptom burden in an advanced lung cancer population report that these patients experience a high number of symptoms related to disease or treatment (Cooley, Short & Moriarty, 2002; Cooley, Short & Moriarty; 2003, Iyer, Taylor-Stokes & Roughley, 2013, Iyer, Roughley, Rider & Taylor-Stokes, 2014; Ma et al., 2014; Tishelman et al., 2005; Tishelman, Petersson, Degner & Sprangers, 2007). Patients in this study, however, reported a low symptom burden experience. Findings from this study are inconsistent with one published report that found an association between physical symptoms and HRS (Cataldo & Brodsky, 2013).

A combination of factors likely explains the relatively mild symptom burden experienced by this study sample in comparison to other published studies. The MDASI-LC asks patients to rate symptom severity only in the previous 24 hours and the majority of patients in this sample completed the questionnaire on the day they returned to the clinic to receive chemotherapy, therefore, the prior 24 hours was relatively free of

symptoms. It is also plausible that the symptoms in this sample were consistently well managed by the treating physician thereby lowering the overall symptom burden experienced by the patients. The majority of patients in this study received care at the Vanderbilt-Ingram Cancer Center from the same physician.

Psychological Symptoms. No statistically significant correlation was found between the psychological symptoms of depression and anxiety and HRS. Additionally, internal stigma was not significantly correlated with distress. Unlike other published studies, patients in this sample reported few symptoms of depression or anxiety. Both depression and anxiety have been reported to be high in both advanced cancer populations (Arrieta et al., 2013; Haun et al., 2014; Lekka et al., 2014; Lie et al., 2015; Shi, Gu, Hou & Hu, 2014) and in lung cancer populations (Haun et al., 2014; Lekka et al., 2014).

Findings on the relationship between HRS and depression and HRS and anxiety differ from those previously published. Several studies have shown a significant relationship between HRS and depression (Cataldo & Brodsky, 2013; Gonzalez & Jacobsen, 2010, Gonzalez & Jacobsen, 2012; Lebel et al., 2013; LoConte et al., 2008) and HRS and anxiety (Cataldo & Brodsky, 2013; Cataldo, Jahan & Pongquan, 2012; LoConte et al., 2008). Other published reports have also shows that HRS plays a unique role in HRS experienced by patients with lung cancer (Cataldo & Brodsky, 2013; Gonzalez & Jacobsen, 2012).

One reason the findings from this study may be inconsistent from previously published studies is because the instruments used to measure depression and anxiety differ from other published studies. Although the most common instrument used to

measure depressive and anxiety symptomology in a lung cancer population is the HADS, studies investigating HRS in patients with lung cancer typically selected the CES-D to measure depression (Brown-Johnson, Brodsky & Cataldo, 2014; Cataldo & Brodsky, 2013; Cataldo, Jahan & Pongquan, 2012; Chambers et al., 2015) and the Spielberger State Anxiety Scale (Brown-Johnson, Brodsky & Cataldo, 2014; Cataldo & Brodsky, 2013). At this time a large portion of the stigma literature involves one particular researcher (Cataldo) and this is a significant factor in the choice of measurement instruments used to study stigma in patients with lung cancer.

This study specifically focused on patients with advanced lung cancer. Other studies investigating HRS and depression had fewer patients with advanced lung cancer in the sample (Gonzalez & Jacobsen, 2010, Gonzalez & Jacobsen, 2012) or included other types of cancer in the sample (Lebel et al., 2013).

Patients in this study reported mild to moderate levels of distress. This study found that distress was positively and significantly correlated with three questions which examined external HRS: 1) patient perception that others feel awkward or tense around them, 2) patient perception that there is a stigma with lung cancer, and 3) patient perception that others think less of a person with lung cancer. Although significant, correlations were weak. Findings from this study were consistent with other studies that have examined HRS and distress (Chambers et al., 2015; Lebel et al., 2013). Distress is an understudied phenomenon in patients with lung cancer. While multiple studies have investigated the incidence and influence of depression and anxiety on patients with lung cancer only two previously published studies have examined distress.

Social Support. Social support is an understudied phenomenon in patients with lung cancer. In this study, social support was significantly associated with both internal and external HRS. There were more significant correlations between the patient's reported perception of external HRS and social support than the perception of internal stigma and social support. Patients who reported a higher perception of external stigma also reported less received support from the primary caregiver as well as less general social support (such as having someone to talk to or someone to consult with about treatment related decisions). Patients who reported they blamed themselves for their disease (internal HRS) reported less received social support from the primary caregiver.

This study is the first quantitative study to investigate the relationship between social support and HRS. One qualitative study reported that women diagnosed with lung cancer felt that stigma played a role in how they interacted with healthcare providers (Brown & Cataldo, 2013). Another qualitative study reported that the perception of HRS associated with lung cancer affected the way lung cancer patients interacted with their family, friends, and healthcare providers. The finding from this study supports the earlier published qualitative literature.

Quality of Life. A significant association was found between external HRS and internal HRS and QOL. Like social support, more statistically significant associations were found between external HRS and QOL than internal HRS and QOL. Higher levels of external HRS were associated with a lower quality of life in all domains (physical, emotional, spiritual, and intellectual) as well as overall QOL. Patients who blamed themselves for lung cancer reported a lower physical and emotional QOL and those

who felt others blamed them for lung cancer reported lower physical, intellectual, and overall QOL.

When this study was first designed, no other published studies had investigated the association between stigma and QOL. Since that time two published studies have examined the relationship between lung cancer HRS and QOL. Findings from this study support these earlier findings (Brown-Johnson, Brodsky & Cataldo, 2014; Cataldo, Jahan & Pongquan, 2012).

Brown-Johnson, Bodsky & Cataldo (2014) recruited patients who completed online self-report measures. The study sought to determine if HRS was negatively correlated with QOL and if HRS played a unique role in the QOL experienced by patients with lung cancer. The study found that HRS was negatively correlated with QOL and that stigma played a unique role in QOL in patients with lung cancer. Cataldo, Jahan & Pongquan (2012) conducted a cross-sectional descriptive study with 190 participants. The results of this study found a statistically significant negative correlation between HRS and QOL in patients with lung cancer. Furthermore, results showed that HRS in patients with lung cancer played a unique and significant role in QOL over and above the factors of depression, age, gender, and smoking status.

2. To examine the associations between physical symptoms and social support and QOL in patients with advanced lung cancer.

Social Support. No significant associations were found between physical symptoms and social support in this study. At this time no other studies have examined overall symptom burden or symptom experience and social support in patients with lung cancer. One study investigated the relationship between the individual symptom of pain

and social support. Lekka et al., (2014) investigated the relationship between pain in patients with lung cancer and social support. In that study, pain severity and pain interference was significantly and negatively correlated with family support.

The MDASI-LC measures symptom severity on a summed scale with the rating of all symptoms included in the total scale score. Individual symptoms were not examined within the scope of this dissertation to determine if there is a relationship between the severity of individual symptoms (such as dyspnea or pain) and the perception of social support. Furthermore, symptom interference, as measured by the MDASI-LC, was also outside of the scope of this dissertation and the relationship between symptom interference and social support was not examined.

Quality of Life. In this study, no significant associations were found between physical symptoms and QOL. Findings from this study differ from the one previously published study in the literature. One study that investigated physical symptoms of lung cancer patients found that certain symptoms were a predictor of QOL, including: fatigue, loss of appetite, pain, and shortness of breath (Iyer, Taylor-Stokes & Roughley, 2013; Iyer, Roughley, Rider & Taylor-Stokes, 2014). This dissertation study investigated the association between physical symptoms and QOL by using a summed score of overall symptom severity as reported by patients. The previously published studies looked for associations between specific symptoms, such as fatigue or pain, and QOL.

3. To examine the associations between psychological symptoms and social support and QOL in patients with advanced lung cancer.

Depression and Social Support. In this study, no significant relationship was found between depression and social support in patients with advanced lung cancer.

The influence and relationship of depression and social support found in this study is inconsistent from two previously published studies (Shi, Gu, Hou & Hu, 2014; Walker, Zona & Fisher, 2005). Shi, Gu, Hou & Hu (2014) conducted a study with 104 inpatients with NSCLC in China and multivariate analysis showed that social support was a predictor of self-reported depression in patients with lung cancer. Walker, Zona & Fisher (2005) investigated depression and social support in 119 surgical patients with Stage I or II lung cancer and their results showed a significant relationship between directive instrumental social support and depressive symptoms but no relationship between non-directive social support and depressive symptoms.

There are several major differences between this dissertation study and the two studies that previously investigated depression and social support that may explain the conflicting results. The patients in this study were treated in an outpatient clinic at a comprehensive cancer care center in the United States whereas the patients in the study conducted by Shi, Gu, Hou & Hu (2014) were treated at an inpatient facility and lived in China. Furthermore, this dissertation study measured social support in two ways, main caregiver support and general social support, whereas the study by Shi, Gu, Hou & Hu (2014) used one general measure of social support. The major differences between this study and the study conducted by Walker, Zona & Fisher (2005) is that this dissertation study recruited participants with advanced lung cancer who were receiving chemotherapy as part of their treatment plan and whereas Walker, Zona & Fisher (2005) recruited patients who had Stage I or II disease and who received surgery instead of chemotherapy as treatment.

Depression and Quality of Life. No relationship was found between depression and QOL in this study which is inconsistent with previous findings. Two previously published studies have reported an association between depression and QOL in patients with lung cancer (Arrieta et al., 2013; Brown-Johnson, Brodsky & Cataldo, 2014). Arrieta et al. (2013) investigated the role of depression and QOL in patients with advanced lung cancer and found a negative correlation between the two variables. Additionally, Brown-Johnson, Brodsky & Cataldo found a significant negative correlation between depression and QOL. It is unclear why results in this dissertation study differ from those previously published in the literature though it may be that, overall, patients in this study had a very low incidence of depression compared to other published studies.

Anxiety and Social Support. No significant relationship between anxiety and social support was found in this dissertation study. Only one other published study has investigated the relationship between anxiety and social support. The previous study found a significant negative correlation between state anxiety and trait anxiety in patients with lung cancer (Lekka et al., 2014). Additionally, family support was a unique contributor to the variance in anxiety (Lekka et al., 2014). One major difference between the previously published study and this dissertation is that the previous study was conducted in Greece. Cultural perceptions of anxiety or family support may be perceived differently in different countries. Moreover, patients in this dissertation study reported low overall levels of anxiety when compared to previous reports on incidence of anxiety in patients with lung cancer.

Anxiety and Quality of Life. Anxiety was not correlated with QOL and this finding is inconsistent with one previously published study examining anxiety and QOL in patients with advanced lung cancer. Arrieta et al. (2013) found that anxiety was negatively correlated with QOL. The previously published study was conducted in Mexico where patients may have different perceptions of anxiety or QOL as it relates to a diagnosis of lung cancer and patients in this dissertation study reported lower levels of anxiety than is typically seen in the literature.

Distress and Social Support. Distress was not significantly associated with social support in this study. One previous study examined psychological distress and social support and found that distress was negatively correlated with emotional support (Ell, Nishmoto, Medianski, Mantell & Hamovitch, 1991). The previously published report examining distress and social support included a wide variety of cancer types and only 17% of the sample was reported to have lung cancer.

Distress and Quality of Life. A significant negative correlation was found in this study between distress and four domains of QOL (physical, emotional, spiritual, and intellectual) as well as overall QOL. No previously published studies have examined both distress and QOL in patients with lung cancer. One study that examined the rates of distress in a large cohort of 14 different cancer diagnoses (n=4496) found that of all cancer sites studied, patients with lung cancer reported the highest levels of psychological distress (43.4%) (Zabora, Brintzenhofe, Curbow, Hooker & Piantadosi, 2001).

Study Strengths and Limitations

This dissertation is unique in that it is the first study to look at HRS specifically in an advanced lung cancer population. Furthermore, it is the first quantitative study to examine possible associations between stigma and social support and the first study to examine the relationship between physical symptoms and social support. First, major strengths of this study are discussed in the areas of methodology and research content and then limitations are discussed.

Strengths

Strengths in Methodology. Although other studies have been published regarding HRS in lung cancer this is the first study to limit the sample to patients with advanced lung cancer. Patients with advanced lung cancer have a unique experience of symptoms, treatment, and outcomes therefore it is important to investigate stigma specifically within this population. This study was the first known quantitative study to measure and investigate associations between external and internal HRS and social support in patients with lung cancer. Additionally, this was the known first study to look at possible connections between physical symptoms associated with a diagnosis of lung cancer and social support. This study was also the first known study investigating HRS in patients with lung cancer to use the HADS to measure psychological symptoms. The HADS can be used as a diagnostic tool to indicate depression and anxiety in a patient whereas the CES-D, the most commonly used measure of depression in HRS stigma studies, can only indicate depressive symptomology. This difference in measurement tools allows for a more accurate description of depression and anxiety within this population. In addition to recruitment from a comprehensive cancer center, patients

were recruited nationwide for online participation in this study via two organizations, LUNGevity and the Lung Cancer Alliance. Recruiting patients from a nationwide sample ensured the perceptions of HRS were included from a variety of regions within the United States. Other studies investigating HRS in patients with lung cancer have either used an online only sample or a clinic-based only sample.

Strengths in Research Content. This study identified that patients with lung cancer who perceive greater levels of external or internal HRS also perceive less support from the main caregiver as well as general social support. This finding indicates that patients who perceive a greater HRS due to their diagnosis may be at risk for decreased care or support at a time of great need. Because many patients with advanced cancer must rely on a main caregiver for the bulk of care in the home setting during intensive chemotherapy treatments or during end-of-life care, this finding is clinically important. Nurses can play a key role in assessing patients for the perception of external or internal HRS and how these perception influence relationship between the patient and the main care provider in the home setting and the interactions of the patient with the community at large.

Limitations

This study has several limitations. (1) External validity. A convenience sampling method was used in this study rather than a random sample of patients. The majority of patients were recruited from a single comprehensive cancer care center from the clinic of a single provider. Although nationwide convenience sampling was also utilized there may not have been enough national representation to make these results generalizable to a nationwide sample. Furthermore, this sample was limited in ethnic diversity with

primarily white and black participants. Results may not be generalizable to other minority populations. (2) Internal validity. In a cross-sectional design, a main threat to internal validity is establishing cause. In this study only associations between variables were investigated and therefore statements about causality cannot be made. For example, we can say there is a relationship between HRS and social support in patients with lung cancer but we cannot say if the perception of HRS is what led to fewer available social supports or if fewer available social supports gave patients the perception that others blamed them for the diagnosis of lung cancer. The sample in this study is too small for multivariate analysis. The concept of HRS in patients with lung cancer is complex and therefore a multivariate analysis would offer more explanation than univariate analysis. (3) Measurement validity. HRS in patients with lung cancer has been measured using a wide variety of instruments. The most common instrument to date is the Cataldo Lung Cancer Stigma Scale. This length of this measure, however, was deemed inappropriate for this study, therefore a different instrument was used. The HRS measurement tool for this study has only been previously used in men who received care at the VA. Additionally, the MDASI-LC only captures the symptom experience of patients within the previous 24 hours. This brief period may not accurately reflect the true, overall symptom experience for patients with advanced lung cancer. (4) Other possible confounding factors. All patients in this study received chemotherapy as part of a treatment plan. Current and past chemotherapy regimens varied between participants and were dependent on time since diagnosis. Some participants in this study had only received one dose of chemotherapy while others had a history of multiple chemotherapy drugs, a history of radiation therapy, and a history of

experimental treatment through clinical trials. Therefore, a multitude of unknown confounding factors may influence the results of this study.

Implications

The role of HRS within the experience of patients with lung cancer remains an understudied phenomenon. Published literature demonstrates inconsistencies in some results as well as large inconsistencies in measurement tools used to understand the phenomenon and the factors that may influence HRS. Clinicians have little data from which to develop knowledge or understanding of HRS in patients with lung cancer and how HRS may affect the experience of patients with advanced lung cancer. This dissertation study, based on the theory of Unpleasant Symptoms, examined the relationship between internal and external HRS and psychological symptoms, physical symptoms, social support, and QOL to fill in gaps identified in the literature related to the phenomenon.

The most critical positive finding from this study was the relationship between internal and external HRS and social support. Results from this study identified that patients who had a higher perception of external HRS had a lower perception of support from the main caregiver as well as fewer general available social supports. Furthermore, patients who blamed themselves for their disease also perceived less support from the main caregiver. This finding is especially troublesome considering the large symptom burden typically experienced by patients with advanced lung cancer as they progress towards the end of life. Patients who have an increased perception of

HRS may be receive suboptimal care in the home setting which will influence patient QOL as well as quality of dying.

This study also contributed to the growing body of knowledge that HRS is related to the QOL experienced by patients with lung cancer. Results from this study were consistent with those previously published but this was the first study to exclusively focus on patients with advanced lung cancer. QOL becomes extremely important as patients begin to face the possibility of dying. Even though currently available therapies can extend the life of patients with lung cancer almost all patients with advanced disease will eventually succumb to the disease or a complication of advanced disease rather than die from another cause. For this reason it is important for clinicians to understand factors that may influence patient QOL and work to improve QOL as part of ongoing palliative care for these patients.

Finally, this was one of the few studies that examined the relationship between HRS in lung cancer patients and distress in addition to the more traditionally studied psychological symptoms of depression and anxiety. Although the level of distress reported by participants in this study was relatively mild, it was significantly associated with external HRS and physical, emotional, intellectual, spiritual, and overall QOL. This finding indicates that the level of distress experienced by patients with lung cancer may be a better measure for clinicians to use when assessing the psychological state of patients with lung cancer as distress may be more indicative of mental health and well-being in patients with advanced lung cancer than depression or anxiety.

Important negative findings from this study include no significant association between depression or anxiety and HRS and no association between physical

symptoms and HRS. Findings regarding depression and anxiety in this study are not consistent with previously published literature and may indicate that inappropriate measures of psychological symptoms are being used or that the association between depression and anxiety and HRS have been overstated within the literature. The finding that HRS and physical symptoms are not associated with one another indicates that physical symptoms may not be a part of the experience of stigma within this population. These results, however, must be interpreted with caution due to the limitations of the measurement tool used to evaluate physical symptoms.

There are multiple implications for the findings of this study. Clinicians, especially nurses, must possess the knowledge to understand HRS within the context of a lung cancer diagnosis and how the perception of HRS influences the experience of the patient, especially the availability of social support from a main caregiver or support from other sources, such as family, friends, or the wider community. Healthcare professionals should be aware that HRS is a common experience for patients with lung cancer, regardless of smoking status, and be prepared to discuss the perception of HRS with patients and their main caregivers.

Recommendations for Future Research

The results of this dissertation study can be used to guide future research in the following ways:

Although some patients for this study were recruited online to increase geographic diversity and diversity in care setting, the majority of patients were recruited from one comprehensive cancer care center in a state with a high rate of smoking and a

high rate of lung cancer compared to other states. Furthermore, the majority of participants in this study were white. Future studies would benefit from recruiting from multiple clinical sites with greater geographic diversity and diversity in the type of clinic in which patients receive care, for example, from smaller community clinics. Efforts should also be made to include a larger number of minority participants in studies regarding HRS in advanced lung cancer.

HRS and support from the main caregiver as well as general social support were shown to be associated in this study. This finding suggests that it is essential to conduct future research to discover what types support are utilized by patients with lung cancer and which supports are the most beneficial for these patients.

Because the bulk of care for patients with advanced lung cancer is provided at home it is important to first conduct descriptive studies that investigate how patients perceive support from a main caregiver in order to build a body of knowledge about social support in patients with lung cancer. A qualitative study would be beneficial to understand the experience of support from a main caregiver for patients with lung cancer as well as to understand what types of social support from the main caregiver are most important to patients with advanced lung cancer. A qualitative study would also be beneficial to describe the types of general social support that patients with advanced lung cancer find helpful and to which they have access. Finally, a qualitative study could explore the lived experience of HRS as it relates to social support in patients with advanced cancer.

There is a need to develop a took to be used in a clinical setting that would include a checklist of specific types of social support most commonly received from a

main caregiver as well as a scale to determine the level of specific supports received. Nurses and other healthcare professionals could utilize this tool to evaluate patients and caregiver dyads to determine which patients may be at risk for sub-optimal care at home and to provide appropriate interventions to bolster at home support and care for patients with advanced lung cancer. Descriptive studies are needed to clarify what specific supports within the community lung cancer patients have access to and which supports they utilize more frequently, such as monthly lung cancer support meetings, church, or informal gatherings with friends. These studies need to further address how HRS may influence the patient's by examining multiple factors that may influence the patient's utilization of social support.

Intervention studies are needed to help patients with advanced lung cancer address and reduce feelings of stigma and bolster access to social support at home and within the community. Furthermore, interventions are needed to improve QOL for these patients as they move through the stages of care and towards end of life.

Study findings also indicate that the MDASI-LC may not accurately capture or reflect the true symptom experience of patients with advanced lung cancer. There is a need to develop a validated scale based on the Theory of Unpleasant Symptoms that captures the timing, intensity, distress and quality of the symptoms commonly experience by patients with advanced lung cancer. Furthermore, the scale should assess patient symptoms within a time frame of more than the previous 24 hours so that the overall picture of patient symptoms can be captured by the clinicians and appropriately treated.

Due to conflicting results reported within the literature, more studies are needed to address the role between HRS and depression, anxiety, and distress. Studies are also needed to address the relationship between HRS and function in patients with lung cancer.

New knowledge generated from these proposed studies would inform healthcare professionals, such as bedside nurses and nurse practitioners, and could make significant contributions to improving the experience of patients with advanced lung cancer in the areas of HRS, social support, and the management of physical and psychological symptoms.

APPENDIX A

PATIENT CONTACT SCRIPT

PATIENT CONTACT SCRIPT DISTANCE PARTICIPANTS

“Thank you for calling about our study. I need to get some basic contact information. Is that okay?”

Can I have the correct spelling of your name?_____

Your home phone number is _____

Your work phone number is _____

What is your correct street address? _____

What is your correct city and state? _____

Do you want to give us your email address?

_____

How old are you? _____ (if not 18, or older, “Thank you for allowing me to verify the information, but right now our studies require that you be over 18 years old”. and go to #15.

“Thank you for giving me that information. I would like to tell you about our study if you have a few minutes.”

This study is about stigma that patients with lung cancer may or may not feel. I am interested in finding out the different ways that stigma may influence the way patients with lung cancer feel.

You will:

Receive an invitation by email to take several surveys online

Be asked about demographic and medical history information

I will have you sign a medical chart release form so that your doctor can send me your medical records specific to your lung cancer diagnosis and any treatments

you may have had. This may include information about biopsies you may have had or chemotherapy or radiation treatments.

If you think you are interested, I will need to ask you several questions to see if you qualify for the study.

Subject: RedCap Survey Invitation

Thank you for agreeing to participate in Lee Ann Jarrett's lung cancer research study. This is your invitation to complete your survey in RedCap. Please complete and submit this survey in the next week.

If you need to leave your survey and return later, please click the "Save and Return Later" tab and make note of your validation code. If you lose your validation code, call the study office at 615-343-6313 or 1-800-xxx-xxxx. You can also email us at lee.a.jarrett@vanderbilt.edu and we'll provide it to you. When you are ready to finish your survey, click on this survey link and enter your code to continue where you left off.

PATIENT CONTACT SCRIPT LOCAL PARTICIPANTS

"Hello Mr./ Ms./ Mrs. _____(state the person's name) I am _____(state your name). I am _____ a student at the Vanderbilt School of Nursing."

"Your doctor, _____(insert Dr's name) has asked me to talk to you about a research study that is available to you. May I have a few minutes of your time?" If no, thank them and leave.

If yes, "Thank you. The study I would like to tell you about does not involve medication and will not impact your cancer treatment. We are trying to learn more about how people feel after a diagnosis of lung cancer."

Then review the following bullet points, giving them time to ask questions.

1. What will happen and how long will you be in the study?

If you agree to be in the study, you will fill out surveys one time.

2. Procedures to be followed and approximate duration of the study:

We will talk to you and ask about:

- Where you live, if you have insurance, do you work, what is your household income
- Alcohol and tobacco use.

We will write these answers down.

You will fill out forms (we will help you if you need us to) that asks about:

- Stigma: How you view yourself and how others may view you.
- Any physical problems you may have with pain, fatigue, breathing, and appetite.
- Any emotional problems you have such as feeling sad or anxious.
- What kinds of support you have available.
- How well you are able to care for yourself.
- How you feel about the overall quality of your life.

Review of Records (We will do this the whole time you are in the study. The information we write down comes from your standard medical care record and reflects services that are not done for research only.)

- We will look at and record your medical history on our forms. This will include things like any heart, stomach, bone, or other problems you may have.
- We will record any medications you are taking during your treatment.
- We will record any problems (toxicities) that your doctor has recorded that may be related to your treatment.

APPENDIX B

SCREENING FORM

Eligibility Criteria-Checklist For Distance Participants

Health-Related Stigma in Advanced Lung Cancer

Criteria:		
1) Is the patient age 18 or over?	If yes go to #2	If no STOP
2) Has the patient received chemotherapy for treatment of a primary lung tumor?	If yes go to # 3	If no STOP
3) Does the patient speak English?	If yes go to # 4	If no STOP
4) Did the patient pass the Short Portable Mental Status Questionnaire?	If yes go to #5	If no STOP
5) Does patient have any other active cancer?	If no go to #6	If yes STOP
6) Is the patient enrolled in hospice?	If no patient meets criteria and you can discuss the study with the patient.	If yes STOP

APPENDIX C

DEMOGRAPHIC AND BACKGROUND INFORMATION

1. What is your birthdate?
____/____/_____ (month/day/year)

2. Gender:
(1) Female ____(2) Male____
(3) Other____ (4) Do not care to respond ____

3. What is your race?
(1) American Indian/Alaskan Native ____
(2) Asian ____
(3) Native Hawaiian or Other Pacific Islander ____
(4) Black or African American ____
(5) White ____
Nation of Origin: _____

4. What is the highest grade of education you completed? (Please circle)
1 2 3 4 5 6 7 8 9 10 11 12(high school) 13 14 15 16(college) 17 18 (master) 19 20(doctorate)

5. What is your marital status:
(1) Single ____
(2) Single, living with partner ____
(3) Married ____
(4) Widowed ____
(5) Other ____

6. What is your marital status?
(1) Employed full time ____
(2) Employed part time ____
(3) Homemaker ____
(4) Retired ____
(5) Unemployed ____
(6) Other ____
Vocation _____

7. What best describes your area of residence?
(1) City ____ (2) Country ____ (3) Other ____

8. Health Maintenance

8.1 Smoking

(1) No

(2) Yes ____ (Tobacco __ or Marijuana __or _____)

____years _____cigarettes per day

(3) Quit

(4) Not Quit

_____cigarettes per day (Current)

8.2 Drinking Alcohol

(1) No ____

(2) Yes ____

_____years _____ times per week

(3) Quit

(4) Not Quit _____

_____ times per week (Current)

9. What is your insurance coverage?

(1) Medicare____ (2) Medicaid ____

(3) TennCare ____ (4) Private Insurance ____

(5) HMO ____ (6) None _____

(7) Other _____

10. Do you have any medical problems?

(1) No

(2) Yes (e.g., HBP, BM, Obesity, Injury History) _____

11. What is your yearly household income?

(1) $10,000 or less ____

(2) $10,001 to $20,000 ____

(3) $20,001 to $30,000 ____

(4) $30,001 to $40,000 ____

(5) $40,001 to $50,000 ____

(6) $50,001 to $60,000 ____

(7) Over $60,000 ____

(8) Do not care to respond ____

APPENDIX D

INTERNAL AND EXTERNAL STIGMA SCALE

Please read the following questions carefully. Circle the number that best represents how you true you find the statement.

	Not at all True 1	A Little True 2	Somewhat True 3	Completely True 4
1. I feel that some people avoid me because I have lung cancer.	1	2	3	4
2. I feel that some people feel awkward and tense around me because I have lung cancer.	1	2	3	4
3. I feel there is a stigma that goes with having my condition.	1	2	3	4
4. I feel that most people think less of a person who has lung cancer.	1	2	3	4
5. I feel I am to blame for my illness.	1	2	3	4
6. I feel other people think I am to blame for my illness.	1	2	3	4

APPENDIX E

SOCIAL CONTRAINTS SCALE

Sometimes, even when your spouse or partner has good intentions, he may say or do things that upset you. Think about the PAST MONTH and indicate how often your spouse/partner did the following things.

Use the scale that ranges from 0-10

How often in the past month has your spouse/partner/caregiver…

1. Changed the subject when you tried to discuss your illness?
0 1 2 3 4 5 6 7 8 9 10
Never Always

2. How often did it seem your spouse/caregiver did not understand your situation?
0 1 2 3 4 5 6 7 8 9 10
Never Always

3. How often did your spouse/caregiver minimize your problems?
0 1 2 3 4 5 6 7 8 9 10
Never Always

4. How often did your spouse/caregiver seem to be hiding his/her feelings?
0 1 2 3 4 5 6 7 8 9 10
Never Always

5. How often did your spouse/caregiver act uncomfortable when you talked about your illness?
0 1 2 3 4 5 6 7 8 9 10
Never Always

6. How often in the past month has your spouse/caregiver trivialized your problems?
0 1 2 3 4 5 6 7 8 9 10
Never Always

7. How often did your spouse/caregiver complain about his/her own problems when you wanted to share your own?
0 1 2 3 4 5 6 7 8 9 10
Never Always

8. How often did your spouse/caregiver act cheerful around you to hide his/her true feelings and concerns?
0 1 2 3 4 5 6 7 8 9 10
Never Always

9. How often did your spouse/caregiver tell you not to worry so much about your health?

0 1 2 3 4 5 6 7 8 9 10
Never Always

10. How often did your spouse/caregiver tell you to try not to think about the cancer?

0 1 2 3 4 5 6 7 8 9 10
Never Always

11. How often did you get the idea that your spouse/caregiver didn't want to hear about your cancer?

0 1 2 3 4 5 6 7 8 9 10
Never Always

12. How often did your spouse/caregiver make you feel as though you had to keep your feelings about your cancer to yourself, because they made him/her upset?

0 1 2 3 4 5 6 7 8 9 10
Never Always

13. How often did your spouse/caregiver make you feel as though you had to keep your feelings about your cancer to yourself, because they made him/her upset?

0 1 2 3 4 5 6 7 8 9 10
Never Always

14. How often did your spouse/caregiver let you down by not showing you as much love and concern as you would have liked?

0 1 2 3 4 5 6 7 8 9 10
Never Always

APPENDIX F

M.D. ANDERSON SYMPTOM INVENTORY SCALE—LUNG CANCER

Date: _____ **Institution:** _____

Participant Initials: _____ **Hospital Chart #:** _____

Participant Number: _____

M. D. Anderson Symptom Inventory - Lung Cancer (MDASI-LC)

Part I. How severe are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been ***in the last 24 hours***. Please rate each of these symptoms from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be).

CORE Items	Not Present 0	1	2	3	4	5	6	7	8	9	As Bad As You Can Imagine 10
1. Your **pain** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
2. Your **fatigue (tiredness)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
3. Your **nausea** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
4. Your **disturbed sleep** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
5. Your feeling of being **distressed (upset)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
6. Your **shortness of breath** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
7. Your problem with **remembering things** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
8. Your problem with **lack of appetite** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
9. Your feeling **drowsy (sleepy)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
10. Your having a **dry mouth** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
11. Your feeling **sad** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
12. Your **vomiting** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
13. Your **numbness or tingling** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

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Date: _____ Institution: _____

Participant Initials: _____ Hospital Chart #: _____

Participant Number: _____

Lung Cancer - Specific Items	Not Present 0	1	2	3	4	5	6	7	8	9	As Bad As You Can Imagine 10
14. Your **coughing** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
15. Your **constipation** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
16. Your **sore throat** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

Part II. How have your symptoms **interfered** with your life?

Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items **in the last 24 hours**:

	Did not Interfere 0	1	2	3	4	5	6	7	8	9	Interfered Completely 10
17. General **activity**?	○	○	○	○	○	○	○	○	○	○	○
18. **Mood**?	○	○	○	○	○	○	○	○	○	○	○
19. **Work** (including work around the house)?	○	○	○	○	○	○	○	○	○	○	○
20. **Relations** with other people?	○	○	○	○	○	○	○	○	○	○	○
21. **Walking**?	○	○	○	○	○	○	○	○	○	○	○
22. **Enjoyment** of life?	○	○	○	○	○	○	○	○	○	○	○

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APPENDIX G

NCCN DISTRESS THERMOMETER

Study #: _____ PT ID: _____ Date: _____

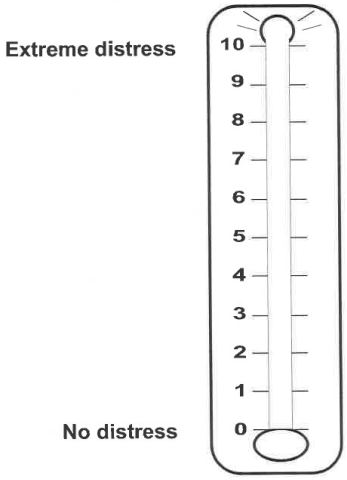
National Comprehensive Cancer Network®

NCCN Guidelines Version 3.2012
Distress Management

NCCN Guidelines Index
Distress Management TOC
Discussion

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions

YES	NO	Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues

YES	NO	Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities

YES	NO	Spiritual/religious concerns
❑	❑	

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling Swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

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DIS-A

APPENDIX H

HOSPITAL ANXIETY AND DEPRESSION SCALE

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underling the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

I feel tense or "wound up"
Most of the time
A lot of the time
From time to time, occasionally
Not at all

I still enjoy the things I used to enjoy
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

I can laugh and see the funny side of things
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind
A great deal of the time
A lot of the time
Not too often
Very little

I feel cheerful
Never
Not often
Sometimes
Most of the time

I can sit at east and feel relaxed
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down
Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like "butterflies" in the stomach
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or television programme
Often
Sometimes
Not often
Very seldom

APPENDIX I

MEDICAL OUTCOMES SURVEY—SOCIAL SUPPORT SURVEY

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kids of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support	1	2	3	4	5
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5
Positive social interaction	1	2	3	4	5
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5

Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

APPENDIX J

QUALITY OF LIFE SCALE (LINEAR ANALOG SELF-ASSESSMENT)

Directions: Please circle the number (0-10) best reflecting your response to the following that describes your feelings during the past week, including today.

1. How would you rate your physical well being over the past week?
This questions refers to such things as fatigue, activity, etc

0 1 2 3 4 5 6 7 8 9 10
As bad as as good as it can be
It can be

2. How would you rate your emotional well being over the past week?
This question refers to such things as depression, anxiety, stress, etc.

0 1 2 3 4 5 6 7 8 9 10
As bad as as good as it can be
It can be

3. How would you rate your spiritual well being over the past week?
This question refers to such things as a sense of meaning and purpose, relationship with God, etc.

0 1 2 3 4 5 6 7 8 9 10
As bad as as good as it can be
It can be

4. How would you rate your intellectual well being over the past week?
This question refers to such things as the ability to think clearly, to concentrate, to remember, etc.

0 1 2 3 4 5 6 7 8 9 10
As bad as as good as it can be
It can be

5. how would you rate your overall well being over the past week?

0 1 2 3 4 5 6 7 8 9 10
As bad as as good as it can be
It can be

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